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**Eating Disorders, Recovery, and Social Work Practice in Quebec:
An Exploratory Study**

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Table of contents

A Note to the Reader	1
Use of the First Person	1
Introduction	2
Chapter 1: Review of Literature	5
1.1 Eating Disorders	5
Box 1 - Eating Disorder Diagnostic Criteria or Description	7
1.2 Eating Disorders and the DSM	11
1.3 The Power of the DSM	13
1.4 Etiology of Eating Disorders	15
1.5 A Complicated Picture of Eating Disorders in North America	16
1.6 Eating Disorders in Canada, in Quebec	21
1.7 Gaps in Treatment	24
1.8 Social Causes, Social Consequences	26
Box 2 – Social Factors Related to Eating Disorders	27
1.9 Social Work and Eating Disorders: A Short Review of Literature	27
Chapter 2: Theoretical Framework	33
2.1 Recovery	33
2.1.1 Recovery and Quality of Life	34
2.1.2 Relapse	35
2.1.3 Support in the Recovery Process	36
2.2 Feminist Perspectives on Eating Disorders	36
2.2.1 Four Feminist Readings of Eating Disorders	37
Box 3 – Feminist Perspectives on Eating Disorders	39
2.2.2 A Critical Stance on the Psychiatrization of Eating Disorders	41
2.2.3 Understanding the Cultural Meanings of Fat and Thin	43
2.2.4 The Gender Blind Spot	47
2.2.5 Race and Class	48
Chapter 3: Methodology	51
3.1 Feminist Research	51
3.2 Research Orientations of this Study	52

3.3 Research Questions	53
3.4 Data Collection Method	53
3.5 Sampling Strategies.....	55
3.6 Data Analysis.....	56
3.7 <i>Le référenciel des compétences des travailleuses sociales et des travailleurs sociaux</i>	57
3.8 Participants Define their Eating Disorder and Level of Recovery	58
3.9 Defining Recovery	59
Table 1 – Recovery Dimensions	59
3.10 Inclusions	61
3.11 Exclusions.....	62
3.12 Safeguards for Working with a Vulnerable Population	63
3.13 Community-Based Recruitment.....	64
Table 2 - Community Organization’s Mission and Services.....	66
3.14 Number of Participants.....	67
3.15 Data Collection.....	68
3.16 Compensation	68
3.17 Confidentiality.....	69
3.18 Evolution of the Research Protocol	69
Chapter 4: Results and General Discussion.....	71
4.1 Research participants.....	72
4.2 Defining Recovery	76
4.2.1 Relapse.....	81
4.3 What Worked in the Recovery Process.....	84
4.3.1 Transformation of self-perception.....	84
4.3.2 Services	86
4.3.3 Group Work.....	89
4.3.4 Professionals	92
4.3.5 Supportive Relationships	95
4.3.6 Intuitive Eating	97
4.3.7 Resolution of Underlying Eating Disorder Causes.....	99
4.3.8 Giving Back.....	102
4.4 Barriers in the Eating Disorder Recovery Process.....	103

4.4.1 Inadequate Public Services for Eating Disorders	104
4.4.2 No Services Outside Large Centers	107
4.4.3 Professionals Who Were Not Knowledgeable About Eating Disorders	108
4.4.5 Invisibility of Sub-clinical, Lesser-Known or Emergent Eating Disorders	110
4.4.6 Cost of Private Services	115
4.5 The Body in the Sociocultural Context.....	116
4.5.1 Stigmatization of FAT	117
4.5.2 In the health system.....	117
4.5.3 In the Family.....	122
4.5.4 By Peers.....	124
4.5.5 Generalized	125
4.6 Services Gendered Female.....	129
4.7 Loved Ones Who Needed Information and Support	130
4.8 Experiences with Social Workers	133
4.8.1 Positive Impact on Recovery.....	134
4.8.2 Negative Impact on Recovery	138
4.8.3 No impact on Recovery:.....	140
4.8.4 Advice for Social Workers	141
4.9 Discussion.....	148
Chapter 5: Conclusion	163
5.1 Conclusion.....	163
5.2 Training for Social Workers.....	168
5.3 Limits of This Study	169
5.4 Further Research.....	171
REFERENCES	174
Annex 1	180
Annex 2	184
Annex 3	194

A Note to the Reader

The School of Social Work at *Université de Sherbrooke* has given me permission to write my master's level thesis in English.

Use of the First Person

As this study has been conceived within a feminist research framework, I have written in the first person in sections pertaining to research design and analysis. Making transparent that I am the person designing the research, conducting the interviews and analysing the data makes my subject position clear to the reader.

Introduction

This study is an investigation of eating disorder recovery in a Quebec community setting and the potential role that social workers might play in this highly social process. Recovery refers to the singular and subjective experience that is informed by an individual's values and goals as they redefine and pursue balance and well-being while experiencing serious mental illness (Davidson, Tondora, Staeheli Lawless, & Rowe, 2009, p. 35; Provencher, 2002). The recovery perspective focuses on both the strengths and limits of the person and their environment, making this approach particularly relevant to social work practice.

In the first chapter, an overview of the current psychiatric understandings of eating disorders is presented, along with an introduction to emergent and diagnostically vague categories of eating disorders. A critical examination of how psychiatric understandings have shaped current eating disorder research and treatment follows, with a particular focus on what populations are excluded in the current eating disorder literature. This section also includes a description of the Quebec eating disorder context, as this study is focused on recovery in a Quebec community setting. Finally, a short review of the existing social work literature on the subject of eating disorders is presented. Though little research has been done on this topic specifically, the concept of quality of life in the recovery from an eating disorder has been identified as playing a determining role in the recovery and prevention of eating disorders (Mitchison, Dawson, Hand, Mond, & Hay, 2016). Quality of life includes many areas in which social work is already specialized: empowerment, connection with community, relationships and meaningful life projects (work, leisure, education) (Mitchison et al., 2016; OTSTCFQ, 2012). Investment in these areas was found to reduce eating disorder symptoms and was linked to "spontaneous factors associated with the onset and remission of eating disorders" (Mitchison et al., 2016, p. 2), which would support a recovery oriented approach to eating disorders that goes beyond food and weight (Mitchison et al., 2016).

In the second chapter, the theoretical foundation for this study is presented. The recovery perspective, which is a novel and alternative approach in mental health, is expounded and linked to the community reality of eating disorders. This perspective is different from the "cure" narrative that is dominant in the

field of eating disorders, as it is person-centered and focused on a sense of well-being and purpose, rather than on eradicating symptoms and stabilising weight (Davidson et al., 2009; Gremillion, 2002; Mitchison et al., 2016; Provencher, 2002). Feminist perspectives on eating disorders are also submitted as a framework for understanding the social factors contributing to the development and maintenance of eating disorders. Gender, race and class, as they relate to the body, are at the core of a feminist analysis of disordered eating. In addition, special attention is paid to the Western cultural context in which eating disorders are most prevalent, exposing the elevated status attributed to disciplined bodies (thin for women, muscular for men) and corresponding cultural distain for fat (Melcher & Bostwick Jr., 1998; Rail, Holmes, & Murray, 2010; Vinette, 2001). Feminist perspectives are highly critical of the psychiatrization of eating disorders, suggesting that the classification of eating disorders as a mental illness masks the gendered social forces that are at play in the development and maintenance of eating disorders. Finally the *Référenciel des compétences des travailleuses sociales et des travailleurs sociaux* is introduced as a tool for connecting both recovery and feminist perspectives on eating disorders to the practice of social work in Quebec.

A third chapter is focused on the methodology of this study. A feminist research approach was adopted to correct some of the research bias identified in the first section of the paper: focus on a minority of eating disorders in hospital settings, lack of firsthand accounts from people living with an eating disorder, exclusion of men, older women and ethnically diverse populations, etc. As feminist research champions transparency in the research process, this section is written in the first person, and includes a segment on the potential impacts of my status as an eating disorder counsellor in Quebec. This section also includes the sampling strategy chosen to maximize the diversity of the sample and ensure the orientation of the research: recovery from an eating disorder in a Quebec community setting. A detailed and transparent description of the research process, research tools (interview questions, consent form, recruitment flyers) is also included. Finally, thematic analysis conducted in the spirit of grounded theory is presented as the lens through which the research data is analysed.

In the fourth and final chapter, the results of the study are presented in relation to the research question: What are the lived experiences of a community-based sample of people in recovery from an eating

disorder in Quebec? The research participants demographic specificities are presented in rich detail, with an emphasis on how this community-based sample is both diverse and novel in the field of eating disorders. Research participants' definitions of recovery from an eating disorder, including their perception of relapse, are presented as a foundation for exploring three other aspects of their experiences: barriers to recovery, what worked, and the role of social workers in the recovery process. In keeping with the study's stated goal of generating useful knowledge for change (Hesse-Biber, 2014b), participants advice for social workers on how to offer recovery-supportive interventions for individuals living with eating disorders are also included in this chapter. Next, the lived experiences of this diverse, community-based sample of individuals recovering from an eating disorder are linked to the larger context of eating disorder treatment and services in Canada and Quebec, with a emphasis on the role of community organizations and social workers. Finally, the overlap in recovery-oriented practices and the core values of social work practice are discussed in relation to the issue of eating disorder recovery in a Quebec community setting.

Chapter 1: Review of Literature

1.1 Eating Disorders

Eating disorders are categorized as a serious mental health problem in the West (American Psychiatric Association, 2018; Black, 2003; Gremillion, 2002; Leblanc, Duncan, & O'Neill Gordon, 2014). Though there are several types of eating disorders (anorexia, bulimia, binge-eating disorder, bigorexia/muscle dysmorphia, orthorexia, etc.), some have an official psychiatric diagnosis and others do not. What is common to all is an obsession with food and weight that impairs physiological, psychological and social functioning (American Psychiatric Association, 2018; Public Health Agency of Canada, 2002). People living with eating disorders report having a low quality of life, and suffer greatly due to the chronic nature of these disorders (Hart, Granillo, Jorm, & Paxton, 2011). Beyond the obsession with food and weight are deep social and emotional issues that manifest themselves through the body (Black, 2003; Bordo, 2003; Daly, 2016; Gremillion, 2003; Petrucelli, 2016). Eating disorder specialist Jean Petrucelli (2016) explains:

Patients with eating disorders live under the assumption that if they feel their sensations and feelings these will overwhelm them 'forever'. The fear of being consumed by these terrible feelings leads them to believe that 'not feeling' - or even not existing- is the only answer. (Petrucelli, 2016, p. 18)

Though exact causes of eating disorders are unclear, there is consensus in the research that eating disorders "result from a combination of biological, psychological and social factors" (American Psychiatric Association, 2018; Government of Canada, 2006; National Eating Disorder Association, 2018; National Eating Disorder Information Center, 2014; Public Health Agency of Canada, 2002).

It was previously believed that eating disorders existed only in Western industrialized nations, however as the influence of the West reaches further through its media and its economies, eating disorders are increasingly present across cultures (Katsounari, 2009; J. Slevic & Tiggemann, 2011, p. 151; Tiggemann, Verri, & Scaravaggi, 2005; Wilson, 2004). More recent eating disorder research has identified the rise of eating issues in "Taiwan, China and Japan as globalization and advances and technologies blur the traditional West/non-West dichotomy" (Wilson, 2004, p. 151). The emergence of eating disorders in the Mediterranean, specifically Italy (Tiggemann et al., 2005) and Cyprus (Katsounari, 2009) has also been

documented. Tiggemann et al. (2005) report that “in general the literature suggests that the rates of eating disturbance in European countries are on par with the United States, while rates in Asia, Africa and South America are somewhat lower, but have been increasing markedly in recent years” (Tiggemann et al., 2005, p. 294). “Western attitudes and ideals, including the thin ideal [for women]” (Katsounari, 2009, p. 455) and the muscular ideal for men (Bunnell, 2016; Griffiths, Murray, & Touyz, 2015) have been linked to the epidemic of eating disorders in the West, and the emergence of body dissatisfaction and eating disturbances in other cultures (Katsounari, 2009; Tiggemann et al., 2005).

In the table below, I have included a description of seven types of eating disorders that are divided into two categories: Eating Disorders included in the Diagnostic and Statistical Manual of Mental Illness (DSM-5) and Emergent Eating Disorders. I have started with the diagnostic criteria for Anorexia Nervosa (anorexia), Bulimia Nervosa (bulimia), Binge-Eating Disorder, Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED) as they appear in the fifth edition of the DSM. I have also included definitions of two emergent disorders: Orthorexia, Bigorexia/Muscle Dysmorphia. There are many other emergent eating disorders, but I have chosen to focus on the two disorders that are most commonly described by eating disorder community organizations (ANEB Québec, 2011, Arrimage Estrie, 2017, NEDIC, 2016, NEDA 2016) and in popular eating disorder literature.

Though there is scant academic research about emergent eating disorders, a Dutch study conducted before the publication of the DSM-5 partly supports the inclusion of orthorexia and muscle dysmorphia in the review of literature for this study. In a survey of 111 Dutch and Belgian professionals who are “actively involved in research, prevention, or treatment of eating disorders” (Vandereycken, 2011, p. 148), orthorexia was identified as the emergent eating disorder most observed in the respondent’s own practices, and the eating disorder they considered “deserving more attention from researchers and clinicians” (Vandereycken, 2011, p. 149). Conversely, the same study found that muscle dysmorphia (or bigorexia) “was viewed as the most “fashionable” [eating disorder]: a creation of the popular media and not deserving more attention” (Vandereycken, 2011, p. 150). As muscle dysmorphia affects men disproportionately, it is possible that the popular belief that men are not affected by eating disorders may have influenced the respondent’s perception of this disorder (Bunnell, 2016). Bunnell (2016) asserts

that “assumptions about the role of gender in eating disorders contribute to the invisibility of men and boys who are struggling with these illnesses” (Bunnell, 2016, p. 99). A deeper analysis of the Dutch survey found that among professionals who devoted more than 60% of their time to eating disorders, 84% stated that muscle dysmorphia “deserves more attention from researchers and clinicians” (Vandereycken, 2011, p. 150), which would confirm that this emergent disorder is well known to professionals who are most familiar with eating disorders.

Definitions and criteria for the two emergent disorders in the table below were drawn from eating disorder community organizations that provide information to the general public. The definitions chosen are representative of the way the emergent disorders are described by similar organizations and in popular literature on the subject. The definitions are also in keeping with those used to describe orthorexia and muscle dysmorphia in the aforementioned Dutch study (Vandereycken, 2011)

Box 1 - Eating Disorder Diagnostic Criteria or Description

Eating Disorder	Diagnostic Criteria or Description
Eating Disorders included in DSM-5	
Anorexia Nervosa	<ol style="list-style-type: none"> 1. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected. 2. Intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, even though at a significantly low weight. 3. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight. <ul style="list-style-type: none"> • Restricting type: During the last 3 months, the individual has not engaged in recurrent episodes of binge eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise. • Binge-eating/purging type: During the last 3 months, the individual has engaged in recurrent episodes of binge eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).(DSM-5, 2013)

<p>Bulimia Nervosa</p>	<ol style="list-style-type: none"> 1. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: <ol style="list-style-type: none"> 1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances. 2. A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). 2. Recurrent inappropriate compensatory behaviors in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise. 3. The binge eating and inappropriate compensatory behaviors both occur, on average, at least once a week for 3 months. 4. Self-evaluation is unduly influenced by body shape and weight. 5. The disturbance does not occur exclusively during episodes of anorexia nervosa. <p style="text-align: right;">(DSM-5, 2013)</p>
<p>Binge-Eating Disorder</p>	<ol style="list-style-type: none"> 1. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: <ol style="list-style-type: none"> 1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances. 2. A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). 2. The binge-eating episodes are associated with three (or more) of the following: <ol style="list-style-type: none"> 1. Eating much more rapidly than normal. 2. Eating until feeling uncomfortably full. 3. Eating large amounts of food when not feeling physically hungry. 4. Eating alone because of feeling embarrassed by how much one is eating. 5. Feeling disgusted with oneself, depressed, or very guilty afterward. 3. Marked distress regarding binge eating is present. 4. The binge eating occurs, on average, at least once a week for 3 months. 5. The binge eating is not associated with the recurrent use of inappropriate compensatory behavior as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.(DSM-5, 2013)

<p>Other Specified Feeding or Eating Disorder (OSFED)</p>	<p>This category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The other specified feeding or eating disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding and eating disorder. This is done by recording “other specified feeding or eating disorder” followed by the specific reason (e.g., “bulimia nervosa of low frequency”).</p> <p>Examples of presentations that can be specified using the “other specified” designation include the following:</p> <ol style="list-style-type: none"> 1. Atypical anorexia nervosa: All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual’s weight is within or above the normal range. 2. Bulimia nervosa (of low frequency and/or limited duration): All of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory behaviors occur, on average, less than once a week and/or for less than 3 months. 3. Binge-eating disorder (of low frequency and/or limited duration): All of the criteria for binge-eating disorder are met, except that the binge eating occurs, on average, less than once a week and/or for less than 3 months. 4. Purging disorder: Recurrent purging behavior to influence weight or shape (e.g., self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating. 5. Night eating syndrome: Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness and recall of the eating. The night eating is not better explained by external influences such as changes in the individual’s sleep-wake cycle or by local social norms. The night eating causes significant distress and/or impairment in functioning. The disordered pattern of eating is not better explained by binge-eating disorder or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication. <p style="text-align: right;">(DSM-5, 2013)</p>
<p>Unspecified Feeding or Eating Disorder (UFED)</p>	<p>This category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The unspecified feeding or eating disorder category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific</p>

	<p>feeding and eating disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g., in emergency room settings).</p> <p style="text-align: right;">(DSM-5, 2013)</p>
Emergent Eating Disorders	
Orthorexia	<p>The word 'orthorexia' was coined in 1998 and means an obsession with proper or 'healthful' eating. Although being aware of and concerned with the nutritional quality of the food you eat isn't a problem in and of itself, people with orthorexia become so fixated on so-called 'healthy eating' that they actually damage their own well-being.</p> <p>Some of the signs of orthorexia may include:</p> <ul style="list-style-type: none"> • Compulsive checking of ingredient lists and nutritional labels • An increase in concern about the health of ingredients • Cutting out an increasing number of food groups (all sugar-all carbs -all dairy-all meat -all animal products) • An inability to eat anything but a narrow group of foods that are deemed 'healthy' or 'pure' • Unusual interest in the health of what others are eating • Spending hours per day thinking about what food might be served at upcoming events • Showing high levels of distress when 'safe' or 'healthy' foods aren't available • Obsessive following of food and 'healthy lifestyle' blogs on Twitter and Instagram • Body image concerns may or may not be present <p style="text-align: right;">(NEDA, 2016)</p>
Muscle Dysmorphia/ Bigorexia	<p>Muscle dysmorphia or Bigorexia is a disorder that causes a person to constantly obsess and/or worry about being too small, underdeveloped, and/or underweight. Typically those who have Muscle Dysmorphia are not frail or underdeveloped at all, and actually have large muscle mass. A person with muscle dysmorphia obsesses about having the perfect physique and believes their muscles are inadequate.</p> <p>Warning Signs of Muscle Dysmorphia May Include:</p> <ul style="list-style-type: none"> • Distorted self-image • Missing social events, skipping work, and cancelling plans in order to work out • Never being satisfied with one's muscle mass • Working out despite an injury • Maintaining extreme workout methods

	<ul style="list-style-type: none"> • Maintaining a strict, high-protein and low-fat diet • Using excessive amounts of food supplements • Steroid abuse, unnecessary plastic surgery, and even suicide attempts <p>(McCallum Place Eating Disorder Centers, 2018; The Alliance for Eating Disorders Awareness, 2017)</p>
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1.2 Eating Disorders and the DSM

As eating disorders are considered a mental health problem, they are defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The DSM is a repertory of mental illnesses published by the American Psychiatric Association; it “offers a common language and standard criteria for the classification of mental disorders” (American Psychiatric Association, 2017). This manual is “used, or relied upon, by clinicians, researchers, psychiatric drug regulation agencies, health insurance companies, pharmaceutical companies, the legal system, and policy makers” (Wikipedia, 2018), making it a culturally powerful document.

In DSM-5, Anorexia Nervosa (anorexia), Bulimia Nervosa (bulimia) and Binge-Eating Disorder are the three eating disorders that have full diagnostic criteria. Two categories exist for eating disorders that do not meet the diagnostic criteria for the three main disorders: Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED). The DSM explains that OSFED is a category to be used “when the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding and eating disorder (e.g. bulimia nervosa of low frequency)” (DSM-5, 2013). This category does not seem to include the possibility of emergent disorders such as orthorexia, an eating disorder that has distinct symptoms.

It also important to note that I have excluded some of the Feeding and Eating Disorders that appear in the DSM-5. In the above table, I have included only eating behaviors that are part of a “culturally supported or socially normative practice” (DSM-5, 2013) and excluded all disorders that do not have a socio-cultural element. These eating disorders are characterized by purely disordered eating such as

“eating non-nutritive, non-food substances” (American Psychiatric Association, 2018)(e.g.: glue, paper, etc.) as is the case with Pica, “repeated regurgitation of food which “may re-chewed, re-swallowed or spit out” (American Psychiatric Association, 2018) as with Rumination Disorder, or avoiding foods “based on sensory characteristics” (American Psychiatric Association, 2018) as with Avoidant/Restrictive Food Intake Disorder. These eating disorders are often present in individuals who are suffering from another psychiatric disorder; they do not have a body image component and are not linked to cultural pressure to achieve an ideal body type.

According to the DSM-5, anorexia, bulimia, binge-eating disorder, Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED), “despite a number of common psychological and behavioural features, the disorders differ substantially in clinical course, outcome and treatment needs” (DSM-5, 2013, p.329). However, a common thread in this group of eating disorders is the role of culture in the development and maintenance of weight and eating issues. For example, in the *Risk and Prognostic Factors* section for anorexia the DSM-5 states that “historical and cross-cultural variability in the prevalence of anorexia nervosa supports its association with cultures and settings in which thinness is valued” (DSM-5, 2013, p. 342). For bulimia, an “internalization of a thin body ideal has been found to increase risk for developing weight concerns, which in turn increases the risk for the development of bulimia nervosa” (DSM-5, 2013, p. 348). Other than its occurrence in “most industrialized countries”, no culture-related diagnostic issues are mentioned for binge-eating disorder, likely due to its recent inclusion in the DSM-5 as a distinct disorder in 2013 (American Psychiatric Association, 2018). For the purposes of this research, which is interested in the potential role of social work in the recovery process from an eating disorder in community settings in Quebec, I will focus exclusively on eating disorders that have a socio-cultural component, including those that are not included in the DSM-5.

Finally, the review of literature on the subject of eating disorders and the DSM has revealed an important and yet unresolved issue with the diagnostic criteria for eating disorders. Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED), the last two diagnoses in the Feeding and Eating Disorder chapter of the DSM-5, would appear to be the most likely categories for

emergent and sub-clinical disorders, as they act as a “catch-all” for eating disorders that “cause clinically significant distress or impairment in social, occupational, or other important areas of functioning” (DSM, 2013) but do not meet the full criteria for the other disorders. In previous editions of the DSM, these categories were represented by Eating Disorders Not Otherwise Specified (EDNOS). However, contrary to the pages of description for the three distinct eating disorders, a very short description is given for Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED), offering little information to practitioners who may encounter a patient living with an emergent or subclinical eating disorder. OSFED, UFED and the previous term EDNOS (Eating Disorder Not Otherwise Specified) have been called the “diagnostic wastebasket” (Myers & Wiman, 2014) of the DSM, as these diagnoses are vague and do not translate into specialized treatment or services. The limits the OSFED/UFED and EDNOS diagnoses is particularly concerning when coupled with the fact that “research demonstrates that most disorders identified in community settings would be classified as Eating Disorder NOS [Not Otherwise Specified][EDNOS]” (Simblett, 2013, p. 123). Furthermore, it has been “estimated that over 50% of clients diagnosed with an eating disorder using the DSM-IV criteria are diagnosed with the residual diagnosis of EDNOS” (Myers & Wiman, 2014, p. 87). This number may have decreased somewhat due to the inclusion of binge-eating disorder in DSM-5, however it is troubling to consider that a significant number of people living with eating disorders are relegated to a diagnostic category that effectively leads nowhere in terms of appropriate support and treatment.

1.3 The Power of the DSM

It can be easy to forget that the DSM is a cultural construct, as it is such a powerful one. Commonly referred to as the “bible of psychiatry” (First, 2016) the DSM’s purpose is to “provide a common language for clinicians to communicate about their patients and establish consistent and reliable diagnoses that can be used in the research of mental disorders” (American Psychiatric Association, 2017). First published in 1952 with a description of 102 disorders, this document has come to dominate the field of mental health and mental health care in the United States and beyond, describing 297 different disorders in its latest edition (Simblett, 2013, p. 115). Translated into 13 languages, each edition of the DSM has sold over a million copies (First, 2016) making it the international standard for diagnosing mental illness.

Psychiatrist Glenn Simblett (2016) asserts that “in a span of 60 years, DSM has come to textualize the dominant discourse on the nature of mental illness for a large number of mental health practitioners around the world” (Simblett, 2016, p. 115). Providing a common language and set of criteria for mental illnesses has had the advantage of standardizing treatments, based on research evidence (Simblett, 2013, p. 123) and legitimizing conditions that might have otherwise been dismissed. For Simblett, the “DSM’s apparently unshakeable dominance over mental health professionals’ ways of conceiving and categorizing human experience and distress” (Simblett, 2016, p.115) has also be deeply problematic as this document has become intrinsically linked to research, access to mental health care and the medical insurance industry (Simblett, 2013; The Economist, 2013). In short, if there is no DSM diagnosis there is no research, limited access to specialized mental health care and denial of insurance coverage for services and treatments. For people living with eating disorders that do not meet specific diagnostic criteria, the DSM effectively acts as a gatekeeper to mental health services and insurance coverage.

In a post-structuralist perspective, Simblett aptly asserts that the “DSM [is] a textual codification of power/knowledge that creates a version of reality, individuality and what is known about the nature of mental illness. But only one possible version” (Simblett, 2013, p. 116). This codification is neither stable, nor without controversy. Major changes have been made to the DSM in the years since it was first introduced, reflecting changes in cultural and social values. The inclusion of homosexuality in the first three editions of the DSM being the most salient example of these shifts (Drescher, 2015). The same has been true for eating disorders, anorexia being the first eating disorder to be included as a distinct disorder in 1980 (DSM-III), followed by bulimia in 1987 (revised edition of DSM-III) and finally binge-eating disorder in 2013 (Myers & Wiman, 2014, p. 87). The diagnostic criteria for all three disorders has evolved over the years, a reminder that the DSM is significant both as a cultural and a scientific document, whose contents are in constant evolution.

Finally, the DSM has played an important role in claiming eating disorders as a psychiatric problem requiring psychiatric, medical and psychological treatments and services. In some ways, diagnostic criteria has made the experiences of people living with eating disorders legitimate and paved the way for research, treatment programs and the training of specialized health professionals. However, for

Simblett (2013) as well as many feminist authors and researchers (Arnaiz, 2009; Black, 2003, 2003; Gremillion, 2002; Malson, 2003; Wilson, 2004), “the required measurement practices to establish the diagnostic category are diminishing of the person, and, potentially, strongly supportive of the eating disorder” (Simblett, 2013, p. 123). In a hospital setting, these practices include frequent weighing, counting calories to make sure a patient maintains their weight, quantifying purging and other compensatory behaviors, limiting the number of minutes or hours that a person can exercise per day, etc (Arnaiz, 2009; Gremillion, 2002; Kendall & Hugman, 2013). After spending more than a year doing an ethnographic study in a specialized hospital program for eating disorders, Helen Gremillion (2002) confirms that “one of the reasons anorexia is so difficult to cure is because treatment practices re-create forms of bodily control that are already defining features of anorexia” (Gremillion, 2002, p. 390).

Though the DSM does not provide treatment guidelines, treatment and research are based on its criteria, which are consistent with the biomedical model of treatment; focus on is placed on treating symptoms and an overall objective of finding a cure (Gremillion, 2002). The review of literature on the subject of eating disorders was consistent with this view; an overwhelming majority of the articles written on the subject of eating disorders use the DSM as a starting point for research design and focus on clinical samples, as they exhibit the most severe symptoms. Absent are the voices of those who have not sought, or had access to, highly specialized treatment. According to Mitchison et al. (2016), an estimated “75% of those who suffer from an eating disorder never seek treatment” (Mitchison et al., 2016, p. 2), which means that the current research is focused disproportionately on a fraction of the affected population.

1.4 Etiology of Eating Disorders

There is considerable debate as to why eating disorders occur and how long these disorders have existed. An overwhelming majority of the literature on the subject is dedicated to anorexia, as it is the oldest recorded eating disorder. Wilson (2004) affirms that the term “Anorexia Nervosa” was coined in 1874 by Dr. William Gull, who could not identify the cause of dramatic weight loss in some of his female patients (Wilson, 2004, p. 152). Before that time, Wilson notes that “historical accounts of self-starvation are varied and reveal the tensions between religious, magical, and scientific interpretations of fasting

behavior” (Wilson, 2004, p. 152) suggesting that the origins of anorexia, like other eating disorders, have always been rooted in cultural practices as well as in the body. Correspondingly, Gremillion (2002) states that “no clinical study to date has been able to determine an etiology for anorexia that can be framed in terms of an “objective” psychological or biological cause (every physiological disturbance associated with anorexia can be shown to be secondary to extreme weight loss)” (Gremillion, 2002, p. 382).

Feminist authors take the position that the medicalization of eating disorders locates pathology in the individual female body instead of in the social and political context in which the problem occurs (Arnaiz, 2009; Black, 2003; Bordo, 2003; Gremillion, 2002; Wilson, 2004, p. 151). According to Wilson (2004), “not only is a psychiatric discourse inadequate in offering understanding about women and self-starvation (anorexia), this paradigm also contributes to the oppression of women through social control, surveillance and it’s high regard for ‘objective’ expertise over personal ‘lived’ experience” (Wilson, 2004, p. 151). For many feminist authors and researchers, women’s bodies (and their reproductive capabilities) are at the center of an ongoing cultural power struggle that seeks to dominate them in the most intimate of spheres (Arnaiz, 2009; Black, 2003; Bordo, 2003; Vinette, 2001). As cultural standards of beauty are constantly evolving, so are eating disorders either as an expression of the crystallization of culture or as an act of resistance (Bordo, 2003; Gilbert & Thompson, 1996; Wilson, 2004). As such, the feminist perspective does not identify a specific moment when this struggle began but suggests that women’s bodies have been the site a power struggle throughout history.

New research does suggest the possibility of a genetic component of eating disorder etiology. The DSM-5 states that “there is an increased risk of anorexia nervosa and bulimia nervosa among first-degree relatives of the individuals with this disorder” (American Psychiatric Association, 2018), however it remains unclear how much of this tendency can be attributed to “nurture” and how much may be accredited to genetic predisposition. In either case, there is consensus that eating disorders are complex and multifactorial, which in itself problematizes the current unilateral psychiatric response to them.

1.5 A Complicated Picture of Eating Disorders in North America

There are many statistics that attempt to paint a portrait of eating disorders in North America, though there are several issues that complicate these numbers. Firstly, a Public Health Agency of Canada report published in 2002 found that “women were more likely than men to report an eating disorder: 0.8% versus 0.2%, respectively” (Public Health Agency of Canada, 2002). This tendency may be related to the fact that women traditionally seek help earlier and more often than men, a trend which can be linked to cultural ideals of masculinity which encourage men to be strong and self-sufficient even in the face of life-threatening illness (Bunnell, 2016, p. 100). In addition, women are more likely to meet the diagnostic criteria for an eating disorder, even if they have not received a formal diagnosis. For example, the same Canadian report found that “0.5% of Canadians aged 15 years and over reported that they had been diagnosed with an eating disorder in the previous 12 months” however, “through a separate set of questions, the survey also found that 1.7% of Canadians aged 15 and over reported symptoms that met the 12-month criteria for an eating attitude problem” (Public Health Agency of Canada, 2002). In the eating disorder literature, it is common for researchers to administer eating disorder assessment tools in non-clinical settings such as university campuses in order to estimate the prevalence of eating disorders. Often the studies are limited to women aged 18-25, a practice which reinforces the archetype of the young, white, affluent woman who exhibits disordered eating (Gremillion, 2002; Leblanc et al., 2014).

Secondly, statistics are often limited to a select group of eating disorders. Anorexia and bulimia are the most widely known and researched eating disorders, as they have been in the DSM the longest (1980 and 1987 respectively). Surveys are often constructed to identify one or both of these eating disorders, leaving out binge-eating disorder, which was added as a distinct eating disorder in 2013. This fact is particularly disturbing as 2007 study found that, in the United States, « binge-eating disorder is more than three times more common than anorexia and bulimia combined » (Hudson, Hiripi, Pope, & Kessler, 2007; National Eating Disorder Association, 2018).

As with binge-eating disorder, statistics gathered also fail to consider Other Specified Feeding or Eating Disorders (OSFED) or Unspecified Feeding or Eating Disorders (UFED) (formerly EDNOS), categories which include subclinical and emergent eating disorders that have no specific diagnostic criteria. This

blind spot in data collection must be taken into account given that “in community clinics, the majority of individuals were historically diagnosed with EDNOS” (Myers & Wiman, 2014; National Eating Disorder Association, 2018). What’s more, people in this “catch-all” eating disorder category were “just as likely to die as a result of their eating disorder as people with anorexia and bulimia” (National Eating Disorder Association, 2018).

Thirdly, it is important to consider that eating disorders are complex and often long-term conditions that are not always medicalized. Many people who live with an eating disorder manage to keep their struggle with food and body image secret in their daily lives, and can appear to be functioning normally (professionally, academically and within their relationships) for many years before seeking treatment. A 2011 systemic review of American and Australian literature on the unmet need for treatment of eating disorders, confirms that, on average, people living with eating disorders seek treatment after a long delay: “a median of 10 years for bulimia and 15 years for anorexia” (Hart et al., 2011, p. 728). Together with the stigma, shame and secrecy that are inherent in eating disorders, underreporting may be a problem generally (Hart et al., 2011; Leblanc et al., 2014). This is especially true for people living with disorders that are less visible such as bulimia (the person often maintains a normal or slightly above normal body weight) or binge-eating disorder (the person is seen as overweight or obese, not as a person with an eating disorder) or some of the emerging eating disorders (bigorexia/muscle dysmorphia, orthorexia, etc.) which have yet to be formally included in the DSM and thus remain invisible to most first-line health care professionals.

Fourthly, strictness in the application of diagnostic criteria in research design can be a barrier to accurate reporting on the eating disorder population. According to the National Eating Disorders Association (NEDA) (2018), variations in the strictness of criteria for anorexia and bulimia accounted for “lower prevalence estimates” in “older data and [data] from other countries” such as the UK and Europe (National Eating Disorder Association, 2018). The National Eating Disorder Association asserts that “more recent studies in the US have used broader definitions of eating disorders that more accurately reflect the range of disorders that occur, resulting in higher prevalence of eating disorders” (National Eating Disorder Association, 2018).

In addition, diagnostic criteria for certain disorders have been found to be gendered "female", thus excluding men from the eating disorder portrait. In the case of anorexia, one of the long-standing diagnostic criteria for the disorder was amenorrhea (the absence of menstruation). This criteria was present in DSM-IV and previous editions, however it has been removed in the DSM-5 (2013) (Myers & Wiman, 2014, p. 87). Renowned Quebec eating disorder specialist Dr. Jean Wilkins (2007) wrote that he deems a case of anorexia serious when he identifies the presence of "The four "A's"": « *A pour anorexia (conduite alimentaire restrictive), A pour amaigrissement, A pour amenorrhée, A pour adolescence* » (Wilkins, 2007, p. 72) making it very clear that he views anorexia as an exclusively female condition. This element of the diagnostic criteria is clearly gendered and may contribute to the overwhelming representation of women in this category: 90% women (Government of Canada, 2006; Gremillion, 2002; Wilson, 2004).

More recent research suggests that men make up to "33% of cases of anorexia and bulimia diagnoses" (Griffiths et al., 2015, p. 108; Hudson et al., 2007). These numbers may still be low, due to the fact that "the gold standard assessment inventories, such as eating disorder examination (EDE), have been normed on female populations" (Bunnell, 2016, p. 100) thus EDE scores for men often "underestimate their degree of eating pathology" (Bunnell, 2016, p. 100). Of course, the increase in males living with eating disorders does not diminish the link between cultural pressure to be thin, that has been specific to women in North America since the 1970's and the parallel rise in eating disorders since then (Gremillion, 2001, p.381, Wilson, 2004, p.151). New research simply includes men in the cultural obsession with eating and body control.

Finally, in keeping with issues of gender, it would seem that eating disorders are widely viewed as a women's issue, both within the medical and psychiatric professions and within popular North American culture (Bunnell, 2016, p.100; Griffiths et al., 2015, p. 100; Leblanc et al., 2014; National Eating Disorder Association, 2018). As such, men may feel stigmatized if they are suffering from an eating disorder and may be hesitant to report (Bunnell, 2016; Griffiths et al., 2015, p. 108). Bunnell (2016) confirms that "masculinity norms foster and support the stigma men with eating disorders face by reinforcing the fear

that these men will be seen as less masculine because they have a “female disorder” and because they are seeking assistance” (Bunnell, 2016, p. 101). Furthermore, it has been shown that medical professionals are less likely to identify an eating disorder in male patients, which exacerbates underreporting (Bunnell, 2016, p. 100). The apparent invisibility of men is also present in research design, which often excludes them “a priori” (Hart et al., 2011, p. 733). A 2011 review of literature on treatment seeking for eating disorders identified that men, the very young, and the elderly were excluded as participants in all but one of the 14 American and Australian studies reviewed (Hart et al., 2011, p. 733). The result is that men often live their eating disorders in total isolation, or wait until their situation is dangerous or life-threatening before seeking help. NEDA (2016) affirms that “males living with anorexia nervosa are at a higher risk of dying; in part due to the fact that they are often diagnosed later since many people assume that males don’t have eating disorders” (National Eating Disorder Association, 2018).

While it is true that Western women live in a cultural context where “thinness, eating and femininity are intricately linked” (Wilson, 2004, p.154), men are increasingly called to perform their gender through the muscular body and muscularity-oriented eating (Bunnell, 2016; Griffiths et al., 2015, p. 108). Griffiths and Murray (2015) posit: “the masculinity hypothesis proposes that conformity to masculine gender roles [dominance, power, status, confidence, success, the exercise of physical and emotion self-control] is a risk factor for muscularity-oriented body image pathology in males” (Griffiths et al., 2015, p. 108), as muscularity offers a men a way to showcase their masculinity through fitness and the body.

More recent American eating disorder studies show that males represent “approximately 40% of those with binge-eating disorder” (Government of Canada, 2006; National Eating Disorder Association, 2018) and 90% of those experiencing muscle dysmorphia (Griffiths et al., 2015, p. 108). Bunnell (2016) submits that “the culture is more accepting of binge-eating in men” (Bunnell, 2016, p. 99) on the one hand, and congratulates those who “overexercise, [use] dietary restriction or highly disciplined eating” (Bunnell, 2016, p. 99) on the other. These findings problematize the “oft-quoted statement that men account for 1 in 10 eating disorder diagnoses” (Griffiths et al, 2014, p.108) and reveal that men are also struggling with weight and body issues within a complex and gendered cultural context.

Finally, the review of eating disorder literature also revealed two trends that, together, limit the portrait of eating disorders in North America: who is studied and in what context. An overwhelming majority of eating disorder studies are conducted in one of two contexts: specialized hospital units or university campuses (Hart et al., 2011; J. Slevec & Tiggemann, 2011; Gremillion, 2002). In both cases, the context of data collection contributes to a limited view of who lives with eating disorders (mainly young women with anorexia or bulimia (Leblanc et al., 2014), which in turn limits treatment efficacy. Research has likely been steered by the DSM's conclusion that anorexia and bulimia "rarely begins before puberty or after 40" (American Psychiatric Association, 2018), though the DSM-5 also highlights the highly variable "course and outcome of anorexia" (American Psychiatric Association, 2018) and the persistence of bulimia "for at least several years in a high percentage of clinical samples" (American Psychiatric Association, 2018). Thus, even if onset is less likely to occur in older populations, the struggle with an eating disorder can extend beyond adolescence or young adulthood into middle-age and beyond. In the case of binge-eating disorder, the DSM-5 asserts that though "little is known about the development of binge-eating disorder", "individuals with binge-eating disorder who seek treatment usually are older than individuals with either bulimia or anorexia who seek treatment" (American Psychiatric Association, 2018). Similarly, Slevec and Tiggemann (2011) report that "a considerable number of studies have found that middle-aged women commonly report disordered eating attitudes and behaviors" (J. Slevec & Tiggemann, 2011, p. 617) and that older women are exposed to the same sociocultural variables "thought to promote eating pathology": "family, peers and the media" (J. Slevec & Tiggemann, 2011, p. 618). The result is that "much less is known about the factors that contribute to disordered eating in middle-aged women (aged 35-55 years)" (J. Slevec & Tiggemann, 2011, p. 617), the very young, the elderly and men (Hart et al., 2011, p. 733) making it difficult to create interventions designed for these groups.

1.6 Eating Disorders in Canada, in Quebec

Bearing in mind limits of eating disorder statistics, it is apparent that truly accurate statistics on the number of people living with eating disorders in any North American region are simply not available. To

situate this research in a Quebec and Canadian context, some statistics will be discussed, though they must be considered as incomplete.

The 2006 report “The Human Face of Mental Health and Mental Illness in Canada”, states that “approximately 3% of [Canadian] women will be affected by an eating disorder in their lifetime” (Government of Canada, 2006). This study only included anorexia, bulimia and binge-eating disorder in its data collection and did not offer a similar statistic for men. The report focused almost exclusively on females living with eating disorders and studies which examined how women and girls are affected by “images of female beauty portrayed in magazines and on TV [which] are often unrealistic and unattainable” (Government of Canada, 2006) going so far as to list “media imagery concerning girls and women” (Government of Canada, 2006) as a social risk factor for developing an eating disorder. No equivalent social factor was mentioned for men and boys, though the study did find that “boys across all grades were more likely than girls to indicate that they were too thin rather than too fat” (Government of Canada, 2006). Instead of linking this trend to an increasing cultural association between masculinity and muscle mass (Griffiths et al., 2015), this data was used to imply that men and boys feel less pressure to shape and control their bodies (Government of Canada, 2006). When coupled with the findings of an Ontario study that found “4% of boys in grades nine and ten reported anabolic steroid use” (Boyce, 2004 cited in National Eating Disorder Information Center, 2014), boys reporting that they are too thin points to another trend: “that body preoccupation and attempts to alter one’s body are issues affecting men and women” (Boyce, 2004 cited in National Eating Disorder Information Center, 2014).

Some of the most up to date Canadian eating disorder statistics are found in The Standing Committee on the Status of Women’s 2014 report “Eating Disorders Among Girls and Women in Canada”. The committee states that “600,000 to 990,000 Canadians may meet the diagnostic criteria for an eating disorder, primarily anorexia nervosa, bulimia nervosa, or binge-eating disorder” (Leblanc et al., 2014, p. 1). The committee suggests that 80% of those individuals are women and girls, a significant statistic as most eating disorder statistics suggest that women make up 90% or more of this population (Bunnell, 2016; Wilson, 2004). This number is likely reflective of the inclusion of binge-eating disorder, which

affects almost as many men as women (Bunnell, 2016; Government of Canada, 2006; Public Health Agency of Canada, 2002).

Specific to Quebec, a 2002 Statistics Canada study found that 116 000 Quebecoise aged 15 and up presented a significant number of eating disorder symptoms (Public Health Agency of Canada, 2002). *Anorexie et Boulimie Québec* (ANEB) a regional eating disorder organization, reports that in 2011, 65 000 women and girls in Québec were living with anorexia and bulimia (ANEB, 2011). These numbers do not provide an accurate portrait of eating disorders in Quebec, but they suggest that eating disorders are a significant issue in a province which has seven specialized hospital programs for eating disorders: *Institut Universitaire en Santé Mentale Douglas*, *CHU Ste-Justine*, *L'Hôpital de Montréal pour enfants*, *Centre Universitaire de Santé McGill*, *CHUS Fleurimont (pédiatrie)*, *CHUS Hôtel-Dieu (clinique externe)*, *Programme d'intervention des troubles des conduits alimentaires (PITCA) (CIUSS de la Capitale-Nationale)* and a transdisciplinary program devoted to the subject at *Université du Québec à Trois Rivières (Programme d'intervention intégratif, dimensionnel et transdisciplinaire des troubles du comportement alimentaire)* (Université du Québec à Trois-Rivières, 2017; CIUSS Centre hospitalier universitaire de Sherbrooke, 2018; Léonard, 2015).

What the research does suggest is that eating disorders can “affect people of all ages, genders, sexual orientations, races and ethnicities” (Leblanc et al., 2014; National Eating Disorder Association, 2018) and also of different social classes (Black, 2003). The numbers also reveal that eating disorder symptoms are beginning earlier in both males and females (Government of Canada, 2006; National Eating Disorder Association, 2018). Unsurprisingly, studies are also showing an increase in body dissatisfaction in school-aged girls and boys, that tends to increase with age (Government of Canada, 2006; National Eating Disorder Association, 2018; National Eating Disorder Information Center, 2014). Furthermore, research has established that, of the three eating disorders with specific diagnostic criteria (anorexia, bulimia, binge-eating disorder), binge-eating disorder is more common than anorexia and bulimia (Hudson et al., 2007, p. 8) even though it is the newest addition to the DSM and is often confused with obesity (National Eating Disorder Association, 2018).

Finally, studies indicate that men are increasingly affected by eating disorders, accounting for almost half of the people living with binge-eating disorder (Bunnell, 2016; Government of Canada, 2006; Leblanc et al., 2014; National Eating Disorder Association, 2018; National Eating Disorder Information Center, 2014), a third of anorexia and bulimia combined, and 90% of those living with bigorexia/muscle dysmorphia (Bunnell, 2016; Griffiths et al., 2015). Though most studies suggest that rates of anorexia and bulimia have remained stable over the past two decades (National Eating Disorder Association, 2018), it would appear that Eating Disorders Not Otherwise Specified (EDNOS), Other Specified Feeding and Eating Disorders (OSFED), and Unspecified Feeding and Eating Disorders (UFED), the “catch-all” eating disorder categories have seen increases for both men and women (National Eating Disorder Association, 2018), which may be due to the fact that so many emergent eating disorders are yet to be included in the DSM.

1.7 Gaps in Treatment

Eating disorders are complex disorders due to the fact that they are caused by a combination of biological, psychological and social factors (American Psychiatric Association, 2018; National Eating Disorder Association, 2018) that manifest in a variety of ways. There are some regional differences in treatment for eating disorders, but the psychiatric treatment model is both dominant and problematic, according to research.

Firstly, as treatment and specialization have relied on psychiatric diagnoses, the eating disorders that have been included in the DSM the longest have the most developed treatment programs and services. Thus, anorexia is the eating disorder with the most established and available treatments, followed by bulimia. For this reason, it is shocking that “anorexia nervosa has the highest mortality rate of any psychiatric illness” (Gremillion, 2002; National Eating Disorder Information Center, 2014; Wilson, 2004). It is estimated that between 10% and 15% of people with anorexia die (Government of Canada, 2006; Leblanc et al., 2014; Public Health Agency of Canada, 2002), usually due to side effects of self-starvation (e.g.: organ failure) or suicide (Wilson, 2004, p.151). In addition, “anorexia has one of the highest relapse rates of any psychiatric illness” (Kennedy & Garfinkel, 1992 cited in Wilson, 2004), and represents the

“third most common chronic disease among young people, after asthma and type 1 diabetes”(National Eating Disorder Association, 2018; National Eating Disorder Information Center, 2014). Mortality rates for bulimia are estimated at 5% (Leblanc et al., 2014, p. 1). Together, anorexia and bulimia account for “an estimated 1,000 to 1,500 Canadians per year” (Leblanc et al., 2014, p. 1) though this number is thought to be low as eating disorders are not always recorded as cause of death (Leblanc et al., 2014, p. 1). The high mortality rates and chronicity of these disorders make it clear that the current response to anorexia and bulimia is lacking.

In treatment models for anorexia and bulimia there is a strong focus on nutrition and behavior modification, cognitive behavior therapy (CBT) being the dominant approach to eating disorders (Maier, 2015, p. 154). According to a 2006 Government of Canada report, “nutritional stabilization has replaced the former practice that emphasized long term psychotherapy and potentially harmful medications; once an individual’s nutrition status has improved a variety of psychotherapies can improve the illness” (Government of Canada, 2006). Indeed, there are no known pharmaceutical treatments for anorexia, although antidepressants have been used to treat symptoms of bulimia (Government of Canada, 2006). Curiously, even though this same report identifies social factors in the development of an eating disorder (gender, media imagery, cultural differences and sex difference affecting ideal weight images and calculations, etc), there are no proposed interventions that address these causes. Many feminist authors have called attention the fact that eating disorders have been framed as an individual pathology, when the cultural context within which they exist is as important as the biological and psychological aspects of the disorders (Arnaiz, 2009; Black, 2003; Bordo, 2003; Gremillion, 2002; Maier, 2015; Malson, 2003; Wilson, 2004) As it stands, eating disorder expertise has been dominated by the psychiatric profession, despite the low success rates for its most developed treatments.

Secondly, little specialized treatment for binge-eating disorder, Other Specified Feeding or Eating Disorders (OSFED), Unspecified Feeding or Eating Disorders (UFED) and emergent eating disorders is available. Due to its short time as a formal disorder in the DSM-5, binge-eating disorder, though not a new disorder, has few specialized, publicly funded services in Canada. In addition, a review of treatment seeking literature reveals that people seeking medical help for eating disorders were overwhelmingly

offered weight-loss treatment instead of mental health care (Hart et al., 2011, p. 733), which points to a generalized incomprehension of eating disorders and a powerful cultural stigma around fat (Melcher & Bostwick Jr., 1998; Rail et al., 2010; Vinette, 2001).

What's more, individuals living with Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED) OSFED are often excluded from existing specialized treatment due to the fact that meeting specific diagnostic criteria is generally a prerequisite for receiving most publicly funded services (Leblanc et al., 2014; Simblett, 2013). This fact is disturbing when considering that OSFED/UFED (formerly EDNOS) represent the largest category of eating disorders diagnosed in community clinics in the United States (Myers & Wiman, 2014). It begs the question: Where do these people find help? OSFED/UFED (formerly EDNOS) cases appear to be an important segment of the eating disorder population with few options for treatment (National Eating Disorder Association, 2018).

1.8 Social Causes, Social Consequences

A 2002 Public Health Agency of Canada report on eating disorders states that “existing data provides a very limited profile of eating disorders in Canada” and that there is need to complete hospitalization data with other sources of information (Public Health Agency of Canada, 2002). This study noted that “most treatment of eating disorders takes place in the community” (Public Health Agency of Canada, 2002). The list of treatments include: “monitoring of physical symptoms, behavioral therapy, cognitive therapy, body image therapy, nutritional counselling, education, medication (if necessary)” (Public Health Agency of Canada, 2002). As with all descriptions of eating disorders, the Public Health Agency of Canada report lists two categories of social risk factors for developing an eating disorder (see table below). However, none of the medical, psychiatric, nutritional or educational interventions proposed in this and other studies on the subject of eating disorders seem to address the social issues that underpin the disorders.

Box 2 – Social Factors Related to Eating Disorders

Eating Specific Social Factors	Generalized Social Factors
<ul style="list-style-type: none"> • Maladaptive family attitudes to eating, weight • Peer group weight concerns • Pressure to be thin • Body-relevant insults, teasing • Specific pressure to control weight (e.g. through ballet, athletic pursuits) • Maladaptive cultural values assigned to the body 	<ul style="list-style-type: none"> • Family dysfunction • Aversive peer experiences • Social values detrimental to stable, positive self-image • Destabilizing social change • Values assigned to gender • Social isolation • Poor support network • Impediments to means of self-definition

Source: Public Health Agency of Canada. (2002). *A Report on Mental Illnesses in Canada*. Retrieved from Health Canada website: <https://www.canada.ca/en/public-health/services/reports-publications/report-on-mental-illnesses-canada/eating-disorders.html>

1. 9 Social Work and Eating Disorders: A Short Review of Literature

In reviewing the eating disorder literature, it is clear that the social aspects of the problem represent an unmet need in the current treatment model. Could social work fill this gap in the research and treatment of eating disorders? An initial review of eating disorder literature revealed little or no specific role for social workers in the prevention, treatment or recovery from an eating disorder. However, social factors that cause, maintain and exacerbate eating disorders were cited repeatedly, including in the DSM's *Risk and Prognostic Factors* for both anorexia and bulimia (American Psychiatric Association, 2018). According to Arnaiz (2015), clinicians agree that "psychological and physical aspects should be treated with a combination of nutritional rehabilitation, weight gain and long term psychotherapy. However, very few proposals are made to address the sociocultural aspects [of eating disorders]" (Arnaiz, 2009, p. 192).

The limited scope of current research and poor outcomes of psychiatric treatments for eating disorders, in addition to the seemingly ignored socio-cultural underpinnings of this problem, suggest that social work may have a unique role to play in both the treatment and prevention of eating disorders. Arnaiz (2015) comes to a similar conclusion in her ethnographic study of nutritional treatment for eating disorders: “If the medical theories have made anything clear, it is that we are facing ailments that are highly malleable, and that their signs and symptoms vary under changing social circumstances” (Arnaiz, 2009, p. 196). Social workers are trained to “acknowledge the impact of forces such as racism, family dynamics, spirituality, sexuality, gender roles and a history of trauma” (Dean & Rowan, 2014, p. 222), all of which are linked to eating disorders in the current psychiatric literature. A social work view of eating disorders situates the individual within larger social systems, with a focus on the individual and environmental strengths that can improve quality of life (Dean & Rowan, 2014). These skills are particularly valuable when considering the poor quality of life reported by the eating disorder population generally (Hart et al., 2011; Mitchison et al., 2016) and the importance of quality of life in the recovery from an eating disorder (Mitchison et al., 2016). Even so, a review of social work literature on the subject of eating disorders reveals that the social work profession has struggled to situate itself with regards to this problem.

Three distinct trends emerge in the review of the social work literature related to eating disorders. Firstly, social work practice as part of a “multidisciplinary, multidimensional approach” (Shekter-Wolfson, Woodside, & Lackstrom, 1997, p. 17) is the most common role attributed to the profession. In general, this approach “recommends treating four areas: the medico-psychiatric, the psychological-educational, the environmental and the familial” (Arnaiz, 2009, p. 198), though most eating disorder treatment focuses on the first two areas disproportionately (Arnaiz, 2009; Gremillion, 2002).

In a 1997 review of social work literature on the subject of anorexia and bulimia, Canadian researchers from The Toronto General Hospital suggest that “the largest contribution by social work is in the area of family therapy” (Shekter-Wolfson et al., 1997, p. 7), followed by group work (psycho-educational, family), and individual therapy (Shekter-Wolfson et al., 1997, p. 7). It must be noted that this review of literature is focused, as is much of the eating disorder literature, on hospital-based treatment programs that are psychiatric in nature. As such, the role of the social worker is molded to fit the psychiatric

treatment model. The researchers note, that “sadly lacking is information about the larger social context in which eating disorders develop; and there is a lack of research especially in the area of [social work] treatment effectiveness” (Shekter-Wolfson et al., 1997, p. 10). Though this research is somewhat dated, it reflects a prevailing notion that social workers can be pseudo-therapists or pseudo-psychoeducators that work within the psychiatric treatment model of eating disorders (Kendall & Hugman, 2013). In other words, none of the specificities or distinct approaches of the social work profession are applied to the problem of eating disorders. Dean & Rowan (2014) qualify this type of situation as “professional drift, which is the neglect of a profession’s traditional purpose and functions in favor of activities associated with another professional discipline” (Dean & Rowan, 2014, p. 226). Jennifer Wilson (2004) also found that “social workers have had little influence over the construction and meanings or service delivery models” (Wilson, 2004, p. 152) with regards to self-starvation (anorexia), which is the most medicalized eating disorder of the three described in DSM-5 (Gremillion, 2002). In a 2004 Australian study of women and self-starvation (anorexia), Wilson concluded that “[social workers] are also largely absent from the research and theorizing about self-starvation, particularly research that explores the socio-political context in which this issue develops” (Wilson, 2004, p. 152).

Secondly, more recent social work literature has sought to bridge the gap between the psychological and the social through a socio-therapeutic model (Hertz, Addad, & Ronel, 2012, p. 120). A 2016 special issue of *Clinical Social Work Journal* was devoted to the topic of eating disorders and body dissatisfaction: *Body Meets Mind: Eating Disorders and Body Image – A Twenty-first Century Perspective*. The collection of articles in this issue represent an emergent trend in social work which combines social theory, feminist theory (embodiment, intersubjectivity) and interpersonal theory (object relations theory, attachment theory, and developmental theory) to understand the interplay between the relational issues that underpin eating disorders and the larger social context (Daly, 2016; Petrucelli, 2016; Starkman, 2016). In general, this type of “treatment” is not solely focused on individual pathology, but is also an exploration of the familial/affective and socio-cultural factors that cause and maintain eating disorders. Jean Petrucelli (2016) describes this work as assisting people who live with eating disorders in a process of “developing alternative skills to assist them in the physical, psychological and interpersonal/relational changes necessary for health” (Petrucelli, 2016, p. 23) whilst acknowledging the sociocultural context

that promotes and ascribes “value to a virtually unattainable thin physique while stigmatizing fatness” (Daly, 2016, p. 47) for women, especially.

These approaches associate a lack of secure attachment in early childhood with future difficulties in “socio-emotional functioning” (Starkman, 2016, p. 59), which can lead to a maladaptive use of food to manage difficult emotions or trauma (Petrucci, 2016, p. 20). Insecure attachment is also associated with vulnerability to gendered sociocultural messages about food and the body that are omnipresent in visual culture (Daly, 2016, p. 51). What’s more, this approach views bodies, family and culture as indissociable (Daly, 2016, p. 51). Daly (2016) explains that the family and, more specifically, the bodies of caregivers, act as “culture carriers” during childhood development through mirroring the cultural expectations to the child” (Daly, 2016, p. 51). Interestingly, this approach acknowledges that social workers/health care professionals are affected by the same sociocultural context of body dissatisfaction as eating disorder patients, which undoubtedly has an effect on their work with this population.

Though this social work approach to eating disorders applies social and feminist theories of the body to the issue of eating disorders, it is clear that psychological theories and the individual therapy model occupy a central role. The role of the socio-cultural context appears to aid the social worker in their understanding of eating disorder development, but the target of the intervention remains the individual or the family system. The fundamental role of peers, the community and other social networks is notably absent in this model, though group work is sometimes cited (Starkman, 2016). As social workers are distinguished from other professionals by their expertise in “enhancing social functioning” (Dean & Rowan, 2014, p. 222), this approach seems to lack some elements of the profession’s social orientation.

Thirdly, the social work literature also includes a category of alternative approaches to eating disorders, which are group and community oriented. Feminist social work approaches are predominant in this category, as they are particularly critical of how women’s bodies and experiences are medicalized (Arnaiz, 2009; Black, 2003; Gremillion, 2002; Vinette, 2001; Wilson, 2004). Though this research may be the closest to social work’s mandate to “focus on how the environment and other influences affect a person’s overall health and well-being” (Dean & Rowan, 2014, p. 222), it is also considered the most

marginal as it situates itself outside the psychiatric model (to varying degrees). In addition, much of this research is qualitative, with a particular emphasis on the voices of social workers and people who live with eating disorders (Black, 2003; Wilson, 2004). Giving importance to women's lived experience is a feminist research strategy that acts "as a way to correct the biases of traditional quantitative methods" (Gilbert & Thompson, 1996, p. 185) that are considered 'objective' and therefore more credible, but fail to put human behavior into context or acknowledge cultural bias inherent in scientific research (Gilbert & Thompson, 1996).

Finally, new psychiatric research has found that quality of life plays a determining role in the development, recovery, and prevention of eating disorders (Mitchison et al., 2016). Quality of life is defined by the World Health Organization as "perceived life satisfaction and role functioning, which is informed both by societal values and norms as well as individual goals and expectations" (The WHOQOL Group, 1993 cited in Mitchison et al., 2016, p.1). A 2016 Australian study found that quality of life was linked to both the development of and recovery from eating disorders. Participants in the study identified "sense of self, mental wellbeing, social skills, leisure, physical health, work/education and relationships [as] the domains of quality of life they perceived as being most impaired by their illness [eating disorder]" (Mitchison et al., 2016, p. p.2). Interestingly, the respondents identified improvement in these same areas as directly related to their recovery (Mitchison et al., 2016, p. 2). This finding is notable not only because it goes beyond the individual pathology perspective of eating disorders, but because its sample was community based and diverse, both in terms of participant's ages and eating disorders (anorexia, bulimia, binge-eating disorder and subthreshold cases of these eating disorders) (Mitchison et al., 2016). The study focused exclusively on women, which is somewhat problematic as it included binge-eating disorder, which affects men almost as much as women (Government of Canada, 2006; National Eating Disorder Association, 2018). Still, these research findings are supportive of a social work approach to eating disorders as the participants rated social and relational aspects of quality of life equal to, and sometimes higher than, the physical aspects of their recovery (Mitchison et al., 2016, p. p.6). Consequently, Mitchison et al. (2016) join the chorus of feminist researchers in calling for "alternative treatment models that reduce focus on core symptoms of eating disorders" (Mitchison et al., 2016, p. 11) in favor of intervention targets that emphasize "personal empowerment and

improvement in quality of life” (Mitchison et al., 2016, p. 11). Social work is a profession that is well positioned to work on “improving life outside the eating disorder” (Mitchison et al., 2016, p. 12) and by doing so fostering recovery in a community setting. Considering that a large segment of the eating disorder population does not seek formal treatment (Hart et al., 2011; Hudson et al., 2007; Mitchison et al., 2016, p. 2), often receiving a general EDNOS/OSFED/UFED diagnosis in a community clinic (Myers & Wiman, 2014; National Eating Disorder Association, 2018) and that “most treatment of eating disorders takes place in the community” (Public Health Agency of Canada, 2002), a shift towards “prioritizing quality of life and reducing the focus on weight in treatment [might] provide a backdoor approach to achieving symptom remission” (Mitchison et al., 2016, p. 11) by using the existing strengths and approaches of the social work profession.

Chapter 2: Theoretical Framework

2.1 Recovery

At its core, the concept of recovery differs from a cure perspective as it is process oriented, and person focused, which are both hallmarks of social work practice (Davidson et al., 2009; OTSTCFQ, 2012; Provencher, 2002). Spaniol et al (1994) define recovery as:

...a process by which people [...] rebuild and further develop personal, social, environmental and spiritual connections in their lives. Recovery is a process of adjusting one's attitudes, feelings, perceptions, and goals in life and a process of self-discovery, self-renewal, and transformation. (Spaniol et al 1994 cited in Provencher, 2002, p. 38)

In her 2002 review of theoretical perspectives of recovery, H el ene L. Provencher (2002) identifies the most salient aspects of this alternative approach in the field of mental health. Above all, the recovery perspective values and draws upon the personal experiences of people in recovery from mental illness (Provencher, 2002). As noted in the previous section, the voices of people living with eating disorders are often eclipsed in the scientific literature by the voices of experts who research and treat them. In keeping with the recovery perspective, this study emphasizes the lived experiences of people who are recovering from an eating disorder.

Provencher's review of recovery literature identifies that recovery is a singular and subjective experience that is informed by an individual's values and goals (Provencher, 2002, p. 35). As such, recovery is not a linear process, but is a unique journey towards well-being as it is defined by the person living with mental illness (which would include eating disorders) (Davidson et al., 2009; Deegan, 1996; Provencher, 2002). Provencher found that the essential elements of recovery, as identified by people living with mental illness, include having power over one's living conditions, the development of life projects that optimize personal and environmental resources, and attaining a state of balance and well-being that is in harmony with an individual's strengths and limits (Provencher, 2002, p. 38). It goes without saying that social workers have a potential role to play in this process, as they are "expert[s] in enhancing social functioning" (Dean & Rowan, 2014, p. 219) who are trained to "focus on how the environment and other influences may affect a person's overall health and well-being" (Dean & Rowan, 2014, p. 222; OTSTCFQ, 2012). The interviews in this study investigate what elements of the research participants recovery were

most supportive, with the ultimate goal of identifying ways that social workers can contribute to this process.

In most eating disorder literature, the term “recovery” is used interchangeably with the term “cure”. The “cure” narrative is dominant in the biomedical perspective of eating disorders; it is defined as the absence of symptoms or a return to a “premorbid state” (Provencher, 2002, p. 38). Being cured of an eating disorder generally refers to the process of attaining weight gain/loss goals and getting disordered eating behaviors (binges, purges, restriction) under control (Arnaiz, 2009; Bordo, 2003; Gremillion, 2002). In the case of anorexia, Gremillion (2002) explains that once a patient reaches and maintains their “target weight” “they are considered “cured”” (Gremillion, 2002, p. 406). In this perspective, the “return to health” (Provencher, 2002, p. 38) is evaluated in purely physiological terms, which ignores the well-documented social and psychological aspects of the eating disorder experience (American Psychiatric Association, 2018; Black, 2003; Mitchison et al., 2016). The cure perspective also fails to account for relapse, which is very common for people living with eating disorders (Kennedy & Garfinkel 1992 cited in Wilson, 2004; Gremillion, 2002). In a cure perspective, relapse would be interpreted as a return to illness, instead of a natural part of the recovery process.

2.1.1 Recovery and Quality of Life

Four dimensions at the “heart of the transformative experience of recovery” (Provencher, 2002, p. 39) were identified by Provencher in her review of literature: « *la redéfinition et l’expansion de soi, la relation à l’espace temporel, le pouvoir d’agir et la relation aux autres* » (Provencher, 2002, p. 39). Each of these dimensions overlap with aspects of quality of life identified as most impaired in Mitchison et al’s 2016 study: sense of self, mental well-being, social skills, physical health, work/education and relationships (Mitchison et al., 2016, p. 1). Mitchison et al. (2016) confirm that alternative interventions that “reduce focus on core symptoms of eating disorders, have reported positive findings” (Mitchison et al., 2016, p. 11) begging the question: “Might prioritizing quality of life and reducing focus on weight in treatment provide a backdoor approach to providing symptom remission?” (Mitchison et al., 2016, p. 11). This study is interested in the diversity of strategies participants have used in their recovery processes. It is

well known that the majority of eating disorders are treated in the community, if formally treated at all (Government of Canada, 2006; Hart et al., 2011; Public Health Agency of Canada, 2002). However, little research has focused on the long-term recovery from an eating disorder. For this reason, participants in this study are recruited through community organizations who offer non-medical services for people living with eating disorders.

Provencher notes that intervention models that support recovery include: valuing reciprocity, taking into account the influence of a person's environment and an optimization of possibilities (Provencher, 2002, p. 37). It would appear that recovery oriented approaches are in harmony with social work's core values and professional skill set (OTSTCFQ, 2012). Is it possible that people recovering from an eating disorder have found this type "backdoor" (Mitchison et al., 2016, p. 11) approach in community organizations and other informal community services? It is the aim of this research is to explore this largely uncharted territory of eating disorder recovery in order to uncover potential social work applications at the community level.

2.1.2 Relapse

For people living with eating disorders, the recovery perspective offers a constructive look at relapse. Relapse is a well documented reality of eating disorder recovery that can be incredibly discouraging if it is viewed as a failure to stay "cured" (Gremillion, 2002; Wilson, 2004, p. 30). In a recovery perspective, *« la distanciation du trouble mental offre [à la personne] la possibilité d'observer les manifestations du trouble mental d'une manière plus "objective" et d'utiliser des stratégies de rétablissement favorisant une meilleure qualité de vie et de bien-être »* (Provencher, 2002, p. 41). In other words, relapse is viewed an integral part of recovery that offers the person living with the disorder the opportunity to collect information and develop better symptom management strategies (Davidson et al., 2009; Provencher, 2002). Learning about what triggers relapse can empower people in recovery to develop proactive strategies for managing, preventing or minimizing the effects of future relapses (Provencher, 2002, p. 44). As relapse is such an integral part of eating disorder recovery, it is central in this research.

2.1.3 Support in the Recovery Process

In the recovery perspective, receiving quality support from professionals, peers, family and the community is crucial. Drawing on a Quebec study of alternative treatment resources, Provencher asserts that elements such as respect for the person's rhythm, a feeling of being listened to by staff and a focus on the "possibilities of transformation" (Provencher, 2002, p. 37) were key elements that supported recovery. Many felt that having a safe "practice space" in the alternative resource allowed them to test-drive new ways of being that were conducive to recovery (Provencher, 2002, p. 37). Contrary to many hospital treatment programs offered to people living with eating disorders, alternative resources offer users a flexible, respectful structure that is focused on positive transformation and personal strengths (Provencher, 2002). As Gremillion (2002) and many other authors have noted, many eating disorder treatment models "recreate forms of bodily control" (Gremillion, 2002, p. 385) that contribute to the creation of the disorder in the first place, by focusing excessively on food and weight (Arnaiz, 2009; Black, 2003; Gremillion, 2002; Malson, 2003; Simblett, 2013; Wilson, 2004). As eating disorders are a mental illness that manifests itself in the body, medical treatment is often prioritized over psychological or social interventions (Gremillion, 2002). However, recovery from an eating disorder is a long-term process that happens, in large part, outside of formal treatment spaces (Myers & Wiman, 2014; Public Health Agency of Canada, 2002). Though the recovery approach remains underdeveloped in Quebec (Provencher, 2002, p. 36), is it possible that community and alternative eating disorder resources are offering recovery-supportive models of care? This study aims to make these practices more visible, through the lived experiences of research participants recovering from an eating disorder.

2.2 Feminist Perspectives on Eating Disorders

As mentioned in the review of literature, feminist writers and thinkers have focused on eating disorders as they are a perfect example of how the body, culture, gender and power dynamics collide. Feminist authors such as Susan Bordo (1993), Suzie Orbach (1978, 1982), Helen Gremillion (2002, 2003, 2005), Catherine Black (2000, 2003) and Jennifer Wilson (2002) have investigated the particularities of the Western social context within which eating disorders not only exist, but flourish. In her book *Unbearable Weight: Feminism, Western Culture and the Body*, Bordo concludes that eating disorders "reflect and call

our attention to some of the central ills of our culture – from our historical heritage of disdain for the body, to our modern fear of loss of control over our future, to the disquieting meaning of contemporary beauty ideals in an era of greater female presence and power than ever before” (Bordo, 2003, p. 139). Bordo’s reading of eating disorders fits into the larger feminist discourse on the female body and the protection of women’s reproductive rights. The publication of *Our Bodies Ourselves* in the 1970’s, the health manual by and for women, is a central feminist document on this issue. In the introduction to the 1998 edition, Jane Pincus explains the manual’s importance:

[Our Bodies Ourselves] places women’s experiences within the social, political, and economic forces that determine all of our lives, thus going beyond individualistic, narrow, “self-care” and self-help approaches, and views health in the context of the sexist, racist, and financial pressures that affect far too many girls, women and families adversely. (The Boston Women’s Health Book Collective, 1998)

In keeping with feminism’s goal of producing useful knowledge for change (Hesse-Biber, 2014a), the manual’s goal is to empower women to “value and share your own insights and experiences, and to use [the book’s] information to question the assumptions underlying the care we all receive so that we can deal effectively with the medical system and organize for better care” (The Boston Women’s Health Book Collective, 1998).

In this section, I present four common themes in the feminist perspective on eating disorders and extract the aspects of these approaches which I will use when examining the question of what role social workers could play in the recovery from an eating disorder in a community setting. As feminist perspectives pay special attention the socio-cultural context in the development, maintenance and recovery from eating disorders, they are particularly relevant to social work practice in this field.

2.2.1 Four Feminist Readings of Eating Disorders

In an article published in 1996, Stephanie Gilbert and J. Kevin Thompson conducted a review of the existing feminist literature on eating disorders (anorexia and bulimia only) and divided their findings into four overarching “etiological influences on eating disorders delineated by feminist perspectives” (Gilbert & Thompson, 1996, p. 183): “Culture of Thinness”, “Weight as Power and Control”, “Anxieties about

Female Achievement” and “Eating Disorders as Self-Definition” (Gilbert & Thompson, 1996). Though the article is dated, many of these perspectives remain relevant and the four categories summarize a large fraction of feminist thought on eating disorders throughout the last fifty years. These perspectives are an important addition to the dominant psychiatric and relational views of eating disorders as they address the socio-cultural gap in understanding these disorders, with an emphasis on the role of gender. Malson (2003) confirms that “increasingly, socio-culturally orientated researchers and theorists working in the field [of eating disorders] have pointed to the potentially damaging effects of our societal idealization of the thin female body as the standard of feminine beauty” (Malson, 2003, p. 138).

The table below is a summary of the four feminist perspectives on eating disorders identified by Gilbert and Thompson (1996). An outline of each perspective is provided in addition to statements linking the perspectives to anorexia and bulimia. An extra column for binge-eating disorder was added, as this article was written before its inclusion in DSM-5. Considering that binge-eating disorder is the most common eating disorder in North America (Hudson et al., 2007), it was essential to include this disorder in the feminist perspectives on eating issues. To achieve this, the logic of each perspective has been extended to binge-eating disorder using statements from the text coupled with current information on the disorder.

Feminist perspectives on eating issues use gender as a lens through which to focus on social issues (Hesse-Biber, 2014a, p. 3), with a specific focus on power-relations. In each of the four categories presented in the box below, different feminist readings of eating disorders are proposed. As they are complex biopsychosocial issues, feminist readings of eating issues can be viewed as complimentary to the dominant biological and psychiatric understandings of these disorders. In fact, the complexity of eating disorders lies in the interplay between all three of these perspectives (Gremillion, 2003; Malson, 2003).

Box 3 – Feminist Perspectives on Eating Disorders

FEMINIST PERSPECTIVES ON EATING DISORDERS				
Perspective	Summary	Anorexia	Bulimia	Binge-Eating Disorder
Culture of Thinness	<p>Male dominance through focus on female attractiveness: “Patriarchal society has effectively subjugated women through its emphasis on the importance of women’s appearance “ (Gilbert & Thompson, 1996, p. 185).</p> <p>Capitalism’s vested interest in women’s anxieties about appearance: Fueled by media images and messages that “suppress women by attacking their appearance and generating anxiety about appearance and attractiveness” (Gilbert & Thompson, 1996, p. 186) thinness, cosmetic, and cosmetic surgery industries are heavily invested in women’s dissatisfaction with their bodies as they make billions in profit by providing consumer “solutions” to weight and appearance issues (Wolf, 1991, Brown, 1989 cited in Gilbert & Thompson, 1996, p. 186).</p>	<p>“The anorexic woman symbolically translates society’s wishes for weak and powerless women through visual physical impoverishment” (Gilbert & Thompson, 1996, p. 186).</p> <p>“Anorexics physically alter their bodies so as to appear without need for even the most essential element of nurturance – food” (Gilbert & Thompson, 1996, p. 194).</p>	<p>“The female with bulimia has tried to compete in the arena of thinness but has regularly failed in her dieting attempts (Martin, 1989)” (Gilbert & Thompson, 1996, p. 185).</p>	<p>“The stigmatization of fatness and the glorification of thinness constitute forms of sexism and misogyny (Brown, 1989) and are methods of controlling women” (Gilbert & Thompson, 1996, p. 185).</p> <p>Women who live with binge-eating disorder are often overweight or obese, making them the target of gender-specific body shaming and overall social stigmatization. (Rail et al., 2010)</p>
Weight as Power and Control/ Protection against sexual violence	<p>Weight control as a substitute for control over one’s life: “Eating disorders may offer women a sense of control in areas that have been regularly experienced as controlled by others” (Gilbert & Thompson, 1996, p. 188).</p> <p>“Paradoxically, in their efforts to achieve a sense of control, women surrender to society’s pressures to focus on issues of real importance to their lives(Orbach, 1978; Szekely, 1989) and accept society’s appearance oriented definition</p>	<p>“The anorexic’s shapeless body represents a rejection of society’s visual objectification of women’s bodies (McLorg & Taub, 1987) and serves to protect the anorexic woman from being viewed as a sex object, increasing the respect she receives in the work place (Wolf, 1991)” (Gilbert & Thompson, 1996, p. 188).</p>	<p>“Sexual violation resulted in fears of safety, compromising the individual’s sense of control over her body” (Cole, 1985 cited in (Gilbert & Thompson, 1996, p. 188).</p> <p>Bulimia can be seen as a cycle of control and loss of control of the body through extreme food and weight management.</p>	<p>Just as the anorexic body can be seen as a “physical regression to a prepubertal appearance [that] may produce a diminution of secondary sexual characteristics and sexual drive (Crisp, 1980), thus possibly removing physical and psychological reminders of the abuse” (Gilbert & Thompson, 1996, p. 188), the obese body may be a perceived protection from future</p>

	<p>of women's success and self-worth" (Gilbert & Thompson, 1996, p. 188).</p> <p>Eating disorders as response to sexual assault: "Disordered eating [may be] a "gender-specific response to sexual assault" (Root, 1991 cited in Gilbert & Thompson, 1996, p. 188).</p>			<p>sexual assaults as it is deemed unattractive culturally (Gremillion, 2005, p. 17).</p>
<p>Anxieties About Female Achievement</p>	<p>Achievement includes excelling at femininity: "Women face [pressure] to achieve academically and professionally, while concurrently being acceptably feminine" (Gilbert & Thompson, 1996, p. 190).</p> <p>Desire for power = social barriers for women: "The eating disorder may resolve the conflicts between women's desires for achievement and society's barriers to such achievement" (Gilbert & Thompson, 1996, p. 191).</p>	<p>"The pursuit of the anorexic physique" serves to conform to stereotypical femininity thus allowing the woman to resolve the beauty/achievement dilemma (Gilbert & Thompson, 1996, p. 190).</p> <p>"In attempting to placate society's anxiety about women's power, she alters her physical shape to that of an adolescent girl. In so doing, she reduces her symbolic threat to male dominated society by virtue of her incapacitating illness (Chernin, 1981 cited in Gilbert & Thompson, 1996, p. 190).</p>	<p>"Given the negative stereotypes of successful women, high-achieving women may react to their successes by utilizing compensatory measures that engender some perceived assurance that they will be viewed as acceptably feminine" (Lawrence, 1984 cited in (Gilbert & Thompson, 1996, p. 190).</p> <p>"Successful career women have been shown to be more concerned with dieting than women in lower social classes (Zegman, 1983)." Chronic dieting has been shown to be a pre-cursor to both anorexia and bulimia (American Psychiatric Association, 2018).</p>	<p>"Heightened pressure [on women] to achieve may have led to an increased reliance on unhealthy methods of coping, including eating-disordered behaviors" (Gilbert & Thompson, 1996, p. 191) such as binge eating (using food for escape and comfort) (Gilbert & Thompson, 1996, p. 193).</p>
<p>Eating Disorders as Self-definition</p>	<p>"The body as a sense of self": Women in today's society experience difficulty "defining themselves as autonomous, worthwhile human beings" (Gilbert & Thompson, 1996, p. 193).</p> <p>"Women who possess an underdeveloped sense of self</p>	<p>"Robertson (1992) précise qu'à la fois les discours médical et profane font correspondre la féminité à la retenue et à la maîtrise de soi. Celles qui se privent excessivement – comme les anorexiques – et celles qui de toute évidence n'exhibent pas</p>	<p>"Impaired by their inadequately developed sense of identity, bulimic individuals may turn to their bodies as a means of defining themselves" (Gilbert & Thompson, 1996, p. 193)</p>	<p>"Binging as a cognitive escape": "When negative feelings become too great, binging offers an escape by which distressing feelings and thoughts can be avoided and a more comfortable state achieved" (Gilbert &</p>

	<p>may be more vulnerable to society's dictates of how they should look and act and thus are at greater risk for developing an eating disorder" (Gilbert & Thompson, 1996, p. 193).</p> <p>"Women as nurturers": Women experience difficulty "assuming the[socially] devalued roles of wives and mothers" (Gilbert & Thompson, 1996, p. 193)</p> <p>"...eating disorders represent an acknowledgement of the low status of women's nurturing" which results in "ambivalence about being female and the expression of that ambivalence through an eating disorder" (Gilbert & Thompson, 1996, p. 194).</p>	<p>suffisamment de contrôle – comme les personnes obèses – deviennent l'objet d'admiration ou de dégoût; ces réactions permettent à leur tour de façonner la signification et l'identité que la personne entretiendra dans sa relation avec la nourriture » (Vinette, 2001, p. 139)</p>	<p>"The bulimic woman uses food metaphorically as a means of emotional regulation"(Gilbert & Thompson, 1996). "The binge thereby enables the bulimic woman to escape the uncomfortable states of self-awareness, while the purge helps her to cope with the negative affect she experiences following the binge" (Gilbert & Thompson, 1996, p. 193).</p> <p>"Bulimia is viewed as a woman's failed attempt to completely deny her own needs for nurturance". Binging represents the bulimics' surrender to her needs for nurturance, while purging reflects society's rejection of women's need for nurturance" (Wurman, 1989 cited in Gilbert & Thompson, 1996, p. 194).</p>	<p>Thompson, 1996, p. 193).</p> <p>The person who has binge-eating disorder does not use compensatory methods to cope with negative affect, which often triggers the next binge (National Eating Disorder Association, 2018).</p> <p>"Eating disordered patients communicate a statement of their caretaking needs through their eating behaviors" (Gilbert & Thompson, 1996, p. 195). Thus the person who lives with binge-eating disorder communicates their "intense longing for comfort" through "consuming large quantities of food" (Gilbert & Thompson, 1996, p. 195).</p>
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2.2.2 A Critical Stance on the Psychiatrization of Eating Disorders

Some feminist authors have questioned whether we should consider eating disorders a psychiatric problem at all. In a 2004 article on self-starvation (anorexia), Wilson suggests that "total reliance on psychiatric theories and methods reify the 'anorexic condition' as separate from culture" (Wilson, 2004, p.151). Wilson's investigation into the history of women's self-starvation revealed that the "discovery of anorexia nervosa coincided with the emergence of the medical profession and the medicalization of deviance" (Wilson, 2004, p.152) in the early 19th century. In that period, "women's lives became

increasingly under the scrutiny of doctors” (Wilson, 2004, p.153) and many disruptive behaviors were labelled as mental illness. Gremillion (2002) also questions the notion of anorexia as a psychiatric issue stating that “no clinical study to date has been able to determine an etiology for anorexia that can be framed in terms of “objective” psychological or biological cause (every physiological disturbance associated with anorexia can be shown to be secondary to extreme weight loss)” (Gremillion, 2002, p. 382). The same can be said for all other eating disorders, which are defined and treated within biomedical and psychiatric frameworks.

Wilson (2004) and Gremillion (2002) point to an element of social control and control over women’s bodies that is problematic in the psychiatrization of eating disorders (Gremillion, 2002; Wilson, 2004). Black (2003) also identifies the limits of “the traditional tools used to evaluate eating issues” (Black, 2003, p. 129) referring to the Eating Disorder Inventory (EDI), which is one of the most widely used eating disorder evaluation instruments. Feminist practitioners and researchers have found the EDI and other eating disorder measurement tools restrictive due to the fact that they are overwhelmingly “fat and food focused instruments [which] may not measure the core motivations underlying women’s disordered relationship with food and their bodies” (Katzman & Lee cited in Black, 2003, p. 129). According to Black, “there are currently no alternative measures that address these issues” (Black, 2003, p. 129) in the field of eating disorders.

Black (2003), Gremillion (2002) and Wilson (2004) all suggest that a cultural reading of eating disorders is necessary as it is “explicitly concerned with issues of class, race and gender and explores the link between psychological distress and the broader contexts of women’s lives” (Wilson, 2004, p.154). As such, it cannot be ignored that an overwhelming majority of those living with anorexia are women who live in Western, industrialized nations where « *la minceur est synonyme de moderation, de maîtrise de soi, de succès et d’acceptation sociale* » (Vinette, 2001, p. 133). This logic can be extended to the high number of men who are experiencing muscle dysmorphia in the current cultural context where the “ideal body coveted by males tends to be overtly muscular in comparison to the thin body coveted by most females” (Griffiths, Murray, Touyz, 2014, p. 108). Griffiths, Murray and Touyz (2015) posit that “formerly stable pathways to achieving a masculine identity have become destabilized because of increasing parity

between the sexes, and that men are building muscles in increasing numbers in an attempt to reclaim and communicate their masculinity” (Griffiths et al., 2015, p. 109), an issue yet to be fully explored in the eating disorder literature.

In short, socio-cultural shifts are having an impact on how gender is performed and embodied. Feminists suggest that eating disorders are a consequence of these shifts; a true example of how “the personal is political”, the body being the most personal and intimate space. And yet, eating disorders are largely viewed as an individual pathology, the social nature of gender roles often ignored in favor of individual or family dysfunction in understanding and treating them (Black, 2003; Gremillion, 2002). Despite the ineffectiveness of current psychiatric and biomedical responses to eating disorders, the social elements of these disorders continue to be ignored. Zola (1992) offers a potential explanation : « *dès qu’un problème est identifié comme une maladie, il n’est plus, par définition, social et on ne s’attend plus à ce que les mesures correctives soient sociales* » (Zola, 1992, cited in Vinette, 2001, p. 138).

The purpose of this research is to investigate the untapped potential of the social work discipline in dealing with the sociocultural aspects of eating disorders through an examination of the recovery process of a varied group of individuals in three community settings (Montreal, Sherbrooke, Quebec). Though critical of the psychiatric perspective on eating disorders, this research is open to a diversity of perspectives on eating disorders and includes non-psychiatric strategies for recovery.

2.2.3 Understanding the Cultural Meanings of Fat and Thin

Perhaps the most important contribution of feminist theorists to the field of eating disorders has been a focus on what fat and thin mean in a given culture, at a particular historical moment (Bordo, 2003; Gremillion, 2005; Vinette, 2001). Feminist and non-feminist researchers alike have linked eating disorders to the Western obsession with the thin, fit female body (Black, 2003; Bordo, 2003; Gremillion, 2002; Vinette, 2001; Wilson, 2004) but the “thin ideal” is only one half of the cultural narrative. Sophie Vinette (2001) explains that for women « *la silhouette est ainsi devenue une indication de la valeur personnelle des gens, le corps pouvant se présenter comme un symbole de santé, de succès et de richesse,*

ou encore être jugé tout à fait à l'opposé » (Vinette, 2001, p. 133). In addition to being socially desirable in the Western world, the thin body also has « *une valeur économique d'échange plus élevée que ceux et celles qui ne peuvent, ou qui ne désirent pas s'approprier de telles images [de la jeunesse, de la santé, de la bonne forme physique et de la beauté]* » (Vinette, 2001, p. 133) as they are culturally dictated. Putting the drive for female thinness into a socio-historical context, Gremillion posits:

...contradictory imperatives for women to consume while also controlling consumption through diet and exercise [are] imperatives that produce female bodies and subjectivities as battleground sites for forging "new" femininities against "older" (and persistent) domestic and maternal ones. (Gremillion, 2005, p. 19)

In the current cultural context, and for people of all genders, the disciplined body is held up as evidence of self-control and moral fortitude in a context of consumption and excess (Holmes, Murray, Perron, & Rail, 2006; Melcher & Bostwick Jr., 1998; Vinette, 2001).

Of course, the thin or controlled body is only one pole of the current Western body continuum. The cultural worship of the disciplined body is counterbalanced by the outright disdain for, and fear of, the fat or obese body (Bordo, 2003; Melcher & Bostwick Jr., 1998; Rail et al., 2010; Vinette, 2001). Vinette (2001) asserts that in affluent Western society « *l'obésité est considérée comme un échec moral, une incapacité à retarder la satisfaction et à se contrôler, un manque de discipline ou encore une tendance à la paresse et à l'avidité* » (Vinette, 2001, p. 133). Both public health and media messages collude in disseminating the information that fatness leads to ill health and that it is a personal, moral responsibility to control one's weight (Bordo, 2003; Rail et al., 2010; Vinette, 2001). According to Melcher & Bostwick Jr. (1998) "the belief that body size can be controlled gives the general public permission to be openly unkind to people who are heavier than average, especially those who are considered most obese" (Melcher & Bostwick Jr., 1998, p. 197). It is widely understood in Western culture that the fat body is a deviant body that must be brought under control (Rail et al., 2010; Vinette, 2001). What's more, the failure to discipline the body is perceived as a direct strain on health resources that are shared by all (Rail et al., 2010). Unlike other socially rooted health problems, the perception of excess weight is one of very personal failure "the implicit message is that [overweight or obese people] are weak willed, unacceptable, unlovable, psychopathological and out of control" (Melcher & Bostwick Jr., 1998, p. 197).

When applied to eating disorders, the importance of understanding the cultural fat/thin polarity may provide some insight as to why there has been so much attention paid to anorexia and so little paid to binge-eating disorder. As so aptly expressed by Susan Bordo (2003) in a chapter titled “Anorexia Nervosa: Psychopathology as the Crystallization of Culture”, the female anorexic body is, in a sense, bringing cultural norms of female beauty to their horrible, logical end (Bordo, 2003). In all four feminist perspectives on eating disorders (Culture of thinness, Weight as Power and Control, Anxieties about Female Achievement and Eating Disorders as Self-Definition), the shrinking female body becomes too frail and weak to achieve the initial goal of social acceptance, achievement, control, access to power, protection, or agency (Gilbert & Thompson, 1996). When restriction goes too far, women become small, fragile and in need of care - a cultural narrative that is somehow very appealing (Bordo, 2003; Gilbert & Thompson, 1996; Gremillion, 2005). Anorexic stories are told in movies, tv shows and books; the image of emaciated female body being the cultural hallmark of eating disorders. At the same time, binge-eating disorder produces overweight or obese bodies, that do not receive the same attention either culturally or within the medical system- as evidenced by the lack of research and specialized treatments offered to people living with this disorder.

Research clearly shows that binge-eating disorder represents the largest category of eating disorders in the United States: binge-eating disorder representing 5.5 percent of the US population, whereas anorexia represents 1.2 percent and bulimia 2.2 percent (Hudson *et al.*, 2007 cited in Downs & Blow, 2013, p. 3). The statistics include a significant number of men and women over the age of 25 (American Psychiatric Association, 2018; National Eating Disorder Association, 2018; National Eating Disorder Information Center, 2014). Furthermore, Hudson *et al.*'s 2007 eating disorder study (published 6 years before the binge-eating disorder was included in the DSM-5) found that binge-eating disorder “is at least as chronic and stable as anorexia nervosa or bulimia nervosa” (Hudson *et al.*, 2007, p. 8) and that the disorder represents “a public health problem at least equal to that of the 2 better established eating disorders [anorexia, bulimia]” (Hudson *et al.*, 2007, p. 8).

In terms of alleviating disease burden, it would make sense that binge-eating disorder should receive equal attention and resources in both research and treatment, if not more as it affects the largest and most varied group of people. Although this may be true, anorexia and bulimia continue to receive the

lion's share of resources in research and maintain their place as the eating disorders with the most widely available treatments and services (Leblanc et al., 2014).

Some may attribute the inequitable distribution of eating disorder resources to the fact that binge-eating disorder has only recently been added to the DSM as a distinct disorder, which may be partly true. However, a feminist reading of the current eating disorder portrait would locate underlying cultural attitudes towards fat and thin bodies in the virtual invisibility of binge-eating disorder (Daly, 2016; Gremillion, 2002; Rail et al., 2010). This point is emphasized by Hudson's et al's (2007) observation that "physicians infrequently assess patients for binge eating (Crow et al 2004) and often fail to recognize bulimia nervosa and binge-eating disorder (Johnson et al 2001)" (Hudson et al., 2007, p. 7). Similarly, Hart et al.'s 2011 study found that concerns about weight and eating were consistently not identified as a possible eating disorder by health professionals, which speaks to the power of the fat/obesity discourse within the health system. Within the "dominant 'obesity discourse', obese and 'at risk bodies' are constructed as lazy and expensive bodies that should be submitted to disciplinary technologies (for example surveillance), expert investigation and regulation" (Rail et al., 2010, p. 260) but are not seen as "ill" in the same way the anorexic body is.

This cultural reading of the "out of control" body triggers all the cultural prejudices attributed to fat (Rail et al., 2010). Thus, instead of offering mental health care for eating disorders, the cultural meaning of fat leads lay people and health professionals alike to prescribe weight loss or lifestyle changes, which are consistent with the "neoliberal notion of individualism that positions individuals as primarily responsible for changing their lifestyle via a range of disciplinary measures and control techniques" (Rail et al., 2010, p. 261) (i.e. diet, exercise, etc.). In addition, people living with binge-eating disorder experience overt stigmatization in many aspects of their daily lives, which has measurably negative effects on their quality of life (Melcher & Bostwick Jr., 1998). Thus, social stigmatization of fat adds to the already heavy burden of physical, psychological and social difficulties of living with an eating disorder. According to Melcher and Bostwick Jr. (1998), social work has a role to play with regards to the stigmatization experienced by people who are considered overweight or obese by debunking myths about fat being unhealthy, "educating clients about cultural and social biases" and in helping them to "deal with social prejudice" (Melcher & Bostwick Jr., 1998, p. 204).

A feminist reading of binge-eating disorder would also suggest that cultural discourse of obesity/fat intersects with race, class and gender to make this disorder culturally unappealing. Binge-eating disorder is associated with people of all genders, ethnic groups and social classes, in contrast to anorexia, which is understood as an affliction of the young, affluent, white female (Gremillion, 2002; Leblanc et al., 2014). Surprisingly, treatment for binge-eating disorder has been found to be more successful than other eating disorder interventions (Hart et al., 2011), making it all the more incomprehensible that treatment is not more widely available.

In this study, special attention is paid to how participants interpret the fat/thin cultural discourse with regards to their recoveries. Access and barriers to treatment and services is also an area of inquiry, in light of the inequitable treatment options available to people with different eating disorders.

2.2.4 The Gender Blind Spot

Gender is an aspect of feminist perspectives on eating disorders that is both a strength and a weakness. Bordo accurately states that “female bodies have historically been significantly more vulnerable than male bodies to extremes in both forms of cultural manipulation of the body” (Bordo, 2003, p. 143). Her book, originally written in 1993 and updated in 2003, focuses on the disproportionate number of females suffering from anorexia and bulimia in the late 1970’s and 1980’s in the United States. In an astute observation of the gender double-standard in visual culture (film, fashion, television, and advertising) Bordo notes that: “individual style, wit, the projection of intelligence, experience, and effectiveness still go a long way for men, even in our fitness-obsessed culture. But no female can achieve the status of romantic or sexual ideal without the appropriate body” (Bordo, 2003, p. 154). Though Bordo’s statement remains essentially true today, new technologies have dramatically increased the daily contact North Americans have with visual culture, which has had a significant effect on men’s body image and the subsequent rise in eating disorders among men (Bunnell, 2016). The same is true for people who identify themselves outside the man-woman gender binary (Jones, Haycraft, Murjan, & Arcelus, 2016). Moreover, Gilbert and Thompson (1996) assert that “feminists also advocate for the investigation of

more varied samples who might more accurately represent the diversity of members of each gender” (Gilbert & Thompson, 1996, p. 184).

Widening the scope of gender in eating disorder research is particularly relevant at this moment in North American history, as so much of culture is being transmitted visually. Increasingly, gender is being learned and reproduced through visual culture (social media, advertising, internet, pornography, tv and film) providing citizens with specific images of what bodies should look like and how gender should be performed (Vinette, 2001, p. 133). As such, both masculine and feminine bodies are clearly and narrowly defined. For both, the ideal is heterosexual and as pervasive as it is unrealistic. The pursuit of these ideal bodies leads to a myriad of behaviors that can be dangerous and damaging to the body (i.e. extreme exercising, dieting, plastic surgery, steroid use, etc.) for people of all genders (Bordo, 2003).

Though feminists do pay special attention to gender, eating disorders have been studied, theorized and understood as a predominantly female issue, which is simply no longer accurate (Bunnell, 2016; Griffiths et al., 2015; Leblanc et al., 2014). For this reason, particular attention is paid to gender (in all its forms) in the investigation of social work’s potential role in the recovery from eating disorders. In this study, gender is not limited to a male/female binary but welcomes other gender identities such as two-spirited, gender-fluid etc. which is in keeping with social work’s commitment to diversity and inclusiveness.

2.2.5 Race and Class

Feminist perspectives have shed light on the race and class issues that underpin eating disorders in a way that the prevailing psychiatric approach ignores. In fact, feminist research has exposed a significant flaw in participant selection in most studies of eating disorders. The prevalence of young, white, affluent women as the primary group of interest in eating disorder research has reinforced the belief that eating disorders afflict this group disproportionately (Gilbert & Thompson, 1996, p. 184; Gremillion, 2005, p. 24; Leblanc et al., 2014). However, “estimates of the prevalence of anorexia nervosa and bulimia nervosa in non-Caucasians range from 1% to 4%, depending on the age, ethnicity and location of the subject” (Gilbert & Thompson, 1996, p. 196). These estimates are significant when considering the age

of the study (1996) and the fact that it does not include binge-eating disorder or Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED) (formerly EDNOS), the largest categories of eating disorders in North America (Hudson et al., 2007; Myers & Wiman, 2014). The belief that cultural factors protect non-white women from the thin ideal is so widely held that little attention has been paid to other ethnic groups in research on anorexia and bulimia (Katsounari, 2009; Leblanc et al., 2014; Tiggemann et al., 2005). In the case of binge-eating disorder, where the role of the thin ideal is not as obvious as with anorexia, there is also very little research that investigates how race intersects with other factors in the development and maintenance of eating disorders.

Class is another little explored factor in eating disorder research that feminists have scrutinized. The “Anxieties About Female Achievement” theme touches on this issue as it connects professional achievement with control of the body, as a means for women demonstrate accomplishment in the realms of both career and of femininity (Gilbert & Thompson, 1996, p. 190). What this theme does not deal with explicitly is how the body can be used as a means of elevating one’s socioeconomic status, as a disciplined female body is associated with personal success in Western culture (Bordo, 2003; Brown, Weber, & Ali, 2008; Gremillion, 2002). Race and class intersect when the body is used as a strategy to elevate or change status groups when “the widespread pressure to be slim articulate with narratives of whitening, assimilation, moving up the social ladder, and “grooming girls to be heterosexual” (Thompson, 1994 cited in Gremillion, 2005, p. 24). According to Catherine Black (2003) “eating issues characterise women’s experiences as they move social classes, countries or gender boundaries or they attempt to straddle the private and public domains of society” (Black, 2003, p. 128), which makes eating disorders “‘problems of disconnection, transition and oppression rather than dieting, weight and fat phobia’ (Katzman & Lee, 1997, p.392 cited in Black, 2003, p. 128).

Given these points, feminist perspectives have directly impacted this study, particularly in the diversity of the participants and design of interview questions. Instead of investigating participant’s relationship to food and weight, this research’s focus is on relationships, identity, family and community support, perceptions, expression of gender etc. In fact, food and weight are purposely avoided in interview

questions as a strategy for exploring the social aspects of eating disorders, which are most relevant to the research topic as it applies to social work practice.

Chapter 3: Methodology

3.1 Feminist Research

Gilbert and Thompson (1996) define feminist inquiry as “research [that] examines subject matter relevant to the lives of women and demonstrates sensitivity to gender issues” (Gilbert & Thompson, 1996, p. 185). The authors identify that feminist research is critical of science as “value free”, noting that as “science has historically been conducted by white, middle-class men, it has been biased accordingly and continues to support society’s “prevailing power elites” (Gilbert & Thompson, 1996, p. 184). When applied to eating disorders, feminist research has identified the need for investigating “historical, political, and cultural forces that may shape and reinforce behavior patterns in women and men” (Gilbert & Thompson, 1996, p. 184) with relation to food and body issues. Even within the current feminist research, little attention has been paid to men living with eating disorders. Similarly, binge-eating disorder has been largely ignored as it does not involve restricting or punishing the body to achieve the thin or muscular body prescribed by social norms.

One of the aims of this study is to work both within and outside of the DSM’s definitions of eating disorders to create a more accurate portrait of this issue in a Quebec community context. Feminism’s critical stance on the psychiatrization of eating disorders was considered when investigating what elements of the participant’s recovery were most helpful to them. Thus, interview questions were not limited to professional or psychological interventions but probed all manner of recovery strategies.

Feminist research seeks to give a voice to those who have been excluded or marginalized. In the eating disorder literature there has been a noted absence of the lived experiences of people experiencing an eating disorder. As such, this study focuses on those voices, with an emphasis on the diversity of narratives (men, people of other genders, older women, people of color, etc.). According to Malson (2004) “research focus in this field has tended to remain on outcomes rather than on the ways in which eating disorders are constituted, experienced and practiced, on constructions and experiences of treatment or the power-relations embedded therein” (Malson *et al*, 2004, p. 476). This approach to research is particularly problematic when considering the poor outcomes of existing eating disorder treatments (Government of Canada, 2006; Gremillion, 2002; Leblanc et al., 2014, 2014; Malson, 2003;

Public Health Agency of Canada, 2002; Wilson, 2004). As this study is focused on a social work perspective of the recovery process from eating disorders, the lived experiences of the research subjects are an essential source of information. An exploration of lived experiences of eating disorder recovery in a feminist research perspective is interested in how different aspects of identity (gender, race, class, weight, etc.) within a specific sociocultural context inform an individual's experience (Hesse-Biber, 2014a). Citing sociologist Patricia Hill Collins (1990), Hesse-Biber (2014) asserts that "it is only by exploring the intricate matrix of difference that we can truly understand a given individual's lived experience" (Hesse-Biber, 2014a, p. 7). For this reason, special attention was paid to participants' identities when collecting and analysing the data. In addition to in-depth demographic questions (see Interview Guide, Annex 1), the ways in which participants' complex identities informed their recovery process was considered. This way of approaching lived experience attends to both the "specific circumstances, conditions, values, and relations of power that influence one's particular context" (Hesse-Biber, 2014a, p. 5) and the "dominant ideological structures" through which that experience is discursively constructed (Hesse-Biber, 2014a, p. 5). Thus, this approach to eating disorder recovery explores the unicity of each recovery process and shared experiences of both empowerment and oppression in a specific historic, cultural, and geographical context.

3.2 Research Orientations of this Study

The study has two distinct orientations. The first orientation is exploratory; very little is known about the lived experience of recovery as it relates to eating disorders, and even less is known about the community context in which most recovery occurs (Public Health Agency of Canada, 2002; Mitchison et al., 2016). As the voices of the people living with or recovering from an eating disorder are largely absent in the research (Leblanc et al., 2014), a feminist qualitative research approach is particularly relevant to this topic. Furthermore, community-based samples are rare in the eating disorder literature, as many studies are conducted in dedicated hospital units or specialized eating disorder clinics (Gremillion, 2002; Hart et al., 2011; Public Health Agency of Canada, 2002). As such, the literature does not reflect the wide variety of eating disorder recovery experiences that occur in the community.

The second orientation of this study is more pragmatic: to reflect on the potential role that social work could play in the eating disorder recovery process. The review of literature revealed that the social aspects of eating disorders have been largely ignored in dominant eating disorder treatment models. However, social factors that cause, maintain, and exacerbate eating disorders have been well documented (American Psychiatric Association, 2018; Government of Canada, 2006; Public Health Agency of Canada, 2002; Mitchison et al., 2016). Arnaiz (2015) confirms that “very few [treatment] proposals are made to address the sociocultural aspects [of eating disorders]” (Arnaiz, 2009, p. 192), a gap in the current treatment model that perhaps social work could fill. This pragmatic orientation is rooted in feminist research’s commitment to going beyond knowledge generation as the ultimate goal of research to “using knowledge for change” (Hesse-Biber, 2014a; Quinn Patton, 2002, p. 129).

3.3 Research Questions

The main research question in this study is:

What are the lived experiences of a community-based sample of people in recovery from an eating disorder in Quebec?

In order to explore this question in an in-depth manner, I have generated four research sub-questions:

- **What were the most helpful elements in the recovery process?**
- **What were some of the barriers encountered in the recovery process?**
- **What role did community-based resources play in the recovery process?**
- **What role did social work play in the recovery process?**

Each of the sub-questions is directly related to the domains of interest identified in the attached research guide and questions document (Annex 1).

3.4 Data Collection Method

At the core of feminist research is the drive to “uncover subjugated knowledge” by exploring the lived experiences of women and other marginalized populations (Hesse-Biber, 2014b, p. 184). Sharlene Hesse-Biber (2014) describes this knowledge as “hidden from mainstream knowledge building” (Hesse-Biber, 2014b, p. 228). In the case of recovery from an eating disorder in a community setting, the experiences

of people living this reality have been subjugated in the research. Malson (2004) supports that eating disorder research has ignored “the ways in which eating disorders are constituted, experienced and practiced, on constructions and experiences of treatment or the power-relations embedded therein” (Malson *et al*, 2004, p. 476). To be clear, “community-setting” and “community-based resource” are defined in this study as supports and services that are provided outside of a specialized hospital program for eating disorders. As the Public Health Agency of Canada states “most treatment of eating disorders takes place in the community” (Public Health Agency of Canada, 2002) in a variety of settings, both publicly and privately funded. Consequently, an investigation of the lived experiences of eating disorder recovery in the community is a relevant research topic in both the eating disorder and social work fields.

To explore the experiences of people recovering from an eating disorder in a community setting (a context outside the specialized hospital programs for eating disorders), I have conducted in-depth, semi-structured interviews in a feminist approach. The goal of the in-depth interview is to “gain rich data from the perspectives of selected individuals on a particular topic” (Hesse-Biber, 2014b, p. 195), which is particularly relevant when the sample size is small, as is the case in this study. The “particular topic” in this case is recovery from an eating disorder in the community, a specific topic that has not been explored in the eating disorder research (subjugated knowledge).

The interviews were conducted in a feminist approach, which implies that the researcher (myself) strives to achieve equality between herself and the research participants, makes visible the power and authority dynamics in the data collection process, uncovers subjugated knowledge, and engages in a participatory research process that “supports consciousness raising and researcher reflexivity” (Hesse-Biber, 2014a), with the ultimate goal of social justice and change (Quinn Patton, 2002; Hesse-Biber, 2014b).

“Feminist researchers view social reality as complex and multi-dimensional and this opinion shapes their opinion of the interview” (Hesse-Biber, 2014b, p. 209). As such, the interview itself is viewed as complex and multi-dimensional. The feminist researcher is aware of the interplay between their background, identity and role and those of the research participants in how experiences are shared, and what effect these nuances may have in knowledge production. Feminist research is also unique as it is interested in

both emotions and facts (Hesse-Biber, 2014a). In any narrative, emotion points to what elements are important, often revealing situations of oppression. The feminist posture was taken in all aspects of the interview process: in preliminary phone and email conversations, in where the interview was conducted, in the tone of the interviews, and the final step of validating the interview excerpts with each participant.

3.5 Sampling Strategies

In this study, the purpose is to investigate a range of eating disorder recovery experiences in Quebec community settings. Recovery is a theoretical approach which is particularly relevant to social work practice as its focus is on the person's experience of empowerment and transformation (Davidson et al., 2009; Provencher, 2002). In order to achieve my research objectives, I have employed deductive theoretical sampling (Quinn Patton, 2015, p. 288). This type of purposeful sampling strategy is relevant to the study's object of inquiry, as recovery constitutes a "manifestation or representation of [an] important theoretical construct" (Quinn Patton, 2015, p. 289). Recovery is an alternative approach in the field of mental health that has yet to be studied in the field of eating disorders, making it all the more relevant to "deepen and verify" this theory in "new contexts, new time periods or new situations" (Quinn Patton, 2015, p. 289). What's more, as eating disorders have been claimed as a psychiatric disorder, this problem has been studied extensively through a biomedical lens which considers a person "cured" once the symptoms of their illness subside (Arnaiz, 2009; Bordo, 2003; Gremillion, 2002). As mentioned previously, the cure perspective is problematic when applied to eating disorders as they are caused by complex biological, psychological, and social factors that cannot be resolved by simply stabilizing weight or eating behaviors (Arnaiz, 2009; Black, 2003; Gremillion, 2002; Malson, 2003; Mitchison et al., 2016; Wilson, 2004). Consequently, applying the theoretical construct of recovery to eating disorders represents a "new context" to study, and the community a "new situation" in which recovery is operationalized (Quinn Patton, 2015, p. 289).

Finally, as this research is feminist in orientation, it "presumes the importance of gender in human relationships and social processes and orients the study in that direction" (Quinn Patton, 2002). Hesse-Biber asserts that feminist research is "frequently concerned with the intersections of gender with other

identity standpoints, such as sexual orientation, race, ethnicity, class or nationality” (Hesse-Biber, 2014a, p. 3), to which I would add type of eating disorder.

3.6 Data Analysis

As stated earlier, the overarching data analysis approach in this study is feminist. This orientation informed what participants were selected, from what context, and how the interview questions were developed and used to collect data on the eating disorder recovery experiences in the community. While feminist research steered all aspects of the research, the data collected in this study was analysed using a combination of two specific approaches: a thematic analysis of the participant’s recovery stories in the spirit of grounded theory. By this I mean that I approached the data with “the mental blank slate” (Quinn Patton, 2002, p. 493) that grounded theory demands, to allow concepts to emerge from the data, all the while being transparent about the biases that I bring to the data analysis, as feminist research suggests (Naples & Gurr, 2014, p. 26). There are some obvious limits in this study that prevent me from doing a true grounded theory analysis. The sample size is small, due to the fact that research was conducted in the context of an exploratory, unfunded, master’s level thesis - making it impossible to pursue the research as exhaustively or as in-depth (to saturation) as grounded theory demands. The possibility of adding to the sample size as new concepts emerge was also limited by the financial and time constraints associated with this study, though adding to the sample was possible to a certain extent. Due to the fact that this research is exploratory, the objective is to identify the emergent concepts, generate a “conceptual ordering” (Quinn Patton, 2002, p. 487) and offer some preliminary insight into the lived experiences of eating disorder recovery in a community context. Practically, this process meant that each interview was analysed before proceeding to the next. Thematic analysis allowed me to “identify core consistencies and meanings” (Quinn Patton, 2002, p. 453) in the data, while grounded theory as described by Glaser and Strauss (1967 cited in Quinn Patton, 2002) offered a method to “connect induction and deduction through the constant comparative method” (Quinn Patton, 2002, p. 125). As such, when certain themes required further validation, three additional cases were added to the sample to strengthen them.

Thematic analysis, with a partial grounded theory approach was combined with feminist reflexive research practice that makes visible how my identity as a researcher affects all aspects of the research, even as I strive to put my biography, experiences and biases aside (Naples & Gurr, 2014, p. 26). Moments in the interviews where I was aware that my identity was affecting data collection, were noted and considered when analysing the data. Naples and Gurr (2014) remind feminist researchers that all knowledge is situated and partial (Naples & Gurr, 2014), even in the process of “elucidating the concepts that are the building blocks of theory” (Glaser, 1993 cited in Quinn Patton, 2002, p. 127). Additionally, themes that emerged from the data were analysed within a feminist framework that sought to identify of each participant’s specific “matrix of difference” (Hesse-Biber, 2014a, p. 5) that informed their recovery process, and also hinted at underlying oppressions at work in the experiences of others. Feminist research emphasizes that lived experiences of the researched is always “subjective, power-imbued, and relational” (Hesse-Biber, 2014a, p. 5), as is the act of research and knowledge making. As such, the study does not seek to generalize eating disorder recovery experiences but to explore how they are experienced by individuals with different identities in a specific context.

The second step in the data analysis is related to the study’s objective of generating useful knowledge for change (Hesse-Biber, 2014b). After the conceptual ordering and preliminary analysis were generated from the data, I used « *Le référentiel des compétences des travailleuses sociales et des travailleurs sociaux* » to connect the lived experiences of recovery from an eating disorder in the community to the practice of social work in Quebec. This step was also exploratory, as I sought to connect social work’s values, skills and expertise to the lived experiences of recovery in the community in a pragmatic way. As social justice and active citizenship are core values of social work, exposing experiences of empowerment and oppression in the eating disorder recovery process were relevant to how the profession might situate itself in the recovery process.

3.7 Le référentiel des compétences des travailleuses sociales et des travailleurs sociaux

Le référentiel des compétences des travailleurs sociales et des travailleurs sociaux details « les principaux savoirs associés à l’ensemble de ces compétences quant au champ du travail social, aux fonctions du

travailleur social, aux méthodes de pratique et à la maîtrise du processus d'intervention » (OTSTCFQ, 2012, p. 4) and was used to identify how social work might approach the issue of eating disorder recovery in a community setting.

For social workers in Quebec, and for those studying social work, *Le référentiel des compétences* is an essential reference for all aspects of the profession. This resource was useful in the analysis of participant's recovery stories, as the goal of this research is to connect community-based recovery-oriented practices with the practice of social work.

3.8 Participants Define their Eating Disorder and Level of Recovery

In the context of this study, I am using the term « eating disorder » to encompass eating disorders that appear in the DSM, including Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED) (formerly EDNOS), as well as emergent disorders that have no formal diagnostic criteria (e.g. : orthorexia, muscle dysmorphia, etc.). As I have suggested in previous sections, using exclusively DSM criteria to identify people living with and recovering from eating disorders is problematic and limits the collection of data to individuals who have a formal diagnosis (Myers & Wiman, 2014). Research has indicated that many people who live with eating disorders are undiagnosed, diagnosed with Other Specified Feeding or Eating Disorders (OSFED) or Unspecified Feeding or Eating Disorders (UFED) (two vague and understudied diagnostic categories), or live with an emergent eating disorder that has no diagnostic criteria at all (Hart et al., 2011; Vandereycken, 2011; Myers & Wiman, 2014). My aim in this study is to collect information from a range of people who are recovering from an eating disorder, to reflect on social work's possible contributions to this field. In keeping with this goal, research subjects were not required to provide a formal eating disorder diagnosis, as I am interested in the community reality of recovery, not in defining the research participant's experiences in diagnostic terms. Contrary to standard eating disorder research practice, the participant's eating disorder was not validated by a medical professional or by an existing eating disorder evaluation tool, nor was the participant asked to disclose their weight.

The participant’s own description of their disordered eating was the only information used to categorize them. Giving participants the right to define their own experience with eating disorders is in keeping with feminist research’s commitment to validating “women’s experiences and expertise” (Black, 2003, p. 128) and recognizing them as valuable. Obviously, in this research the experiences of all genders are valid and important in understanding how eating disorder recovery is lived in the community. An exclusive focus on women with an eating disorder diagnosis would be a denial of the diversity of experiences of recovery. Furthermore, the community organizations through which participants were recruited do not require a diagnosis to participate in their activities and services, a distinguishing feature of eating disorder recovery in the community context (ANEB Québec, 2017; Arrimage Estrie, 2015; Maison l’Éclaircie, 2014).

3.9 Defining Recovery

Due to its highly subjective nature, the use of the terms “recovery”, “recovered” and “recovering” may have different meanings for different participants. For this reason, I have specified that the research participants be at a point in their recovery where the eating disorder is no longer at the center of their daily lives, which is to say that their daily activities and relationships do not revolve around the eating disorder. Using Davidson et al.’s (2009) collected descriptions of the recovery dimensions (Table 4), participants indicated what dimension(s) of recovery they most identified with. Participants who situated themselves in the final three dimensions of recovery: *assuming control*, *fighting stigma* and *becoming an empowered citizen* (Davidson et al., 2009, p. 56) were included in this study. It is important to note that it was *not* necessary for participants be symptom-free to be considered in recovery. In the recovery perspective, living with managed symptoms and experiencing relapse are considered part of the process (Davidson et al., 2009; Provencher, 2002).

Table 1 – Recovery Dimensions

Recovery Dimension	Experience of Person in Recovery
Renewing Hope and Commitment	<ul style="list-style-type: none"> • Having a reason to get out of bed. • Having a sense that my life can get better. • Being able to tackle every day. • Realizing that there is more to life than mental illness. • Feeling good about the future. • Being determined to live well and take care of myself.

	<ul style="list-style-type: none"> • Believing I can manage my life and reach my goals. • Having dreams again. • Having people I can count on.
Being Supported by Others	<ul style="list-style-type: none"> • Having people I can count on. • Being loved and accepted as I am. • Having people in my life who believe in me even when I don't believe in myself. • Having something to give back. • Feeling like a worthwhile human being. • Being able to help others when they need me.
Finding your Niche in the Community	<ul style="list-style-type: none"> • Getting involved in things I enjoy (e.g.volunteering, dating, taking classes, playing sports, visiting friends, attending support groups) • Having nice places to hang out with my friends. • Having a routine I enjoy. • Making new friends. • Catching up with old friends. • Filling my day with things I like.
Redefining Self	<ul style="list-style-type: none"> • Seeing myself as a person with strengths and resources. • Knowing my illness is only a small part of who I am. • Not allowing "label" or diagnosis to take control of my life. • Exploring life outside the mental health system. • Learning what I have to offer. • Proving wrong the people who said I'd never do anything with my life.
Incorporating Illness	<ul style="list-style-type: none"> • Knowing when I need to ask for help. • Not feeling defeated. • Dealing with setbacks. • Avoiding things that make me feel bad. • Knowing how to take care of myself in good times and in bad. • Accepting that there are some things I can't do yet. • Being proud of the things I can do. • Taking one day at a time.
Managing Symptoms	<ul style="list-style-type: none"> • Learning how my illness affects me. • Asking questions when I don't understand something. • Having ways to cope and be good to myself. • Controlling my symptoms so that they don't get in the way of my life. • Understanding what medication can and cannot do for me. • Finding other tools to help me in my recovery. • Knowing when to ask for help. • Taking time to relax. • Giving myself some slack. • Giving myself permission to be human.
Assuming Control	<ul style="list-style-type: none"> • Knowing when and how to voice my opinion. • Having control over my life and treatment. • Taking risks and trying new things.

	<ul style="list-style-type: none"> • Accepting the consequences and learning from my mistakes when things don't work out as planned. • Being able to appreciate someone else's view and reach a compromise. • Telling people what I want and need from them. • Not taking no for an answer!
Overcoming Stigma	<ul style="list-style-type: none"> • Feeling good about myself. • Learning ways to overcome the negative attitudes of others. • Finding places in the community where I feel at home. • Not feeling ashamed about having mental illness. • Being proud of myself. • Having role models. • Not letting people put limits on me. • Knowing when I am being discriminated against. • Standing up for myself when I have been mistreated. • Not buying into stereotypes of mental illness. • Realizing that other people have problems too. • Knowing when I deserve better and demanding it.
Becoming an Empowered Citizen	<ul style="list-style-type: none"> • Feeling like I have choices. • Choosing where I live and how I spend my time. • Voicing my opinion. • Giving back and sharing my experiences with other people working towards recovery. • Being a responsible citizen (e.g., by voting, volunteering, working, paying taxes, managing my own money, keeping up with my bills). • Having other people respect me. • Being a responsible parent, caring friend, or a good neighbor. • Making a difference in my community. • Taking responsibility for my recovery.

Source: Davidson, L., Tondora, J., Staeheli Lawless, M., & Rowe, M. (2009). *A Practical Guide to Recovery-Oriented Practice: Tools for Transforming Mental Health Care*. Oxford, New York: Oxford University Press.

3.10 Inclusions

Participants included in this study were at least 25 years old, have participated in the activities or services of an community organization as part of their recovery, speak English or French, and have progressed in their recovery enough to be experiencing the following components in the recovery process: *assuming control, fighting stigma and becoming an empowered citizen* (Davidson et al., 2009, p. 56) (see Table 4 for a full description of recovery dimensions). Participants had to be able to participate in an interview in one of the three cities where data collection occurred: Montreal, Sherbrooke, Quebec. Individuals of

all genders and all types of eating disorder were invited to participate in the study, in order to reflect the diversity of eating disorder recovery experiences in the community.

Both English and French speaking research participants were recruited to participate in this study as I am researching the subject of recovery from an eating disorder in the Quebec community context. Two of the three organizations through which I recruited participants offer some bilingual services (ANEB Québec, Arrimage Estrie) and one offers exclusively French services (Maison l'Éclaircie). Both ANEB Quebec and Arrimage Estrie are based in cities that are home to English language universities (McGill University, Concordia University, Bishop's University), which increased the possibility of recruiting both English and French speaking participants. As a bilingual researcher who lives and works in Québec, conducting research in both languages was both natural and necessary to explore this topic fully.

3.11 Exclusions

Persons under the age of 25 were excluded from the study. Despite the fact that many people have lived with an eating disorder from an early age, I am interested in the strategies, services, treatments and community support that people have received throughout their long-term recovery process. For this reason, I chose to recruit research subjects who are at least 25 years old. Statistics gathered by ANEB Québec (2017) on the age of eating disorder support group participants uphold that recovery is an ongoing process that affects individuals of all ages. In fact, the 17-20 year old age range, which is frequently studied in the eating disorder literature, represents the smallest percentage of participants in 2016-2017 at the Montreal-based organization (ANEB Québec, 2017, p. 24). In fact, ANEB Quebec (Montreal) and Arrimage Estrie (Sherbrooke) offer services to adults, aged 17 and up (Anorexie et boulimie Québec, 2018; Arrimage Estrie, 2015). Maison l'Éclaircie (Quebec) offers its services to youth and adults, starting at age 14 (Maison l'Éclaircie, 2014).

It is important to state that I have been employed by Arrimage Estrie (Sherbrooke) as an eating disorder counsellor who is responsible eating disorder services for the past five years. As such, I have excluded potential research participants with whom I have had contact in the closed eating disorder support

groups offered by Arrimage Estrie (each group is 16 weeks long). I believe that interviewing participants with whom I have had a relationship in my professional role would be a conflict of interest. Facilitation of the closed groups (Groupe rétablissement TCA) is done in rotation with other counsellors, which means that I had access to potential research participants from the groups which I did not lead.

Arrimage Estrie also offers an open eating disorder support group in collaboration with ANEB Quebec, which I facilitate for 4-6 months each year. I have included potential participants who have had contact with me in this setting as it is an anonymous, “drop-in” style group that hundreds of people use each year for short periods of time (200 people used this service in 2016-2017) (Arrimage Estrie, 2017, p. 20). Potential participants were made aware that I was conducting the research and decided whether they felt comfortable sharing their recovery stories with me in the context of this research. Please see Interview Guide (Annex 1) for specific questions about my professional role.

Finally, individuals who are currently hospitalized for an eating disorder, or who are unable to carry out their daily activities (work, study, family responsibilities, etc.) due to the severity of their eating disorder, were excluded from this study. Despite the fact that relapse is common for people recovering from an eating disorder, the interview questions have the potential to bring up strong emotions that could interfere with the recovery process of a person who is living an important relapse episode, or who has not arrived at a state of “new normal” (Davidson et al., 2009), in which the eating disorder is no longer at the center of their lives.

3.12 Safeguards for Working with a Vulnerable Population

It is possible that the interview questions may bring up strong emotions for the research participants, or that research participants may experience a relapse during the course of this study. For this reason, a list of eating disorder organizations for each region where data was collected was provided in the consent forms (Annex 2,2A), along with French and English language eating disorder helplines (National Eating Disorder Information Center (EN), ANEB Québec (FR)). Finally, as I have been working with individuals recovering from an eating disorder for more than five years at Arrimage Estrie, I am both

comfortable with this population and aware of the fragility of the recovery process. My work experience provided me with additional tools to ensure the safety and well-being of the research participants in the context of this study.

3.13 Community-Based Recruitment

The foundation of feminist research is the belief that “grounding an analysis in the everyday lives of ordinary people, especially women, could be the start of an improved understanding of social forces as they operate to confirm and constitute inequities and privileges of dominant groups” (Acker, 2000, p. 195). Recovery is by nature social and community-based, as this theoretical construct seeks to activate both the person living with mental illness and their environment in the long-term and ongoing process of transformation that leads to balance and well-being (Provencher, 2002; Davidson et al., 2009). The review of eating disorder literature exposed that much of existing eating disorder research has been conducted in clinical settings, despite the fact that research has shown that many people recover from eating disorders “spontaneously” (Mitchison et al., 2016, p. 2) (without medical intervention) or receive support in a community setting (Public Health Agency of Canada, 2002). Thus, a focus on the lived experiences of people recovering in a community context represents an unexplored area of eating disorder research, which may have significant implications for the practice of social work, a profession that is exercised with and within the community (OTSTCFQ, 2012).

To construct a community-based sample, I have chosen to recruit research participants through existing, non-medical oriented, eating disorder community organizations in three major Quebec cities: ANEB Quebec (Montreal), Arrimage Estrie (Sherbrooke) and Maison l'Éclaircie (Quebec). The fourth eating disorder organization in Quebec (Éki-Lib Santé Côte-Nord) was excluded due to the fact that it is located in Sept-îles, which is simply too far for me to travel to in the context of this study. All three organizations are rooted in the community and are financially accessible to all. Each works with people of all genders, on a voluntary basis, and does not require a diagnosis or a referral to access services (Anorexie et boulimie Québec, 2018; Arrimage Estrie, 2015; Maison l'Éclaircie, 2014). The inclusiveness of these community organizations is important as gender and type of eating disorder are restrictive categories in

the current eating disorder literature, which studies women living with anorexia and bulimia disproportionately.

Furthermore, statistics gathered by ANEB Québec (2017) on the age and income of individuals who participated in the organization's eating disorder support groups indicate that there is a great deal of diversity in both categories. In 2016-2017, 36% of group participants were 20-29 year olds, 28% were 30-39 years olds, and 28% were 40 years and older (ANEB Québec, 2017, p. 25). The average age of participants for 2016-2017 was 31 years, and the previous year (2015-2016) the average age was 37 years (ANEB Québec, 2017, p. 25). Individual annual income was also varied in 2016-2017, the three largest income groups were \$5000-\$15,000 (23%), \$55,000 or more (19%), \$35,000-\$45,000 (18%) (ANEB Québec, 2017, p. 25). These statistics hint at the age and class diversity that may be present in similar community organizations in other cities, making recruitment through this type of organization a means to reach a more diverse sample of people than are traditionally included in eating disorder research.

Gender is the category with the least amount of variation in ANEB Quebec's eating disorder support group statistics, as 96% of the 2016-2017 participants identified as women and only 4% identified as men (ANEB Québec, 2017, p. 24). ANEB Québec states that they are « *toujours soucieuse de la clientèle masculine* » and are « *en perpetual questionnement quant à une stratégie de rejoindre davantage cette clientèle et de répondre à ses besoins* » (ANEB Québec, 2017, p. 24), which suggests that there is an inherent challenge in including individuals who identify as men in eating disorder services at the community level. Few statistics on gender, income and age were available for Arrimage Estrie and Maison l'Éclaircie, however Maison l'Éclaircie gathered data on the gender of individuals who called the organizations' eating disorder helpline. In 2016-2017, 5% of the callers to the helpline identified as men and 95% of the callers identified as women (data on other gender categories was not collected) (Maison l'Éclaircie, 2017, p. 11). These numbers suggest that even though eating disorder services in these two community organizations are open to all genders, the majority of people in contact with the organization identify as women.

To recruit participants, ANEB Québec, Arrimage Estrie and Maison l'Éclaircie were asked to post a recruitment message on their social media platforms and/or websites and message boards. I also prepared a flyer that could be distributed in various eating disorder support groups offered by these organizations, to connect with people of all ages who may not have access to the internet or be active on social media. A description of each organization's mission and services can be found in the table below. The bilingual recruitment message can be found in Annex 3.

Table 2- Community Organization's Mission and Services

Community Organization	City	Mission	Services
Anorexie & boulimie Québec (ANEB)	Montreal (regional organization)	<p>La mission d'ANEB et ses objectifs</p> <p>Mission Garantir une aide immédiate, spécialisée aux personnes atteintes d'un trouble du comportement alimentaire et à leurs proches.</p> <p>Objectifs Offrir une aide spécialisée aux personnes souffrant d'un trouble de l'alimentation et à leurs proches. Sensibiliser la population et les partenaires potentiels aux troubles de l'alimentation Prévenir et diminuer les conséquences des troubles de l'alimentation en collaborant avec d'autres organismes Développer des programmes de formation visant le dépistage rapide des troubles de l'alimentation</p> <p style="text-align: right;">ANEB Québec, 2017</p>	<p>Ligne d'écoute et de référence régionale</p> <p>Aide en ligne</p> <ul style="list-style-type: none"> • Forum • Clavardage <p>Groupes de soutien ouverts</p> <ul style="list-style-type: none"> • Groupes pour personnes souffrant d'un trouble alimentaire • Groupes pour les proches <p>Groupes de soutien fermés</p> <ul style="list-style-type: none"> • Niveau 1 • Niveau 2 • Hyperphagie • Sexualité • Art • Pour les proches
Arrimage Estrie	Sherbrooke	<p>Mission de l'organisme Arrimage Estrie est un organisme d'action communautaire autonome qui favorise le développement d'une image corporelle positive dans la collectivité en plus d'accompagner les personnes touchées par un trouble du comportement alimentaire (anorexie, boulimie, hyperphagie, bigorexie, orthorexie ou obsession de la minceur) ou une préoccupation envers leur corps, leur poids ou leur apparence. L'organisme valorise la diversité corporelle et prône une approche anti-régime basée sur l'écoute des signaux de faim et de satiété ainsi que le plaisir de manger.</p> <p>Valeurs de l'organisme Dans un climat d'ouverture et de non-jugement, l'organisme prône les valeurs suivantes:</p>	<p>Rencontres d'accueil et de référence</p> <p>Groupes de soutien ouverts TCA (offerts en collaboration avec ANEB Québec)</p> <p>Groupe rétablissement TCA</p> <p>Rencontres individuelles de soutien et d'information pour les proches</p>

		<p>L'appropriation du pouvoir d'agir (individuel et collectif) L'engagement L'entraide et la solidarité L'équité et la justice sociale</p> <p>Objectifs de l'organisme Sensibiliser la population à l'importance d'une image corporelle positive et une relation saine envers son corps, son poids et son alimentation Valoriser la diversité corporelle Favoriser l'appropriation de son propre corps et l'acceptation de soi Lutter contre l'utilisation du corps comme outil de marchandisation Privilégier l'approche féministe et préventive</p> <p style="text-align: right;">Arrimage Estrie, 2015</p>	
Maison l'Éclaircie	Québec	<p>Notre mission est de venir en aide aux personnes de 14 ans et plus de la région de Québec (03) qui vivent des comportements associés à l'anorexie ou à la boulimie. L'organisme offre également du soutien aux proches.</p> <p>Les services offerts par la Maison l'Éclaircie sont empreints de différentes valeurs, telles que :</p> <p>La réappropriation du pouvoir L'intervention individualisée La responsabilisation L'action sociale</p> <p style="text-align: right;">Maison l'Éclaircie, 2014</p>	<p>Écoute Téléphonique</p> <p>Rencontre initiale</p> <p>Ateliers Cohorte</p> <p>Rencontres d'accompagnement et de soutien</p> <p>Rencontres individuelles avec une nutritionniste</p> <p>Groupe estime</p> <p>Rencontres de soutien pour les proches</p> <p>Groupe de soutien pour les proches</p>

3.14 Number of Participants

In the context of this study, 12 participants were recruited. The number of participants was chosen to achieve a certain degree of geographical, identity (gender, race, ethnicity, sexual orientation, class, age) and eating disorder diversity within the limits of an exploratory, unfunded master's level study. As the purpose of this qualitative research is to explore the ""process" and "meanings" individuals attribute to their given social situation, not necessarily to make generalizations" (Hesse-Biber, 2014b, p. 192), the small sample size is appropriate. The minimum number of participants for the study was 9, but 3

additional participants were added as the data analysis progressed. As mentioned earlier, data was analyzed in the spirit of grounded theory, which makes it necessary to add to the sample if an emergent concept requires testing (Quinn Patton, 2002, p. 125).

3.15 Data Collection

Data collection for this study took place in three cities (Montreal, Sherbrooke, and Quebec) between June 2018 and September 2018. To keep travel time and costs low, specific dates were proposed for interviews in Montreal and Quebec. Participants from the Sherbrooke area had more flexibility in choosing the times and dates of their interviews, as I live closer to that city.

In keeping with the feminist approach to doing research, it was imperative that participants be in an environment in which they felt comfortable and free to express themselves. For this reason, I met with participants in a location of their choosing (their home, school, office, etc) for a 1.5 hour individual interview. I explained to participants that the location had to be private, as our conversation was confidential. Additionally, I reserved a private room at a public library in each city, in the case that a participant did not wish to choose a location or did not have access to a private space in which to participate in the interview. Each interview was audio recorded with the written consent of the participant (see Consent forms: Annex 2, 2A)

3.16 Compensation

Participants did not receive any financial compensation for their participation in this study. However, as a thank you for giving their time to the study, two movie vouchers were given to each participant who completed a full interview. Movie vouchers were chosen as a way of acknowledging participants' contribution to this research, as the length of a movie was similar to the amount of time that research participants spent doing an interview (1.5 hours). The movie vouchers were paid for using my personal funds and were given to participants at the end of their interview.

3.17 Confidentiality

In her article *In/Out/Side: Positioning the Researcher in Feminist qualitative research*, Sandra Acker reflects on the confidentiality challenges of doing research in “small worlds” (Acker, 2000, p. 192). Acker’s “small world” was research conducted in a Canadian university context, in which “promises to informants about anonymity and confidentiality needed to be taken seriously when narratives about their lives might be recognized by their colleagues” (Acker, 2000, p. 193). The same can be said of the Quebec eating disorder community. Despite the fact that I am doing research in three different cities, it is highly possible that the narratives of the research participants could be recognized by professionals or other patients/participants/clients in any of those locations. As eating disorder services in Quebec are limited, it is not uncommon for individuals living with eating disorders to travel to other centers to receive treatment and services. Group work in any of these contexts is common (support groups, hospital outpatient programs, group therapy, etc.), which further increases the possibility that participants’ narratives will be recognizable. It is also possible that I will recognize other eating disorder professionals with whom I have professional or personal ties to, or organizations and services that I work with, in the narratives of the research participants. Participants may also be critical of the services offered by Arrimage Estrie (my employer), services which I have been active in creating and delivering over the past 5 years. These considerations were top of mind during the data collection process as well as the data analysis. During the interview process I documented instances where my “insider status” could have been problematic and validated my interpretations with my thesis supervisor. These instances are included as a note in the transcription of interviews. Additionally, I validated participants’ narratives (as they appear in the analysis and conclusion sections of the thesis) with each person before submitting my thesis to the university, to support participants in making informed choices about how their lived experiences are portrayed.

3.18 Evolution of the Research Protocol

Over the course of data collection, the interview guide and questions (Annex 1) used to collect data shifted very little. Three notable adjustments were made in the data collection process. First, the way in which I established participants stage of recovery shifted from a formal approach, to an informal,

conversational approach. The first participant was sent a PDF of Davidson's recovery description (Table 4) and asked to situate herself within the descriptions. This approach proved to be too formal, and made the participant feel as though she was taking a test. Consequently, the following 11 participants' recovery phases were established through a short telephone conversation in the recruitment phase, in which the participant was asked to tell me where they were in the recovery process. This technique felt much less like an evaluation and set a tone of friendliness for the interview.

Secondly, in the section on demographic information I added the question: What makes you, you? This question allowed participants to define themselves in a more open manner and yielded rich information about how participants defined themselves, outside of the demographic facts. Often this question colored how the participant shaped their recovery narrative, as for many participants elements of their identity had a significant impact on their recovery process.

Finally, questions about the experience of gender in a community organization were added to the interview with the study's male participant. As he was the only male participating in a community support group, I was interested in how he perceived his place in the group, how the group's content resonated for him, and whether he would have preferred having a higher ratio of men in the group. These questions also yielded rich information on how the participant perceived both his gender, and of the support group's content.

Chapter 4: Results and General Discussion

The goal of this study is to explore the realities of recovery in a community context, a relatively uncharted territory in the fields of eating disorders and social work research. As this area of research is new, the volume and quality of data collected in this study are overwhelming. As a researcher, I am faced with the dilemma of what aspects of the participants' recovery narratives to include, as the amount of data analysed surpasses the limits of a master's research thesis. For this reason, I have chosen to address only the strongest themes that emerged from the data, and the themes that are most relevant to social work practice as the stated goal of this study is to answer the question of what role social workers might play in the eating disorder recovery process. The remaining information, which is rich and merits to be explored in the context of further research, will be touched on in the final section: future research.

As an eating disorder counsellor, I am aware of how damaging it can be to highlight how much a person weighs, how many or little calories they consume, how much they work out, etc. These types of facts sensationalize the symptoms of the eating disorder and detract from the underlying causes. This type of information also opens the door to comparison, which is a major issue for all people living with eating disorders. As such, the verbatims included in this section will not include numbers (weight, calories, frequency of workouts, clothing size etc.). If a number is part of what a research participant has said, it will be replaced with "x".

In order to protect the research participant's identities in the "small world" (Acker, 2000, p. 192) of Quebec eating disorder services, I have used pseudonyms for each interviewee. Participants have also been made aware of the interview passages that have been included this study, as they have the final say on how their narratives are used (Hesse-Biber, 2014b).

Finally, the interviews were conducted in a feminist approach which seeks to reveal "experiences that are often hidden" (Hesse-Biber, 2014b, p. 190), specifically the "voices of those who are marginalized in a society" (Hesse-Biber, 2014b, p. 190). In the context of this study, the voices of individuals living with eating disorders have been marginalized in the literature on the subject. As mentioned in an earlier section, the research on this topic can only be considered incomplete as "eating disorder literature is

often limited by the use of unrepresentative samples (i.e., clinical samples, college samples, convenience community samples)” (Kendall & Hugman, 2013, p. 1282), often excluding men (Bunnell, 2016; Griffiths et al., 2015; Kendall & Hugman, 2013), women beyond college age (J. Slevac & Tiggemann, 2011), people of color (Katsounari, 2009) and people outside the male-female gender binary (Jones et al., 2016). Coupled with the fact that expert voices dominate the biomedical literature on the topic of eating disorders, the experiences of many individuals living with these disorders have been effectively silenced. The resulting treatment models for eating disorders have “problematically result[ed] in definitions of treatment that measure patient progress and recovery on the basis of patient compliance with the goals of professionals” (Gremillion, 2002; Kendall & Hugman, 2013, p. 321) instead of taking the person’s wishes, values, and conceptions of quality of life into account (Davidson et al., 2009; Kendall & Hugman, 2013; Simblett, 2013). Often “patient” knowledge and self-determination are perceived as a form of resistance to treatment, especially in the case of anorexia (Gremillion, 2002; Kendall & Hugman, 2013, p. 321). As Kendall & Hugman (2013) state that “addressing these conditions is consistent with the social work value of ‘social justice’; this involves working to change systems that devalue patient knowledge and that exclude their voices from knowledge production” (Kendall & Hugman, 2013, p. 321). Taking both the feminist research stance on marginalized voices and the social work value of social justice into account, I have chosen to include a higher volume of interview excerpts in this section. The experiences participants had to share were complex and reveal elements of the community recovery context that have not been documented in the current eating disorder literature. As such, I felt it was important to let the participants speak for themselves as much as possible in this section. Similarly, interview excerpts appear in the language of the research participants (the majority of whom spoke French) in order to preserve the meaning and linguistic nuance used to describe the realities of recovery in a French speaking province.

4.1 Research participants

Using a purposeful sampling strategy, to “deepen and verify” (Quinn Patton, 2015, p. 289) recovery from an eating disorder as theoretical construct; and the community as a new context within which to explore this construct, interviews were conducted with 12 adults recovering from an eating disorder in their

community. To achieve a diverse, community-based sample, research participants were recruited through 3 eating disorder community organizations (ANEB Québec, Arrimage Estrie, Maison l'Éclaircie) in three cities (Montreal, Sherbrooke, Quebec). These organizations are rooted in the community and offer their services to individuals of all genders and social classes, without a medical referral or diagnosis. Except for Maison l'Éclaircie (whose services are focused on anorexia and bulimia), the organizations offer non-medical support to individuals with all types of eating disorder, including binge-eating disorder, emergent and sub-clinical eating disorders. Each organization diffused the recruitment message through Facebook, the organization's web page, and printed flyers were distributed. Participants who met the research criteria were accepted on a first-come, first-served basis.

The resulting sample is diverse in many ways, which is likely more representative of the community reality than the clinical samples used in most eating disorder research (Kendall & Hugman, 2013). In terms of geographical diversity, 8 participants live in Sherbrooke, 2 live in Quebec, 1 lives in the Abitibi-Temiscamingue region (but accessed community resources in Quebec), and 1 lives in Montreal. All participants identified their race as Caucasian, however there was some ethnic diversity: Canadian, French, Quebecois, Quebecois-Acadian, Quebecois-Cree, Quebecois-Gaspésien, Quebecois-Italian, Quebecois-Lebanese, and Western-Canadian-Anglophone. There is also considerable age diversity in the sample. Participants ages range from 25 to 62 years old; the mean age of the sample being 41 years. As noted by Slevic & Tiggemann (2011), middle-aged women have been excluded from current eating disorder literature, but have been found to be experiencing eating issues (Mitchison et al., 2016; J. H. Slevic & Tiggemann, 2011). All twelve individuals identified themselves as middle-class, though some indicated they were lower or upper middle class. Except for 1 participant, all are employed.

The study's participants are overwhelmingly female, as 11 of the research participants identified as women (1 identified as a man). As noted in an earlier section, women represent the majority of participants in community organization's eating disorder support groups, making up 96% of ANEB Quebec's 2016-2017 participants (ANEB Québec, 2017, p. 24). As such, a majority female sample may be reflective of the community organization's membership, and the general stigma associated with men seeking help for an eating disorder (Bunnell, 2016; Griffiths et al., 2015). Though no specific questions

on sexual orientation were asked, more than half of the participants stated that they are in a relationship with a person of the opposite sex. In addition, 5 participants have biological children, 2 participants are co-parenting their partner's children, 2 participants were co-parenting with a partner they are separated from, and 1 is a single parent.

Participants identified their own eating disorder in both the recruitment and interview phases of the study. As stated earlier, DSM criteria often do not represent the reality of eating disorders in the population due to the high number of individuals who receive a diagnosis of Other Specified Feeding or Eating Disorders (OSFED) or Unspecified Feeding or Eating Disorders (UFED) (formerly EDNOS) (Myers & Wiman, 2014; Public Health Agency of Canada, 2002), or do not receive or seek treatment for their disordered eating (Hart et al., 2011; Mitchison et al., 2016).

In this study, 3 participants are recovering from anorexia, 3 from binge-eating disorder, 2 from orthorexia, 2 from anorexia and bulimia, 1 from orthorexia and bulimia, and 1 from orthorexia and binge-eating disorder. A total of 3 participants have a formal eating disorder diagnosis. A third of participants have accessed specialized eating disorder treatments (eating disorder hospital programs or specialized psychiatrists) in addition to using community resources. All participants accessed more than one community resource in their recovery process. These resources include: community organizations, professionals in the private sector (nutritionist, occupational therapist, psychologist, kinesiologist), and first-line health care professionals (doctors, nurses, social workers, psychologists, dieticians). The average number of community resources accessed was 3.8, with the lowest being 2 and highest number of resources accessed being 9. These numbers may be related to the high number of years some participants have been struggling with eating issues. All but 3 participants identified the start of their eating disorder in either childhood or adolescence, though 3 experienced an eating disorder in their teens, followed by a second episode in adulthood. In the case of the oldest participant, the recovery process started after more than 40 years of living with an eating disorder. According to Maier "it is common for eating disorders to go unnoticed due to the level of denial individuals and families often present with after discovering symptoms" (Maier, 2015, p. 153). In addition, individuals often continue to function in many of areas of their lives (work, relationships, education, etc.) while struggling with an

eating disorder (Mitchison et al., 2016). The number of years research participants have lived with their eating disorder as adults (1-45 years) also troubles the portrait of eating disorders as affecting only the young (Leblanc et al., 2014; McCormick, 2008; J. Slevic & Tiggemann, 2011), which is the reality most often portrayed in the eating disorder literature.

Some participants indicated living with other physical or mental health issues, though not all had a formal diagnosis: anxiety (1), attention deficit and hyperactivity disorder (2), depression (4), fibromyalgia (1), hoarding (1), and multiple sclerosis (1). The incidence of comorbid mental health issues among individuals living with eating disorders is well documented in the eating disorder literature (Hudson et al., 2007; Leblanc et al., 2014), and has been identified as being a possible barrier to receiving specialized eating disorder treatment by some (Hudson et al., 2007; Leblanc et al., 2014).

In 3 cases, participants reported experiencing sexual violence, either in childhood or adulthood (or both) which may have played a role in the development of the eating disorder (Petrucci, 2016). In addition, some participants reported experiences of general family dysfunction, which has also been identified as a generalized social factor related to the development of eating disorders (Public Health Agency of Canada, 2002). Finally, 2 participants indicated that an immediate family member had an eating disorder (mother, brother), which may also predispose an individual to develop an eating disorder (American Psychiatric Association, 2018).

In this sample, 3 participants reported that their eating disorder symptoms began during or after having been involved in high-level sport as a teenager. In all cases, the participants related the start of the eating disorder to a major life event (death, separation, break-up, illness, moving to a new country, parent's divorce, experience of sexual violence, job loss, menopause, etc.) that they were unequipped to handle.

Many of the participants spoke more than one language, however all the interviews were conducted in the participant's first language: 11 in French and 1 in English. As such, interview excerpts in this section appear in both French and English.

4.2 Defining Recovery

The principal research question in this study is: **What are the lived experiences of a community-based sample of people in recovery from an eating disorder in Quebec?**

As the concept of recovery has rarely been applied to the issue of eating disorders, it was important to understand how research participants understood this concept. As noted in an earlier section, the term recovery tends to be used interchangeably with the term “cure” both in the eating disorder literature, and in the ways individuals are perceived by loved-ones and health professionals to be “better” if they stabilize weight and get disordered eating under control (Arnaiz, 2009; Gremillion, 2002; Wilson, 2004).

To better understand how participants perceived their recoveries, they were asked to define the recovery process in relation to their lived experiences. From the participants’ answers emerged 6 distinct recovery themes. Firstly, many of the participant’s emphasized that **the eating disorder does not go away, but it gets better**, which troubles the notion of an objective “cure” to eating issues. Vanessa explains this perspective:

Vanessa : ...c’est pas la disparition du trouble alimentaire au complet le rétablissement pour moi là. [...] « Ça fait comme 9 mois là je suis sortie de traitement pis je te dirais que [l’obsession] a diminué de comme 80%, faque je me dit peut-être que dans un an le 20% qui reste va être encore plus petit. » Mais c’est ça, ça veut pas dire le rétablissement c’est avoir 0 symptôme.

Many participants expressed that the recovery process was ongoing by comparing the eating disorder to addiction. Jennifer explains that some of her symptoms (thoughts, rigidity about certain foods, etc.) have not completely disappeared in her recovery process:

Jennifer : [...] c’est juste qu’il y a des affaires qui reste un peu; moi je compare ça un peu à un alcoolique là, que l’alcoolisme ne part jamais complètement. Pis la première fois c’est ça, c’était pas mal disparu pis là [à cet épisode d’anorexie] il y a une couple d’affaires qui sont restées. [...]

Though the important nuance of food being necessary for survival (thus eliminating the possibility of abstinence) was also present in the participant’s descriptions. Lili explains:

Lili : Mais quand tu parles de nourriture, c’est une autre affaire. C’est comme présent dans ta vie pis tu ne peux pas l’éliminer. Si tu l’élimines, ben il y a des grosses chances que tu sois plus sur la planète. Donc c’est au niveau du rétablissement je pense que c’était un...quelque chose qui était difficile au départ. Comment se réconcilier avec la nourriture quand t’as eu toutes sortes de problèmes avec.

The theme of **recovery as a long-term process** was also noted in the participant's discourses. Accepting that the process is slow and occurs over time was an element of recovery that several participants struggled with. Lydia explains how she integrated this aspect of recovery :

Lydia : [...] *c'est sûr que, je suis consciente que le rétablissement c'est un phénomène qui est...c'est du très long terme, que j'accepte aussi maintenant. Faut beaucoup de patience et d'indulgence et de bonté envers soi-même pour accepter ça. J'accepte ça.*

Jason also touches on this theme in his spontaneous definition of recovery as: "Slow A F [as fuck]!" (Jason). Others described recovery as a "grand voyage" (Megan) or as a process without a clear end destination (Sophie). All participants expressed that the recovery was a **non-linear process, rife with ups and downs**. Megan explains her experience of recovery as follows:

Megan : [...] *c'est un grand voyage là, ça l'a ses hauts et ses bas. Ouin c'est une grande expérience; faut juste comme pas abandonner, faut se laisser le temps, pis je pense que [le rétablissement] nous réserve des surprises autant agréables que moins agréables, mettons.*

The recovery process was defined in many ways by participants, however the notion of **self-acceptance** was present in many of their responses. As Jason states: "[Recovery]...it's growing into who I wanna [sic] be, and who I am, and accepting certain things that I can't change" (Jason). Chloe describes this self-acceptance as the emergence of her "true self": «*Je bouge, je m'amuse, je ris, je... ouais, la vraie Chloe elle ressort* » (Chloe).

Many of the participants also described learning to forgive themselves as part of the self-acceptance process. As Lili describes:

Lili : *C'est un peu comme ça que je vois le rétablissement, c'est une forme de pardon aussi. Moi je me suis tapée dessus, wow, comme ça se peut pas. Pis c'est de...d'apprendre à s'aimer malgré nos petits travers.*

For Cassie, forgiving herself is daily process that is intimately linked to her relationship to food and her body, she explains:

Cassie : [...] *on dirait que c'est comme si malgré tout, je le sais que même si je suis encore grosse, pis que même si je me nourris de toutes les choses que je déteste et que je ne voudrais pas manger, je suis capable de voir pis de prendre conscience des choses qui sont, selon moi, mieux pour moi. Faque c'est ça, d'accepter de m'aimer quand même; même si j'aime pas mon corps, ou de me pardonner même si je mange ça.*

Though food and weight were rarely mentioned in the participants definitions of recovery, the notion of **eating disorder symptoms occupying less “mental space”** did emerge. Vanessa shares how the obsession with food shaped her life pre-recovery:

Vanessa : *C'est quoi le rétablissement? Ben c'est sûr que c'est une diminution des obsessions là. Ça c'est comme, faut que ça aille. Dans mon cerveau y'a beaucoup plus de place pour autre chose, comme que : « Ok qu'est-ce que j'ai mangé ce matin? » « Qu'est-ce que je vais manger ce midi? » « Est-ce que je vais le garder? » « Qu'est-ce que je vais manger ce soir? » C'était que ça, toute ma journée était consumée par mes prises alimentaires, par mon poids, par me peser, me peser avant de faire pipi, après de faire pipi, le matin, comme à jeun, tout nu, le soir avant de me coucher pour voir comment j'avais pris.*

This description reveals the “functional impairment” (Mitchison et al., 2016, p. 1) associated with eating disorders and their obvious impact on Vanessa’s quality of life. For Jennifer, less obsession represents freedom in her social life. She explains how this feels to her:

Jennifer : *Ah ben je dirais c'est vraiment juste un sentiment de liberté généralisé. De me dire, parce qu'avant ça, c'est ça aller au... Comme je disais les événements sociaux ou là je suis invitée à souper : « Ouh, ça va être quoi qu'on va manger? » « Euh, je suis invitée au restaurant? » Ben je vais aller voir le menu en ligne avant pis je vais essayer de me choisir de quoi qui va me convenir. En voyage c'est la même affaire, tsé? Faque c'est vraiment moins contraignant de tous ces côtés-là, social et plaisir général je dirais là.*

For Chloe, who struggled with an eating disorder for many years, recovery represents being freed from a metaphoric cage:

Chloe : *[...] première chose qu'on fait à [l'organisme communautaire] je pense c'est comment on se voyait avec notre TCA et moi ça été la cage, pis après ça avec un oiseau. Ben là, la porte est ouverte pis si tu penses que j'ai l'goût de retourner dans la cage? Y'en ai pas question là! [...]*

Finally, for some participants recovery was intimately linked to **self-care**. For Vanessa, maintaining a healthy weight represents caring for herself without having to “put life on hold” to be hospitalized for several months at a time for an eating disorder:

Vanessa : *[...] Faque c'est beaucoup ça, de maintenir [un poids santé] pis veux, veux pas c'est comme quand j'ai un poids santé, j'ai comme pu de bonnes raisons. C'est ça, mais c'est des croyances là. Je suis vraiment... Je le sais, mais c'est comme si j'avais pu de bonnes raisons d'être, d'arrêter de travailler. J'avais pu de bonnes raisons de... Faque c'est comme...c'est ça, c'est un big deal pour moi maintenir un poids santé là.*

Vanessa's experience resonates with Davidson's (2009) emphasis on "the everyday nature of recovery" which is "exemplified by such mundane activities as washing one's own dishes, playing with a child, or walking a dog" (Davidson et al., 2009, p. 1). For Vanessa, maintaining her weight symbolized maintaining a daily routine that kept her at work and school, a stability that was impossible when the eating disorder was more present.

The research participants' definitions of recovery as an ongoing, long-term, non-linear process which involved self-acceptance, a decrease in eating disorder symptoms and a healthy dose of self-care echoes Spaniol et al's (1994) definition of recovery as "...a process of adjusting one's attitudes, feelings, perceptions, and goals in life and a process of self-discovery, self-renewal, and transformation" (Spaniol et al 1994 cited in Provencher, 2002, p. 38). The descriptions also resonate with Deegan's (1997) definition, which is based on her own recovery experience:

[...] [recovery is] process, not an end point or a destination. Recovery is an attitude, a way of approaching the day and the challenges I face. Being in recovery means that I know I have certain limitations and things I can't do. But rather than letting those limitations be an occasion for despair and giving up, I have learned that in knowing what I can't do, I also open up upon the possibilities of all the things I can do.

(Deegan, 1997, p.21-22 cited in Provencher, 2002, p. 38)

Many of the participants indicated that they were living a "new reality" in recovery, which Davidson et al. (2007) describe as developing a "positive sense of identity apart from one's condition while rebuilding a life despite or within the limitations imposed by that condition" (Davidson et al., 2007 cited in Davidson et al., 2009, p. 29). Lili's description of the rediscovering herself in the recovery process illustrates this perspective:

Lili : [...] *C'est que je me suis dit : « Bon ben, je vais être comme un canevas, un canevas peinture là, blanc. Sauf que mon canevas va avoir des dimensions illimitées et je vais pouvoir mettre ce que je veux dans mon canevas. » C'est comme un work in progress.*

The notion having an identity "apart from the condition" (Davidson et al., 2009, p. 29) is particularly relevant in the case of eating disorders, which are all-pervasive and can easily become both an identity and a lifestyle for those living with them. This is especially true when individuals "have experienced the onset of a serious mental illness in late adolescence or early childhood and whose normal development

may therefore have been disrupted or delayed” (Davidson et al., 2009, p. 55), as is the case with the majority of research participants in this study. As Megan explains:

Megan : [...] *[le trouble alimentaire] été là de façon très intense [à l’adolescence], des périodes assez formatrices de la personnalité. Faque je me sentais là, c’était une partie de moi là. Faque si on m’enlève ça, je suis qui? Faque, j’avais...je redécouvrais que j’étais autre chose.*

Finally, it is important to note that the eating disorder symptoms remained present for many of the participants. As Davidson et al. (2009) explain: “complete symptom remission is unnecessary for a person to be in recovery and most people also find it necessary nonetheless to gain some degree of control over their symptoms” (Davidson et al., 2009, p. 49). For Jason, attaining a certain control of his eating disorder symptoms was a key element of recovery, which he explains as follows:

Jason : I have some type of an eating disorder, maybe I don’t really know why, maybe I’m starting to understand my triggers, maybe I can figure out how to go around episodes or whatever and get stronger, get better so they’re less and less frequent but yeah, it’s just...it’s slow. It’s not, I was going to say slow and painful but it’s not. It’s not painful, it’s just a really long process and I’m okay with that.

For many, eating disorder symptoms were perceived as a sort of alarm system that lets them know it is time to connect with themselves. Chloe describes knowing something is wrong when she experiences an eating disorder symptom:

Chloe : *Ben je veux dire, c’est minime [les comportements], c’est minime. Mais c’est pendant là, je me pose toute suite la question : « Bon, qu’est-ce qui se passe ?! ». Pis avant, jamais je faisais ça. Mais aujourd’hui je me pose la question.*

Sophie also describes how she perceives her eating disorder symptoms as a need to check-in with herself:

Sophie : *Faque je me dis déjà c’est une grosse victoire [d’avoir moins de crises alimentaires], même si ça m’arrive. Pis aussi c’est d’être; que je vais accueillir ces crises là quand elles arrivent plutôt que de me taper sur la tête : « Bon, qu’est ce qu’il y a Sophie-là? » Tsé?*

For others, the symptoms are thoughts, or a desire to engage in the disordered behavior. Laurie illustrates this nuance in her description of what types of “relapse” (Laurie) she experiences:

Laurie : [...] *Oui, des fois, ce sont des rechutes alimentaires ou des rechutes d’estime de soi, et je tombe dans une inquiétude ou un désir de recommencer [la restriction] que je ne fais pas parce que j’ai littéralement mal au cœur quand je repense à recalculer mes choses.*

Some interviewees perceived the eating disorder symptoms as part of the recovery process and accepted that, at times, using food to deal with emotions or difficult situations will still occur. Sophie explains:

Sophie : *Je veux dire, oui c'est arrivé là l'autre jour que, encore une fois, j'ai mangé mes émotions, mais pour moi c'est pas une rechute grave. C'est dans le processus. Pis, j'ai pas l'impression que je vais perdre tout ce que j'ai vu, toutes les notions [...]*

Whether they are experiencing eating disorder symptoms or not, most participants shared that the eating disorder does not prevent them from participating in the other aspects of their lives: professional, personal, social, academic, etc. Lili describes her new way of functioning as follows:

Lili : *[...] c'est d'apprendre à vivre avec les sentiments du moment. Je pense que c'est pas mal ça que t'as à faire. C'est aussi, le rétablissement c'est aussi de voir que t'as des limites en tant qu'être humain là, aussi. C'est d'accepter d'en avoir et de bien vivre avec. C'est ça, c'est cultivé ton bonheur une journée à la fois. Je pense c'est pas mal ça le rétablissement.*

As Lili's description expresses, the research participants' perceptions of recovery are intimately linked to achieving a better quality of life through a connection to themselves and a respect for their limits.

4.2.1 Relapse

Traditional definitions of eating disorder recovery have been focused on the absence of symptoms and the stabilization of weight (Arnaiz, 2009; Bordo, 2003; Gremillion, 2002; Malson, 2003), however the research participants' perceptions of relapse are consistent with what Provencher describes as : « *la distanciation du trouble mental [qui] offre la possibilité d'observer les manifestations du trouble mental d'une manière plus « objective » et d'utiliser des stratégies de rétablissement favorisant une meilleure qualité de vie et de bien-être.* » (Provencher, 2002, p. 41). For the participants in this study, relapse was not defined as the presence of eating disorder symptoms, as many participants still experienced symptoms (though much less frequently). Instead, relapse was perceived as the inability to function in daily life. Megan's description of a relapse episode illustrates this:

Megan : *[...] ça allait vraiment, vraiment pas bien là. J'étais pu capable d'écouter en classe, j'étais vraiment toutes mes pensées étaient concentrées là-dessus. Mais j'étais assez consciente pour, c'est ça, ben je suis allée chercher de l'aide à [l'organisme communautaire] là à ce moment-là.*

The reality of relapse was also an important element of many participant's conception of recovery. Lili explains her perception of relapse :

Lili : *Ben, elle est présente. Faut en tenir compte. Parce que la rechute est là pour qu'on se relève pis qu'on continue. C'est pas agréable quand ça arrive, pis... Mais elle est nécessaire je pense, dans le processus de rétablissement. En fait, la rechute nous aide à avoir les deux pieds sur terre.*

For others, relapse was related to moments of stress or transition. Anne shares:

Anne : *[...] je sais pas si on en guérit complètement à 100 %. Moi je me considère à 95%, mais y'a 5% c'est mon buffer de faire attention quand j'arrive en période de grands stress; que ça peut revenir.*

Many of the interviewees' perceptions of relapse had transformed in the recovery process. Lydia explains how her view of relapse has changed:

Lydia : *[...] La rechute, avant ça j'avais peur d'elle avant qu'elle arrive. Maintenant c'est comme j'y pense moins. OK ? Quand ça arrive, ça arrive, mais tu sais, j'essaye de pas trop focuser là-dessus.*

Understanding relapse, having systems of support and having emotional tools to handle difficult situations was often cited as the reason relapse was less frequent, or less of a fear for participants (Anne, Chloe, Megan, Jason, Jennifer, Sophie). Anne says : « *Je pense pas, je pense pas [à la rechute] parce que je considère que j'ai beaucoup d'outils, j'ai un bon coffre d'outils* » (Anne).

Globally, the research participants felt that the possibility of relapse was an integral part of recovery. There was a generalized understanding that the eating disorder symptoms were related to underlying issues that could be triggered by a future event.

Anne : *[...] je pense qu'un trouble alimentaire c'est un symptôme de quelque chose d'autre. Moi, en tout cas, ça s'est traduit par j'avais pu de contrôle, énormément d'anxiété donc le seul contrôle que j'avais c'était sur ce que je mangeais pis sur ce que je pouvais faire avec, pis je me punissais[...]*

Overall, the skills and knowledge acquired in the recovery process were perceived as a protective factor with regards to relapse; both as a motivation to engage in the routine self-care that recovery requires, and the confidence that they would know what to do in the case of a relapse. Megan's perception of relapse illustrates this perception:

Megan : *Moi je pensais que : je suis une personne qui a l'humeur un peu up and down faque moi je me disais : « Bon, je vais être up and down. Y'a des périodes de ma vie où que ça va mieux aller pis d'autres où je vais avoir plus de pensées. » Pis finalement là ça fait 2 ans et demi que je me considère comme rétablie pis j'ai pas eu de pensées là. [...] peut-être que dans une autre période de ma vie ça va réapparaître mais en même temps je me dis là j'ai vraiment les outils; je sais pourquoi c'était là [le trouble alimentaire] à ce moment-là, pis je suis pas sûr je vais en avoir besoin à un autre moment de ma vie.*

As Provencher (2002) affirms, « toute tentative de définition du rétablissement doit mettre en perspective l'expérience subjective de l'individu dans ses efforts de surmonter les symptômes et de dépasser les limites imposées par le trouble mental et les conséquences sociales associées » (Provencher, 2002, p. 39). Deegan (1996) also emphasizes the unicity of each recovery: "The goal [of recovery] is to become the unique, awesome, never to be repeated human being that we are called to be" (Deegan, 1996). Thus, the diversity of definitions and experiences of recovery reflect the subjective experiences of the people in this sample.

It is interesting to note, however, that participant's perceptions of recovery are far from the biomedical view "which defines cure as the absence of clinical symptoms" (Mitchison et al., 2016, p. 11). As Black asserts "the medical conceptualisation of eating issues as forms of individual psychopathology, and the corresponding bio-medical treatment approach has been challenged by feminist critiques of practitioners in the fields of social work, psychology and psychiatry" (Black, 2003, p. 127). This view has also been challenged by proponents of recovery oriented practices in mental health, who identify as problematic the "clinical settings, where the focus typically remains on the disorder, deficit, and disability" (Davidson et al., 2009, p. 14). As eating disorders are treated primarily in clinical settings in Canada (Gremillion, 2002, 2003; Leblanc et al., 2014), this critique is relevant to eating disorder diagnosis and treatment practices, which both Gremillion (2002) and Simblett (2013) have described "as diminishing of the person, and, potentially, strongly supportive of the eating disorder" (Simblett, 2013, p. 123). Instead, participants in this study define recovery in terms of a process that was ongoing, leading to a better quality of life and a stronger sense of self, a perception of recovery which would support a "Recovery Model" for eating disorders that "emphasises personal empowerment and improvement in quality of life" (Mitchison et al., 2016, p. 11), which may include nutritional and weight stabilization but not as the primary objective of intervention.

4.3 What Worked in the Recovery Process

To better understand the research participants' experiences of recovery from an eating disorder in the community, they were asked what elements in their recovery process were most helpful, or supportive. Despite having very different recovery trajectories, ages and eating disorders, many common themes emerged from the participants' interviews. The strongest elements of "what worked" are grouped into the following themes: **Transformation of Self-perception, Services, Professionals, Supportive Relationships, Intuitive Eating, Resolution of Underlying Eating Disorder Causes, and Giving Back.**

4.3.1 Transformation of self-perception

The first, and most cited theme in the interviews, was a transformation in self-perception. This theme was expressed in many ways: self-love, self-acceptance, self-affirmation, self-care, putting self first, self-forgiveness, self-confidence, self-expression and self-esteem. Participants described how their perception of self shifted dramatically in the recovery process. Megan shares that : « *Je suis passée à genre : « Je suis une merde » à je suis capable d'être indulgente envers moi-même pis de reconnaître que j'ai des qualités même si j'ai une mauvaise journée* » (Megan). Many participants referred to feeling worthless and low when the eating disorder was at the center of their lives. In fact, the feeling of « *être une merde* » came up several times in the interviews. Thus, engaging in self-care was, for many participants, an expression of a changing perception of self as important and worthy or care. Lili states:

Lili : *En fait j'y vais une journée à la fois, je prends pas mal plus soin de moi. Pis c'est pas égoïste de prendre soin de soi là, c'est juste de prendre le temps de s'écouter, de s'aimer aussi, dans notre monde complètement dément.*

Self-care was described as both psychological and physical care, as Vanessa states:

Vanessa : *[...]c'est ça continuer de prendre soin de soi là. Parce que souvent tu vas penser que c'est comme égoïste là, de prendre soin de toi là, mais... (Sarah: C'est la base.) C'est la base, c'est ça. Pis je pense c'est ça, j'ai jamais appris à prendre soin de moi. Faque c'est comme un apprentissage là.*

Laurie shares a similar story, associating being connected to her hunger signals to self-respect. As she explained to a loved one:

Laurie : « [...] Ça fait 13 ans que je ne mange pas ce que je veux quand je veux. » Mon chum sait toujours quand il n'a plus faim et il arrête. Mais, j'ai dit : « Moi, ça, je n'ai pas appris à me respecter, je l'ai étouffé pendant des années. Ça, je le réapprends. » [...]

Getting to know oneself was also cited as helpful in recovery, especially for participants who had been living with an eating disorder since childhood. Cynthia explains: « j'avais l'impression d'être l'ombre de plein de personnes. Mais pas être moi. Donc, ouin. Donc ça c'a m'a beaucoup aidé [d'apprendre à me connaître] » (Cynthia). As Davidson (2009) noted, early onset of a mental health problem can interfere with an individual's sense of self. In the case of eating disorders, so much energy is devoted to the obsession with food and weight that there is little room for construction of an identity outside the eating disorder.

The ability to protect oneself from the judgement and expectations of others, was also described in the interviews. Cynthia explains:

Cynthia : *Moi le rétablissement c'est...comment je peux dire ça? Juste être capable de un : d'essayer d'arrêter la maudine de jugement des autres...tsé? Vivre ma vie à moi sans bâdrer avec le reste. De un. Pis ça, c'est tellement dur, ah, my god c'est dur!*

Globally, participants expressed that recovery was a process of coming back to the self, or of discovering themselves for the first time. As Provencher (2002) found in her review of recovery literature, many people in recovery from a mental illness relate to this process of « découverte d'un nouveau soi » that is more complex and includes « une plus grande reconnaissance de ses forces et faiblesses » (Provencher, 2002, p. 39). In her description of feminist approaches to eating disorders, Black (2000) also asserts that “a central aspect of the process is enhanced self-worth; that is, women believing that they are worthwhile and have a right to have their needs met” (Black, 2000, p. 42). As both Lili and Vanessa emphasize « c'est pas égoïste de prendre soin de soi là » (Lili), in their descriptions of learning to take care of themselves in the recovery process. Self-care is intimately linked to the re-definition of self, which Davidson et al. (2009) describe as an important step in the recovery process, as the person distances themselves from the mental illness and begins to see themselves as whole, of which the mental illness is only a small part (Davidson et al., 2009, p. 45).

4.3.2 Services

For many participants, the simple act of reaching out for help represented an important step in the recovery process. Jason explains: “Honestly, I think the...I think my recovery process started when I called the [community organization]. Where I did realize that I, one: I have a problem, two: I really wanted to get it fixed” (Jason). Participants reported a variety of experiences related to finding and receiving services in the community. In this study, participants often turned to a community organization or a family doctor to access services initially. The following elements of those services were identified as helpful: **quick access to services, affordable services, holistic approaches to eating disorders, group work** and **ongoing support** in the recovery process.

The moment participants sought help for their eating disorder was described as significant for many, as they were ready to start the work of recovery. Vanessa explains the pivotal role a community organization played when she was “desperate” to get help:

Vanessa : [...] mon premier, vraiment le premier soin que j'ai eu c'était avec [l'organisme communautaire] pis une chance qu'ils étaient là parce que pour vrai là, j'étais...Je sais pas ce que je faisais, j'étais comme désespérée. Je voulais de l'aide pis c'était toute des mois et des mois d'attente partout. Faque s'il n'y avait pas eu cet organisme communautaire là en première ligne, pour vrai je sais pas ce que j'aurais faite là. Peut-être que je serais même pu là aujourd'hui là, parce que j'étais vraiment désespérée là.

In many of the participant's narratives, **quick access to services** was important because the eating disorder symptoms had become intolerable. As mentioned in an earlier section, Hart et al (2011) identified that people living with eating disorders seek treatment after a long delay, “a median of 10 years for bulimia and 15 years for anorexia” (Hart et al., 2011, p. 728). Numbers for people living with binge-eating disorder, sub-clinical or emergent eating disorders are not available, but in this sample, participants had been living with an eating disorder between 1 and 45 years before seeking help. Receiving services at this critical moment in their recovery was for many, a question of life or death. Laurie describes trying to find help after oscillating between orthorexia and weight gain for most of her adult life. She explains how dire her situation had become:

Laurie : [...] c'est là que j'ai prié Dieu et que j'ai dit : « Là, tu vas m'ouvrir une porte. Ce n'est pas vrai que je vais retourner dans l'obésité. » Moi, je m'étais fait un pacte de suicide : si je

redevenais grosse, je m'enlevais la vie. Je m'étais juré de ne plus jamais, jamais, jamais être laide et grosse comme ça. [...] J'avais la corde très proche du cou.

As Davidson et al. (2009) emphasize « being in recovery involves actively using treatment, services, supports or other resources, rather than being only a passive recipient of care provided by others” (Davidson et al., 2009, p. 45). In this sample, all participants came to a point where they sought care and services themselves, because they were ready to do so. Participant’s also reported that community organizations in particular provided quick access to services and information about eating disorders (Chloe, Cynthia, Laurie, Lili, Megan, Jason, Jennifer, Sophie, Vanessa).

Additionally, access to affordable services perceived as helpful in the recovery process, even essential for some. Megan shares the reality of being a student in need of services:

Megan : *[...] [l’organisme communautaire] était venu faire une conférence à l’université faque là je connaissais l’existence de leur services, pis j’ai recrashé [sic] comme en automne. Faque, vu que c’était...en tout cas j’avais pas beaucoup de sous non plus là comme étudiante là [...]*

Several participants shared that the cost of private eating disorder services was simply too high. Laurie describes her experience of seeking help at a private clinic for eating disorders:

Laurie : *J’ai commencé à chercher et j’ai appelé à [une clinique privée dans la région de Montréal]. Aïe! Elle me sort que ça coûte 5000 et quelques piastres. Je lui ai dit : « Écoute-moi bien, j’ai de la misère à faire mes fins de mois. » Elle m’a dit : « Ah! Il faut que tu choisisses tes priorités dans la vie. »*

In contrast to private eating disorder services, community organizations offered low-cost or free eating disorder services: « ...[l’organisme communautaire], c’était merveilleux, ça coûtait une peanut et ils font ce que [la clinique privé] fait; j’ai payé quoi et ce que ça a valu... » (Laurie). In all three regions, the eating disorder community organization offered affordable specialized psychosocial and/or nutritional services irrespective of the participant’s income. Jason says: “Actually, not even basically, I believe [the service] was free. They asked...I think they asked for people who could, pay like 25\$ or something” (Jason). However, in some cases, services were limited due to the organizations being underfunded. Sophie explains:

Sophie : *Financièrement, c’est incroyable [l’organisme communautaire]. Je connais peu de thérapies de 15 semaines qui coûtent 80\$. Ce que je trouve dommage c’est que, les ressources*

financières font que vous devez fermer l'été, je trouve ça horrible. Pour toutes les personnes qui en a besoin, pis même de pouvoir ouvrir plus de groupes fermés.

At least one of the organizations through which participants were recruited has reported lack of financing having an impact on service delivery (Arrimage Estrie, 2018). In the eating disorder research, it has been well documented that the costs related the current system of acute care for eating disorders come at “enormous personal and systemic cost” (de Oliveira, Colton, Cheng, Olmsted, & Kurdyak, 2017; Shekter-Wolfson et al., 1997). What’s more, binge-eating disorder, emergent and sub-clinical eating disorders are often excluded from specialized hospital programs for eating disorders, making community organizations a vital resource for those who cannot access other services. In fact, Rice and LaMarre (2014) assert that hospital care “should not be considered as the first course of action or the only appropriate response to eating disorders” (Rice & LaMarre, 2014 cited in Leblanc et al., 2014, p. 45) as some individuals respond better to “other treatment settings” (Leblanc et al., 2014, p. 45). Coupled with the fact that the eating disorder “research indicates that early intervention leads to the best treatment outcomes” (Leblanc et al., 2014, p. 45), both the cost and the accessibility of eating disorder services offered through community organizations represent significant supports in the recovery process.

Another helpful aspect of services identified was a **holistic approach to eating disorders**. The Cambridge dictionary defines holistic as “dealing with or treating the whole of something or someone and not just a part” (Cambridge Dictionary, 2019). Several participants expressed that receiving services that addressed complexity of the eating disorder were effective in their recovery process. Laurie explains her experience of participating in an eating disorder recovery support group:

Laurie : *Le groupe m’a aidée à faire le ménage. Le groupe est tellement bien structuré; on touche à l’aspect social et à l’aspect familial, et on va même faire ton... pas l’arbre généalogique? (Sarah: Ton génogramme.) Ton génogramme. C’est excellent de faire ça car tu réalises tellement de choses. Tous les aspects; on touchait à tout. J’ai adoré ça.*

Sophie expresses a similar experience of services going beyond food and weight in her description of an eating disorder support group:

Sophie : *Qu’est-ce qui a fonctionné? Mais je pense que toute a fonctionné. Tout m’a tellement changé. Tous les outils qu’on a eus dans le groupe, toutes les remises en question quand on parlait de qui nous soutient, qu’est-ce qui est important dans notre...c’est quoi déjà...on avait*

un...dans toutes les sphères de vie qui était là [...] Mais y'a tellement d'outils qui...dans [l'organisme communautaire] qui ont été...phouf! [...]

For Megan, the combination of group and individual support she received through an eating disorder community organization helped her to address the complexity of her eating issues:

Megan : *Oh mon dieu, ben, en tout cas, c'est un succès là global pour moi, mais je pense que le fait qu'y ait autant du groupe que de l'individuel, même si le groupe je trouvais ça extrêmement confrontant au départ, je pense que c'est, au contraire, c'est vraiment positif, leur offre globale est vraiment on point. [...]*

Mitchison et al.'s (2016) study on the role of quality of life in the recovery from an eating disorder found that “studies conducted with recovered patients have highlighted the importance of life satisfaction and functioning in reducing eating disorder symptoms” (Mitchison et al., 2016, p. 2). “Social support and development of healthy relationships, satisfaction with study and the home environment, engagement in leisure activities” (Mitchison et al., 2016, p. 2) were some of the areas that contributed to a higher quality of life and were addressed in holistic eating disorder services the participants described in this study.

4.3.3 Group Work

Group work was also cited as helpful by participants, 11 of whom participated in 1 or more eating disorder support groups through a community organization or hospital program. The group setting was appreciated because participants were in a “safe space” where everyone understood eating disorders and would not judge them (Black, 2003). Social isolation is a paralyzing consequence of eating disorders (Public Health Agency of Canada, 2002), as so much of social life involves food and eating. Thus, integrating a group was an important step for many participants in their recovery. Jason states: “So, for me the benefits of the group was...and it's super obvious, but hearing other stories, hearing you're not alone” (Jason). Jason describes an element of group work identified as important by Catherine Black (2003) who found that group work in her eating disorder community organization “provided a space in which women could identify with others and that normalized and validated their experiences” (Black, 2003, p. 137). As Jennifer describes :

Jennifer : *[...] c'est juste d'être en groupe pis de regarder les autres filles pis que tu dis : « Ben voyons dont! Ces filles-là ont un trouble alimentaire? » Des super de belles filles, mais super intelligentes, faque là tu te dis : « Ouin ok, ben ça peut vraiment arriver à tout le monde. » Faque là y'avait ce côté-là de support, disons.*

Being in a group also helped participants to express what they were feeling, which is often an important step in recovery. Megan explains how the group helped her develop this skill:

Megan : *[...] [le groupe] me challengeait beaucoup parce que, c'est ça je me comparais. Mais tu te rends compte au final que c'est des filles qui vivent à peu près les mêmes choses que toi pis que c'est ça, qu'on peut s'aider. Pis des fois y'en a qui sont capables de mettre des mots sur des choses que moi j'étais pas encore capable de mettre.*

For both Sophie and Megan, hearing other people's experiences was supportive their recovery process.

Sophie states:

Sophie : *Pis de voir aussi les petites victoires de chacun, à chaque semaine : « Ah aujourd'hui j'ai réussi à... », « Cette semaine j'ai réussi à le dire à quelqu'un : « Aie! ce que tu dit c'est blessant! » ». Toutes les petites affaires comme ça, qui font aussi : « Ben, moi aussi je suis capable de le faire! » Ouin, vraiment ce groupe c'est incroyable.*

As Starkman (2016) asserts “a core foundation of the group model is the relational context that fosters connections between women members and promotes self-efficacy” (Starkman, 2016, p. 57). As Sophie, Megan and Jennifer describe, the group acted as a relational practice space, as well as a context to test new perceptions of themselves. Katzman and Lee (1997) affirm that “women in group work may use new relationships to examine past ones and to heal in the process, creating new images of self and the body” (Katzman and Lee, 1997 cited in Black, 2003, p. 137). This was also so true for this study's male participant. Jason describes his experience in a group as follows:

Jason: *[...] So, when I went in there and it was just a group of regular people, and maybe one person was skinny, maybe one person was not, but everyone was in between and we all had our body types and it wasn't a criteria of having an eating disorder. You didn't need to be fat, you didn't need to be skinny. You just needed to be. But hearing their stories and understanding, or trying to understand mine within that, and being accepted and being allowed to say...being allowed to cry, being allowed to laugh, being allowed to be part of something where you can latch onto someone else, and..and understand what they're going through. [...]*

Simply having a space to express oneself freely was also identified as beneficial by interviewees. Lili explains her experience:

Lili : [...] j'ai eu beaucoup de tribunes pour exprimer ce que je ressentais, dans le groupe ouvert en particulier. J'ai beaucoup aimé ça parce qu'étant donné que c'était moins encadré que le groupe fermé, ben on avait plus la chance d'exprimer ce qu'on ressentait par rapport à... Pis je pense c'est...j'ai jamais autant parlé de ma vie là.

In Black's study of a therapeutic eating disorder support group, participants described "the benefits of feeling listened to and validated regarding their experiences" (Black, 2003, p. 137) with disordered eating. As in this study, participants (male and female) "overwhelmingly expressed relief at knowing they were not alone or 'weirdos'" (Black, 2003, p. 137).

Finally, in a recovery perspective, the group plays a very important role as it is related to hope. As Sophie and Megan described, the role modeling and peer support that occur in a group context are elements that nourish hope in recovery: "hope might stem from seeing other people who have suffered in the same way and experienced the same challenges as the sick person and who are now living better or more fulfilling lives" (Davidson et al., 2009, p. 39). Provencher also asserts the importance of the group in the recovery process: « l'espoir est contagieux, d'où l'importance des lieux d'échange sur les expériences personnelles entre paires » (Provencher, 2002, p. 43). Thus, for many participants in this study the group was a helpful element in their recovery.

At the end of the group, many of the participants kept in touch with other members by phone, email or social media. This **ongoing support** was identified by many as supportive of the recovery process. Lydia describes the ongoing support the group provides for her:

Lydia : [...] en [groupe Facebook] privé et c'est les filles qui étaient dans le groupe que j'ai participé. Fait que des fois on se donne des nouvelles. Des fois quand on : « Bon j'ai eu une rechute. » Ou, tu sais y'en a qui ont écrit qu'elles étaient en arrêt de travail. Fait que là on s'encourage comme ça quand y'a quelque chose ou si on voit un article qui peut être intéressant pour nous, on se le partage là.

Though at the beginning the group was a challenge for Megan, she explains how the group continues to offer support and friendship through social media:

Megan : [...]Mais en fait, au fil du temps tu te rends compte que c'est peut-être des gens qui sont des alliés là. Tsé, de ma cohorte initiale on a un groupe Facebook; on s'écrit une fois de temps en temps pis...faque c'est devenu des amis de cœur un peu là [...]

Megan and Lydia's experiences with post-group support illustrates how "groups enable the creation of a 'counter culture' and an experience of a 'mini-community', where women may be able to examine and recreate their relationships to others, food and the body" (Black, 2003, p. 138). This 'counter culture' is particularly powerful for individuals who have experienced stigmatization related to their body size, as is the case with many of the participants who have experienced binge-eating disorder or are perceived as overweight in their recovery.

What's more, many of the community organizations offered ongoing support through individual services and groups. Jason explains how it feels to know he can go back to the organization if he needs to:

Jason: [...] I'm lucky because of [the community organization] ...the ongoing support that they offer, they made it accessible for...regardless of who you are: gender, or age or whatever. Financially accessible, as well. The information that they gave, and the fact that they still...even today I could call them and say: "Shit, I need help!" and they'd say: "Come on down."

Though current research has not identified universally successful eating disorder treatments for anorexia, bulimia or binge-eating disorder (Leblanc et al., 2014), there is some agreement that "successful treatment of eating disorders depends on a comprehensive plan that includes ongoing monitoring of symptoms and stabilizing of nutritional status; psychological interventions that include cognitive behavioral therapy, personal psychotherapy, and family counselling; education and nutrition counselling; and in some cases medication" (Leblanc et al., 2014, p. 49). The ongoing nature of eating disorder treatment was emphasized by the committee, as were the barriers to accessing support services in the long-term (Leblanc et al., 2014). As Petrucelli (2016) states: "real recovery from an eating disorder takes a long time" (Petrucelli, 2016, p. 24) and this process requires "maintenance, consistency, reliability, being centered and grounded, all of which comes through the practice of living" (Petrucelli, 2016, p. 24). As most of the participants perceived their recovery as an ongoing process occurring in tandem with their lives (which included the possibility of relapse), the ongoing support provided by groups and community organizations was viewed as an important support in the recovery process.

4.3.4 Professionals

Many types of professionals supported the recovery processes of the research participants in this study: community workers, doctors, kinesiologists, nurses, nutritionists, psychiatrists, psychologists, social workers, therapists, etc. These professionals were accessed through community organizations, public services (family doctor or Family Medicine Groups (FMG)), universities, and the private sector. In some cases, the professionals were **knowledgeable about eating disorders**, which was deeply appreciated by participants.

For participants who had lesser-known or emergent disorders (often unknown to their doctor or psychologist), a professional who was knowledgeable about what they were going through was influential in their recovery. Lili explains her experience with a community worker:

Lili : *Et puis c'est ça, en parlant avec...c'était [l'intervenante de l'organisme communautaire] qui m'avait reçue. Et puis, après m'avoir posé beaucoup de questions ben elle m'a dit : « Ben, t'as tous les...t'as toutes les caractéristiques de quelqu'un qui est orthorexique. Là je me suis dit : « Ortho quoi? » Là elle m'a expliqué qu'est-ce que c'était l'orthorexie puis j'ai dit : « C'est exactement ça! »*

Until that point, Lili did not know what she was experiencing had a name. She explains:

« Ben le fait que mon problème, mais mon trouble, a été identifié déjà là moi ça me rassurait beaucoup là. C'est comme : « Bon enfin y'a un nom à ce problème là-là » (Lili). For other participants, a professional who was knowledgeable about eating disorders was able to say or do the right thing in their intervention. Anne and Megan share how a knowledgeable professional said something that had a lasting impact on their recovery:

Anne : *[...] d'aller voir [la nutritionniste], pis c'était juste 3 séances avec elle pis un moment donné elle m'avait fait comprendre : « Si tu veux faire une maîtrise, continuer à l'école, comme manger du pain, ton cerveau en a de besoin. » (Sarah : Oui, oui c'est le carburant du cerveau.) Exact, pis ça avait été ça le déclic, de me remettre à manger des féculents.*

Megan : *[...] je me souviens j'étais assis de même: les bras croisés les jambes croisées. Pis là on fait un petit relevé de ce que je mange pis [la nutritionniste] est comme : « Qu'est-ce qu'on peut ajouter ? » Pis je suis comme : « Rien. » Pis elle m'a dit : « Ouin, pas beaucoup de flexibilité. » Pis ça faite comme: « Fuck, je veux pas être la fille qui a pas de flexibilité. Je veux pu être ça. » Ça juste pris ça, elle a dit genre la phrase qui me fallait. [...] Elle a dit la chose que j'avais besoin.*

For Lydia, a social worker who was informed about eating disorders and body image issues was able to challenge her perception of her body and weight.

Lydia : *[le travailleur social] m'avait dit : « Tu penses pas.. » il dit : « qu'à un moment donné, que tout le monde est pas fait pour être dans le même gabarit ? Que tout le monde n'est pas fait pour être mince ? » Moi je voulais pas qu'il me pose cette question-là, pis je ne voulais pas que ce soit « Oui » la réponse.[...] Mais il a quand même semé une graine, tu comprends ? Fait qu'à partir de là je me suis dit...y'a des choses que j'ai commencé à accepter un peu plus.*

In most cases, participants had a **positive relationship** with the professionals who helped them most. Professionals who **listened**, who did **not judge**, who saw them as a **whole person**. Professionals who had these skills were often helpful even if they were not specialized in eating disorders. Anne's description of the care she received from her family doctor illustrates this type of relationship:

Anne : *[...] tu le sens qu'elle care là, qu'elle s'en fait. Pis qu'elle...mais pas comme la psy qui avait failli se mettre à pleurer comme dépourvue. [Mon médecin] vraiment, t'es pas un numéro là dans son bureau. Puis elle prend le temps; pas grave si y'en a un autre; oui il va attendre, il va être fâché mais là, ouin.*

For Lydia, a psychologist and a social worker with whom she had a positive relationship played an important role in addressing some of the underlying issues related to her eating disorder:

Lydia : *[...] la psychologue de la maison de la famille, ça m'a aidé dans le sens à lâcher prise sur vouloir à tout prix qu'il y arrive rien à ma fille. OK. Ça j'ai compris. Avec [le travailleur social] il m'a fait beaucoup avancer, beaucoup évoluer dans l'acceptation.*

As Davidson et al. (2002) emphasize in their *Practical Guide to Recovery-Oriented Practice*: “what appears to be crucial to people in recovery in relation to [being supported by others] is that they be *supported*, accepted, and if possible, loved as a person of value and worth” (not as a person with a mental health issue) (Davidson et al., 2009, p. 39). In the participant's descriptions of professionals who had a lasting and meaningful impact on their recovery from an eating disorder, these qualities were emphasized.

Finally, for some participants, professionals who modelled body positivity and self-acceptance had a positive impact on recovery. Jennifer describes how a community worker's body positivity had an impact on her : « ...[mon intervenante] c'était comme je disais : « T'es vraiment un genre de modèle à suivre pour moi. » Tsé? Elle avait tellement l'air bien dans sa peau, pis non était pas parfaite » (Jennifer). Megan describes a similar experience at the community organization where she received services:

Megan : *[...] je les sentais [les intervenantes] humaine pis qu'elles étaient capables de comprendre, mais fortes malgré tout, qu'elles étaient capables d'être bien là-dedans pis que ça prenne pas toute la place là [l'image corporelle]. Faque ouais, c'était quand même des jeunes femmes aussi, tsé dans la trentaine peut-être là, mais c'était pas très loin de ma réalité faque ça pouvait être un exemple tsé, quelque chose vers lequel je m'en allais.*

These professionals, who may be highly aware of the role their bodies play in intervention, were able to “model a secure attachment to her own body” (Daly, 2016, p. 51) which requires a significant personal investment. Orbach (2004) describes the importance of this process when working with individuals who have experienced an eating disorder: “if we are interested in making it possible for our clients to be in their bodies and feel them as generative and animated, then a far more demanding engagement is required of us in relation to our own bodies” (Orbach, 2004, p. 107 cited in Daly, 2016, p. 51).

4.3.5 Supportive Relationships

In most of the participant's narratives, a small network of loved-ones was credited with providing the day-to-day support they needed to recover from an eating disorder. These networks were generally made up of a partner, close friends and, occasionally, family members (parents, siblings, extended family members).

Contrary to much of the existing eating disorder literature that emphasizes family therapy and the role of immediate family (parents, siblings) in recovery, the participants in this study depended on their “chosen family” (partners and friends) to provide support. Much of the existing eating disorder literature is focused on adolescent girls and young women (Arnaiz, 2009; Gremillion, 2002; Leblanc et al., 2014; Wilson, 2004) which makes family therapy relevant, as parents and siblings are often the primary support system. However, for adults recovering from an eating disorder the role of family members can be much different. In the interviews, many participants identified biological family members as being directly related to the development and maintenance of the eating disorder. Anne explains how her mother's obsession with food and weight became problematic during her recovery:

Anne : *[...] elle me voyait pis était : « Heille tu devrais manger du riz brun, ça aide à faire maigrir. » Je suis comme : « C'est comme si tu donnais une boîte de beignes au boulimique. » Je*

veux dire tu fais pas ça; tu dis pas ça à ta fille quand tu le sais qu'elle a...[un trouble alimentaire]. Parce que je réussissais à le nommer là: j'allais pas bien.

Anne : *Mais aussi, avec le recul pis les années, ma mère a longtemps; ben elle l'es encore : obsédée par son physique. J'étais jeune pis elle pouvait se nourrir de carottes et de céleris, elle s'entraînait énormément, donc... Y'a un boute qu'elle était sur les shakes, faque je pense, indirectement; je veux pas mettre le blâme sur ma mère, mais, ça peut avoir été un [...]*

Instead, participants described surrounding themselves with people who provided non-judgemental and loving support. Jason describes how his girlfriend supports him on “bad days”:

Jason: *...being ridiculously open with my girlfriend about [the eating disorder] totally helps and she's like...if I told, you know: “I had a bad day.” Which means I purged, she's like: “Ok.” She accepts it, she's like, you know: “You want to talk about it?”*

Being able to talk about what she is going through is also important for Lili, who is supported by a close friend:

Lili: *Ben y'a ma meilleure amie qui a été là, tout le temps. Ben, c'est grâce à elle si je me suis retrouvé [à l'organisme communautaire]. Faque c'est sûr qu'elle a compté, c'est surtout pour le psychologique en fait là, mais le fait d'en parler pis de pas me sentir toute seule [...]*

Cynthia describes how a relationship with her neighbor was important in her recovery process:

Cynthia : *[...] Faque je lui ai dit [que je vivais de l'hyperphagie]. Parce qu'elle me parlait de son trouble aussi...de ramassage. Faque là c'est ça. Là je me suis mis à lui en parler. Faque là, dès fois quand j'arrivais de travailler, elle a m'appelait elle me disait : « Viens dont prendre un petit café avec moi en bas ». Parce qu'elle savait que si je m'en allais chez nous toute seule que j'étais pour manger.*

For many of the interviewees, having people who would just listen to them was critical. Megan explains:

Megan : *[...] j'ai, mettons, [mon chum] c'est mon numéro 1 là, pis y'a 2 de mes amies qui m'ont vraiment beaucoup appuyée là-dedans. Faque si j'ai quelque chose, mettons je me chicane avec mon chum, ça serait elles que j'appelleraient. On est tout le temps on phone call away là, pis c'est des filles que pendant mon rétablissement des fois j'ai fait, même si on était dans la même ville, je les appelais; je faisais juste pleurer. Je parlais pas pendant une demie heure, pis après ben c'est fini. Tsé, c'est correct. « Merci, t'as fait ce que t'avais à faire. »*

Provencher (2002) confirms that of the few studies on the role of loved ones in recovery, Young and Ensing (1999) report that « *les conjoints et les enfants des 18 personnes utilisatrices participant à leur étude [sur le rétablissement] se retrouvaient au centre de leur réseau social, alors que leurs parents se*

situaient en périphérie » (Young & Ensing, 1999 cited in Provencher, 2002, p. 49). Mitchison et al. (2016) also found women with eating disorders had benefitted from their partner's support in addition to "family, friends, and other networks, in initiating recovery behavior, and maintaining recovery" (Mitchison et al., 2016, p. 10). Davidson et al. (2009) emphasize that "this sense of being accepted and supported" (Davidson et al., 2009, p. 39) "appears to be crucial to people in recovery" (Davidson et al., 2009, p. 39). In this study, partners, friends, children, and neighbors all played an important role in participant's recovery from an eating disorder.

4.3.6 Intuitive Eating

Many tools and approaches were cited as helpful in the interviews. For most participants, **intuitive eating** was identified as an approach that was helpful in recovery, irrespective of what type of eating disorder the person was living with. Megan explains this method: « *c'est vraiment l'approche de l'alimentation intuitive, faque tu manges de tout selon tes signaux de faim et de satiété pis c'est vraiment de la recherche du poids naturel. Faut tu fasses confiance à ton corps* » (Megan). Linda Bacon et al. (2005) describe this approach as eating "in response to internal cues of hunger, satiety, and appetite" as opposed to "cognitively controlling food intake through dieting" (Bacon, Stern, Van Loan, & Keim, 2005, p. 930). In the case of people who have an eating disorder, intuitive eating is a process of reconnecting to the body's signals which have been suppressed through restriction, bingeing or purging. Intuitive eating is intimately linked to the Health At Every Size movement, which "encourages health at every size rather than weight loss as necessary precondition to improved health" (Bacon et al., 2005, p. 930), a stance that is in line with the feminist critique of restrictive cultural norms that define health very narrowly in relation to weight, especially for women (Gremillion, 2002, 2005; Rail et al., 2010). In an eating disorder recovery context, intuitive eating may lead to either weight gain, loss or stability depending on the associated symptoms (restriction, bingeing or purging). The goal of intuitive eating is to achieve a stable, natural weight (Bacon et al., 2005).

For some, intuitive eating was an essential step in decreasing food obsession. According to Lili :

Lili: [...] [la nutritionniste] elle s'est plus occupée de l'aspect alimentaire, mais psychologique aussi. Elle travaillait fort là-dessus pour enlever mon obsession des étiquettes. Pis de me dire finalement, ben y'a pas de bons pis de mauvais aliments.

In her case, this approach worked quickly. Lili says: *“Donc la nutritionniste a beaucoup travaillé sur l'aspect obsessionnel; puis assez étrangement, l'aspect obsessionnel a disparu quasiment du jour au lendemain »* (Lili). Laurie also describes being freed from food obsession through intuitive eating: *« Je mange de tout, tout, tout, tout, tout, et je ne calcule plus rien du tout, du tout, du tout, du tout. Ça fait deux ans que je ne me suis pas pesée »* (Laurie). This comment is significant, as Laurie's weight has changed dramatically since reconnecting with her hunger signals after years of restriction. She explains how learning to eat intuitively has also been a process of accepting her changing body, and her self-perception:

Laurie : [...] [la nutritionniste] dit que je suis un des cas de restriction les plus sévères qu'elle a eus. Ça a été difficile pour ça. [Mon mari] trouve ça difficile en ce moment parce que le surplus de poids handicape ma vie. Mais, dans un autre sens, on va en parler, [l'organisme communautaire] a littéralement changé ma vie, je me suis libérée d'un poids, ironiquement [...]

For people who have lived with an eating disorder, achieving a natural weight is an important milestone. It implies a healthy relationship to food, a daily connection with the body, and accepting the resulting physical transformation. Weight loss, gain or stability are all possible outcomes. Sophie shares her experience:

Sophie : J'ai complètement arrêté d'être obsédé par certains aliments parce que j'ai enlevé des barrières de : *« Non, tu ne peux pas »* et depuis ce temps-là je n'ai pas pris de poids. Là je sais que je me pèse encore pis je devrais pas, ça je le sais. Mais à chaque fois c'est une victoire de faire comme : *« Aie! Regarde! Je te l'ai enlevé les barrières pis tu prends pas de poids! »*

Many of the respondents shared that the intuitive eating philosophy has fundamentally changed their relationship to eating, allowing them to reintegrate foods they had not eaten for years:

Vanessa : [...] C'est comme, c'est la restriction qui amène à la compulsion, faque c'est ça maintenant aujourd'hui je mange de tout là. C'est comme j'ai mangé une poutine y'a 2 semaines. J'aurais jamais pensé manger la poutine. Tsé? Jamais, jamais. Jamais juste, comme pour souper j'ai mangé une poutine.

Participants accessed nutritionists who supported them in the intuitive eating approach through community organizations (ANEB Quebec, Arrimage Estrie, Maison l'Éclaircie) and professionals working

in the private sector. They also attended conferences, read books and found online support for this eating philosophy.

4.3.7 Resolution of Underlying Eating Disorder Causes

All twelve of the research participants in this study indicated that the resolution of some of the underlying causes of the eating disorder was directly related to their recovery. For many, the underlying causes are part of how they explain the evolution of the eating disorder, as well as their recovery process:

Cynthia : [...] *Je pense que le rétablissement a commencé la journée, la journée que je me suis dit que mon père c'était un parent toxique, pis que c'est ça...que là j'ai comme allumé sur ben des choses. Pis sur mon travail, que ça aussi c'est un travail très toxique...donc. [...]*

Cynthia : [...] *Mais juste à travailler sur ces trois choses principales là [travail, relation avec père, connaissance de soi], puis de me détacher de ça, ça faite que je suis bien. Je suis pas toute, toute équilibré là, mais la balance est plus égale, mettons. [...]*

The underlying causes of the eating disorder were multiple and unique to each person in the study. However, the following themes emerged in many of the narratives (though they often overlapped): **resolution of childhood/family issues, learning to express emotions, developing identity/autonomy, healthy relationships, body image, self-esteem/self worth**. In many of the participant's narratives there is a distinct "before" and "after" related to these themes and their effect on quality of life.

In Vanessa's case, living with her chosen family (friends and their children) helped her to deal with the deep insecurities of her childhood. She explains how this experience has helped her to become more independent in her life and in her recovery:

Vanessa : *Faque je pense que [les amis chez qui j'habite] aussi m'ont beaucoup aidé, c'est ça. C'est quoi être en sécurité? C'est quoi une famille normale? Parce que moi je savais pas c'était quoi une famille normale là. Faque c'est ça, parce que mon père y'avait beaucoup de violence verbale en plus de son travail qui était très violent; pis ma mère qui disait rien là-dedans. Faque c'est comme, c'est ça.[...] Pis qu'il y avait plein d'autres choses. Mais c'est ça, faque c'est plus ça dans le fond. Ouais. C'est quoi être en sécurité dans la vie. Faque je pense que ça m'a beaucoup...Pis je pense c'est ça qui m'aide, qui m'a aidé à faire comme : « Ok, je suis prête à aller en appartement là. »*

For Chloe, learning to express anger which was taboo in her childhood, was at the center of her recovery process. She explains how she learned this new skill in a recovery support group:

Chloe : *[...]Pis moi la colère, j'ai jamais connu ça. La colère, c'est avec [le groupe de soutien], pis là [le groupe] m'a faite sortir ma colère. [...]Pis j'en prenais conscience de ma colère, on a l'droit d'en vivre de la colère. Ben c'est ça, moi j'ai jamais connu ça de la colère, j'ai connu ça avec [le groupe]. [...]*

Chloe's experience of learning to suppress anger is common among individuals who experience eating disorders. According to Fox & Froom (2009) "a number of studies demonstrate that people with eating disorders experience both higher levels of anger, but also demonstrate higher levels of anger suppression" (Fox & Froom, 2009, p. 329). "Due to the perception that anger is dangerous, it is inhibited" (Fox & Froom, 2009, p. 329) or turned inward through disordered eating behaviors.

Learning to manage and express difficult emotions was also an important part of Megan's recovery, as was allowing herself to open-up to her loved-ones about her feelings.

Megan : *[...]mais j'étais comme un verre d'eau qui est plein. J'avais aucune marge de manœuvre émotionnelle. J'avais pas faite mon deuil de mon ami faque j'étais tout le temps là, sur le bord de déborder là. Faque je pense pendant le processus [de rétablissement], je me souviens qu'il y avait des soirs où je faisais juste brailler là pis je le savais pas pourquoi là. Mais c'est juste toute ce que j'avais pas laisser-aller dans le temps. Faque je pense que juste le processus m'a permis d'avoir cette marge de manœuvre là, je suis pu tout le temps sur le bord de craquer pis oui, j'exprime vraiment mieux mes émotions. [...]*

Megan's experience typifies the function of eating disorders in that "what is dissociated has more to do with failures in human relatedness to regulate and respond to affective states, or self-experiences of unbearable need in various forms, or physical or emotional pain that result in eating disordered symptoms" (Petrucci, 2016, p. 20). For Megan, when underlying issues were addressed, the function of the eating disorder was replaced with other tools for managing emotions and difficult situations.

Lili understands her eating disorder as a response to a feeling of loss of identity in two important spheres of her life. In the following excerpts she explains how the eating disorder emerged in relation to those losses.

Lili : *[...] Ben en fait j'ai perdu mon identité. Je savais plus qui j'étais vraiment. En fait, j'ai commencé à perdre cette identité-là quand j'ai pris ma retraite du sport de compétition. Pis j'ai*

reperdu cette identité-là une deuxième fois quand (on parle d'identité professionnelle dans ce cas si), je suis redevenue travailleuse autonome à temps plein.

Lili : *Ouin. C'est ça. C'est ces deux pertes d'identité-là qui ont fait qu'un moment donné je savais pu qui j'étais là. [..]Mais en fait, étant donné que je contrôlais plus rien à l'extérieur ben j'ai trouvé un élément à contrôler pis ça été [la nourriture]. Ça me donnait l'illusion que j'avais le contrôle sur quelque chose, mais en réalité je contrôlais absolument plus rien.*

For Sophie, emancipation from extremely controlling parents was intimately related to her disordered eating. In these two excerpts she explains how her bingeing started, and how she is learning to stop the internalized judgement of her parents when she eats:

Sophie: *C'est l'endroit où je pouvais avoir un contrôle parce que j'allais à l'école secondaire et juste en dessous y'a un resto. Donc moi j'allais manger avant de prendre le bus scolaire et à la maison je faisais comme si de rien était, je mangeais un deuxième repas complet. Pis, je pense c'est comme...un peu comme une victoire de ça : « Vous me contrôlerez pas, pis c'est mes sous » parce que je travaillais [...]. Donc je pense que [le trouble alimentaire] a commencé pas mal vers cet âge-là.*

Sophie : *Je me restreignais pendant longtemps. Je réfléchissais à : « OK, si je mange ça est-ce que mes parents vont être contents? » Tsé? Cette quantité-là...ou même au restaurant; on a un restaurant qu'on aime toute la famille pis si jamais [mes parents] arrivaient pendant que j'étais en train de manger je me disais : « Est-ce que j'ai pris la bonne affaire? Oui, c'est correct. Ma mère me jugera pas. » [...] Mais ça, de plus en plus, non. Je me justifie plus, ça mon chum m'aide énormément, lui il est très, très là-dedans. J'ai pas à me justifier de mes choix.*

Laurie, who has lived in two bodily extremes (obesity and orthorexia) most of her adult life describes how her “before” body image was related to feelings of being alone and empty and her “after”, in which she abandons a suicide pact she made in the event she gained the weight back (which she did):

Laurie : *[...] Quand j'étais très jeune, je voulais qu'on m'aime et qu'on me trouve belle; j'étais vraiment vide, c'était toujours...toujours, toujours en moi, je me sentais seule au monde. [...]*

Laurie : *[...] [le moment] où j'ai abandonné le pacte de suicide, où j'ai renoncé à ça, ça a été salvateur. Chaque fois que j'ai fait les pas [dans le rétablissement], ça a été mes plus beaux moments. Mais, le poids ou le vide que j'ai presque toujours eu très jeune dans ma vie et que je te nommais n'est presque plus là.*

For Jennifer, self-esteem and a difficult relationship with her parents was identified as an underlying cause of the eating disorder. She explains how she understands this issue in the context of her eating disorder and her recovery:

Jennifer: [...] *l'estime de soi ça beaucoup remonté pis je pense vraiment c'est de quoi qui faisait défaut avant le [trouble alimentaire], c'est sûr. Je pense que la rupture a, ça été notre trigger mais c'est de quoi qui était là depuis longtemps probablement comme je te dis, à cause de la relation bizarre avec mes parents. [...] de toute façon là comme, le trouble alimentaire c'était presque une façon de disparaître à petit feu là.*

Many of the participants in this study associated the emergence of their eating disorder with a major life event that they were ill equipped to deal with. The events were described as a “trigger” (Jennifer, Jason) that was cocked due to a complex mix of underlying issues, unique to each person. Just as unique were the ways the participants found to resolve the underlying issues, which greatly increased their quality of life while decreasing, or even eliminating, the eating disorder symptoms.

As discussed in an earlier section, Mitchison et al. (2016) found quality of life played a determining role in both the development and recovery from an eating disorder. Contrary to the current eating disorder treatments which focus primarily on food and weight (Arnaiz, 2009; Black, 2003; Gremillion, 2002; Malson, 2003; Wilson, 2004) participants in this study, as in Mitchison et al.'s (2016) research, described that “when quality of life impairment in specific domains triggered the development of ED symptoms, later improvement in the same domain was integral for recovery” (Mitchison et al., 2016, p. 5). These findings would suggest that psychosocial aspects of treatment may be as important as physiological/nutritional interventions, findings are strongly mirrored in the data collected in this study.

4.3.8 Giving Back

The final aspect of “what worked” is **giving back** as part of recovery. Many of the participants found that being able to inform the public about the reality of eating disorders or help others who were struggling was a significant step in their recovery. Jason explains:

Jason: [...] it feels good helping people too. Like when I was talking to my friend, like, that felt good. I felt that I had succeeded in something, or I had progressed in my journey so that I was able to say: “Well, you know, this is what I went through and this is how this can help and, for

me, this was beneficial, I don't know if it will be for you, but..." So I mean it's good to sorta [sic], to have that.

Many participants were engaged in an activity or project to educate the public or help others recovering from an eating disorder: writing an article, writing a memoir, giving a testimonial, volunteering for an eating disorder community organization, making a video about recovery, helping someone who has an eating disorder, or choosing to specialize in eating disorders as a career path are a few examples. What's more, many of the participants were motivated to participate in this study because they felt it might help other people who are recovering from an eating disorder: "...I'd love for things like this [research] to...for my little small contribution to help other people, or one on one with other people. Or, like, my experience can help someone else. I mean, this [eating disorder] sucks! It really sucks!" (Jason).

Both Davidson (2009) and Provencher (2002) identify giving back as an important element of recovery. Provencher associates giving back with « *le pouvoir d'agir axé sur la communauté* » (Provencher, 2002, p. 45), as it involves « *l'intérêt que nourrit la personne face aux changements à apporter pour diminuer le stigmata et la discrimination et développer de nouvelles opportunités pour la collectivité de personnes engagées sur la voie du rétablissement* » (Provencher, 2002, p. 45). Davidson also attributes the desire to give back to "being an empowered citizen" (Davidson et al., 2009, p. 60), one of the final steps in recovery. Service users in Davidson's study identified "giving back and sharing my experiences with other people working towards recovery" and "making a difference in my community" (Davidson et al., 2009, p. 60) as important steps in their recoveries, as it was sign that they were stable enough to turn their energies toward others in the community.

4.4 Barriers in the Eating Disorder Recovery Process

In this study, two distinct types of recovery trajectory emerged: participants who sought help for their eating disorder through the public health and social service system, and those who received care in the community directly (from community organizations and private sector professionals). For the participants who sought help in the healthcare system, many structural barriers to recovery were

identified. These barriers often forced participants to seek services in the community, where support was more accessible.

Many of the barriers identified by participants were related to the context of severely limited treatment and services in Quebec, a situation that is not limited to this province. The 2014 report *Eating Disorders Among Girls and Women in Canada* describes a context in which specialized eating disorder resources are so limited that only acute care can be offered, only in certain regions and for only for certain types of eating disorders (anorexia and bulimia) (Leblanc et al., 2014). The committee concluded that there are major gaps in public health treatment for eating disorders, which made it difficult, or impossible, for some individuals to access treatment (Leblanc et al., 2014). In this context of scarce resources, many people seeking services and support for disordered eating turned to health resources in their community: doctor's offices, emergency rooms, family medicine clinics, etc. However, research participants identified barriers in these settings as well. For many of the participants in this study, barriers encountered in their interactions with health services and professionals shaped their recovery process and led them to find alternative solutions in the community.

It is important to note that some of the barriers participants experienced were generalised affecting many or all the participants, irrespective of eating disorder: **inadequate public services for eating disorders, no services outside large centers, professionals who were not knowledgeable about eating disorders, and loved ones who needed support**. However, some of the barriers were specific to certain eating disorders or body types. The following themes emerged from sub-groups in the sample: **invisibility of sub-clinical, emergent and lesser known eating disorders** was identified as a major barrier for all participants who did not experience the most well-known eating disorders: anorexia or bulimia. The theme of **weight** was identified as a direct barrier to recovery for participants who were perceived as overweight (by themselves and others), as participants experienced **stigmatization of fat** in every area of their lives. For those whose eating disorder manifested itself in a thin or starving body, the experience of **cultural value of thinness/bodily control** was experienced and identified as a barrier to recovery by some.

4.4.1 Inadequate Public Services for Eating Disorders

In general, participants felt that services for eating disorders in Quebec's public health and social service system were inadequate. For some, the lack of services was a regional issue. Anne explains how she perceived eating disorder services in her region: *« Mais vraiment à l'époque, force de l'admettre qu'à part à [l'hôpital] à Montréal qu'il y avait pas de ressources là »* (Anne). For others, services were available but wait lists were very long. Vanessa explains: *« j'avais cogné à comme plein de portes pis tout le monde m'avait dit : « Il y a de la liste d'attente, des listes d'attentes »* (Vanessa). Vanessa did get specialized treatment in the public system, but only after a long wait. She explains her perception of how the system works: *« ben au début ça été long avant, ben pour avoir des soins à [l'hôpital]. Faut que tu sois en train de mourir ou en train de mourir encore plus »* (Vanessa). Vanessa's comments echo testimony heard by The Standing Committee on the Status of Women on the reality of eating disorders in Canada. As a parent who lost her child to anorexia, eating disorder activist Elaine Stevenson says: "to me, there is something inherently wrong with a public health care system that often only becomes available when someone is on death's door" (Leblanc et al., 2014, p. 44). Vanessa and Elaine's experiences may be explained by a reality exposed in the report: "the insufficient number of programs [for eating disorders] and the uneven distribution of programs across the country" (Leblanc et al., 2014, p. 44). Coupled with the fact that a biomedical approach to eating disorders is focused primarily on physical symptoms such as low body weight (Arnaiz, 2009; Gremillion, 2002; Mitchison et al., 2016), the few available treatments appear to address restrictive eating disorders disproportionately. Gremillion (2002) confirms that "the medical justification for hospitalization is the need for weight gain" (Gremillion, 2002, p. 387), and that "bulimia and binge eating tend to be treated in an outpatient basis" (Gremillion, 2002, p. 387). In Quebec however, many outpatient services exclude binge-eating disorder from their services. As Cynthia describes: *« C'est juste si tu as un moyen compensatoire. Ben moi, j'ai aucun moyen compensatoire. Faque eux autres, pour [la clinique trouble alimentaires à l'hôpital] je suis pas malade »* (Cynthia). Other participants had a difficult time finding the few services that were available in the public system, access to which requires a referral from a family doctor, many of whom had no knowledge of eating disorders or the specialized services available to their patients.

Lydia found that her condition (binge-eating disorder) was simply not taken seriously, she explains: *« Moi, j'ai toujours frappé aux portes quand j'ai eu besoin de quelque chose. Pis je te dirais que même,*

au point de vue médical, les troubles alimentaires sont banalisés » (Lydia). Lydia's experience of "not being taken seriously" was also noted by The Standing Committee on the Status of Women, who identified stereotypes and stigma attached to eating disorders as a major barrier to "diagnosis of, treatment of and recovery from eating disorders" (Leblanc et al., 2014, p. 28) as these disorders are "not well understood and the disease tends to be viewed as taboo or a pseudo-illness" (Leblanc et al., 2014, p. 28).

It is important to remember that in Quebec, the only publicly funded, specialized treatments for eating disorders are offered through hospitals and 1 university clinic in 4 major centers (Montreal, Quebec, Sherbrooke, Trois-Rivières) (ANEB Québec, 2019). Resources for a province with at least 65 000 women and girls living with eating disorders (ANEB Québec, 2017) and thousands of others who have not been counted because of their age, gender or type of eating disorder (Bunnell, 2016; Griffiths et al., 2015; J. Slevac & Tiggemann, 2011; Hart et al., 2011), can be considered as very limited and focused on acute care (Leblanc et al., 2014). In this climate of limited resources, Vanessa's impression of having to be on death's door to receive treatment, and other participants impression that there were no services for them, reveal several elements that underly how eating disorders are treated in this province: 1) physical symptoms are paramount in the evaluation of who receives services (American Psychiatric Association, 2018; Gremillion, 2002; Leblanc et al., 2014) 2) anorexia and bulimia are the two eating disorders that manifest physical symptoms that are deemed urgent (weight, electrolyte imbalance, dehydration, etc. (Leblanc et al., 2014)) and for which specific services are developed 3) the person's psychosocial functioning is not the primary criteria for access to specialized services (Leblanc et al., 2014). Instead, objective measures (established by DSM diagnostic criteria) such as BMI, weight, number of eating disorder symptoms experienced per week, etc. are evaluated to decided who will have access the limited eating disorder services that are available in the public system (Gremillion, 2003; Leblanc et al., 2014, p. 32).

There are many reasons that individuals do not fit this narrow treatment model for eating disorders: living with an emergent eating disorder, living with binge-eating disorder, experiencing sub-clinical anorexia or bulimia, comorbidity (personality disorders, depression, anxiety, addiction, post traumatic stress disorder, etc.) (Leblanc et al., 2014). For the participants in this study, and for many others who

spoke to The Standing Committee on the Status of Women, limited and inadequate services for people with eating disorders constitutes a major barrier to recovery.

4.4.2 No Services Outside Large Centers

In this study, 11 of the 12 participants recruited live in a city with one or more hospital programs for eating disorders (generally only for anorexia and bulimia) as well as private clinics, specialized professionals and eating disorder community organizations. In their recovery processes, they met people who had come from other regions to receive services, often having to pay out of pocket for the connected costs of transportation, lodging, absence from work, childcare, etc. Vanessa explains :

Vanessa : *[...] je te dirais que je répons pour comme toutes les filles avec qui j'ai faite des traitements qui étaient justement au Lac St-Jean. [...] Qui venaient de loin pis qui se prenaient un appartement à Montréal pour pouvoir venir au day program à l'hôpital de jour [à Montréal] c'est comme, ça fait pas de sens là. Faque moi je pense que oui ça l'a un impact [la région ou on vit].*

Megan who now works in the health system, experiences the absence of eating disorder services outside major centers as a daily reality:

Megan : *[...] moi je viens [d'une autre région]. Comme jeune fille qui avait un trouble alimentaire j'ai pas reçu d'aide. Pis là actuellement, je suis retournée travailler [dans ma région] pis y'a pas plus d'aide là. Faque oui, clairement je trouve que à l'échelle...dans l'ensemble du Québec y'a vraiment un gros gap de services. [...]*

Even in a region where some resources were available, Anne was faced the dilemma of whether to travel for services. She says:

Anne : *Manque de ressources, moi je dirais un flagrant manque de ressources surtout quand, c'est comme on dirait y'avait juste Québec, Montréal. Les autres, ben en région y'a rien là. Pis c'était impensable là pour moi d'aller à Montréal une fois par semaine pour rencontrer des spécialistes de [l'hôpital] là. [...]*

The participants in this study described what is a reality for the entire Canadian eating disorder population: “there is often only one treatment for [eating disorders] available in their region, and if they do not respond to that form of treatment, they have no other options” (Leblanc et al., 2014, p. 46). Thus,

for many participants seeking help outside formal treatment spaces was more of an obligation than a choice.

4.4.3 Professionals Who Were Not Knowledgeable About Eating Disorders

For many research participants, consulting a family doctor, social worker or emergency room staff was the logical starting point to get help for their eating disorder. However, many encountered health and social service professionals who had little or no knowledge of eating disorders and thus, did not provide adequate treatment, or direct them to appropriate services. Anne's trajectory illustrates this barrier; she sought help for her eating disorder (orthorexia) from several health professionals (family doctor, emergency room professionals, psychologist) before getting the help she needed. Anne explains:

Anne : [...] *on va à l'hôpital, je vais à l'urgence, rencontre l'infirmière, elle me pèse pis je me mets à pleurer faque là je sors de là avec une prescription d'antidépresseur. [...] Mais y'a pas eu non plus de suivi, après ça. Faque moi en [été] je suis allée voir mon médecin de famille, elle a faite des tests pour la mononucléose, [un mois après] : urgence. Faque là l'été se passe, mais y'a pas de suivi là, mais moi je continue à pas aller bien. En faite, là je fais juste penser à ça: à m'entraîner, à pas manger; pis, j'ai pas de fun là.*

Only after identifying her eating disorder with her family doctor, and meeting with a nutritionist who was trained to support people living with eating disorders did Anne receive some appropriate support. However, she had been actively seeking help for some time before she received appropriate services from knowledgeable professionals.

For other participants, even though a possible eating disorder was identified by one professional, they were referred to another who had no knowledge of eating disorders, or to an inappropriate service altogether. Often, the result of these situations was more supportive of the eating disorder than of the person. Megan explains her experience of being referred to a school psychologist for an eating disorder:

Megan : [...] *Faque je pense que y'avait sûrement une méconnaissance de la problématique [des troubles alimentaires]. Faque [la psychologue] a juste axé sur ce côté-là anxieux. Je me souviens qu'on avait abordé la nourriture, je me souviens qu'a m'avait demandé de faire des journaux alimentaires là. Mais je veux dire, moi ça juste nuit à ma problématique. À minute que j'ai commencé à écrire ce que mangeais j'ai juste coupé, coupé, coupé, coupé, coupé, tout en sachant c'est quoi. Je savais c'était quoi manger normalement faque j'en faisait un [journal]*

pour elle pis je m'en faisais un pour moi. Faque ça m'a vraiment, ça m'a nuit. En fait, je pense c'est vraiment par une méconnaissance de la problématique, je pense.

At several points in her interview Megan expressed that she might have been able to start her recovery as a teenager if she had been referred to a competent professional.

Megan: *[...] je trouve ça quasiment triste d'avoir gaspillé du temps, tsé? Il est jamais trop tard pour se rétablir mais ouais, je suis contente de l'avoir fait [dans la vingtaine] parce que là j'ai toute ma vie devant moi pour en profiter beaucoup mieux. Mais si j'avais pu le faire avant, si j'avais eu les ressources, si on m'avait bien accroché à [l'adolescence] je pense j'aurais moins perdu de temps.*

Maier (2015) confirms that often eating disorders are “misdiagnosed due to co-occurring psychiatric disorders, such as depression, anxiety (McElroy, Kotwal, & Keck, 2006), substance abuse disorders (Harrop & Marlatt, 2010), and obsessive-compulsive disorders (Altman & Shankman, 2009)” (Maier, 2015, p. 153), making it difficult for individuals to receive appropriate treatment and services. This fact is cause for concern as research confirms that there is “a high prevalence of lifetime comorbid psychiatric disorders in individuals with all [eating] disorders except subthreshold binge-eating disorder” (Hudson et al., 2007, p. 7).

In other situations, a doctor unknowingly contributed to the development of the disordered eating through their interventions. This type of situation was often linked to the participant's weight, and the assumption that a person who presents concerns about their weight requires prescriptive lifestyle changes (Rail et al., 2010). Lili explains how a doctor's recommendations contributed to her developing orthorexia:

Lili : *Bon, j'ai paniqué [par la prise de poids]. Puis je suis allée voir ce monsieur-là [un médecin, préparateur physique]. Il est très compétant, c'est juste que j'ai pas tout à fait compris ce qui m'avait expliqué pis j'ai poussé assez loin le, je dirais le symptôme orthorexique là. J'ai éliminé des groupes alimentaires, comme tout ce qui est les céréales, les pains et céréales; j'avais tout éliminé ça. Bref, j'ai commencé à éliminer des groupes alimentaires puis à moment donné je me sentais vraiment mal - mal physiquement. J'étais fatigué, j'avais pas d'énergie, je dormais longtemps, longtemps. [...]*

Laurie experienced a similar situation when a family doctor referred her to an obesity specialist when she was struggling weight with body image issues.

Laurie : [...] *Moi, à 18 ans, selon l'indice de masse corporelle, j'étais dans l'obésité morbide et j'ai été référée en médecine par une spécialiste, un médecin qui se spécialisait en obésité. À ce moment-là, on a rentré un régime, pas selon les calories, mais selon le nombre d'aliments. C'était un régime restrictif. J'avais x portions de pain ou équivalents par jour; si on prenait un riz, on enlevait... J'avais droit à x onces de viande. Je n'avais pas droit à plus de tant de légumes de cette sorte-là. Pas de fruit x. J'ai suivi ça pendant 13 ans, dont 10 ans côte à côte. [La nutritionniste] dit que je suis un des cas de restriction les plus sévères qu'elle a eus.*

Lili and Laurie's experiences of being supported in weight-loss strategies that led to disordered eating was also noted by The Standing Committee on the Status of Women in their report on eating disorders. The committee highlighted that "some doctors have an established ideas of the "ideal body" and hold the common perception that "thin" is healthy and extra weight is not" (Leblanc et al., 2014, p. 32). Thus, when the desire to lose weight is perceived as normal and "healthy", eating disorders can be in a medical professional's blind spot (Hart et al., 2011; Hudson et al., 2007; Leblanc et al., 2014). The committee suggested that "health care professionals should examine and individual's relationships with food and his or her body" (Leblanc et al., 2014, p. 32) instead of focusing on weight or BMI. Furthermore, Hudson (2007) concludes that in order to correct the underdiagnosing of eating disorders, medical professionals must question patients about eating problems even when they do not include such problems among their presenting complaints" (Hudson et al., 2007, p. 7).

For Lili and Laurie, their doctor's advice put them on a path to orthorexia. Once the eating disorder took hold, Lili had difficulty finding specialized services for her emergent disorder. She says: « *C'est dommage à dire, mais les TCA c'est encore méconnu. Mon médecin, elle a entendu parler [de l'organisme communautaire qui offre des services troubles du comportement alimentaire] à cause de moi* » (Lili). The Standing Committee on the Status of Women heard many such testimonials, concluding that "it was imperative that health care professionals – family physicians, nurses, emergency room doctors and others – be educated about eating disorders" (Leblanc et al., 2014, p. 32) and that this information be included "in the curriculum in medical schools, family practice residency programs and psychiatry programs" (Leblanc et al., 2014, p. 33).

4.4.5 Invisibility of Sub-clinical, Lesser-Known or Emergent Eating Disorders

For those participants living with binge-eating disorder, orthorexia or sub-clinical anorexia or bulimia, the impression that their disorders were invisible was perceived as a barrier to recovery. Megan, who is now a professional working in the health care system explains how she is frustrated by this reality:

Megan: *[...] quelque chose qui me met en colère là, parce que là actuellement mettons dans [ma région] moi je vois les pires cas [de troubles alimentaires] mais il y en a vraiment...je connais pas de pourcentage là, mais il y a vraiment une grosse partie des gens qui sont dans l'entre-deux, qui vont toujours passer sous le radar pis qui ont pas de services, mais que la souffrance est la même là.*

Megan's comments are consistent with Hudson et al.'s 2007 population-based study of eating disorders in the United States, which found that "the majority of respondents with bulimia nervosa, binge-eating disorder, or any binge eating reported at least some role impairment (mild, moderate, or severe) in at least 1 role domain" (Hudson et al., 2007, p. 5) in the previous 12 months. Mitchison et al.'s (2016) community-based study also found that "participants with eating disorders reported that a sense of self, mental wellbeing, social skills, leisure, physical health, work/education, and relationships were domains of quality of life perceived as being most impaired by the illness" (Mitchison et al., 2016, p. 1). Furthermore, The Standing Committee on the Status of Women identified that there is a "gap in services for individuals with mild and moderate cases of eating disorders" in Canada (Leblanc et al., 2014, p. 45). The committee emphasized that this reality was especially problematic as "research indicates that early intervention leads to the best treatment outcomes [for eating disorders]" generally (Leblanc et al., 2014, p. 45).

For many of the participants, the fact that they were living an eating disorder was invisible even to themselves, as their eating disorder was so little known. Cynthia explains how she discovered that she was experiencing binge-eating disorder:

Cynthia: *[...] Moi y'a fallu que je tape dans Google: « trop manger », « vomit », je sais pas trop... Pis à moment donné ça poppé [sic], mais sinon je pensais que j'avais un problème de, j'avais pensé que j'avais un problème en dedans moi là. [...]*

Jason is also an example of this type of situation. When asked what eating disorder he was recovering from he said: "what type of eating disorder I have? Even today I don't know, back then I didn't know" (Jason) because his symptoms did not fit any of the specific diagnostic criteria (for the purposes of this study his disorder has been identified as anorexia/bulimia). He knew he had a problem because his eating

and physical activity were “getting crazy” (Jason), so he sought help at an eating disorder community organization and from a specialized psychologist. Jason’s experience of completely by-passing the medical system in his recovery process was experienced by half the sample in this study, an experience that appears to be common in a community context (Hart et al., 2011; Mitchison et al., 2016). The reality of recovering from an eating disorder exclusively in the community troubles both the way eating disorder data is collected and the service model that is based on research that excludes this recovery trajectory.

For both Laurie and Cassie, the years when they were receiving treatment may also have played a role in the invisibility of their eating disorder. Before 2013, binge-eating disorder did not have distinct diagnostic criteria and orthorexia remains unknown to many health and social service professionals (Vandereycken, 2011). Cassie explains : « *Moi j’ai toujours dit que j’étais une boulimique qui se faisait pas vomir* » (Cassie) to explain her binge eating. Laurie says : « *En fait, j’étais carrément orthorexique; ce n’était pas encore dans le DSM, mais j’étais terriblement orthorexique* » (Laurie).

The fact an eating disorder was little known or did not appear in the DSM was a barrier to receiving appropriate services for many reasons: the person’s health care professional was uninformed, there were no available services, the person did not have the language to describe their eating disorder to professionals, or they felt they were not eligible to receive services. For Lili, knowing that eating disorders were not well known to professionals was a barrier for her to seek psychological support. She explains:

Lili : *Mais j’ai pas consulté de psychologue professionnel parce que j’avais l’impression que je me sentrais peut-être incomprise par rapport au TCA; Parce qu’ils sont pas tous outillés pour travailler avec des gens qui ont des troubles du comportement alimentaire. [...]*

Also notable was the omnipresence of the archetype of the young, female woman living anorexia or bulimia (Gremillion, 2002; Leblanc et al., 2014) in the narratives of the participants seeking services for binge-eating disorder, emergent and sub-clinical eating disorders. Anne explains :

Anne : *Ben surtout aussi c’est important de le mentionner moi, dans ma tête vu que je me faisais pas vomir, c’est comme si j’étais gênée d’aller chercher des services, parce que j’étais pas non plus à x lbs; j’étais pas à l’étape d’être hospitalisée à Sainte-Justine là. Donc vu que j’en parlais on dirait j’étais gênée encore plus d’aller chercher... Comme si j’étais pas une vraie, c’est con hein?*

The popular belief that eating disorders present in just one way (young, very thin, Caucasian girl (Leblanc et al., 2014, p. 29) was also identified as a barrier to recovery by many women and girls in the report published by The Standing Committee on the Status of Women. Anne's description of feeling like an imposter speaks to the consequences of this stereotype which "feeds into stigma, which fuels shame among individuals with eating disorders, making it more difficult for them to acknowledge they have the disorder, to seek diagnosis and to accept and maintain treatment" (Leblanc et al., 2014, p. 29).

In most cases, the participant's who had a sub-clinical, emergent or lesser known eating disorder had a family doctor who never asked questions or investigated the possibility of an eating issue, even when the participant shared related symptoms.

Cynthia: [...] *[mon médecin] je me souviens, écoute, à un moment donné il avait été méchant avec moi. [...] Je me souviens que j'avais des troubles, j'avais des troubles de vésicule biliaire, pis il me disait : « Maigri ça va se passer. » Là je disais : « Ouin, mais j'ai mal. » Ouin, mais : « Maigri ça va se passer ». C'était tout le temps ça. Mais tu ne peux pas maigrir du jour au lendemain là. Pis moi là, même si je faisais les cinquante-six-mille régimes possibles, je m'empiffrerais après quand j'étais toute seule après. Donc ça balançais pas mon affaire là.*

In Lydia's case, she informed her family doctor that she was living with binge-eating disorder as a means to change the doctor's constant focus on her weight: « *Oui, je lui ai dit de toute façon [que j'avais un trouble alimentaire]. Je lui ai dit que...pis la ben, je veux dire, elle a modifié son comportement pis c'est correct maintenant* » (Lydia). Family doctors act as gatekeepers to more specialized treatments in the Quebec medical system; they are the first and most accessible health professionals and their referral gives access to 2nd and 3rd line services. For many participants, myths about how eating disorders present made their eating issue invisible to these gatekeepers, which represented a significant barrier in the recovery process.

What's more, few specialized services for binge-eating disorder or emergent eating disorders are offered in the public system. As Vanessa asserts « *c'est pas tout le monde qui ont accès au traitement de 3^e ligne pis je trouve ça plate, vraiment. Je trouve ça vraiment plate. Même juste l'hyperphagie.... Je trouve ça, je veux dire c'est aussi souffrant* » (Vanessa). This fact is particularly disturbing considering that "binge-eating disorder is the most prevalent eating disorder reported among women" (Starkman, 2016, p. 44) in North America (Hudson et al., 2007). Cynthia's experience illustrates the scarcity of treatment

for binge-eating disorder; she received a formal diagnosis and explains what services were available to her:

Cynthia : [...] *je suis sortie de là comme je disais tantôt, c'était diplômé trois fois avec anxiété sévère, TDA et puis hyperphagie boulimique. [...] Après ben, c'est ça. Là ben, j'attends. Parce que, là tu commences à... parce que vu que j'ai l'hyperphagie boulimique, y'a pas de groupes, y'a pas de soutien. Y'a pas d'aide pour ça, à l'hôpital. Y'a rien pour ça.*

Like Cynthia, many participants in this study shared the experience of not fitting the service model for eating disorders, despite living the most prevalent eating disorder in North America. Cassie explains how she felt after being referred to an obesity clinic's services, in her search for binge-eating disorder services:

Cassie : [...] *la première journée que je suis arrivée à la clinique d'obésité ils m'ont dit; encore là dans mon honnêteté j'ai expliqué qui j'étais et puis une après l'autre, les intervenantes (je pense c'était toute pas mal des femmes) m'ont dit que mon chien était mort, qu'ils n'allaient jamais m'opérer [chirurgie bariatrique] parce que mon trouble alimentaire était trop sévère.*

Cassie : [...] *faque là je me suis dit: « Bon ben je vais être pénalisée parce que j'ai été honnête [par rapport à mon trouble alimentaire]. » Faque j'ai pas eu j'ai eu le choix: soit que je continue à me suicider à petit feu ou bien que, pour une centième fois dans ma vie, j'essaie de reprendre le contrôle pis de reperdre le poids de façon plus [...]*

Cassie's experience resonates with Hart et al.'s (2011) finding that “across the studies reviewed, medical treatment for weight loss was found to be much more common than mental health care for an eating problem” (Hart et al., 2011, p. 732), especially in the case of binge-eating disorder (Hart et al., 2011). In Cassie's case, the treatment for obesity was focused on lifestyle changes (diet, exercise, etc.) and did not address the psychological or social aspects of living with an eating disorder. Hart et al. (2011) conclude that “given that weight loss treatment is not indicated for binge-eating disorder, it appears that there is a group of individuals who are not receiving optimal treatments for their eating pathology, despite being in contact with health services” (Hart et al., 2011, p. 732). As Starkman (2016) asserts: “because individuals with BED [binge-eating disorder] can have difficulty differentiating between emotional distress and physiological cues for hunger, successful treatment aims to promote increased awareness of mind, body and self” (Starkman, 2016, p. 57). In the current study, the none of participants living with binge-eating disorder received this type of treatment within the health care system. Instead, services for obesity were systematically offered to participants living with this eating disorder, suggesting that

referrals to inappropriate treatment for binge-eating disorder may also be common occurrence in Quebec.

The experience of not fitting-in or having an “unknown disorder” was also experienced by participants who sought support from other professionals. Anne describes her experience with a psychologist:

Anne : [...] *en parallèle j’allais voir une psychologue à l’université puis honnêtement, durant une des rencontres elle a vraiment faite : « Je sais pas quoi te dire. » Pis c’est ce qui m’emmène à participer à [cette étude] parce qu’elle était vraiment dépourvue.*

Some participants expressed that, even in community organizations that were knowledgeable about their emergent eating disorder, they felt othered because their eating disorder was rare.

Lili: [...] *même [à l’organisme communautaire] dans ma thérapie je me sentais démunie. Parce que j’avais l’impression que je parlais de mon problème mais les gens, ils vivent pas mon problème. Oui, on a un trouble de comportement alimentaire à la base, mais on le vit pas de la même manière parce c’est pas la même pathologie. [...]*

Witnesses who shared their eating disorder experiences with The Standing Committee on the Status of Women emphasized that “the very nature of eating disorders makes it difficult for individuals to seek treatment” (Leblanc et al., 2014, p. 47) as “their disorder makes them want to continue their disordered eating” (Leblanc et al., 2014, p. 47). For participants living sub-clinical, lesser-known and emergent eating disorders, the moment in their recovery when they reached out for help was the same as those living with anorexia or bulimia: living with the eating disorder had become intolerable. However, because their disorder was generally unknown to the medical and social service professionals they turned to for help, the already arduous process of finding the right professionals and services needed in the recovery process was complicated. As for prevention or early detection of a sub-clinical, emergent or lesser known eating disorders, few of the medical and social service professionals in the participants’ narratives knew enough about eating disorders to ask the right questions or identify that an individual might be struggling with disordered eating.

4.4.6 Cost of Private Services

Outside of the public health and social service system exist many private eating disorder clinics and specialized professionals who are concentrated in the four major centers mentioned earlier: Montreal,

Quebec, Sherbrooke, Trois-Rivières (ANEB Québec, 2019; Léonard, 2015). As few public services are available for binge-eating disorder, sub-clinical and emergent eating disorders, private sector clinics and professionals are often the only way a person living with these disorders can see a specialist. For participants who had no insurance or who were struggling financially, the cost of private services was a major barrier in the recovery process. Sophie describes how a private clinic suggested she pay for services : « *[la clinique privée] nous suggère d'hypothéquer notre maison parce que ça vaut la peine* » (Sophie). Finding affordable private services was a challenge for many participants in this study. Laurie explains how she managed to see a nutritionist in the private sector :

Laurie : *Puis, c'est des sous; moi, je n'ai pas d'assurance, mais, pour moi, aller chez [la nutritionniste], c'est un investissement dans mon budget. Ce n'est pas l'argent de [la clinique privée], mais, pour moi, [la nutritionniste], c'était non négociable. Là, j'avais des sous pour y aller une fois par mois et j'y vais.*

Others found ways to work around the limits of the public system to access the services they needed. Lydia explains : « *j'avais vu une psychologue [dans ma région] parce qu'elle était psychologue et elle était médecin de famille aussi, parce que j'avais pas les moyens de me payer une psychologue* » (Lydia).

The Standing Committee on the Status of Women also identified the cost of private eating disorder services as a barrier to recovery, stating that “living with an eating disorder results in a significant financial burden for the individual, a partner, and family members” (Leblanc et al., 2014, p. 34). The committee found that the multidisciplinary approach that is required to successfully treat eating disorders was, in the private sector, “prohibitively expensive if an individual is required to pay for it with no assistance” (Leblanc et al., 2014, p. 34). The committee also noted that many people did not seek treatment because they could not afford to leave their jobs (Leblanc et al., 2014, p. 35), a financial reality that is perhaps unique to eating disorders as many individuals are able to continue some level of functioning in their daily activities despite having a serious mental health problem.

4.5 The Body in the Sociocultural Context

In addition to encountering barriers related to receiving adequate services for eating disorders, the research participants located several recovery barriers in the sociocultural context. As Daly (2016)

asserts, “Western sociocultural values of appearance have been found to significantly contribute to eating pathology through the promotion and ascription of value to a virtually unattainable thin physique while stigmatizing fatness” (Daly, 2016, p. 47). Additionally, McCormick (2008) states that “the rules and norms of our culture establish and regulate women’s bodies and, by this means, women’s sense of self” (McCormick, 2008, p. 316). As the majority of participants in this study identified as women, this section will be focused on how gendered cultural norms regarding food and the body were identified as barriers to recovery. In the interviews, many themes related to cultural messages about the body emerged, however I have chosen to focus on the strongest of those themes, which are: the **stigmatization of fat**, which includes its counterpoint: the **cultural value of thinness/bodily control** in relation to eating disorder recovery.

4.5.1 Stigmatization of FAT

In this study, stigmatization of fat was experienced by all the participants recovering from binge-eating disorder, 1 participant recovering from orthorexia and binge-eating disorder and 1 participant recovering from orthorexia and bulimia. The sense that they were being shamed and discriminated against because of their body size was felt in several spheres of the participants’ lives: **within the health system, in their families and with their peers, and in society** (generalized).

4.5.2 In the health system

Firstly, it is important to underline that 2 of the 3 participants recovering from binge-eating disorder, 1 recovering from binge-eating disorder and orthorexia and 1 orthorexia and bulimia were all referred to an obesity clinic or an obesity specialist. In many cases, the participants were referred by a professional who was aware they were living with an eating disorder. For Cassie, being referred to an inappropriate treatment program for obesity when she was living with binge-eating disorder gave her the tools and encouragement that contributed to her developing orthorexia:

Cassie : [...] [à la clinique d’obésité], alors ce qui me suggéraient tant de % admettons, parce que là c’est ça, eux autres. Je suis certaine qu’ils le voyaient tranquillement pas vite là, mon orthorexie s’installer. Faque là, mais moi je demandais admettons : « OK, oui mais c’est quoi mon % admettons là? » ou « Les grammes de protéines, de gras ou de fibres que je devrais théoriquement manger là? » Faque bon, ils me donnaient des guidelines pis toute ça. [...]

Laurie experienced a similar situation when a family doctor referred her to an obesity specialist when she was struggling with food and body image issues.

Laurie : [...] *à 18 ans, j'avais déjà commencé [le trouble alimentaire]. À 18 ans, j'ai eu [la spécialiste en obésité]. [...] À chaque semaine, elle me pesait et me mesurait et elle prenait ma pression. J'ai écrit ma nourriture pendant dix ans.*

In both cases, being referred to an inappropriate service resulted in the deepening and transformation of the eating disorder (Cassie) or the development of an eating disorder (Laurie). Services offered for obesity generally consist of diet, exercise and other lifestyle changes (Holmes et al., 2006) which are very different from the “cognitive-behavioral psychotherapy and structured self-help” that are “considered the first-line of treatment for clients with binge-eating disorder” (Myers & Wiman, 2014, p. 91). Cynthia describes how she experienced the services offered at the obesity clinic, to which she was referred with a diagnosis of binge-eating disorder:

Cynthia : [...] *Pis lorsque j'ai vu la nutritionniste [de la clinique d'obésité], je lui ai demandé, j'ai dit : « J'aimerais apprendre à bien manger. » J'ai jamais appris ça, j'ai été élevé au confort food pis c'était ça, tsé? [...] Mais tout ce qu'elle m'a dit c'est : « Garde, ça c'est ton assiette, ça sa doit être ta protéine, pis tu dois avoir la moitié...non, un quart de protéine, un quart de féculent, puis une moitié de légumes. » Mais oui, mais, y'a pas hein que ça dans la vie là!*

Cynthia also met with a kinesiologist at the clinic who encouraged her to exercise. Neither of these treatments are prescribed for binge-eating disorder. Even though it has only been a distinct disorder since 2013 (American Psychiatric Association, 2017), “there has been significant research into the treatment of BED” (Myers & Wiman, 2014, p. 91) and it has been established that “weight loss treatment is not indicated for binge-eating disorder” (Hart et al., 2011, p. 732). Individuals who live with binge-eating disorder are often overweight or obese because they frequently binge (symptom of the eating disorder), not because they don't know how to eat or because they do not exercise. As Cynthia said in her interview : « *Pis moi là, même si je faisais les cinquante-six-mille régimes possibles, je m'empiffrerais après quand j'étais toute seule après. Donc ça balançais pas mon affaire là* » (Cynthia).

Participants also distinguished bingeing from their regular eating. Sophie explains: « *Pis l'autre problème c'est que je réalisais que c'était pas normal que je m'empiffrait, tsé c'est plus manger là – je devrais* » (Sophie). As others have said in this study, bingeing is related to dealing with painful emotions and difficult

situations (Sophie: « *j'ai mangé mes émotions* »); Lydia explains : « *si je vis des situations un peu plus difficiles j'ai de la misère [avec la nourriture], pis si je suis déçue, si je suis; si j'ai besoin d'attention ou d'affection pis que je ne l'ai pas* » (Lydia). Petrucelli (2016) explains that « individuals struggling with eating disorders believe that if they pay attention to their bodies and feel their feelings – they will overwhelm their minds” (Petrucelli, 2016, p. 19) and that “food is used to drown out the noise in their heads” (Petrucelli, 2016, p. 19) whether through bingeing, purging or restriction. Thus, services offered through obesity specialists and clinics to individuals who have an eating disorder are not in line with “treatment guidelines which state that eating disorders require medical *and* mental health treatment, specifically designed to alleviate the symptoms associated with disordered eating and exercising” (Hart et al., 2011, p. 729). For the women in this study, medical professionals’ reading of their “overweight” bodies was experienced as discriminatory, as it led them to be referred to inappropriate services for obesity instead of specialized services for an eating disorder, even when the professional was aware of an eating disorder diagnosis.

Participants in this study also experienced stigmatization from their family doctors, none of whom suspected an eating disorder or asked participants questions about their relationship to food. Instead, the family physician’s focus was weight and weight loss (Leblanc et al., 2014). This amounted to fat shaming for some participants :

Lydia : [...] *Il y eu un moment donné que, parce que j'ai mon...à chaque fois que tu vois un médecin, tu parles : « Je suis en surplus de poids. » T'arrives chez le médecin, ben là « Faudrait que tu perdes du poids », « Faudrait que t'essayes de maigrir », « C'est peut-être à cause de ton poids. » Toute est relié à ton poids.*

Cynthia : [...] *j'avais des troubles, j'avais des troubles de vésicule biliaire, pis [mon médecin] me disait : « Maigri ça va se passer. » Là je disais : « Ouin, mais j'ai mal. » Ouin, mais : « Maigri ça va se passer ». C'était tout le temps ça. Mais tu ne peux pas maigrir du jour au lendemain là. [...]*

Laurie describes reaching out to her family doctor when she was a teenager, struggling with her weight and body image:

Laurie : *Là, je me suis dit : « Aïe! 5 pieds et 5 pouces, x livres! » J'ai appelé mon médecin et elle a dit : « Oui, tu es vraiment, vraiment obèse. Tu vas aller rencontrer le médecin [spécialiste en obésité] et ça va changer ta vie. » Ce qui est vrai.*

Laurie's life did change, as she followed a very restrictive eating plan prescribed by the obesity specialist. Laurie went from being overweight to becoming obsessed with controlling her food intake. She explains:

Laurie : *En fait, j'avais mes tasses à mesurer et ma balance, que je traînais avec moi. Wow! Oui. Beurk! [sic] Oui. C'était le running gag. Et je tapais sur les nerfs des gens parce que j'enlevais x grammes de poulet. Je n'ai jamais jugé, mais je regardais les recettes des gens et je disais : « Mon doux! Elle est en train de manger x calories. »*

The obesity specialist not only prescribed the diet but engaged in close monitoring of her patient's eating and weight, weighing and measuring Laurie regularly. When asked how she feels about this doctor today Laurie says:

Laurie : *[...] J'ai su d'elle beaucoup de choses personnelles. [...] Je pense qu'elle s'est beaucoup réfugiée là-dedans, elle s'est créé une grosse forteresse, mais moi, je ne veux pas de cette forteresse-là, je n'en ai pas besoin. C'est ça. Je n'ai pas de haine. Des fois, je me dis : « Aïe! J'ai perdu dix ans de ma vie à calculer. » Oui et non. Oui, il y a toujours cette frustration-là, mais, en même temps, je me dis que Laurie ne serait pas ce qu'elle est aujourd'hui.*

As Hart et al. (2011) conclude in their review of eating disorder literature, “studies clearly demonstrate that individuals with eating disorders are much more likely to receive treatment for a (perceived and not necessarily actual) weight problem than they are to receive treatment for a problem with eating” (Hart et al., 2011, p. 731) and that individuals with binge-eating disorder were the most likely to experience this type of “phenomenon” (Hart et al., 2011, p. 731). As it is well known that “binge-eating disorder is the most prevalent eating disorder reported among women” (Starkman, 2016, p. 57), this “phenomenon” can be considered as a form of discrimination based on both weight and gender. This discrimination, embedded in the health care system, has serious impacts on the physical and mental health of women. As Austin (1999) asserts “contemporary nutritional public health's profound allegiance to the biomedically conceived body and naivete about the centrality of cultural meaning-making regarding eating, food, fat, and gender do more harm than simply hobble efforts to promote more healthful behavior” (Austin, 1999, p. 246). For some participants in this study, women who sought help for their eating disorders (with or without knowing they were living with an eating disorder) were misdirected due to perceptions about their weight and gender.

With regards to eating disorders in Canada, Dr. Blake Woodside (medical director of the Program for Eating Disorders at the Toronto General Hospital) shared the following statement with The Standing Committee on the Status of Women:

...there is a clinic for prostate cancer in every hospital in this country. Compare that with the situation for anorexia nervosa where, in the province of Ontario there are only three treatment centers that have in-patient beds for a population of 12 million. If that is not discrimination, I don't know what is. (Black, 2013 cited in Leblanc et al., 2014, p. 30)

Both the treatment situation for anorexia (the most well known and well funded of all eating disorders) and the virtual non-existence of specialized treatments of binge-eating disorder illustrate the double discrimination experienced by some female participants in this study: having a “pseudo-illness” (Leblanc et al., 2014, p. 28) experienced primarily by women that is grossly undertreated in the Canadian public health system, and living the eating disorder that is totally ignored by the same system as it manifests itself in “fat” or “obese” bodies. As Rail et al. (2010) assert, emphasis on “obesity as a personal failure” (Rail et al., 2010, p. 273) in the dominant obesity discourse masks the “socio-cultural and environmental factors that affect health and that reinforce the unequal distribution of health-related resources” (Rail et al., 2010, p. 273). For the women in this study living in perceived overweight or obese bodies, the obesity discourse dominated their interactions with the health care system, as evidenced by the high amount of obesity services offered to these participants in contrast to the total absence of eating disorder services. As Lydia asserts : « *la barrière s'est vraiment limitée aux préjugés et pis les médecins ont des préjugés* » (Lydia); these prejudices both within the medical system, and from individual medical professionals affected the level and quality of care received by participants who were perceived as overweight or obese.

Conversely, participants whose disorder was more restrictive or manifested itself in a thin body reported feelings of pride and achievement:

Vanessa : *Oui. Pis [les personnes hyperphagiques] vivent beaucoup plus de honte alors que dans l'anorexie, pour l'avoir vécu, tu vis de la fierté. Je dis pas que c'est tout le monde, mais moi un point j'étais, y'a un point que je cachais mon corps parce que j'étais consciente que c'était rendu too much. Mais à un point j'étais fière de monter que moi je suis capable de perdre du poids [...]*

Jennifer shares a similar feeling of accomplishment with regards to her lifestyle, which was deeply influenced by anorexia.

Jennifer : *[...] mais c'est ça je pense que si je relèverais pas d'un trouble alimentaire je serais vraiment juste fière de voir que je fais attention à ce que je mange raisonnablement bien, je fais attention à ce que je mange, je fais du sport. Dans le fond, c'est un rythme de vie disons, ou un mode de vie plutôt, que la plupart des gens veulent réussir à atteindre, c'est juste que moi je l'ai atteint mais par l'autre bord là [...]*

The participants feelings of pride related to restriction is the logical counterpoint to the obesity discourse. Culturally, “the thin body is given recognition as reflecting control, virtue and goodness” (Rail et al., 2010, p. 261). In fact, Hart et al. (2011) indicate that “there is some evidence to suggest that the social acceptability of non-purging weight-control behaviors, such as fasting or over-exercising, does not lead to the same level of psychological distress as is experienced by those who engage in more stigmatized [binging and] purging methods and therefore is associated with lower levels of help seeking” (Hart et al., 2011, p. 733), which is in itself a significant barrier to recovery.

4.5.3 In the Family

The stigmatization of fat experienced by participants was not limited to the health sector. Participants also shared experiences of stigmatization of fat within their families, often starting in childhood. Cassie explains how a family member talked about her body as a child:

Cassie : *[...] mais j'étais pas mal toujours quand même, pas mal la plus grosse. J'étais pas grosse, mais la plus grosse. Aujourd'hui je l'aurais pas été, mais dans le temps je l'étais et pis mon père pour me faire, tsé y faisait des: « Fait attention! » Mais lui sa façon c'était de m'appeler « Gros jambon. »*

For Laurie, the way her mother's body was discussed influenced her body image:

Laurie : *[...] Mon père est un homme nerveux qui aime faire des blagues et il faisait toujours à ma mère des blagues désobligeantes, pas pour la détruire, mais c'était des jokes de mononcle [sic] : « Hihihhi! Envoie, ma grosse toutoune [sic]. En tout cas, avec toi, je ne manque pas de gras. » Juste comme ça. Mais, avec le groupe [de soutien], j'ai réalisé jusqu'à quel point ça me dérangeait.*

The participant's memories of fat shaming in their childhoods speak to the fact that "for women in Western cultures, particularly in the 20th and 21st centuries, food and eating have been used to control and create the "right" body" (McCormick, 2008, p. 312). Culturally, the "right" body for women has been a thin body for more than half a century (Bordo, 2003; Gremillion, 2005; Vinette, 2001; Wilson, 2004). The counterpoint to the "right" body that is praised, is the "wrong" body that is reviled. As explored in an earlier section, fat has come to represent being on the wrong side of cultural norms, especially for women (Gremillion, 2005; Melcher & Bostwick Jr., 1998; Rail et al., 2010; Vinette, 2001). Ironically, "overeating is a significant problem in contemporary western society" (Ronel & Libman, 2003, p. 155), as evidenced by the high incidence of binge-eating disorder in the United States (Hudson et al., 2007; National Eating Disorder Association, 2018). Still, "excess weight is considered a morally reprehensible form of deviance" (Ronel & Libman, 2003, p. 165) in Western society (Rail et al., 2010; Vinette, 2001) associated with laziness, greediness, and "lack of willpower" (Ronel & Libman, 2003, p. 165). Rail emphasizes that "obesity discourse draws upon a neoliberal notion of individualism that positions individuals as primarily responsible for changing their lifestyle via a range of disciplinary measures and control techniques" (Rail et al., 2010, p. 260) such as diet, exercise, etc. In both Sophie's and Cassie's household, weight control through restriction and dieting was both normalized and expected. The underlying message that fat was both undesirable and unacceptable had a deep effect on their self-esteem and body image.

Sophie : [...] *mes parents étaient, beaucoup d'emphase sur : « Faut pas que tu t'aimes comme tu es parce que sinon tu perdras pas de poids. » Tsé, la phrase comme ça, qui est très destructrice pis c'est là. C'est à un moment donné que j'ai faite : « Aie! Je suis tanné de ça! Moi j'ai le gout de m'aimer comme je suis ».*

Cassie: [...] *[le trouble alimentaire] vient de ma mère aussi qui m'a embarqué dans les régimes très tôt, c'était pour mon bien, parce que je me trouvais grosse pis toute ça mais, pis elle voulait pas que je devienne grosse, pis que je m'aime pas pis toute ça, mais qui... J'ai pas souvenir de ma mère qui s'aimait. Tsé, qui disait qu'était bien, belle pis qu'elle avait l'air de se sentir bien dans sa peau. Ma mère était toujours en restriction finalement. [...] Faque j'ai trempé là-dedans très très jeune[...]*

The research participants' experiences of stigmatization of fat in their families speak to how family is a vector for culture. Daly (2016) suggests that caregivers act as "culture carriers" during child development through mirroring the cultural expectations to the child" (Daly, 2016, p. 51). As it has been established

that “thinness in Western culture is often associated with femininity, desirability, success and social class” (Daly, 2016, p. 51), girls internalize the thin ideal and are made to understand that if they do not engage in the bodily control required to achieve the ideal they will suffer the consequences (Daly, 2016, p. 51). Messages such as : « *Faut pas que tu t’aimes comme tu es parce que sinon tu perdras pas de poids* » (Sophie) communicate that, for women, there is a higher cultural value placed on « *faire correspondre leur corps aux images idéalisées de la jeunesse, de la santé, de la bonne forme physique et de la beauté* » (Vinette, 2001, p. 133) than on developing other aspects of the self. Thus, a feminist « sociocultural perspective links disordered eating and body image problems in certain cultures to the culture’s elevation of thinness as a significant aspect of beauty while stigmatizing fatness” (Daly, 2016, p. 51). Accordingly, the experiences of participants whose eating disorder corresponded to cultural norms of thinness experienced pride and a sense of accomplishment, whereas those whose disorder included bingeing or weight gain experienced shame and stigmatization. Often these experiences of pride or shame can be traced back to the participants’ childhoods, and the ways in which gendered cultural body ideals were part their socialisation.

4.5.4 By Peers

Experiencing stigmatization of fat from peers was also identified as both a contributor to many respondent’s eating disorder, and a barrier in their recovery process. Moreover, gaining weight can part of the recovery process for individuals with all types of eating disorder. Laurie’s story stands out as the stigmatization of fat is at the center of her eating disorder narrative of extreme restriction. In fact, as she has learned to eat normally she has gained a significant amount of weight, and now deals with the disdain and judgement of her body by others. Her story speaks to how normalized it is for women in North American culture to control their weight (Bordo, 2003; Gremillion, 2002) and how radical it is when they decide not to engage in food restriction. Laurie explains what it feels like to receive feedback about her body’s changes from others:

Laurie: [...] *ce qui m’a le plus blessée, c’est de me faire dire [lorsque j’avais perdu du poids]: « Tu étais tellement laide quand tu étais grosse, ça n’avait pas de bon sens. » Ah oui. [...] Mais l’affaire, ce qu’ils m’ont dit, c’est que je suis redevenue comme ça, dans le sens que je suis physiquement grosse comme ça. Dans le fond, c’est ce qu’ils pensent de moi maintenant.*

Laurie : [...] *J'ai une amie qui est en train de me checker aller et qui me dit : « Ça n'a pas de bon sens. » Son mari a peur qu'elle fasse comme moi aussi [l'alimentation intuitive]. J'ai dit : « Tu ne prendras jamais le poids que j'ai pris. J'ai fait dix ans de restrictions. » Elle a dit : « Je ne deviendrais jamais grosse comme tu l'es devenue, ça n'a pas de bon sens. » Moi, j'ai été longtemps beaucoup plus petite qu'elle. Son mari lui dit : « Tu ne deviendras jamais grosse comme ça, je ne l'accepterai pas. » Mais, j'ai dit : « Tu ne deviendras pas grosse comme moi. »*

Laurie's experiences with peers shed light on how normalized overt fat shaming is Western culture, both from others and from the self. Petrucelli (2016) asserts that "fat talk perpetuates body shame, body dissatisfaction, body image difficulties and contributes to eating disordered behaviors" (Petrucelli, 2016, p. 18). This kind of talk does "not motivate women to make healthier choices or take better care of their bodies" (Petrucelli, 2016, p. 18) but induces shame and low self-esteem. Laurie's conversation with her friends illustrates the social acceptability of fat talk, but also how the receiver of the fat talk is conditioned to accept and participate in what is essentially a stigmatizing conversation.

For participants who oscillated between control and loss of control in their disordered eating, experiences of praise and approval of their disciplined body were common. Cassie, who in an orthorexic phase lost a significant amount of weight, was openly (and materially) praised in her work place. She explains:

Cassie : *Heille, mon boss là quand que je travaillais là, d'un coup y m'avait fait venir dans son bureau. Pis il m'avait proposé de me payer des chirurgies pour me redraper [la peau après la perte de poids]. [...] mais tsé, je le sais que pour lui, c'était un cadeau qui voulait me faire pour me motiver à ne pas me laisser aller là, que là si j'avais toute ramanché la peau pis toute ça ben peut-être que j'aurais pas voulu toute redéfaire ce travail-là, tsé?*

Cassie's story speaks to the cultural capital attributed to weight loss and control. Loss of this capital can be a difficult part of the recovery process. According to Melcher & Bostwick Jr., many people "require help grieving the lost dream of being thin" (Melcher & Bostwick Jr., 1998, p. 204), especially when the individual has experienced both the thin and the overweight body over the course of their eating disorder.

4.5.5 Generalized

Several research participants described a feeling of being stigmatized because of their weight in general. When asked what barriers she encountered in the recovery Laurie responded simply: « *Le poids. Le poids...énorme. Le regard des gens. Les critiques des gens* » (Laurie). Lydia also identified prejudice related to her body size and binge-eating disorder as a barrier to recovery:

Lydia : *Je te dirais, la seule, le seul truc qui est un, qui peut être une barrière c'est les préjugés. Les préjugés des gens. Je trouve que les gens sont, ils banalisent tellement [l'hyperphagie]! C'est, ils banalisent tellement que ça n'en est enrageant. Pis là tu tombes encore dans des émotions négatives pis ça empire tes affaires.*

Cynthia also identified binge-eating disorder as not being taken seriously by others, as it is associated with emotional eating and weight gain:

Cynthia : *Hyperphagie? Ouin. Ça, le monde me disait toujours : « C'est quoi? ». C'est comme la boulimie là, tu manges tout...tu manges beaucoup, mais, tu te fais pas vomir ou t'a pas de moyens. Mais le monde ils pensent pas que c'est un trouble! Moi là, me faire dire que : « Tu manges tes émotions là... ». J'étais jeune me faisais dire ça. [...]*

All participants who had experienced binge-eating disorder associated their disorder with social stigma, often by referencing anorexia as a counterpoint. Sophie describes how her eating disorder is perceived by others:

Sophie : *Ben c'est un trouble qu'on fait juste juger les gens finalement. On se dit pas « Ah pauvre elle, elle est malade! » Mais finalement c'est ça, pour vrai, elle a besoin de soutien. Ouais. Elle a besoin qu'on l'appuie faque ça je trouve ça difficile. [...]Mais je comprends aussi, je veux dire [les personnes qui vivent l'anorexie] ont besoin aussi là, pis c'est peut-être même que leur santé est plus en danger dans l'immédiat, mettons, mais la santé psychologique est aussi très forte dans l'hyperphagie. Donc ça me fâche, ça me fâche beaucoup le jugement des gens. [...]*

In effect, binge-eating disorder is conflated with obesity and is submitted to the same discourse which “offers a mechanistic view of the body and focuses on the presumed relationship between inactivity, poor diet, obesity and health” (Rail et al., 2010, p. 260) in addition to a moral failure and a strain on economic resources (Rail et al., 2010, p. 260). In these two excerpts from Lydia’s interview, the power of the obesity discourse is clear with regards to how others react to her body, and how she perceives the constant judgement/surveillance of others:

Lydia : *[...] Tu sais comme y'en a qui vont dire : « Ben si tu veux perdre du poids, fait du sport. » Ça me fais-tu suer quand que j'entends ça ! T'as même pas idée comment ça m'enrage. Ça m'aide pas pentoute [sic]! Parce que c'est facile de dire ça. Mais c'est un préjugé, gros comme*

la terre. Parce que oui, j'aimerais ben ça en faire du sport. Mais pour arriver à faire du sport y faut que je réussisse à perdre un peu, avant. Parce que c'est dur maintenant, tu comprends? [...]

Lydia: *[...] [Les regards] sur mon corps, sur, exemple : tu vas manger quelque chose quelque part; tu vas manger normalement comme tout le monde, c'est pas, c'est vraiment pas une chute là...c'est, tu manges normalement. Mais heille! « T'es gros et tu manges?! » « Faut que tu manges pu parce que t'es gros? » Garde, ça se passe pas de même.*

Social work professors Melcher and Bostwick Jr. (1998) assert that individuals who are perceived as obese “are confronted daily with the message that thinness is the ideal and that their weight indicates personal shortcomings” (Melcher & Bostwick Jr., 1998, p. 204) and ill health. Correspondingly, Rail et al. (2010) posit that “perhaps the most significant consequence of equating ‘being thin’, ‘having a normal body’ or ‘not being fat’ is the fact that our society has a very restrictive and narrow ideas of ‘normality’ and ‘normal weight’ and that such ideas are grounded in sexist, racist and ableist views” (Rail et al., 2010, p. 273). As such, constructing a positive identity outside ‘normality’ becomes an act of resistance. Laurie’s description of how she perceives herself and her weight illustrate the tension between the dominant obesity discourse and her desire to feel good about herself and her body:

Laurie : *Pour moi, je ne sais pas si je pourrais dire que je suis l’antithèse... Les gens disent qu’on ne peut pas être heureux, que c’est impossible d’être grosse et de se sentir belle, mais pourtant, aujourd’hui, j’ai une paix dans mon cœur plus que jamais dans ma vie. [...]*

Many participants described a change in the way they feel about their bodies in the recovery process, shifting from how they look to how they feel, and what their bodies can do. However, the increasing body acceptance experienced by participants coexists with the gendered cultural norms that place a high value on “slender femininity” (Gremillion, 2005, p. 19). For Cassie, who has experienced both extreme restriction and binge eating, the notion that fat is unacceptable and unattractive is now coexisting with her desire to feel better in her body:

Cassie: *Pis là, je veux dire, je voudrais, je voudrais perdre du poids, mais pas pour mon apparence, faque ça au moins, au moins de ce côté-là j’ai progressé. C’est ben évident que je me trouve hideuse, dégoûtante là, mais pour moi, c’est pu ça qui est important, c’est comme ça, l don’t give a shit. Je voudrais juste être capable d’aller prendre une marche pis prendre plaisir parce que je souffre pas, ou prendre ma douche sans avoir l’impression que je vais crever, tsé? C’est ça.*

For Lydia, accepting that she doesn’t “fit the mold” established in culture is significant in her recovery:

Lydia : *OK. J'ai commencé à accepter un peu plus que je suis différente de certaines personnes. Que je fit pas nécessairement dans le même moule, même si la société veut me mettre dans ce moule-là. J'ai accepté, j'ai lâché prise sur des choses. Maintenant, ça veut pas dire de se laisser aller pour autant. Comprends-tu? Maintenant je suis pu dans le stade de vouloir à tout prix être maigre. Parce que je le serai jamais. Mais me sentir juste bien dans ma peau, c'est tout.*

LeBesco (2004) takes the position that “negotiating questions of fat identity involves a fluid, alternating pattern of invocation and refusal of mainstream tropes of health, nature and beauty” (LeBesco, 2004, p. 123). As the participants narratives illustrate so well, “there is never a neat separation between the power we promote and that which we oppose” (LeBesco, 2004, p. 124). For the participants in this study who are perceived as overweight or obese, inhabiting a “fat” female body in the recovery process from an eating disorder represented very specific challenges. In addition to working on underlying causes of the eating disorder, repairing their relationship with food and their bodies, they also had develop skills to deal with generalized societal prejudice associated with fat, and redefine themselves in a cultural context that reviles their bodies (Gremillion, 2005; LeBesco, 2004; Melcher & Bostwick Jr., 1998; Petrucelli, 2016; Rail et al., 2010) as part of the recovery process.

When speaking to a doctor about her eating disorder, Chloe says : « *Ouais t'es entourée de monde mais, en dedans de moi j'étais seule... seule avec le diable* » (Chloe). “Alone with the devil” is a vivid description of how many participants experienced the multitude of barriers encountered in their recovery processes. Many felt that the public health system had failed them, as few options for eating disorder treatment or support were available to them. Others experienced the invisibility or stigmatization associated with their eating disorder, as their bodies and experience were different from the mythologized young, white, thin, woman living with anorexia (Gremillion, 2002; Leblanc et al., 2014; McCormick, 2008). A lack of knowledge about eating disorders also affected some participants’ loved ones ability to provide adequate support in the recovery process. Finally, many participants experienced overt discrimination in the health system related to their weight when seeking help for an eating disorder. The stigmatization of fat was also experienced in their families and with peers. In fact, the cultural value placed on thin bodies and rejection of fat or “out of control bodies” (Rail et al., 2010) had a negative impact on all participants’ recoveries. However, within formal treatment spaces “no approach [that] deals with

patient's environments" (Arnaiz, 2009, p. 198) are documented, nor are the sociocultural aspects of eating disorders addressed outside feminist approaches to eating disorders (Arnaiz, 2009, p. 192).

4.6 Services Gendered Female

In this study, there was one male participant. Though one voice is certainly not representative of all men recovering from eating disorders, Jason did indicate that he experienced some of the services offered by the community organization where he received support as gendered female.

Jason: ...But yeah, some things in terms of, like, self-esteem and, you know, the different magazines where you see girls in swimsuits or whatever, you know body image and such like that; it's like: "no, it doesn't really resonate so much." [...]

Jason's experience is consistent with what Anderson (2014) describes as pressures that are different from the "drive for thinness and fear of weight gain [that] are cardinal features of eating disorders in women" (Anderson cited in Bunnell, 2016, p. 100). Jason's perception that elements of the group therapy simply didn't address his reality is corroborated by Bunnell's conclusion that "cultural norms that objectify bodies, promote thinness or muscularity, and deify dieting influence both etiology and recovery" (Bunnell, 2016, p. 10) from an eating disorder. This may explain why some of the cultural elements of the eating disorder therapy did not resonate for Jason. Bunnell also adds that "specialized programming [for men with eating disorders] is severely limited" (Bunnell, 2016, p. 103), as men are largely absent in the research and treatment models for eating disorders.

However, Jason expressed that being in a predominantly female support group also had advantages with regards to the expression of emotions, which is associated with weakness and vulnerability in men culturally (Bunnell, 2016) :

Jason: [...] It was easier for me to be surrounded by girls who would cry. Who cried. Who felt things and expressed that. So, I mean, for me to cry...it was like...whatever. It was almost, just part of the group. But yeah, with a bunch of dudes I don't think I would have had that openness to do that.

Bunnell also noted that many men living with eating disorders reported distress "about their decision to seek therapy, dreading the potential exposure of their shameful vulnerabilities" (Bunnell, 2016, p. 101)

as “conventional masculine norms discourage emotionality and relational intimacy” (Bunnell, 2016, p. 103), which are the hallmarks of the eating disorder support group (Black, 2003; Starkman, 2016). For Jason, being in a context where expressing emotions and seeking support were normalized made him feel comfortable. When asked if he would feel the same in a support group with more men, Jason expressed reservations:

Jason: Probably the more guys there were [in the group] the less open I would be to cry and the more girls there maybe...but then maybe if all the dudes were crying too then it'd be easier, but you know you've got this: “Guys are tough.” So, you know? [...]

Jason's experience speaks to the complexity of taking gender into account in eating disorder services, especially in a context of scarce specialized eating disorder resources. Currently, men with eating disorders in Quebec are likely to be included in service and treatment models designed for women, which can represent both advantages and barriers in the recovery process.

4.7 Loved Ones Who Needed Information and Support

In their definitions of recovery, many participants emphasized the long-term nature of this process. Participants emphasized the daily efforts they invest in their recoveries and emphasized that their loved ones (partners, children, close friends, neighbors and family members) were the people who provided the support needed to recover from an eating disorder. However, many of the participants' loved-ones, though well-meaning, were uninformed about eating disorders and did not know how to provide appropriate support. Anne describes how her loved one had difficulty understanding what she was going through:

Anne : [...] *lui il le savait que je mangeais quasiment pu pis je pensais juste à ça, pis il était vraiment dépourvu aussi. Il était comme : « Mange des chips ça va passer là. » Mais pour lui c'était vraiment out of his mind, tsé? [...] Il comprenait pas pis là il demandait des conseils à ses amis, mais son entourage, ses chums de gars qui font de la moto pis toute; comme, il y avait personne qui pouvait comprendre ou lui donner des conseils, à part ben : « Qu'a mange des chips là. »*

Laurie lived a similar experience with her loved one, who encouraged her to start restricting her food intake, the primary symptom of her eating disorder:

Laurie : [...] *En même temps, il voit que je suis comme libérée, mais, après ma grossesse, il m'a dit : « Remets-toi à recalculer. » J'ai dit : « Là, je jette l'éponge, c'est terminé. » Il a dit : « Aïe! Tu ne peux pas faire ça, ça n'a pas de bon sens. » Lui, il m'avait toujours connue... [...] Oui. Je l'avais connu comme ça. Je lui ai dit : « C'est terminé, terminé, terminé. » [...]*

Not understanding the eating disorder, Cynthia's partner tried to support her with food, which was a trigger for her binge eating.

Cynthia : *Y'avait mon chum, que lui savait pas trop comment prendre [le trouble alimentaire], mais qui... Parce que des fois je disais; là il m'achetait plein de cochonneries là, je disais : « Pourquoi tu m'achètes ça? Tu sais j'ai un problème! ». [...]*

In these narratives, the participants are describing their main support person's reactions to the eating disorder or their recovery process. At other moments in the interviews, the participants describe the same loved ones providing other types of support that were deeply appreciated. As Anne and Cynthia explain, their support person's focus on food and weight was rooted in the incomprehension of eating disorders, and a lack of appropriate support. As food and weight are the focus of both dominant medical approaches to eating disorders (Arnaiz, 2009; Gremillion, 2002; Leblanc et al., 2014; Wilson, 2004) and how these issues are portrayed in the media (Leblanc et al., 2014), it is not uncommon for loved ones to be concerned with food intake and weight (gain or loss) of the person they love. Often, the person living with the eating disorder must explain that this type of intervention is not supportive. Sophie describes having to tell her partner to let her manage her own food intake:

Sophie : [...] *Ça aussi j'ai dit à mon chum; j'ai dit : « Dit-moi pas... » Mettons que je dis j'ai pu ben faim, dit-moi pas, rappelle-moi pas : « T'as-tu faim? » Parce que je sais qu'il le fait pour mon bien, mais j'ai l'impression de perdre le contrôle de : « Si moi j'en ai envie, je vais en manger. » Faque là j'ai dit : « Écoute, je vais le gérer moi-même pis si j'ai trop mangé c'est moi de toute façon. ». [...]*

The research participants' rejection of their loved one's injunctions regarding food and weight is directly related to their feelings of autonomy and control, as both Sophie and Laurie describe. Davidson (2009) emphasizes that supportive relationships in recovery are focused on the person's strengths and aspirations, while accepting the risks, failures and setbacks of the recovery process (Davidson et al., 2009, p. 159). Correspondingly, the National Eating Disorder Information Center (NEDIC) explains that friends and family can provide support by becoming knowledgeable about eating disorders. Specifically, understanding "that an eating disorder is a coping strategy that the individual uses to deal with deeper

problems - problems may be too painful or difficult to deal with directly” (National Eating Disorder Information Center, 2019). NEDIC recommends that loved ones avoid discussions about food and weight in favor of discussing feelings and relationships (National Eating Disorder Information Center, 2019). The organization emphasizes that “the person is already too aware of their body. Even if you are trying to compliment them, comments about weight or appearance only reinforce their obsession with body image and weight” (National Eating Disorder Information Center, 2019).

For other participants, loved ones simply could not accept the eating disorder or offer their support, which represented a barrier to recovery. Lydia describes what happened when she told her mother she was struggling with an eating disorder:

Lydia: [...] *C’est sûr, c’est sûr, sûr que je suis assez [seule]. Ma mère est au courant, mais on en parle pas vraiment. (Sarah : Pis elle t’offre pas un soutien en particulier par rapport à ça ?) Non, parce qu’elle saurait même pas quoi faire.*

Vanessa shares a similar situation:

Vanessa : *Ouais mais mes parents c’est beaucoup : « On en parle pas.» Dans l’évitement, tsé? C’est comme ma dernière rechute j’étais comme rendu en train de mourir là tellement que mon poids était bas, mais mes parents ils m’en parlaient pas.*

Finally, for some participants the eating disorder was kept secret from parents (specifically) for fear that they would not understand or worry too much. Jason explains why he hasn’t told his parents about having an eating disorder:

Jason: Yeah, and I don’t think there would be any benefit for me to [tell my parents about the eating disorder] because there would be just another uncomfortable conversation where they just don’t know what to say. They love me, they’d do anything for me. I know that. But, you’re right, I don’t think they could process something like or add any type of benefit.

Lili shares a similar hesitancy to tell her parents about the eating disorder, she says: « *mais que c’est débordé sur l’orthorexie – non, ça elle ne le sait pas. Puis je ne pense pas leur dire. Ben de un : je pense qu’ils deviendraient sans connaissance, ils s’inquièteraient* » (Lili).

For others, stereotypes around eating disorders and why people develop them was a barrier to telling family:

Sophie : *Ma mère je lui en parle pas parce que; ben j'en ai un peu parlé d'alimentation intuitive sans dire, j'ai jamais parlé de crises à ma mère. Mon père non plus parce que je pense qu'ils ne comprendraient juste pas. Pour eux ce n'est que de la gourmandise et du manque de volonté donc... Pis vu qu'ils sont vraiment contrôlants envers nous et envers eux; ils comprennent pas ça.*

As Stevenson explains “eating disorders are cloaked in the three S’s: shame, secrecy, and silence” (Stevenson, 2014 cited in Leblanc et al., 2014, p. 28). The three S’s are often rooted in the stigmatization and disinformation surrounding eating disorders and contribute to the social isolation that is an integral part of these disorders. For those participants who talked about their eating disorder with loved-ones, a generalized lack of knowledge about eating disorders and the ways in which to be supportive of recovery was a difficulty encountered in the recovery process.

Social work has been identified in the eating disorder literature as having a role to play with family members through family therapy, which is focused on “understanding the role of family in the cause and treatment of eating disorders” (Shekter-Wolfson et al., 1997, p. 7) however this type of therapy tends to be applied to adolescents and young women (Shekter-Wolfson et al., 1997) who are often living with their biological families. The role social workers might play to support and inform romantic partners, friends, extended family etc. has not been explored in the context of long-term recovery of adults living with an eating disorder.

4.8 Experiences with Social Workers

One of this study’s practical orientations was to explore the role social workers can or do play in the recovery process from an eating disorder, based on the lived experiences of individuals who know the reality of eating disorder recovery in the community best. Interestingly, for more than half of the individuals in this study, a social worker played a role in their recovery process from an eating disorder. Participant’s recovery trajectories were quite diverse, which put them into contact with social workers and community workers (“intervenants-es sociaux-es” or social work technicians) in many different contexts: community organizations, community clinics (CLSC, CIUSS), Family Medicine Groups, hospitals, schools, etc. Based on elements of the previous two sections (“barriers to recovery” and “what worked”)

interactions with social and community workers have been divided into three types of experience: **interactions that had a positive impact on recovery, interactions that had a negative impact on recovery, or interactions that had no effect on recovery.**

4.8.1 Positive Impact on Recovery

Social workers who were knowledgeable about eating disorders, who had a strong relationship with the participant, or who supported them in resolving underlying causes of the eating disorder, were viewed as having a positive impact on recovery. Lydia's description of a social worker from a CLCS illustrates this type of experience. She describes the social worker as « *un homme fabuleux* » (Lydia) who supported her during some difficult personal and family circumstances. Even though he was not specialized in eating disorders, and eating/body issues were not the reason for consulting the social worker, she explains that « *...avec [l'intervenant], [l'intervenant] y m'a fait beaucoup avancé, beaucoup évoluer dans l'acceptation. [...]* » (Lydia).

Lydia : *[L'intervenant], j'y en avais parlé [du trouble alimentaire], mais [l'intervenant] il était, je pense qu'il était connaissant un peu de ça parce qu'il y a un [membre de sa famille] je pense qui avait un trouble aussi. Fait que c'est sûr que lui était plus, comme tu dis ouvert. [...]*

Similarly, many of the participants noted that “helpful” professionals had some knowledge of eating disorders, which enabled them to navigate some of the particularities related to eating and body issues. Chloe describes how a community worker listened and created a safe and trusting environment that was helpful in her recovery process:

Chloe : *[...]Elle est présente, elle est à l'écoute est comme... Ah, elle est, je pense que, pourquoi que moi aussi le rétablissement a commencé directement la première journée que je suis venue [à l'organisme communautaire], c'est peut-être en partie aussi à cause de [l'intervenante], je me suis sentie en confiance. Ça c'est la base. Pis je pouvais parler, je pouvais m'exprimer, pis... ouais. Ah oui, [l'intervenante] là. Ouais, c'est une perle.*

Chloe's description illustrates an essential social work skill: « *être capable de créer une espace de parole et d'ouverture qui favorise l'expression de la réalité singulière des acteurs* » (OTSTCFQ, 2012, p. 18). The participants who had positive experiences with social workers expressed feeling listened to, respected, cared for and accepted; all of which are related to the “...the core values of social work – self-determination, individuality, and respect for the person” (McCormick, 2008, p. 312). The *référenciel de*

compétences des travailleuses sociales et des travailleurs sociaux (2012) emphasizes this social work skill set, stating that creating and maintaining respectful relationships with individuals that take into account « *la diversité et la singularité de la réalité des acteurs* » (OTSTCFQ, 2012, p. 18), and perceiving the individual as « *expert de sa situation* » (OTSTCFQ, 2012, p. 18) are essential in intervention. These skills are also in-line with what Davidson et al. (2009) describe as “recovery-oriented practice” (Davidson et al., 2009), asserting that “recovery-oriented practitioners” “place as much, or possibly even more, emphasis on their clients’ personal narratives and goals as they do on their client’s symptoms, deficits, and diagnosis” (Davidson et al., 2009, p. 22) in their interventions. As the field of eating disorders is shaped by “mainstream medical discourses [that] have served to reinforce cultural ideals of self-management by focusing on fitness and weight preoccupation to control the body and by representing women with eating disorders as out of, and in need of control” (Brown et al., 2008, p. 103; Gremillion, 2003), social workers focus on autonomy and their professional sensitivity to « *les rapports d’inégalité et de pouvoir, les situations d’injustice, les conditions d’oppression et de discrimination* » (OTSTCFQ, 2012, p. 19) provide a unique professional tool kit that can be applied to the recovery process from an eating disorder.

As identified in the “what worked” section, some social and community workers acted as positive role models in participant’s recovery processes, especially within a group context. For both Megan and Jennifer, community workers who modelled self-acceptance and body positivity contributed to the experience of “a ‘mini-community’, where women may be able to examine and recreate their relationships with others, food and their body” (Black, 2003, p. 138). Megan’s description of the community workers at the eating disorder organization where she received service illustrates this point:

Megan: *[...] Mon dieu, je pense que tout ce que t’as besoin c’est comme de, d’un être humain qui t’écoute pis, moi ce que j’ai beaucoup aimé des intervenantes à [l’organisme communautaire] c’est que, y’étaient quand même authentiques dans leur genre, c’est pas... personne est un humain parfait pis elles aussi y’ont des défauts pis y’ont des préoccupations même par rapport à leur image corporelle. [...] c’était quand même des jeunes femmes aussi, dans la trentaine peut-être là, mais c’était pas très loin de ma réalité faque ça pouvait être un exemple, tsé? Quelque chose vers lequel je m’en allais.*

Megan’s description of how the community workers listened to her, and modelled body acceptance in a realistic way, touches on elements of both recovery-oriented practice, social work practice, and feminist

approaches to eating disorders. Firstly, Davidson et al. (2009) and the *Référenciel des compétences*, emphasize the importance of really listening to people, as they are “the experts in defining their own needs, wants, and preferences” (Davidson et al., 2009, p. 20; OTSTCFQ, 2012). Davidson et al. (2009) assert that “it is certainly not a revolutionary idea that practitioners need to listen, or that they should be trained to listen in a disciplined and respectful way” (Davidson et al., 2009, p. 18). However, much of how mental health care has been conceived and delivered, especially in clinical settings (such as hospital treatment programs for eating disorders), is focused on “the disorder, deficit and disability” (Davidson et al., 2009, p. 14) which in the case of eating disorders are: food, weight, and disordered eating behaviors (Arnaiz, 2009; Black, 2003; Gremillion, 2002; Leblanc et al., 2014; Simblett, 2013).

Secondly, Megan’s perception that the community workers were “not far from her reality” (Megan), speaks to the shared social context that they both live in. A feminist approach to eating disorders considers that, “workers are also individuals living in society. Therefore, it is reasonable to assume that we carry with us many of the social norms and prejudices about weight” (Black, 2000, p. 91; Daly, 2016; Gremillion, 2002; Leblanc et al., 2014). Thus, the effects of the sociocultural context become part of the intervention, both in how the worker perceives and uses their body (Black, 2000; Daly, 2016; Orbach, 2004) and how they incorporate “gender, social and political issues” (Black, 2000, p. 8) into their approach to eating disorders.

As participants had contact with a variety of professionals in their recovery processes, some were able to identify the particularities of a social work approach to eating disorders:

Vanessa : *Mais c’est ça je te dirais c’est beaucoup plus, beaucoup plus les liens avec justement ton réseau social pis... Ouais. [...] Ta famille ouais, c’est ça, ta communauté, les ressources pis tout ça c’était beaucoup plus, c’est ça, centré sur ça; alors que mettons le psychologue était plus mettons sur l’approche TCC [thérapie cognitivo- comportementale] tsé, ils faisaient des exercices au niveau de l’approche TCC, faque c’était différent comme ça je te dirais.*

As the short review of social work literature exposed, work with families has been identified as an effective social work practice related to eating disorders, though much of that research is focused on young women living with anorexia in clinical settings (Shekter-Wolfson et al., 1997). Work with community and peers in relation to eating disorders remains under-researched outside of feminist social

work literature, but as Vanessa alludes to, community and peers are at the core of social work practice and can be included in social work interventions for a person with an eating disorder. She explains:

Vanessa : *Ben sa serait d'inclure ce qui fonctionne, tsé? Pas nécessairement les parents, des fois on focus beaucoup, on va faire une rencontre familiale, mais des fois c'est...des fois c'est pas une rencontre familiale; t'as besoin d'une rencontre d'amis ou une rencontre de... Comme inclure dans les soins ce qui fonctionne avec la personne, tsé? C'est ça. C'est pas nécessairement la famille, même si la personne elle habite avec ses parents. C'est peut-être pas nécessairement faire une rencontre avec la famille. [...]*

Many of the participants explained that as adults recovering from an eating disorder their support networks were varied and extended beyond biological family members. For the participants whose loved one received support in their role, the experience was viewed as both positive and helpful. Chloe explains:

Chloe : *“ Ben mon chum, sur coup ça j'en y ai pas parlé, mais par après, je lui en ai parlé [de mon trouble alimentaire]. Pis, il a été ouvert, il a été - même il est venu rencontrer [l'intervenante à l'organisme communautaire] aussi pis tout ça. [...]*

Vanessa's desire to have her support network considered as part of her recovery team and supported in their role, is in fact a social work competence: being able to situate the person in their personal, community and social context in the intervention process and mobilising personal and environmental resources in a given situation (OTSTCFQ, 2012, p. 18). This skill is also of central importance in recovery-oriented practice, as “having supportive others, whether they are family members, professionals, community members, peers, or animals, to provide encouragement through the difficult times and to help celebrate the good has been noted as being critical to recovery” (Davidson et al., 2009, p. 43).

Social and community workers within eating disorder community organizations were identified by most participants as having a positive impact on recovery, as both the organizations and staff were specialized in eating disorders, and well informed with regards to the recovery process. The social and community workers within these organizations were sometimes the first contact participants had with a knowledgeable professional, especially in the case of binge-eating disorder, sub-clinical and emergent disorders. Other social work professionals who listened, invested in the relationship with the participant and did not judge them (or their bodies) were also viewed as helpful. Finally, in all the positive

experiences with social workers, some knowledge of body image or eating issues was identified as important by research participants.

4.8.2 Negative Impact on Recovery

Overwhelmingly, participant's accounts of interventions having a negative impact on their recoveries were related to social workers lack of knowledge about eating disorders, or their potential role in the recovery process. By far the most common experience was of being referred to another professional, generally a psychologist. Megan explains:

Megan: *[...] Quand j'étais au secondaire je me suis faite rattraper comme par la travailleuse sociale parce que j'étais allée consulter l'infirmière parce que je voulais avoir des médicaments pour manger moins. Ouais. Faque là elle m'a référé à la travailleuse sociale, faque j'ai été dans un bureau de psychologue qui s'y connaissait rien du tout, faque ça allait vraiment pas bien. Mais j'ai pas été rattrapé à ce moment-là, faque j'ai fini mon secondaire comme ça; à fin de mon secondaire j'ai pas eu d'autre suivi parce que j'en voulais pas, ça allait ben mes affaires [dans le trouble alimentaire].*

Being referred to a professional who was also not knowledgeable about eating disorders had a negative effect on Megan's recovery and illustrates the common misconception that all psychologists are trained to deal with eating disorders. Megan also explains that she perceived the social worker as "following protocol" by referring her to another professional:

Megan: *Mais elle je pense que [la travailleuse sociale] l'avait bien identifié la, [le trouble alimentaire] pis je pense que c'est juste dans leur continuum de services ça allait avec la psychologue, mais ouais je pense que c'est ça, ça été une mauvaise identification de la problématique par la psychologue.*

As with other health care providers who were inadequately trained to identify eating disorders, Megan's psychologist focused on another issue (performance anxiety) (Leblanc et al., 2014; Maier, 2015) and no follow-up was done. Cynthia lived a similar experience with a social worker in a Family Medicine Group where she sought services for binge-eating disorder:

Cynthia: *[...] je suis pas sûr que [la travailleuse sociale] avait déjà vu [les troubles alimentaires] beaucoup, avant. Parce qu'elle me parlait plus de mon anxiété, puis de mes autres choses...que ça. [...] Ouin. Pis elle...ça pressait pour que j'aïlle voir un psychologue pis que ça...pitcher [sic] ça à quelqu'un d'autre, mettons.*

Cynthia saw the social worker 2 or 3 times then: « *Pis là j'étais sur les listes d'attentes pour les psychologues, pis psychiatres, pour aller me faire diagnostiquer, pis en tout cas. Pis après ça, ça s'est mis à débouler* » (Cynthia). As mentioned earlier, Cynthia's formal diagnosis did not help her gain access to treatment or services for her eating disorder. She was told she did not fit the eating disorder program's criteria and was referred to an obesity clinic. In her trajectory, the only services specific to binge-eating disorder she accessed were offered by a community organization.

In her interview, Vanessa identifies some of inter-professional tensions that exist with regards to eating disorders, how they are "treated", and by who:

Vanessa : [...] *Tsé pis après ça revient à nos spécialités, tsé? Est-ce que, est-ce que le psychologue est mieux, est meilleur dans la prise en charge des troubles alimentaires qu'une travailleuse sociale ou qu'une infirmière? Moi je pense que chaque spécialité, on a, justement on a toutes nos champs d'expertise pis, je veux dire les travailleuses sociales, ben on faisait des rencontres familiales avec les travailleuses sociales, on faisait pas ça avec les psychologues [à l'hôpital].*

As The Standing Committee on the Status of Women stated in their report, "individuals need a multidisciplinary team to assist in their recovery" (Leblanc et al., 2014, p. 34) from an eating disorder, though currently most specialized eating disorder care in Canada occurs in hospitals, where treatment focus is on acute cases of anorexia and bulimia (Leblanc et al., 2014). As feminist researchers have identified, the biomedical treatment model is dominant in formal eating disorders services (Black, 2003; Brown et al., 2008; Gremillion, 2005; Malson, 2003; Vinette, 2001; Wilson, 2004) thus "the focus of such intervention has been to treat the eating 'behavior' thereby viewing the eating issue in terms of individual psychopathology" (Black, 2003, p. 127). For this reason, many social workers may feel ill equipped to intervene when an eating issue is identified. However, individuals with mild and moderate eating disorders, binge-eating disorder, emergent and sub-clinical eating disorders, are often seeking recovery-supportive services in the community (Hart et al., 2011; Leblanc et al., 2014; Public Health Agency of Canada, 2002), and are likely to come into contact with social and community workers.

4.8.3 No impact on Recovery:

Finally, for some participants contact with a social or community worker had little or no impact on the recovery process. The most common reason cited was that the eating disorder was simply not identified. However, for some participants the social worker's body played a role how their intervention was perceived and, ultimately, discredited. Cassie explains:

Cassie : *Pis avec la travailleuse sociale [de l'université], là on avait parlé un peu plus là au niveau alimentaire pis toute ça pis je pense la, peut-être manger les émotions pis des choses comme ça... (Sarah : Est-ce qu'elle était sensibilisée au trouble alimentaires ou...) Oui sûrement, mais c'est sûr que c'était pas comme aujourd'hui là tsé. ... là on parle de [il y a plusieurs années][...]*

Cassie : *[...] Pis c'est peut-être là aussi la travailleuse sociale, pour essayer de travailler le côté psychologique et puis, mais c'est naïeux mais, la travailleuse sociale elle avait un excès de poids, pis je me sens un petit peu mal à l'aise parce que je veux pas que tu...mais... (Sarah : Pas de jugement, vas-y.) Je trouvais ça difficile, pas d'accepter les conseils mais de, c'est comme si je me disais : « Elle l'a pas réglé son problème, comment qu'a peut m'aider à réparer le mien. »*

Cassie's description of how her social worker's body played a role in their interactions is common in interventions with individuals who have experienced an eating disorder (Black, 2000; Daly, 2016; Orbach, 2004). Clinical social worker Suzanne B. Daly (2016) affirms that "the unconscious experiences of both the client's and the therapist's bodies are influenced by the socio-culturally defined ways that each participant has learned to evaluate body appearance and, in turn, contributes to the intersubjective relating in the room" (Daly, 2016, p. 52). Daly notes that "the practice of comparison is typically even more pronounced for women suffering from eating disorders because they often overvalue appearance and the physical body to interpret the world; thus they are likely hyperaware of the treatment provider's appearance" (Daly, 2016, p. 48). The tendency to evaluate bodies is also clear in Jennifer's comments about a community worker who she perceived as a role model:

Jennifer : *[...] Elle avait tellement l'air bien dans sa peau pis non, elle était pas parfaite, tsé? Mais à la limite je me suis dit : « Cibole, me semble que.. » Je sais pas comment dire : « Quand t'es pas si loin de la perfection on dirait que ça...t'a veut plus. » Quand t'as un couple de défauts ou de..., ben de défauts même à ça, c'est par rapport à ce que la société en dit là. [...] Tu dis : « Bon, ça je l'aurai pas faque... » Pis c'est ça là, le genre d'obsession de l'image. C'est pas de quoi d'agréable, c'est pas de quoi de beau, c'est pas de quoi, en tout cas. C'est tellement superficiel pis c'est ça, moi je me considère quand même pas comme une fille superficielle, pis là ça c'était, c'est ça là. Faque je trouvais c'était hors caractère.[...]*

What is also clear is how the community worker's ability to "feel good in her own skin" (Jennifer) troubled Jennifer's overvaluation of appearance and caused her to reflect on her values and perception of herself. Both participant's experiences with the "transitional body space" (Daly, 2016, p. 51) that can exist between individual and professional speak to the awareness and inner solidity that social workers must develop to work effectively with people who are experiencing an eating disorder.

Daly asserts that being able to use the body in intervention "in a culture that promotes body insecurity, however, is not an easy task for female clinicians" (Daly, 2016, p. 51) specifically, as they are exposed to the same social pressures and barrage of stereotyped images as their "clients" (Daly, 2016, p. 51). She warns that professionals who have not "worked through her own issues around eating and the body" (Daly, 2016, p. 55) may not feel comfortable when their own body is brought into the intervention (which is likely), and can derail an intervention even when the social worker is knowledgeable about eating disorders.

4.8.4 Advice for Social Workers

As a response to the absence of lived experiences of people recovering from an eating disorder in the literature on this topic, each participant was asked to offer advice to social workers who might encounter a person living an eating disorder. Involving the participants directly in the study's goal to produce "useful knowledge for change" (Hesse-Biber, 2014b), was a way to implement a feminist approach to research, in the spirit of a recovery approach to eating disorders (Davidson et al., 2009; Hesse-Biber, 2014a). The participants' answers to this question provide some insight into what community members need from social workers in the recovery process.

Listen

Firstly, several participants emphasized that really listening was one of the most important things a social worker could offer someone recovering from an eating disorder, even if they are not specialised in this area: « *Peut-être juste une bonne écoute. Une bonne écoute. Poser les bonnes questions* » (Cynthia).

Megan : *Ben je pense que tout ça, pis ça je l'ai retrouvé chez toutes les intervenantes sociales : ça prend l'écoute, tsé? Juste, être capable d'écouter. Ben je pense que la gaffe que les intervenants social, que les psychologues y font mettons [dans ma région] c'est justement leur dire : « Ben moi je connais rien là-dedans. » Tsé? Se faire dire « Ah ben je peux pas t'aider.» Ça je pense c'est une attitude à éviter plutôt là. Mais ouin, juste démontrer de l'écoute... [...]*

Secondly, participants indicated that **learning about eating disorders** was necessary to provide further support in recovery. As Cythia asserts « *s'informer, de un : c'est quoi, avant de parler avec quelqu'un qui a un trouble comme ça, ou quoi que ce soit parce que si tu ne sais pas c'est quoi...ça donne quoi?* » (Cynthia).

The notion that learning about eating disorders went beyond being able to identify symptoms was also mentioned by participants. As Jennifer and many other participants expressed, myths about eating disorders are so prevalent (Leblanc et al., 2014) that it is important for social workers to understand eating disordered behavior is not about vanity or appearances.

Jennifer : *Parce que justement tu te dis ben : « Mangé ça parait tellement simple. » Mais, c'est tellement plus possible quand t'es vraiment dans le milieu de...Faque non, ce serait ça là, dans le fond l'aspect éducatif de, peut-être les inviter [les travailleuses sociales et les travailleurs sociaux] à une genre de cohorte ou je sais pas quoi pour observer c'est quoi les gens ont à dire pis c'est quoi y vivent là. [...]*

Megan : *Je pense d'être capable de reconnaître que c'est plus que juste de l'image corporelle aussi. Tsé? Moi c'était toutes mes mécanismes de défense c'était ça dans mon expérience. Moi, j'ai jamais vraiment voulu être mince là. L'image corporelle oui y'avait quelque chose, mais c'était pas là - j'ai pas faite un régime pour être belle. [...]*

Don't judge

As noted in previous sections, shame, secrecy and stigma are experienced by many people living with or recovering from an eating disorder (Black, 2003; Gremillion, 2003; Leblanc et al., 2014). Thus, many participants expressed that an attitude of non-judgement was very important for social workers to have with regards to eating disorders.

Jennifer : *Ben, pas trop juger je dirais. Ouais, pas trop juger juste aider, ce serait déjà pas pire, parce que comme je dis il y a une grosse partie, en tout cas pour moi, mais je pense pour pas mal toute les, ceux qui en souffrent, que c'est honteux parce que tu te dis : « Je m'emmène ça moi-même » [...]*

An attitude of non-judgement with regards to weight, was also stressed by many participants who had experienced stigmatisation of fat in their recoveries. Sophie underlines the importance of challenging the dominant cultural beliefs around fat to be genuinely supportive of individuals whose eating disorder manifests in weight gain.

Sophie : *D’être compatissant avec soi. Je pense que, à la base, ces travailleurs sociaux là devraient... comprendre, ben casser leur propre jugement pour se mettre à la place de la personne que non, elle est pas paresseuse, manque de volonté, gourmande... pour qui puissent le dire aussi à la personne.... mais faut être convaincu, pour pouvoir soutenir quelqu’un là-dedans. [...] D’être compatissant envers les gens le plus possible. Pis que c’est pas juste l’anorexie qui existe là.*

Sophie also underlines the need for social workers to know about binge-eating disorder, sub-clinical and emergent eating disorders, as they represent the most common disorders identified in community settings (Hudson et al., 2007; Public Health Agency of Canada, 2002). Many of the participants identified barriers to recovery that were related to the invisibility or stigmatization of their eating disorder by professionals who were not well informed. Laurie also urges social workers to learn about all types of eating disorders to better intervene: « [connaître l’hyperphagie] et l’orthorexie. Tu ne peux pas aider quelqu’un si tu ne connais pas ça » (Laurie). As few services exist for binge-eating disorder, emergent and sub-clinical eating disorders, it is likely that individuals living these disorders will seek help in the community. Social workers who are well informed are better equipped to identify and support this group of individuals.

Know your limits, and the eating disorder resources in your community

In cases where a social worker is not informed about eating disorders and is unsure of what to do, many participants suggested **not to express powerlessness in front of the person**. As Megan shared, hearing : « Ah ben je peux pas t’aider » from a professional can be devastating, especially if the person has no other resources. Anne also emphasizes this point :

Anne: *Ben un de pas dire que t’es dépourvu. Un, le verbalise pas devant le patient ou la patiente parce que ça te fait vraiment sentir là que « Ah ben, meurt avec ton trouble là. » C’est extrême mais... [...]*

Instead, participants suggested using professional resources (other specialists, community organizations, etc.) to better support the person, whilst respecting personal and professional limits.

Megan : [...] *être capable de reconnaître ses limites parce que ça se peut qu'il y en a, mais y'a des services aussi pour les professionnels là. C'est ça reconnaître ses limites, être capable de profiter des services qui sont offerts aussi pour aider à accompagner.*

Being aware of eating disorder resources available in the community was also identified as a way to better support individuals in recovery. As eating disorders are complex biopsychosocial disorders, many types of professionals are necessary in the recovery process (American Psychiatric Association, 2018; Government of Canada, 2006; Leblanc et al., 2014; Public Health Agency of Canada, 2002). Jason emphasizes that social workers don't have to do the work alone:

Jason: Accessibility, I think too really, right? I mean social workers too, I mean they're big on: "Ok well, you need help, more than I can give you, or at the same time." You know: "In parallel go to the [community organization specialized in eating disorders]." I mean just to have those tools, to have that information, the [community organizations] of the world, you know. Yeah, I just...accessibility with some basic, structural, tangible tools.

The ability to identify resources in the community, collaborate with partners and « *être capable d'utiliser le rôle, les valeurs et les habilités spécifiques au travail social en relation avec celles des disciplines connexes* » (OTSTCFQ, 2012, p. 20) are social work's strengths, which could be particularly relevant to eating disorder recovery. Knowing the limits of one's professional role with regards to eating issues is essential to avoid "professional drift" (Dean & Rowan, 2014, p. 226), and ensure the appropriateness of the intervention. As Megan shared in an earlier excerpt, when professionals engage in interventions that are not within the bounds of their profession (psychologist asking her to do food journal), the effects can do more harm than good.

Create Trust and Explore Underlying Eating Disorder Causes

As eating disorders are often linked to complex underlying causes (Black, 2000; Daly, 2016; Gremillion, 2003; Mitchison et al., 2016; Petrucelli, 2016; Public Health Agency of Canada, 2002), an important part of the recovery process is to explore those issues in a safe space. Thus, participants noted that creating trust and a space to explore painful issues is essential. Chloe explains:

Chloe : *Oui parce que, si t'es pas en confiance, tu t'exprimes pas. Faque c'est peut-être à la travailleuse sociale d'échanger avec pis de te faire des liens avec les possibilités probablement là. Je fais ça là pis, c'est parce que tu peux reculer loin, loin, loin. [...] Faque c'est peut-être de la faire parler sur, comment je pourrais dire... C'est ça, en créant le lien de confiance, en la laissant parler sur elle, sur son vécu, les choses difficiles qu'elle a vécus probablement. Raconter une histoire peut-être là, comme je fais depuis toute à l'heure.*

Chloe is effectively describing part of the social intervention process: « être capable de créer un espace de parole et d'ouverture qui favorise l'expression de la réalité singulière des acteurs, en la situant dans son contexte personnel, communautaire et sociale » (OTSTCFQ, 2012, p. 18). In addition, as Chloe suggests, the recovery process sometimes involves going way, way, back to explore old wounds. This process requires both trust and time. As many studies have shown, individuals living with eating disorders benefit greatly from long term support from professionals (Black, 2003; Leblanc et al., 2014) as the recovery process is ongoing and complex (Davidson et al., 2009; Provencher, 2002).

Emotions are important

Participants in this study highlighted the important role of emotions in both the development and recovery from an eating disorder. Megan emphasizes that social workers need to create a space where difficult or repressed emotions can be expressed:

Megan : *D'autres attitudes aidantes? Je pense qu'il faut être capable de gérer les émotions aussi, être capable de les accueillir, pis même quand y'a pas d'émotion. Il y a des gens pour qui le trouble va aider à represser, je t'apprends rien... C'est d'être capable même d'aller essayer de les chercher ces émotions-là quand la personne ne se les rends pas accessible elle-même là, ouin. [...]*

As Petrucelli asserts « understanding the function of eating disorders in creating dissociative states and the function of dissociation in creating eating disorder symptoms is vital to treatment” (Petrucelli, 2016, p. 20). The reasons individuals create these “dissociative states” through restriction, bingeing and purging are multiple: “trauma history, intense emotions too difficult to process, cultural imperatives, unrealistic emotional or physical expectations, the overvaluation of extreme thinness and the devaluation of internal beauty” (Petrucelli, 2016, p. 19), etc. Many of these issues can be explored with a social worker, if the professional has a good understanding of how to address them. Speaking from experience,

Vanessa states: « *Ben, que même les travailleurs sociaux peuvent prendre en charge les personnes qui ont des troubles alimentaires. Ils ont pas besoin nécessairement d'un psychologue* » (Vanessa).

Offer Support to Support People

As Vanessa stated in an earlier section, her advice to social workers is to widen the circle of people who can receive support in their role. Social work literature has yet to address this potential area of social worker practice related to eating disorders, however as Dean and Rowan (2014) assert social workers are already “expert[s] in enhancing social functioning” (Dean & Rowan, 2014, p. 219) which by definition goes beyond family relationships. In the recovery process, “social worker’s focus on how the environment and other influences may affect a person’s overall health” (Dean & Rowan, 2014, p. 222) is an integral part of the professional skill set that could be applied to the issue of eating disorders. This role may be all the more important when supporting adults who are older than the 18-24 year old demographic typically studied in eating disorder research. As the mean age of this sample is 41 years old, and participants unanimously defined the recovery process from an eating disorder as “just a really long process” (Jason), social work may have a role to play outside the acute phase of these disorders, in the long-term work of recovery. As many of the participants stated, their loved ones play an important role in this process, but often needed education and social support to guide them in their role.

Finally, some participants wished to transmit to social workers a simple message: “you can do it”. As Anne explains, eating disorders are symptoms of underlying issues that social workers are already equipped to deal with:

Anne : *[...] si t'es capable d'accompagner une personne qui vit une difficulté, justement c'est ça. T'es en situation de violence peu importe là, mais t'es capable d'accompagner ça parce que ça cache tellement de choses psychologiques en arrière de ça. Pour moi c'était de l'anxiété, c'était de l'anxiété pis là je voyais mes parents qui venaient de se séparer, mon père allait pas bien; je me retrouvais comme tout seule à l'aider, j'avais tellement de stress là, j'étais toute seule là tout le temps, pis j'étais isolée faque, c'est apparu de même là. [...]*

Many of the participants in this study indicated that the resolution of underlying causes of the eating disorder was helpful in recovery. This finding is similar to Mitchison et al's (2016) study which concluded that “perceived impairment of quality of life is viewed as having triggered the onset of eating disorder symptoms, later perceived improvement in quality of life is viewed as central to eating disorder

recovery” (Mitchison et al., 2016, p. 13). The areas of quality of life that triggered disordered eating in Mitchison et al.’s study were varied and related to all spheres of life (work, relationships, physical health, leisure, etc.), which makes social workers who are “trained generalists” (Dean & Rowan, 2014, p. 222) well positioned to provide support. Petrucelli (2016) proposes the following description of social worker’s role when working with a person recovering from an eating disorder:

We engage [individuals living with eating disorders] in developing alternative adaptive skills to assist them in the physical, psychological, and interpersonal/relational changes necessary for health. Forming new relationships, be it with food, substance, people and their own bodies, takes courage, mindfulness, vulnerability, forgiveness, and moving beyond blame. It requires developing compassion, a presence of being, a belief in the possibility of possibilities, and tolerating the risks of uncertainty and the uncomfortable emotional and physical states that follow. (Petrucelli, 2016, p. 23)

This description can be applied to any issue a social worker might encounter in their practice. As such, eating disorders could be considered as part of the « *ensemble de situations professionnelles, allant du simple au complexe* » (Le Boterf, 2002 cited in OTSTCFQ, 2012, p. 5) that social workers are trained to deal with. As eating disorders are complex and require interdisciplinarity, they necessitate the « *professionnel compétent [qui] est en mesure de combiner ces multiples savoirs dans un savoir agir global qui les confère la capacité de les intégrer dans une situation professionnelle qui demande une certaine dose d’autonomie* » (OTSTCFQ, 2012, p. 5). However, eating disorders remain in the realm of the biomedical, specifically within the professions of psychiatry and psychology, a fact some participants were very aware of.

Vanessa : [...] *mais c’est pas parce que t’es TS que tu peux pas prendre un cas de trouble alimentaire c’est pas réservé au psychologue pis au psychiatre là je veux dire. Tsé? T’es capable là, pis tu peux être très aidant là. [...]*

Many of the participants perceived that social workers could play an important role in the recovery process from an eating disorder, but they were also aware that current public health treatments for eating disorders are highly medicalized and often do not include social workers. The Standing Committee on the Status of Women noted that Canada’s current focus on acute care for eating disorders “places an undue burden on hospitals, when community treatment programs can be very effective for many patients” (Leblanc et al., 2014, p. 45), in particular “individuals with mild and moderate cases of eating disorders” (Leblanc et al., 2014, p. 45). For the participants in this study, eating disorder community

organizations were perceived as helpful, as they offered services and activities that were supportive of recovery: knowledgeable professionals, accessible services, focus on underlying eating disorder issues, nutritional support, group work, opportunities to “give back”, etc. Many of their experiences with social and community workers were related to these organizations, who appear to be offering “alternative treatment models that reduce focus on core symptoms of eating disorders” (Mitchison et al., 2016, p. 11) in favor of “improving quality of life outside of the eating disorder” (Mitchison et al., 2016, p. 12), in addition to providing group and nutritional support.

4.9 Discussion

The purpose of this exploratory research was to investigate the lived experiences of individuals recovering from an eating disorder, in Quebec community context. In the existing literature on the subject, the concept of recovery has been applied to serious mental health problems (Davidson et al., 2009; Deegan, 1996; Provencher, 2002; Young & Ensing, 1999), but not to eating disorders specifically. The recovery perspective places the individual and their environment at the center of the recovery process, shifting the focus of intervention from symptoms to the individual who is experiencing them (Davidson et al., 2009; Provencher, 2002), their values, aspirations, strengths, limitations, relationships and unique life trajectory (Deegan, 1996). Eating disorders are considered a mental health issue, as evidenced by their inclusion in the DSM, though the manual itself states that eating disorders are complex biopsychosocial disorders that require a multidisciplinary response (American Psychiatric Association, 2017). However, the reality of eating disorder treatment models in Canada and beyond, is that the biomedical approach dominates how these disorders are conceived and treated (Black, 2003; Gremillion, 2002, 2003; Leblanc et al., 2014; Malson, 2003). As such, focus on symptoms (Gremillion, 2002; Leblanc et al., 2014) and the construction of eating disorders as an individual pathology (Black, 2003) inform hospital based treatment programs that, in Canada, appear to be designed to treat a small number of acute cases of anorexia and bulimia (Leblanc et al., 2014), despite the fact that these disorders are not the most prevalent in the population (Hudson et al., 2007). Thus, the in-depth interviews conducted with this small but diverse sample of participants have shed light on the reality of eating

disorder recovery, which has been effectively “hidden from mainstream knowledge building” (Hesse-Biber, 2014b, p. 228) and the data collected has contributed to the deepening and verifying of a recovery approach, applied to the issue of eating disorders (Quinn Patton, 2015, p. 289).

Firstly, the research participants’ definitions of the recovery process from an eating disorder are significant, both because the descriptions of recovery are based on lived experience, and because this topic has yet to be explored in either the eating disorder or recovery literature. Though the sample size of this study was small, there was a great deal of diversity among the participants in terms of eating disorder, age, ethnicity, number of years of living with an eating disorder and recovery trajectory. Despite this diversity, definitions of the recovery process had many common themes: the ongoing and long-term nature of recovery, the importance of self-acceptance and self-care in the recovery process, the perception of eating disorder symptoms in both recovery and relapse, and the process of adapting to the “new reality” of recovery.

In fact, the dominant view that a person is “cured” of an eating disorder when symptoms subside, and weight is stabilized (Arnaiz, 2009; Gremillion, 2002; Leblanc et al., 2014) was refuted by the participants in this study, many of whom still experience eating disorder symptoms (though much less frequently) and perceive relapse as indissociable from recovery. Instead, recovery definitions centered on accepting limits and set-backs, self-compassion and self-care, symptom management, quality of life, and a sense of personal freedom. Many of the participants emphasised the ongoing and long-term nature of this process, which is incompatible with a cure perspective of eating disorders “which defines cure as the absence of clinical symptoms” (Mitchison et al., 2016, p. 11). The research participants perceived their ability to function in different spheres of their lives (work, school, family, friends, leisure, etc.) as the measure of their recovery, whether or not symptoms remained present. The participants’ definitions of recovery were consistent with Mitchison et al.’s (2016) community based study of women who had recovered from an eating disorder, which found that “factors that participants most often mentioned as having contributed to improvement or recovery from their eating disorder were broad: increased general satisfaction in life, emotional maturation, prioritizing and improving physical health, having a supportive partner and social group, and having children” (Mitchison et al., 2016, p. 10). Many of these

factors were also identified by participants in this study, aspects of quality of life that are consistent with a recovery oriented approach to eating disorders, which supports individuals in developing a “positive sense of identity apart from one’s condition while rebuilding a life despite or within the limitations imposed by that condition” (Davidson et al., 2007 cited in Davidson et al., 2009, p. 29), especially outside the acute phases of the disorder.

As each person’s identity, challenges and quality of life are different, the recovery process from an eating disorder represents a unique path that cannot be evaluated in terms of physical benchmarks. It is a process that is unique to each person. As Deegan describes: “the goal [of recovery] is to become the unique, awesome, never to be repeated human being that we are called to be” (Deegan, 1996). This is not to say that medical interventions will not be required in the eating disorder recovery process, or that at certain times, weight, food, and obsessive thoughts will be the focus of intervention. Many of the participants in this study explained that when symptoms affected their daily functioning, they sought specialized help from a variety of professionals (community workers, doctors, kinesiologists, nurses, nutritionists, psychiatrists, psychologists, social workers, therapists, etc.) to deal with the eating disorder. However, these moments were identified as part of recovery, not as recovery itself.

Secondly, the experiences of the research participants in this study shed light on the community context where a majority of eating disorder recovery occurs (Hart et al., 2011; Mitchison et al., 2016; Public Health Agency of Canada, 2002). This context has been neglected in the eating disorder literature, as both clinical samples and university campuses represent norm in eating disorder data collection. As mentioned in the review of literature, this research has also focused disproportionately on young Caucasian women with symptoms of anorexia or bulimia (Gilbert & Thompson, 1996; Gremillion, 2002; Katsounari, 2009; McCormick, 2008; J. Slevic & Tiggemann, 2011). Thus, men, people outside the male female binary, older women, and individuals with binge-eating disorder, emergent or sub-clinical eating disorders represent the “voices of those who are marginalized” (Hesse-Biber, 2014b, p. 190) within eating disorder research, treatment and prevention.

In this study's sample, the mean age is 41 years and the diversity of eating disorders is considerable. Though some of the participants have received a formal diagnosis or have had contact with clinical eating disorder settings (eating disorder hospital in-patient and out-patient programs), a majority of participants have recovered from their eating disorder in the community, using a patchwork of services and professionals to meet their recovery needs. In fact, 50% of the participants in this sample are recovering from an eating disorder without any contact with a medical professional (with regards to their eating issue), accessing only community organizations or private sector professionals (nutritionist, psychologist, etc.) in their recovery process. As these contexts are largely absent from the eating disorder literature, many researchers have assumed that some individuals recover from an eating disorder "spontaneously" or "naturally" (Mitchison et al., 2016, p. 2). Mitchison et al. (2016) posit that "given that around 75 % of people who suffer from an eating disorder never seek treatment [12], non-treatment factors must influence such 'spontaneous recovery'" (Mitchison et al., 2016, p. 2). The current study would suggest that many individuals recovering from an eating disorder *do* receive treatment and services, but outside a limited and highly medicalized treatment model for eating disorders. As discussed in the "barriers to recovery section", many of the participants' recoveries occurred in the community out of necessity, as there were few or no specialized eating disorder services available to them.

For some participants in this study, being in an overweight or obese body greatly impacted how they were perceived by medical professionals and what treatments were offered to them. The most common reading of participants' "overweight" bodies in a medical context was obesity, the result of a deficiency in individual lifestyle habits (Rail et al., 2010). Accordingly, participants received advice about weight loss, exercise and referrals to obesity specialists and clinics instead of specialized services for eating disorders (though few such services exist in the case of binge-eating disorder, emergent and sub-clinical disorders). Hart's comprehensive review of eating disorder literature came to a similar conclusion, noting that weight loss treatment was commonly prescribed to individuals who presented an eating issue, and that more generally, "it therefore appears that there is a paradox whereby people with eating disorders have more contact with health services than other populations, yet experience a large unmet need for treatment specifically targeted at the alleviation of disordered eating and its effects" (Hart et al., 2011, p. 728). For research participants in this study, the result of being referred to an inappropriate

service was deepening of the eating disorder, a sense of isolation and shame, or the development of another type of eating disorder. As Rail (2010) suggests, participants were likely experiencing the effects of the powerful and omnipresent obesity discourse in which “obese and ‘at risk bodies’ are constructed as lazy and expensive bodies that should be submitted to disciplinary technologies (for example surveillance), expert investigation and regulation” (Rail et al., 2010, p. 260) as opposed to specialized eating disorder treatment.

Thirdly, the notion that thinness is perceived a sign of health (and that fat is not), was identified by many witnesses who presented evidence to The Standing Committee on the Status of Women as a barrier to receiving adequate treatment from first line health care providers who “are misguided in diagnosing eating disorders solely on weight or BMI” (Leblanc et al., 2014, p. 32). This discourse extends far beyond the health system, a reality that participants described in the interviews conducted in the context of the present study. Fat shaming, fat talk, judgement from others and the perception that their eating disorder “was not real” were experiences described by many participants within their families, with their peers, and in their daily lives. Consequently, the stigmatization of fat was experienced as an important barrier to recovery for some research participants in this study. As it has been established that “binge-eating disorder is the most prevalent eating disorder reported among women” (Starkman, 2016, p. 57) and that this eating disorder generally manifests itself in weight gain, the inadequate services and generalized stigmatization of fat experienced by some participants can be understood as discrimination based on both weight and gender. Weight discrimination increases the existing gendered prejudice associated with eating disorders, which are experienced majoritarily by women (American Psychiatric Association, 2018; Bordo, 2003; Government of Canada, 2006; Gremillion, 2002; Leblanc et al., 2014; Public Health Agency of Canada, 2002), though men are increasingly affected (Bunnell, 2016; Griffiths et al., 2015; Leblanc et al., 2014). The Standing Committee on the Status of Women found that “as with many mental illnesses, the reality for individuals with eating disorders, and their families, is not well understood and the disease tends to be viewed as taboo or a pseudo-illness” (Leblanc et al., 2014, p. 28) both within the health care system and in society generally (Leblanc et al., 2014). This discrimination has serious impacts on all individuals living with or recovering from an eating disorder, including the participants in this study.

Conversely, in a culture in which the “thin body is given recognition as reflecting control, virtue and goodness” (Rail et al., 2010, p. 261), especially for women (Black, 2003; Bordo, 2003; Gremillion, 2002, 2005; Rail et al., 2010; Wilson, 2004) also had a negative impact on some participants’ recoveries. Participants whose eating disorder manifested itself in bodies (both male and female) that corresponded the cultural ideal experienced pride, a sense of accomplishment, and approval from both peers and others. Giving up bodies and lifestyles that were culturally venerated in the recovery process represented a challenge for some participants. Some expressed longing for the sense of pride they experienced when their restrictive eating disorder was at its worst, a barrier to recovery that is nourished by a socio-cultural climate that “communicate[s] contradictory messages about female body and appetite by stressing the need for bodily control and obsession in a fat-phobic culture, while simultaneously encouraging over consumption and indulgence” (Daly, 2016, p. 47).

It is interesting to note that the male participant in this study also experienced this barrier, though differently than the female participants as thinness is less associated with the performance of masculinity (Bunnell, 2016; Griffiths et al., 2015). The cultural approval of the disciplined body however, applies to both sexes (Bunnell, 2016; Griffiths et al., 2015; Holmes et al., 2006). In spite of a general consensus in the eating disorder literature that sociocultural factors play a significant role in the development the disorders (American Psychiatric Association, 2018), “very few proposals are made to address the sociocultural aspects [of eating disorders]” (Arnaiz, 2009, p. 192) in treatment models. Outside formal treatment spaces, both feminist and social work approaches to eating disorders have been identified as taking socio-cultural elements into account in their interventions (Black, 2003; Daly, 2016; Malson, 2003; McCormick, 2008; Wilson, 2004), however these approaches have remained marginal in the current eating disorder context.

In a context of limited public health resources for eating disorders many participants identified the cost of private eating disorder services as “prohibitively expensive” (Leblanc et al., 2014, p. 34), and thus a barrier to recovery. The heavy financial costs associated with recovery were attributed the intensity, length and multi-disciplinary team needed to recover from an eating disorder, which is complicated by

limited (or non-existent) private health insurance and a lack of provincial health insurance coverage for mental health services (Leblanc et al., 2014, p. 34). Similarly, some participants in this study had difficulty accessing affordable services in their recoveries, often going to great lengths to find low-cost alternatives to private care; or using a combination of private professionals, eating disorder community organization services and non-eating disorders specific resources (family doctors, nurses, social workers, etc.) to meet their needs. This barrier was described by many participants even though the entirety of the sample described themselves as middle-class (upper, lower or middle-class).

Again, as individuals with binge-eating disorder, emergent or sub-clinical eating disorders are often excluded from publicly funded eating disorder treatments, the financial barriers to accessing eating disorder services were increased as these participants had fewer treatment and service options. Barriers experienced by individuals living with these disorders illustrate the structural inequalities that are at work in Canada's existing hospital-based eating disorder treatment programs, which are designed to treat acute cases of anorexia and bulimia primarily (Gremillion, 2002; Leblanc et al., 2014). Yet, the eating disorder research clearly shows that Binge-Eating Disorder, Other Specified Feeding or Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorders (UFED), which include emergent and sub-clinical eating disorders, combined represent the overwhelming majority of eating disorders in North America (Hart et al., 2011; Hudson et al., 2007; Myers & Wiman, 2014; Simblett, 2013) and these are the disorders least likely access formal treatments (Hart et al., 2011; Hudson et al., 2007; Myers & Wiman, 2014; Simblett, 2013) despite having contact with health care professionals (Hart et al., 2011). Thus it is unsurprising that research participants in this study described their "dream eating disorder services" as publicly funded eating disorder clinics or "houses", where individuals with any type of eating issue could access a multi-disciplinary team of professionals, quickly and for as long as they needed to (Anne, Chloe, Lydia, Vanessa). For others, simply increasing the existing community organization's services, or implanting them in other regions was imagined (Chloe, Cynthia, Jennifer, Megan).

Despite having identified several structural, social and personal difficulties in the recovery process, the research participants were able to find different resources to meet their needs. In most cases, a combination of services and professionals were accessed in the recovery process. The recovery

trajectories of the participants illustrate this reality, as the mean number of resources accessed was 3.8. These services were often accessed over the months and years participants recovered, a length of time that varied greatly in the sample and could not be quantified as most participants considered recovery as an ongoing process.

As discussed in an earlier section, no studies about the long-term recovery from an eating disorder were identified in the review of eating disorder literature, which makes the lived experiences of this sample all the more important. Davidson asserts “we know very little about how people learn to live with, manage, and reclaim life in the presence of the illness” (Davidson et al., 2009, p. 21), as most mental health research has been concerned with how to “get rid of the mental illness” (Davidson et al., 2009, p. 21) as a precursor to living as an active citizen. When applied to eating disorders, a recovery perspective is more interested in “helping people to live meaningful, gratifying lives despite having a psychiatric disability” (Davidson et al., 2009, p. 21), an approach that requires “different competencies which we suggest differ markedly from those involved in treating or containing mental illness” (Davidson et al., 2009, p. 21). Davidson also emphasizes that the people living with the disorder are the experts that should be consulted in an effort to understand how they “live, work, learn and participate fully in the community” (DHHS, 2005, p.1 cited in Davidson et al., 2009, p. 21) in their recoveries.

In this study of adults recovering in a Quebec community context, participants lived experiences suggest that their recoveries are neither “spontaneous” nor “natural” (Mitchison et al., 2016, p. 2); they represented a process of hard work, resourcefulness, and support from others. Participants identified several elements that were helpful in their recoveries: changes in self-perception, engaging in self-care, having quick access to affordable services when the person was ready to receive help, services that took a holistic approach to eating disorders, intuitive eating and group work. Other types of support were also emphasised, including loved-ones (partners, friends, children, biological family members) and professionals who were either knowledgeable about eating disorders or invested in them as a whole person (not as a person with an eating disorder).

Participants particularly appreciated when support was ongoing, either from their loved ones, support groups, community organizations, or professionals, as they perceived their recoveries as ongoing. In many cases, participants benefited from support groups where they could talk about their realities and be understood by others, both validating their experiences and empowering them to improve the quality of their lives. Recovery, feminist and social work researchers have all emphasized the power of the group to empower participants, while decreasing the shame, secrecy and guilt associated with eating disorders (Black, 2003; Davidson et al., 2009; Provencher, 2002; Ronel & Libman, 2003; Starkman, 2016).

The male participant in this study also benefited from many aspects of the group, though he experienced some of aspects of his group as gendered female (Jason). As men often represent the minority of eating disorder support group participants, they are likely to integrate groups that have been conceived for women instead of specialized groups for men (Bunnell, 2016). However, as Jason expressed, there were some benefits to this model, as the expression of emotions was normalized by both the female participants and community workers in the group.

Part of the holistic model of services described by participants included work on the underlying causes of the eating disorder. This work was done in groups, in community organizations, and with private sector professionals (psychologists, nutritionists, therapists, etc.). An important finding of this study is the importance of resolving the issues underlying the eating disorder in participants' recovery processes. Just as Mitchison et al. (2016) suggest in their community based study of eating disorder recovery, "quality of life conditions played a role both in the development/maintenance of symptoms (a vulnerability factor), as well as in the recovery/improvement of symptoms (a recovery factor)" (Mitchison et al., 2016, p. 5). Similarly, participants in this study described how difficult situations, social contexts, and emotions led them to develop the eating disorders as a coping mechanism, and how working on those same factors contributed to their recoveries. The aspects of the participants lives that triggered the eating disorder were both varied and multi-factorial, they included family/childhood issues, difficult emotions, body image issues, social pressure, self-esteem, trauma, identity, relationships, etc. Many of these issues were addressed as part of the eating disorder support group model offered in the 3 eating disorder community organizations through which participants were recruited. Participants also

worked through these issues with other professionals and noted a decrease in symptoms as they developed alternative tools and strategies to face these difficulties. According to Mitchison et al. (2016), alternative treatment models that reduce focus on core symptoms of eating disorders, have reported positive findings” (Mitchison et al., 2016, p. 11) a finding that would appear to be supported by the current study, though on a much smaller scale.

This not to say that food and weight were absent in the group model or recovery processes of participants. In fact, intuitive eating was identified by most participants as a nutritional intervention that was very helpful in recovery, irrespective of eating disorder. The intuitive eating approach “support[s] homeostatic regulation and eating intuitively (ie, in response to internal cues of hunger, satiety, and appetite) instead of cognitively controlling food intake through dieting” (Bacon et al., 2005, p. 930). This approach is very different from the weight control methods many of the participants were socialized into by parents and peers (restrictive diets, fasts, meal replacements, etc.), or the food and weight surveillance experienced in formal eating disorder treatment settings (Gremillion, 2002, 2003; Kendall & Hugman, 2013; Leblanc et al., 2014) . Bacon et al. (2005) put the intuitive eating approach into context by identifying that the notion “that dieting and weight loss are critical to improving one’s health is reinforced by a social context that exerts enormous pressure on women to conform to a thin ideal” (Bacon et al., 2005, p. 929). Dieting and “self-surveillance” (Rail et al., 2010, p. 261) are also hallmarks of the dominant obesity discourse, that frame “individuals as primarily responsible for changing their lifestyle via a range of disciplinary measures and control techniques” (Rail et al., 2010, p. 261) in an effort to avoid being overweight, which is viewed as a moral failure (Rail et al., 2010). As such, engaging in intuitive eating is significant for individuals have experienced an eating disorder because they are re-establishing a broken connexion with their bodies (through hunger and satiety signals), while also engaging in work on body image as “an essential component of some intuitive eating programs is to encourage health at every size rather than weight loss as a necessary precondition to improved health” (Bacon et al., 2005, p. 930). Size acceptance is important in the recovery process, as learning to eat intuitively may lead to changes in an individual’s weight, whilst challenging the notion of who is healthy, and in what body. As many of the research participants described, intuitive eating not only helped them decrease food obsession, but this approach helped them to change their perception of their bodies.

Participants in this study found helpful elements in many settings, however eating disorder community groups stand out as they combine many of those elements in one service offer. Generally, participants accessed knowledgeable professionals, quickly and without a reference in these organizations. In most cases, they were integrated into a group in a matter of weeks or months and benefited from either individual and group services (or both) at low cost. The services offered by community organizations were described as holistic and included support services for loved ones. Participants with different types of eating disorder were often able to access services, including binge-eating disorder, orthorexia and sub-clinical disorders (though not in all organizations). Many described being able to address their self-perception, the cultural context, and issues underlying the eating disorder in these organizations. Several participants were supported in intuitive eating by professionals at community organizations, in addition to having access to support on an ongoing basis. Finally, participants described accessing services at different moments in their recovery process: as a first contact in the recovery process, before or after hospitalization, during a relapse, etc. which would suggest that these services are being accessed by individuals living mild, moderate and acute eating disorders. A possible bias in the sample may be the recruitment through eating disorder community organizations, however, most participants had accessed a wide variety of community and hospital resources in their recovery trajectories.

Still, eating disorder community organisations may be part of a network of community resources that are providing what Mitchison et al. (2016) describe as “backdoor approaches to achieving symptom remission” (Mitchison et al., 2016, p. 11) related to eating disorders. In like manner, The Committee on the Status of Women’s asserts that hospital care “should not be considered as the first course of action or the only appropriate response to eating disorders” (Rice & LaMarre, 2014 cited in Leblanc et al., 2014, p. 45) as some individuals respond better to “other treatment settings” (Leblanc et al., 2014, p. 45). Interestingly, many participants identified a social work approach to eating disorders in community organizations, which employ a variety of professionals (community workers, social workers, nutritionists, sexologists, special educators, psychologists, etc.) all working to address the complexity of eating disorders at a fraction of the cost of hospital based programs (ANEB Québec, 2018; Arrimage Estrie, 2015; Maison l’Éclaircie, 2017).

The eating disorder literature has established that the majority of individuals recover from an eating disorder in community contexts (Hart et al., 2011; Hudson et al., 2007; Mitchison et al., 2016; Public Health Agency of Canada, 2002). This is especially true for individuals whose eating disorder falls outside of the established treatment models for anorexia and bulimia. As Mitchison et al. (2016) affirm, “the most common eating disorders in the community are often associated with overweight/obesity and involve ego-dystonic behavior such as binge eating” (Mitchison et al., 2016, p. 2). Emergent and sub-clinical disorders are also likely overrepresented in community settings, as the half of individuals who were diagnosed using DSM IV criteria received a “residual diagnosis of EDNOS” (Myers & Wiman, 2014, p. 87) which manifests itself in a variety of symptoms that can exclude individuals from treatment programs that are conceived to treat symptoms of anorexia and bulimia. As such, it is more than likely that social workers are already in contact with individuals living with and recovering from eating disorders in many contexts (schools, CIUSS and CLSCs, Family Medicine Groups, hospitals, community organizations, etc.).

In this study, more than half of the participants had contact with a social worker at some point in their recovery process. Participants met with social workers in a range of settings, and with a range of outcomes. Overall, the social workers' knowledge of eating disorder and body image issues played an important role in the positive experiences described by participants, as did the quality of the relationship with the professional. Neutral and negative experiences were both related to a lack of knowledge about eating disorders and the role a social worker might play in recovery. Being referred to another professional (often a psychologist, who was not necessarily more informed about eating issues) was a common experience, as was the focus on a co-existing mental health condition such as anxiety or depression.

Despite a mixed bag of interactions with social workers, many of the participants felt that social work skills were compatible with many aspects of the recovery process from an eating disorder. Work on issues underlying the eating disorder was identified as an ability social workers applied to many other contexts (addiction, abuse, etc.) as was working with the person's support network (friends, family, community) in the recovery process. Based on their lived experiences, research participants had a variety of suggestions for social workers who may encounter someone living with or recovering from an eating

disorder: listen, create trust, don't judge, be aware of your own beliefs about food and weight, understand that eating disorders are not about vanity, be knowledgeable about all types of eating disorders and their function, know your community and professional resources, and apply your professional know-how to eating disorders.

Some participants were aware that social workers have had difficulty finding their place in eating disorder recovery process, as doctors, nurses, psychologists and psychiatrists tend to be the professionals considered best equipped to deal with these issues (Vanessa, Megan) in a biomedical perspective. However, participants felt strongly that social workers had a role to play in recovery and that social work's unique skill set can and should be applied to eating disorders (Chloe, Jason, Vanessa, Megan, Jennifer, Anne). What's more, some participants identified that community and social workers in community organizations, hospitals and CLSCs were already doing just that (Lili, Lydia, Megan, Vanessa).

When a recovery perspective is applied to eating disorders, social work's potential role with this population becomes clear, as the focus of intervention shifts from symptoms to the individual's quality of life, values, and their place in the community in the long-term (Davidson et al., 2009). Addressing mental health professionals, Davidson (2009) states that there is a need to develop "the new competencies" that are "involved in helping people to live meaningful, gratifying lives despite having a psychiatric disability" (Davidson et al., 2009, p. 21). However, it could be argued that social work's relative exclusion from eating disorder treatment conception and delivery (Wilson, 2004), has preserved the profession's recovery-oriented foundations. In fact, there is significant overlap in social work's core values of social justice, self-determination, individual and collective empowerment (OTSTCFQ, 2012, p. 8), strengths-based approaches, "expertise in enhancing social functioning" (Dean & Rowan, 2014, p. 219) and the principles of recovery oriented practice. Social work's view of the human being at the core of this complementarity:

La personne humaine est d'abord considérée par les travailleurs sociaux dans sa capacité d'autodétermination, soit de développer en tant qu'acteur de sa vie, de développer ses potentialités, de reconnaître ses comportements, y compris la responsabilité de ses erreurs, et

leurs conséquences sur elle-même et sur les autres, d'identifier ses aspirations et ses projets, d'opérer des choix et d'agir en fonction de ceux-ci. (OTSTCFQ, 2012, p. 10)

Thus, social work's most fundamental values can be viewed as recovery-oriented when applied to the issue of eating disorders. As Davidson asserts, recovery-oriented practice is typified by "place[ing] as much, or possibly even more, emphasis on their clients' personal narratives and goals" (Davidson et al., 2009, p. 22) than on their disorders. Furthermore, social work's focus on a constructing a « *projet de vie* » (OTSTCFQ, 2012, p. 11) that enables the person to become an active citizen, is very close to Davidson's descriptions of building a meaningful life in recovery (Davidson et al., 2009).

In the participant's descriptions of "what worked", being seen as a "whole person" by professionals, having their eating disorder approached holistically, working on underlying issues, and a focus on quality of life were all identified as supportive of recovery. In fact, participants described recovery-supportive elements as decreasing obsession and other eating disorder symptoms, which is much different from a biomedical approach to eating disorders which focuses on symptoms first, then on the person's quality of life (Arnaiz, 2009; Davidson et al., 2009; Gremillion, 2002, 2003) due to its focus on acute and chronic cases (Leblanc et al., 2014). Though acute care for eating disorders requires a certain focus on symptoms and weight, many have noted that "treatment practices re-create forms of bodily control that are already defining features of anorexia" (Gremillion, 2002, p. 390) and other eating disorders. What's more, in their definitions of recovery, participants described a transformation in self-perception, a return to functioning in different spheres of their lives (relationships, work, school, leisure, family, etc.), and understanding the function of their eating disorder symptoms as to better manage them. The ultimate goal of recovery being to live a full and meaningful life, even if some eating disorder symptoms remained, or that the possibility of relapse was present. Social work is uniquely positioned to contribute to this process, as it seeks to « *rétablir le fonctionnement social de la personne en réciprocité avec son milieu dans le but de favoriser le développement optimal de l'être humain en interaction avec son environnement* » (OTSTCFQ, 2012, p. 8). What's more, social workers are trained to work with others in order to achieve the individual's optimal functioning, acting as pivot between professionals and including family, friends, and community members in their interventions (OTSTCFQ, 2012).

In addition, social work's understanding of how sociocultural forces shape an individual's reality meets feminism's approach to eating disorders, which identifies both Western beauty standards, obesity discourse, and the medicalization of women's bodies as factors that have greatly influenced the proliferation of eating disorders in Western societies (Black, 2003; Daly, 2016; Gremillion, 2002; McCormick, 2008; Rail et al., 2010; Wilson, 2004). Feminists have also called for an intervention model that takes both gender, race, class and the sociocultural context into account (Arnaiz, 2009; Black, 2003; Daly, 2016; Gremillion, 2003; Maier, 2015; Wilson, 2004), which aligns with social work's « *vision des problèmes sociaux et de l'intervention sociale qui sous-tend la prise en considération des rapports sociaux d'inégalité (classe sociale, genre, race/ethnie, handicap, etc.)* » (OTSTCFQ, 2012, p. 10).

Finally, social work's commitment to social justice is also relevant in the current eating disorder context, in which certain types of eating disorder, certain genders, age groups and certain bodies are being discriminated against in the distribution of eating disorder resources. For social workers, a commitment to social justice and equity implies taking into account « *l'existence de situations d'oppression aux plans individuel, culturel, économique, politique et institutionnel* » (OTSTCFQ, 2012, p. 10) and « *dénoncer et combattre, afin que les personnes puissent se développer dans des environnements favorisant une réponse adéquate à leurs besoins* » (OTSTCFQ, 2012, p. 10). The structural and institutional barriers encountered by many of the research participants in their recovery processes indicate that there is a need for collective action with regards to the inadequate eating disorder services available in Quebec and in Canada (Leblanc et al., 2014).

As the research participants' experiences illustrate, many individuals are recovering from an eating disorder in the community, which is social work's domain. As there are so few services available for mild and moderate cases of eating disorders (Leblanc et al., 2014), binge-eating disorder (Hudson et al., 2007; Myers & Wiman, 2014; Starkman, 2016), sub-clinical and emergent disorders (Myers & Wiman, 2014; National Eating Disorder Association, 2018), men (Bunnell, 2016; Griffiths et al., 2015; Leblanc et al., 2014), or long-term recovery oriented supports, it is clear that social workers are likely to come into contact with this population. As such, social workers could benefit from being educated about eating disorders as part of their core training. Both the participants of this study and The Standing Committee

on the Status of Women assert that being educated about eating disorders is supportive of recovery (Leblanc et al., 2014, p. 32) and that this information should be included in the basic curriculum for all health and social service professionals (Leblanc et al., 2014, p. 33). Adequate training would enable social workers to apply their already recovery-oriented skill set to the issue of eating disorders, which could represent an incredible resource for the underserved eating disorder population in Quebec.

Chapter 5: Conclusion

5.1 Conclusion

To conclude, this exploratory study of the lived experiences of eating disorder recovery in the Quebec community context has uncovered the complex reality of this process. Though diverse in age, region, ethnicity, type of eating disorder, and recovery trajectory, participants' definitions of recovery emphasized the unique and long-term nature of this process, which required a variety of support systems. Most notably, participants expressed that recovery did not represent the absence of eating disorder symptoms, but the ability to function in the various spheres of their lives (relationships, work, school, leisure, etc.) even if some symptoms were present. As mentioned in earlier sections, this conception of recovery is much different than the biomedical view that an eating disorder is "cured" when weight has stabilized, and symptoms have subsided (Arnaiz, 2009; Gremillion, 2002, 2003). A recovery approach to eating disorders is, in fact, compatible with social work's approach to activating the person and their environment to achieve a better quality of life (Dean & Rowan, 2014; McCormick, 2008; OTSTCFQ, 2012), especially outside the acute phases of the disorder.

However, the experiences of the participants in this study and the review of literature indicate that most treatment models in Quebec and Canada are designed to treat acute cases of anorexia and bulimia in hospital settings (de Oliveira et al., 2017; Leblanc et al., 2014; Shekter-Wolfson et al., 1997). As such, there is an urgent need for recovery-oriented services for individuals living with mild to moderate eating disorders of all types. As this study revealed, services for binge-eating disorder, emergent and sub-clinical eating disorders are lacking or nonexistent. What's more, many of the first-line health and social service professionals that participants in this study turned to for support were not well informed about

eating disorders, or worse, totally unaware of their disorder's existence or the services available to treat them. Interestingly, having a formal eating disorder diagnosis did not appear to improve access to services for the participants who had one. Those participants faced long wait lists, referrals to inappropriate services (obesity clinic), or no services at all. Considering that many eating disorders do not have a specific DSM diagnosis or fall into the catch-all category of OSFED/UFED (formerly EDNOS), and that receiving a diagnosis does not guarantee access to appropriate services, it is questioning that services are built around the criteria for only two eating disorders (anorexia and bulimia) that represent a minority of cases (Hart et al., 2011; Hudson et al., 2007). The participants' recovery stories reveal to what extent existing models of care are not responding to the much broader reality of eating disorder recovery in Quebec.

The current service model may, in part, be explained by the lack of resources allocated to eating disorder treatment in Canada (de Oliveira et al., 2017; Leblanc et al., 2014). Focus on acute cases may be a practical response to a lack of resources, however the current study echoes the Standing Committee on the Status of Women's report that deplores the lack of services and treatment for individuals living with mild and moderate cases of eating disorders in the current system of care (Leblanc et al., 2014). The committee's report also finds the hospital model of care restrictive, as many individuals would benefit from receiving services in the community (Rice & LaMarre, 2014 cited in Leblanc et al., 2014, p. 45), where much of eating disorder recovery occurs (Mitchison et al., 2016; Public Health Agency of Canada, 2002). For the participants in this study, using community resources (community organizations, family doctors, nurses, social workers, private sector professionals, etc.) was often a necessity in their recovery process. In fact, half of the sample completely bypassed the medical system in their recovery, accessing only community resources to address their eating disorder. This finding is consistent with Mitchison et al.'s (2016) assertion that a majority of individuals living with an eating disorder never seek formal treatment (Mitchison et al., 2016, p. 2) and Hart et al.'s (2011) finding that many individuals who are in contact with the medical system are not receiving appropriate treatment for an eating disorder (Hart et al., 2011, p. 732). This study sheds light on how individuals navigated the community resources in three Quebec cities to find the services and supports they needed in the recovery process, an area of eating disorder research that has received little attention in the literature on this topic.

This community-based sample accessed an average of 3.8 community resources in their recovery, encountering a wide variety of supports and barriers along the way. Participants shared that holistic interventions that addressed quality of life and eating disorder symptoms were greatly appreciated. Group work was highlighted as supportive, as it countered the social isolation associated with eating disorders. All participants emphasized that the identifying and resolving some of the issues underlying the eating disorder was an important part of recovery, which is also consistent with Mitchison et al.'s 2016 findings. A transformation of self-perception, through self-care, increased self-worth, work on self-esteem etc. was also cited by all participants as helpful in the recovery process.

Another notable finding of this study is that most participants found that a combination of an intuitive eating nutritional intervention and group work that addressed individual, social and familial aspects of the eating disorder was supportive of recovery, irrespective of the type of eating disorder. This finding troubles the current eating disorder service model that is delineated by type of eating disorder (Gremillion, 2002) and heavily focused on symptoms (Arnaiz, 2009; Black, 2003; Gremillion, 2003; Simblett, 2013; Wilson, 2004). Again, in acute cases a focus on symptoms may be necessary, but as the research participants' recovery trajectories indicate: the long-term work of recovery is not symptom-focused but concerned with achieving a better quality of life. As The Standing Committee on the Status of Women asserts, both services for mild and moderate cases of eating disorders, and ongoing support in the recovery process have been identified as best practices for treating eating disorders (Leblanc et al., 2014), however few services exist in the public system that align with these recommendations.

Many of the barriers to recovery identified by participants were related to how eating disorder services are conceived based on DSM criteria and the related psychiatric models of care developed for anorexia and bulimia. The fact that few services for binge-eating disorder exist, despite it having full diagnostic criteria (American Psychiatric Association, 2018) and being identified most prevalent eating disorder in North America (Hudson et al., 2007) is by far the most disturbing finding of this study. What's more, the lack of services for binge-eating appears to be related to a generalized stigmatization of fat, that was experienced by participants whose eating disorder manifested itself in overweight or obese bodies. Whether living with bulimia, orthorexia, OSFED/UFED, or binge-eating disorder, participants

encountered significant barriers in the health and social service system. Systematically, all participants whose bodies were perceived as “fat” were shamed, not taken seriously, and directed to obesity services, even when eating disorder symptoms or a diagnosis were known. A feminist reading of this type of stigmatization locates cultural values that promote thinness for women (Bordo, 2003; Gremillion, 2002, 2005; Vinette, 2001) and muscularity for men (Bunnell, 2016; Griffiths et al., 2015), combined with an obesity discourse that frames fat as the shameful consequence of poor lifestyle habits and lack of moral fortitude (Rail et al., 2010). When combined with the prevalent eating disorder archetype of the emaciated, young, white woman (Leblanc et al., 2014), eating disorders that manifest in bigger bodies are rendered invisible to the medical system, individual health and social service practitioners and the public in general. In addition, the perception that a person living with an eating disorder in an overweight or obese body was experiencing a “less serious” condition was perceived by many participants, as in an acute care model for eating disorders weight loss and low BMI are often necessary to be admitted to a hospital program (Arnaiz, 2009; Gremillion, 2002). In spite of the stigma surrounding binge-eating disorder, successful treatment models exist (Hart et al., 2011) but are not yet implemented in the Quebec health care system. In this study, participants living with binge-eating disorder, emergent or subclinical eating disorders that manifested in weight-gain, found support in community organizations, private sector professionals, and family doctors.

Other barriers reported by participants were a general lack of specialized eating disorder services, which is significant considering that Montreal, Quebec and Sherbrooke are some of the largest centers in Quebec with the most developed eating disorder resources. Additionally, for most participants first-line professionals’ lack of knowledge of eating disorders acted as a barrier to recovery as they were unable to properly identify the eating issue or refer to an appropriate resource. As the Standing Committee on the Status of Women States, health care professionals often do not investigate an individuals’ relationship with food when they consult for weight or eating issues (Leblanc et al., 2014).

Participants’ experiences with social workers in their recovery process were varied, but for most, social workers who had some knowledge of eating disorders had the most positive impact on the recovery process. Social workers who had no knowledge of eating issues often referred to another professional

(who often was not knowledgeable either) or simply did not identify the problem. The participants in this study, who were highly aware of how underlying issues must be addressed in eating disorder recovery, felt strongly that social workers had many of the skills needed to support an individual in eating disorder recovery. Work with families, loved-ones and the community were cited by participants, as were experience with a wide variety of issues that might underlie an eating disorder (relationships, addiction, mental health issues, social stigma, etc.). Participants emphasized the need for social workers to offer non-judgemental support, active listening, a working knowledge of eating disorder resources, and the ability to help support loved ones in their role. Their advice is consistent with both recovery-oriented practice that situates the individual and their environment at the center of the process, with a focus on the person and their quality of life (Davidson et al., 2009; Provencher, 2002) and social work practice's focus on individual and collective empowerment, active citizenship, and social justice (OTSTCFQ, 2012, p. 8).

In the literature on the subject, neither recovery or social work approaches have been applied to eating disorders. Eating disorders are however a mental health issue that is characterized as biopsychosocial, social factors that contribute to the development and maintenance of eating issues being well documented in both psychiatric (American Psychiatric Association, 2018; Government of Canada, 2006; Public Health Agency of Canada, 2002) and feminist research (Arnaiz, 2009; Black, 2003; Bordo, 2003; Gremillion, 2002, 2003; Vinette, 2001). Essentially, social workers have a blank slate with regards to this issue, as there is little in the professional literature on how to address eating disorders outside the psychiatric hospital model (Shekter-Wolfson et al., 1997; Wilson, 2004). In a community setting, which is the context that much of eating disorder recovery occurs (Hart et al., 2011; Mitchison et al., 2016; Public Health Agency of Canada, 2002) the combination of these approaches would appear to meet an overwhelming unmet need for support in the recovery process as both are concerned with quality of life.

Quality of life is a significant when considering that most of this study's participants' eating issues began in childhood or adolescence. As the mean age of study participants was 41 years, their recoveries spanned 1 – 45 years. This study found that in eating disorder recovery, acute phases of the eating

disorder represent short moments in a much longer process. As such, participants noted that receiving ongoing support in recovery was important, as the process was continuous and because relapse was a reality that all participants identified as part of recovery. In general, participants found this type of support in community resources both general and eating disorder specific (i.e.: eating disorder community groups), and from their loved ones. The model of acute care is simply not designed to meet the needs of long-term recovery, making the community the natural context for recovery. As social workers are already present in this context and possess a social and recovery-oriented skill set, the profession would well situated to support individuals in this process if they received some eating disorder training.

5.2 Training for Social Workers

As the participants in this study suggest, social work could provide support to individuals recovering from an eating disorder if they were better trained to identify these disorders and apply social work skills to the social aspects of the recovery process. Social work is perfectly situated to provide support outside of the acute phases of the disorders, to provide support and education to loved ones, to work on issues of quality of life, to assist individuals in finding eating disorder resources inside and outside of the public health care system. Furthermore, social workers are uniquely equipped to address the underlying social factors that contribute to eating disorders: sociocultural factors that make the west a hotbed for the development of eating disorders, and the gender, race and class issues that intersect with them. Advocacy is another domain which social workers are well trained to tackle, as the limited and unequally distributed eating disorder resources represent an issue of social injustice that some individuals may want to address in their recoveries.

The foundation required to provide support to individuals recovering from an eating disorder would require at least three components:

- knowledge of recovery-oriented practices in mental health
- working knowledge of eating disorders both within and outside DSM criteria
- an understanding of the social aspects of eating disorders and eating disorder recovery

Social workers must also be equipped to navigate a professional context where their role has not yet been defined (Arnaiz, 2009; Wilson, 2004). However, through training at both the undergraduate and professional levels this role could be better defined, based on social work theories and approaches in combination with recovery-oriented principles.

As the current psychiatric model of care does not take gender, race, class and body size issues into account, social could fill a significant gap in the eating disorder treatment model. Social workers could also provide non-symptom focused interventions that would be supportive of long-term recovery in the community, outside of acute phases of the disorder. Social workers could also act as pivots, linking individuals to resources in the community and health care system throughout their recoveries. As eating disorder best practices emphasize a multi-disciplinary intervention model (Leblanc et al., 2014), social workers can use their training in working with other professionals, loved-ones, family and community to support individuals in their recovery trajectories. The inclusion of eating disorder recovery practices in Quebec's undergraduate, college-level, and professional social work training, could effectively change the community landscape for the thousands of individuals living with eating disorders in this province, especially outside major centers.

5.3 Limits of This Study

Though this study revealed a dearth of information on the recovery process in a Quebec community context, it has some important limits. Firstly, the sample size was small, as the research was exploratory and conducted in the context of an unfunded, master's-level study. Secondly, the sample was varied in many ways, but lacked in gender, race and class diversity. As mentioned in an earlier section, men and individuals who identify outside the male – female binary are grossly underrepresented in eating disorder research and service models. It is possible that eating disorder research design, evaluation tools and service models have been gendered female, which excludes other genders identities *à priori* in knowledge-making (Black, 2003; Bunnell, 2016; Griffiths et al., 2015; Jones et al., 2016; J. H. Slevic & Tiggemann, 2011). Though gender diversity in the sample is limited (one male participant), it is

representative of the usership of the community organizations through which participants were recruited, which is primarily female (ANEB Québec, 2018; Maison l'Éclaircie, 2017).

Additionally, available statistics on the yearly income of the community organization's users suggest that this sample is not reflective of the class diversity typically found therein (ANEB Québec, 2018). All participants in the sample self-identified as middle-class (which may represent a wide range of incomes), but none identified as being either poor or high-income. As such, this study is relatively homogenous in terms of class.

Regarding racial diversity, this study is consistent with most eating disorder research in that Caucasian participants are overrepresented. Many researchers have called attention to the fact that contexts in which eating disorder data is collected (university campuses and clinical settings) tend to be predominantly white, making non-white eating disorder realities less visible (Black, 2003; Katsounari, 2009; Leblanc et al., 2014; J. H. Slevac & Tiggemann, 2011). Information on the racial and ethnic background of the community organization's usership was limited but is surely more diverse than what is represented in this sample, as in the 2016 census data visible minorities represented 25% of the Quebec sample (Government of Canada, 2017). In this study, participants of all racial and ethnic identities were invited to participate, however participants were selected on a first-come, first-served basis without regard to gender, race or class identity. The result was an all-Caucasian sample, with considerable ethnic diversity. However, the reality of recovering from an eating disorder as a visible minority was not addressed, and merits further research.

Finally, this study was focused on eating disorder recovery in 3 large centers (Montreal, Sherbrooke, Quebec), where all participants had access to public, private and community eating disorder resources. Thus, the study does not reflect the community reality of eating disorder recovery in smaller centers or rural areas where there are fewer, if any, eating disorder services. As one research participant alluded to, many people she was hospitalized with were forced to travel great distances, rent apartments, stop working, and pay for childcare to receive specialized services miles away from their homes (Vanessa). The Standing Committee on the Status of Women also noted that few services for eating disorders exist outside of major centers (Leblanc et al., 2014, p. 46), making living in a large urban center a geographical

advantage in Quebec and Canadian eating disorder recovery. For this reason, the research participants recovery trajectories must be considered specific to their geographic reality.

5.4 Further Research

This study has only scratched the surface of the lived experiences of people recovering from an eating disorder in a Quebec community context. More research in this area is greatly needed, as this group is the largest statistically (Hart et al., 2011; Hudson et al., 2007; Myers & Wiman, 2014; Starkman, 2016), and often the least served by existing eating disorder research and treatment models (Leblanc et al., 2014). As the participants in this study have emphasized, recovery is a long-term process that requires ongoing, non-judgemental, person-centered supports. Research that taps the expertise of adults recovering from eating disorders is also much needed, as the literature in the field has tended to study acute cases of young, white women in highly medicalized contexts (Gremillion, 2003; Leblanc et al., 2014). As so much of eating disorder research has been focused on a minority of disorders (anorexia and bulimia) (Gremillion, 2002; Leblanc et al., 2014), more research on binge-eating disorder, OSFED, UFED, and emergent disorders is greatly needed. Together, these disorders represent the majority of eating disorders in the general population (Hart et al., 2011; Hudson et al., 2007; Mitchison et al., 2016; Myers & Wiman, 2014) and merit equivalent attention in the eating disorder literature in order to develop treatments and services. In a recovery perspective, people living with eating disorders represent “the greatest, if least tapped, resource a mental health system possesses” (Davidson et al., 2009, p. 20). In order to learn more about “how people learn to live with, manage, and reclaim a life” (Davidson et al., 2009, p. 21) in the presence of an eating disorder, individuals living this reality need to occupy a central role in both research and the development of community models of care.

Furthermore, the ways in which identity (gender, age, race, class, body size, etc.) shape the recovery trajectories of individuals is an area of research that necessitates exploration. An intersectional analysis of eating disorder recovery that is not limited to DSM criteria could significantly widen the scope of individuals who are represented in eating disorder research and shed light on the ways that identities intersect in the recovery process.

In terms of eating disorder prevention, the theme of “I don’t know how to eat” was present in many of the participants narratives. Some participants felt that not “learning how to eat” (being exposed to a diversity of foods, learning to cook and shop for food, learning to listen to their bodies’ signals, learning the appropriate role of food in the larger scheme of life, etc.) contributed to their developing an eating disorder. The notion that there is “a right way to eat” led many participants to do extreme diets, seek medical advice, follow nutritional advice from books and websites, and try any number of lifestyle changes to achieve a “healthy weight”. For many, a difficult relationship with food, combined with other factors, led to disordered eating. This theme is multi-layered as the concepts of health, eating well, and healthy weight are largely culturally constructed, and intersect with gender, race and class in how weight, eating and bodies are perceived (Arnaiz, 2009; Rail et al., 2010). The social aspects of eating and healthy weight could be explored in a social work perspective, as education and prevention are two important aspects of social work practice, especially at the community level.

Another theme that was present in the participant’s narratives was the role of applications and social media in the recovery process. Participants shared that some applications were supportive of recovery (ex. Intuitive eating apps that helped them to assess their hunger and emotions at meals), and others supportive of the eating disorder (ex. Calorie counting apps). Social media was also mentioned as being supportive of recovery, as most participants kept in touch with other support group members through Facebook. For others, being in online communities of individuals recovering from an eating disorder was perceived as risky as the tendency to compare bodies, weights, recoveries, etc. was identified as a barrier to recovery. The use of these technologies in the recovery process is an area of research that could be deepened, as new technologies are becoming an integral part of the recovery process.

Finally, community organization’s service model also merits further research. The services developed and offered by these organizations appear to be responding to the overwhelming needs of an invisible and underserved eating disorder population in Quebec (ANEB Québec, 2018; Arrimage Estrie, 2017; Maison l’Éclaircie, 2017) and Canada (Leblanc et al., 2014). More research may lend credibility to these organisations, whose funding is a fraction of eating disorder hospital treatment programs in Canada, despite the fact that they serve a higher number of individuals living with eating disorders, albeit

differently and within the community (ANEB Québec, 2018, 2018; de Oliveira et al., 2017; Leblanc et al., 2014; Maison l'Éclaircie, 2014). Furthermore, studying the recovery-oriented practices of community and social workers in these organizations may have important implications for how social work develops its eating disorder intervention practices, an area that is yet to be fully invested by the profession (Shekter-Wolfson et al., 1997). Application of a recovery perspective to the issue of eating disorders in the community would effectively widen the scope of supports and services that could be developed for the eating disorder population, as means of bolstering individuals' "*own efforts* to live, work, learn and participate fully in the community" (Davidson et al., 2009, p. 21).

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Annex 1

INTERVIEW GUIDE and RESEARCH QUESTIONS

Main Research Question:

What are the lived experiences of a community-based sample of people in recovery from an eating disorder in Quebec?

Sub questions:

- **What were the most helpful elements in the recovery process?**
- **What were some of the barriers encountered in the recovery process?**
- **What role did community-based resources play in the recovery process?**
- **What role did social work play in the recovery process?**

Domains of inquiry:

- Consent
- Identity
- Personal History of Disordered Eating
- Definition of Recovery
- Recovery Timeline
- Services and Supports during Recovery
- What Worked?
- Barriers to Recovery
- Role of Community-Based Resources in Recovery
- Role of Geographical Location in Recovery
- Social Work and Recovery from an Eating Disorder
- “New Normal”: Current State of Recovery
- Recovery Maintenance
- The Future

Domain of Inquiry	Related Interview Questions
Consent	<ul style="list-style-type: none"> • Have you read and understood the consent form? • Do you have any questions or concerns? • Is any part of the form unclear to you? • Are you aware that I am employed by Arrimage Estrie as an eating disorder counsellor? • Does my professional role complicate your participation in this project? • Would you like to take time discuss how my professional role may affect you?

<p>Identity (Demographics)</p>	<ul style="list-style-type: none"> • How old are you? • How would you describe your ethnic background? • What is your occupation? • How would you describe your class background? • What languages do you speak? • What is your relationship status? • Is there anything else you would like to tell me about yourself?
<p>Personal history of disordered eating</p>	<ul style="list-style-type: none"> • How would you describe your eating disorder? • At what age did your issues with food emerge? • Was there a specific context? • How did your loved-ones react to your eating disorder? • How did the eating disorder affect your life? (school, work, relationships, physical health, etc.) • How did the eating disorder progress? • Did you need to receive specialized care? • Is there anything else you would like to tell me about the experience of living with an eating disorder?
<p>Definition of recovery</p>	<ul style="list-style-type: none"> • How do you define recovery? • When did you feel like you had started the recovery process? • Where do you feel like you are in your recovery now?
<p>Recovery timeline</p>	<ul style="list-style-type: none"> • Can you describe how your recovery progressed? • What were some of the important moments of your recovery process?
<p>Services and supports during recovery</p>	<ul style="list-style-type: none"> • What services did you have access to in your recovery? • Who supported you in your recovery?
<p>What worked?</p>	<ul style="list-style-type: none"> • What were some of the most helpful things in your recovery process? • Why do you think the service/approach resonated for you? • Are those elements still helpful to your recovery? • Is there anything else you want to say about what worked for you in the recovery process?
<p>Barriers to recovery</p>	<ul style="list-style-type: none"> • What barriers did you encounter in your recovery process? • What type of barrier were they? (emotional, financial, institutional, geographic, language, etc.) • Did you ever feel like an element of your identity was a barrier to getting what you needed in your recovery process? (gender, ethnicity, class, sexual orientation, religion, etc.)

	<ul style="list-style-type: none"> • How did you deal with the barrier? • What affect did the barrier have on your recovery process? • Is there anything else you would like to tell me about the barriers you encountered in your recovery process?
Role of community-based resources in recovery	<ul style="list-style-type: none"> • Did you use any community based resources in your recovery process? • If yes, can you describe the resource? • What was helpful about this resource? • What was problematic or difficult about the resource? • Is there anything else you want to tell me about the resource?
Geographical location	<ul style="list-style-type: none"> • Do you think that where you live had an impact on your recovery? • Were the resources you needed in your recovery available to you in your area? • Were the resources accessible to you? (physically, financially, linguistically, etc.) • How would you describe the context of your city/region/ province in relation to your recovery from an eating disorder? • Is there anything else you would like to add about recovering from an eating disorder in this city, region or province?
Social work	<ul style="list-style-type: none"> • Did you have contact with a social work in your recovery process? <p>If yes:</p> <ul style="list-style-type: none"> • In what context? • How would you describe your encounter(s) with the social worker? • What role did the social worker play? • Did the social worker know about eating disorders? • Where the social workers interventions supportive of your recovery? • How did you feel about the social workers approach to eating disorders and recovery? • Is there anything else you would like to tell me about your experiences with the social worker? <p>If no:</p> <ul style="list-style-type: none"> • Why not?
New normal: current state of recovery	<ul style="list-style-type: none"> • How would you describe your new normal (current state of recovery)? • What have you learned about yourself that helps you to stay in balance? • Is there anything else you would like to tell me about your current state of recovery?

Recovery maintenance	<ul style="list-style-type: none">• How do you maintain your recovery?• Do you have support systems?• How do you handle relapses or the potential for relapse?• Is there anything else you would like to tell me about how you maintain your recovery?
The Future	<ul style="list-style-type: none">• How do you see your recovery moving forward?• Are there services and/or supports that you would like to see for people recovering from eating disorders?• If you could tell a social worker in a word or a sentence what was most supportive in your recovery, what would you say?• Is there anything else you would like to tell me about how you see your recovery in the future?

Annex 2**INFORMATION AND CONSENT FORM**

You are invited to participate in a research project. The present document will inform you of the modalities of this research project. If there are words or paragraphs in this document that you do not understand, please do not hesitate to ask questions. In order to participate in this research project, you must sign this document. A signed and dated copy of this document will be provided for your records. Please take all time necessary to make an informed decision.

Title of the Research Project

Eating Disorders, Recovery, and Social Work Practice in Quebec

Persons responsible for this research project

Sarah Frost, master's student in the social work program at Université de Sherbrooke, is responsible for this research project. The project is supervised by Suzanne Garon, professor in the School of Social Work at Université de Sherbrooke.

Sarah Frost, researcher responsible for this project

Sarah.Frost@usherbrooke.ca

Suzanne Garon Ph. D., thesis supervisor

École de travail social

Université de Sherbrooke

2500 University blvd.

A5-0402

Sherbrooke, Québec J1K 2R1

819 780-2220 ext. 45145

Suzanne.Garon@usherbrooke.ca

Research project objectives

The research objectives of this project are to explore the lived experiences of a community-based sample of people in recovery from an eating disorder in three Quebec cities (Montreal, Sherbrooke, Quebec City). An investigation what was helpful in the recovery process, what barriers were encountered and the role of community organizations in recovery will be used to reflect on social work's possible contribution to the field of eating disorder recovery.

Rationale and Nature of Participation

Your participation in this research project will necessitate an interview of approximately one and a half hours. The interview will take place at a time and location of your choosing. The location you choose must be private as the interview is confidential. You will be asked questions about your experiences of recovery from an eating disorder. With your consent, the interview will be recorded with an audio recorder.

Possible Advantages Related to Your Participation

It is possible that you may benefit personally from your participation in this research project (for example: taking time to share and reflect on your recovery experience), however we cannot guarantee this outcome. In addition, your participation in this research project will contribute to creating knowledge on the topic of eating disorder recovery and the potential role of social workers in this process.

Possible Risks and Inconveniences Related to Your Participation

Your participation in this research project should not incur any significant inconveniences, with the exception of giving your time to the project. It is also possible that you will have to travel a short distance to the location where the interview will be conducted, if you do not wish to conduct the interview at your home or another private and confidential space of your choosing. At any moment during the interview, you can ask to take a break or to continue the interview at another time.

It is possible that sharing your recovery experiences in the interview may bring up difficult thoughts and feelings. If this is the case, we invite you to consult the following references:

Eating Disorder Helplines:

Ligne d'écoute pour les personnes vivant un trouble du comportement alimentaire

Anorexie et boulimie Québec (ANEB)

1 800 630-0907

8am to 3am EST - 7 days a week

Eating Disorder Helpline

National Eating Disorder Information Center

1 866 NEDIC-20 (1 866 633-4220)

9am to 9pm EST – Monday to Friday

Eating Disorder Community Organizations (by region):

Montreal:

ANEB Québec

5500 Trans-canada Hwy

Pointe-Claire (Québec)

H9R 1B6

1 800 630-0907

www.anebquebec.com

Sherbrooke:

Arrimage Estrie

6 Wellington Street South, office 204

Sherbrooke (Québec)

J1H 5C7

819 564-7885

www.arrimageestrie.com

Quebec:

Maison l'Éclaircie

2860 Montreuil Street

Québec (Québec)

G1V 2E3

1-866-900-1076

www.maisoneclaircie.qc.ca

Voluntary Participation and Possibility of Withdrawal

Your participation in this project is voluntary. You are free to refuse to participate. You are also free to withdraw your participation from this research project at any moment, without having to give an explanation. Simply inform the person responsible for the research project (Sarah Frost) of your desire to withdraw.

If you withdraw from the project, would you ask that the audio and written documents that pertain to you be destroyed?

Yes No

Participants initials: _____

It is always possible to change your decision. In that case, the researcher will ask you explicitly if you want to change your decision.

Financial Compensation

You will not receive any financial compensation for your participation in this project. However, as a thank you for giving your time to this project, two movie vouchers will be given to every participant who completes a full interview (vouchers will be given to you at the end of the interview). The movie vouchers will be paid for with the researcher's personal funds.

Confidentiality, Sharing Information, Oversight and Publications

As part of your participation in this research project, the person responsible for the project will collect all the information about you that is necessary to answer the research project's objectives. This information will be assembled in a research file.

Your research file may contain information such as your name, your sex; age, your ethnic origins, audio recordings, as well as information on your history of living with an eating disorder.

All information collected as part of this research project is strictly confidential within the limits provided by law. You will be identified with a pseudonym that only the person responsible for the research project will be able to link to your identity.

The researcher will keep the data collected in locked cabinet, for a period of at least 5 years. The data will be used exclusively in the context of the current research project and will then be destroyed.

The research data may be published or be the subject of scientific discussions, however it will be impossible to identify you.

For the purposes of oversight and control, your research file may be consulted by a person mandated by a regulatory organization, or representatives of the Research Ethics Committee. These persons and organizations adhere to a strict policy of confidentiality.

You have the right to consult your research file to verify the information and rectify any inconsistencies, if there should be any.

Research Results

If you would like to obtain a synthesis of the research results, please indicate an address that we can send them to you:

Email address: _____

Postal address (if you do not have an email address): _____

Contact Information for Resource People

If you have any questions or have a problem related to this research project, or if you wish to withdraw your participation, you may contact the researcher responsible for the project or her thesis director using the following telephone numbers:

Sarah Frost, researcher responsible for the project
819 919-XXXX
Sarah.Frost@usherbrooke.ca

Suzanne Garon Ph. D., thesis director
819 780-2220 ext. 45145
Suzanne.Garon@usherbrooke.ca

Approval of the Research Ethics Committee

The Research Ethics Committee – Lettres et sciences humaines of Université Sherbrooke has approved this research project and will ensure its pursuit. If you have any questions about your rights as a participant, about this research project, or if you have comments to make to the committee, you may contact the Research Ethics Committee at the following telephone number 819-821-8000 ext. 62644 (or toll free at 1-800-267-8337) or at the this email address: cer_lsh@USherbrooke.ca.

Participant's Signature

I have read and understood the information in this consent form. The research project and this consent form have been explained to me. My questions have been answered and I have had sufficient time to make an informed decision to participate. I have considered the information presented in this form and I consent to participate in this research project and the conditions outlined in this form.

I authorize the researcher responsible for the present research project to communicate with me to ask if I would like to participate in future research.

I accept

I refuse

I authorize the secondary use of the research data for the creation of tools and training for social workers and counsellors who work with persons recovering from an eating disorder.

I accept

I refuse

Name of research participant

Signature

Date

Signature of the Person Responsible for Obtaining Consent

I have explained the research project and present information and consent form to the research participant and have answered all the questions he/she has asked.

Name of the person responsible for obtaining consent

Signature

Date

Researcher's Commitment

I certify that the present information and consent form has been explained to the research participant, and that all their questions have been answered.

I commit to respect to the conditions of this information and consent form and to provide a signed and dated copy to the research participant.

Nom du chercheur ou de la chercheuse responsable

Signature

Date

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Vous êtes invité(e) à participer à un projet de recherche. Le présent document vous renseigne sur les modalités de ce projet de recherche. S'il y a des mots ou des paragraphes que vous ne comprenez pas, n'hésitez pas à poser des questions. Pour participer à ce projet de recherche, vous devrez signer à la fin de ce document et nous vous en remettrons une copie signée et datée. Prenez tout le temps nécessaire pour prendre votre décision.

Titre du projet de recherche

Les troubles alimentaires, le rétablissement et la pratique du travail social au Québec

Personnes responsables du projet de recherche

Sarah Frost, étudiante à la maîtrise en service social à l'Université de Sherbrooke est responsable de ce projet. Le projet est supervisé par Suzanne Garon, professeure à l'École de travail social de l'Université de Sherbrooke.

Sarah Frost, chercheuse responsable du projet

Sarah.Frost@usherbrooke.ca

Suzanne Garon Ph. D., directrice du mémoire

École de travail social

Université de Sherbrooke

2500, boulevard de l'Université

A5- 0402

Sherbrooke (Québec) J1K 2R1

819 780-2220 poste 45145

Suzanne.Garon@usherbrooke.ca

Objectifs du projet de recherche

L'objectif principal du projet de recherche est d'étudier le vécu des personnes qui se rétablissent d'un trouble alimentaire dans un contexte communautaire dans trois villes au Québec (Montréal, Sherbrooke, Ville de Québec). Le projet va également explorer les éléments aidants dans le processus de rétablissement ainsi que les barrières au rétablissement et le rôle des organismes communautaires dans le processus. Le partage de votre expérience contribuera à alimenter une réflexion sur le rôle potentiel des travailleurs-euses sociaux dans le processus de rétablissement d'un trouble alimentaire.

Raison et nature de la participation

Votre participation à ce projet sera requise pour une entrevue d'environ une heure et demie. Vous aurez à répondre à des questions concernant vos expériences de rétablissement d'un trouble alimentaire. Cette entrevue fera l'objet d'un enregistrement audio.

L'entrevue aura lieu à endroit qui vous convient, selon vos disponibilités. Le lieu choisi devra permettre la confidentialité des propos échangés durant l'entrevue.

Avantages pouvant découler de la participation

Il se peut que vous retiriez un bénéfice personnel de votre participation à ce projet de recherche (p. ex., réflexion sur le cheminement de rétablissement), mais nous ne pouvons pas le garantir. À cela s'ajoute le fait que votre

participation à ce projet contribuera à l'avancement des connaissances entourant le rôle potentiel des travailleurs sociaux dans le processus de rétablissement des personnes qui vivent un trouble alimentaire.

Inconvénients et risques pouvant découler de la participation

Votre participation à la recherche ne devrait pas comporter d'inconvénients significatifs, si ce n'est le fait de donner de votre temps et de vous déplacer au lieu de l'entrevue (le cas échéant). À tout moment, vous pourrez demander de prendre une pause ou de poursuivre l'entrevue à un autre moment qui vous conviendra.

Il se pourrait, lors de l'entrevue, que le fait de parler de votre expérience de rétablissement vous amène à vivre une situation difficile. Si c'est le cas et que vous souhaitez obtenir plus de soutien, nous vous invitons à consulter les références suivantes :

Lignes d'écoute :

Ligne d'écoute pour les personnes vivant un trouble du comportement alimentaire

Anorexie et boulimie Québec (ANEB)

1 800 630-0907

8h à 3h – 7 jours semaine

Eating Disorder Helpline

National Eating Disorder Information Center

1 866 NEDIC-20 (1 866 633-4220)

9h à 21h – lundi au vendredi

Organismes communautaires offrant des services aux personnes vivant un trouble alimentaire (par région):

Montréal:

ANEB Québec

5500, route Transcanadienne

Pointe-Claire (Québec)

H9R 1B6

1 800 630-0907

www.anebquebec.com

Sherbrooke:

Arrimage Estrie

6, rue Wellington S. Bureau 204

Sherbrooke (Québec)

J1H 5C7

819 564-7885

www.arrimageestrie.com

Ville de Québec:

Maison l'Éclaircie

2860, rue Montreuil

Québec (Québec)
 G1V 2E3
 1-866-900-1076
www.maisoneclaircie.qc.ca

Participation volontaire et possibilité de retrait

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d’y participer. Vous pouvez également vous retirer de ce projet à n’importe quel moment, sans avoir à donner de raisons, en informant l’équipe de recherche.

Advenant que vous vous retiriez de l’étude, demandez-vous que les documents audio et écrits vous concernant soient détruits ?

Oui Non Initiales du participant : _____

Il vous sera toujours possible de revenir sur votre décision. Le cas échéant, la chercheuse vous demandera explicitement si vous désirez la modifier.

Compensation financière

Vous ne recevrez pas de compensation financière pour votre participation à ce projet de recherche. Cependant, en guise de reconnaissance pour le temps donné au projet, deux laissez-passer pour un cinéma de votre région vous seront offerts à la suite de l’entrevue complétée. Les billets de cinéma sont financés par les fonds personnels de la chercheuse.

Confidentialité, partage, surveillance et publications

Durant votre participation à ce projet de recherche, la chercheuse responsable recueillera, dans un dossier de recherche, les renseignements vous concernant et nécessaires pour répondre aux objectifs de ce projet de recherche.

Votre dossier de recherche peut comprendre des renseignements tels que votre nom, votre sexe, votre âge, votre origine ethnique, des enregistrements audios, des informations concernant votre historique de vivre avec un trouble alimentaire.

Tous les renseignements recueillis au cours du projet de recherche demeureront strictement confidentiels dans les limites prévues par la loi. Vous ne serez identifié que par un pseudonyme que seule la chercheuse responsable du projet pourra relier à votre identité.

Les données recueillies seront conservées, sous clé, pendant au moins 5 ans par la chercheuse responsable aux fins exclusives du présent projet de recherche puis détruites¹.

Les données de recherche pourront être publiées ou faire l’objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

À des fins de surveillance et de contrôle, votre dossier de recherche pourrait être consulté par une personne mandatée par des organismes règlementaires, des représentants de l'établissement ou du comité d'éthique de la recherche. Ces personnes et ces organismes adhèrent à une politique de confidentialité.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin.

Résultats de la recherche

Si vous souhaitez obtenir un résumé des résultats généraux de la recherche, veuillez indiquer une adresse où nous pourrions vous le faire parvenir :

Adresse électronique : _____

Adresse postale dans le cas où vous n'avez pas d'adresse électronique : _____

Coordonnées des personnes-ressources

Si vous avez des questions ou éprouvez des problèmes reliés au projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec la chercheuse responsable ou avec la directrice du mémoire aux numéros suivants :

Sarah Frost, chercheuse responsable du projet
819 919-3863
Sarah.Frost@usherbrooke.ca

Suzanne Garon Ph. D., directrice du mémoire
819 780-2220 poste 45145
Suzanne.Garon@usherbrooke.ca

Approbation par le comité d'éthique de la recherche

Le Comité d'éthique de la recherche - Lettres et sciences humaines de l'Université de Sherbrooke a approuvé ce projet de recherche et en assurera le suivi. Pour toute question concernant vos droits en tant que participant à ce projet de recherche ou si vous avez des commentaires à formuler, vous pouvez communiquer avec ce comité au numéro de téléphone 819-821-8000 poste 62644 (ou sans frais au 1 800 267-8337) ou à l'adresse courriel cer_lsh@USherbrooke.ca.

Signature de la personne participante

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m'a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées.

J'autorise le chercheur responsable de la présente recherche à communiquer avec moi afin de me demander si je suis intéressé(e) à participer à d'autres recherches.

J'accepte **Je refuse**

J'autorise l'utilisation secondaire des données de recherche pour créer des outils et formations destinées aux travailleurs-travailleuses sociaux et autres intervenants-es sociaux qui interviennent avec des personnes en rétablissement d'un trouble alimentaire.

J'accepte **Je refuse**

Nom de la personne participante

Signature

Date

Signature de la personne responsable de l'obtention du consentement

J'ai expliqué au participant le projet de recherche et le présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il m'a posées.

Nom de la personne qui obtient le consentement

Signature

Date

Engagement du chercheur ou de la chercheuse responsable du projet de recherche

Je certifie qu'on a expliqué à la personne participante le présent formulaire d'information et de consentement, que l'on a répondu aux questions qu'elle avait.

Je m'engage à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée et datée à la personne participante.

Nom du chercheur ou de la chercheuse responsable

Signature

Date

Annex 3

Recovering from an Eating Disorder in the community is a unique journey.

Want to share your story?

Little is known about how people recover from an Eating Disorder a Quebec community setting. Sharing your experience of recovery from an Eating Disorder could help social workers better understand how to support Eating Disorder recovery in a Quebec community setting.

If you are recovering from an Eating Disorder and have accessed the services or activities of a community organization or group, you are invited to participate in this study on the subject of recovering from an Eating Disorder in a Quebec community setting.

The study consists of a 1.5 hour interview on the topic of your recovery experiences from an Eating Disorder.

Eligibility criteria:

- You must be at least 25 years old
- You must be able to participate in an interview in one of the following cities:
Montreal, Sherbrooke, Quebec City
- You must be recovering from an Eating Disorder (no diagnosis is required)
- You must have progressed enough in your recovery to be living what you consider to be a functional life (a life that is no longer dominated by the Eating Disorder)
- You must have participated in the groups or activities of a community organization in your recovery process
- You must speak English or French

To participate in this study, please contact **Sarah Frost**, master's student at the School of Social Work at Université de Sherbrooke:

Sarah Frost
819 919-XXXX
Sarah.frost@usherbrooke.ca

Two movie vouchers will be given to each participant who completes a full interview.

This research project is supervised by: Professor Suzanne Garon
This research project has been approved by the Research Ethics Committee of the Université de Sherbrooke



Le processus de rétablissement d'un trouble alimentaire dans la communauté est un cheminement unique à chacun-e.

Vous souhaitez partager votre vécu?

Nous possédons peu d'information au sujet du rétablissement des troubles alimentaires dans le contexte communautaire québécois. En partageant votre expérience de rétablissement, vous pourrez aider les travailleurs-euses sociaux à mieux soutenir les personnes qui sont en démarche de rétablissement d'un trouble alimentaire dans la communauté.

Si vous êtes en rétablissement d'un trouble alimentaire et que vous avez participé à des activités ou à des services offerts par un organisme communautaire, vous êtes invités-es à participer à cette étude concernant le rétablissement d'un trouble alimentaire dans le contexte communautaire québécois.

L'étude se fait sous forme d'entrevue d'une durée de 1.5 heure au sujet de votre processus de rétablissement.

Critères d'admissibilité:

- Vous devez être âgé-e de 25 ans ou plus
- Vous devez être en mesure de participer à une entrevue dans l'une des trois villes suivantes : Montréal, Sherbrooke, Québec
- Vous devez être en rétablissement d'un trouble alimentaire (un diagnostic n'est pas requis)
- Vous devez avoir progressé dans votre rétablissement au point où votre quotidien n'est plus dominé par le trouble alimentaire
- Vous devez avoir participé à des activités ou à des services offerts par un organisme communautaire pendant votre rétablissement
- Vous devez parler français ou anglais

Pour participer à cette étude, contactez Sarah Frost, étudiante à la maîtrise à l'École de travail social à l'Université de Sherbrooke :

Sarah Frost
819 919-XXXX

Sarah.frost@usherbrooke.ca

Deux billets de cinéma seront offerts aux participants-es qui compléteront une entrevue.

Projet de recherche supervisé par: Suzanne Garon, professeur à l'École de travail social
Étude approuvée par le Comité d'éthique de la recherche Lettres et sciences humaines de l'Université de Sherbrooke