Not on My Own: Eating Disorder Recovery in Context

by
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Eating disorder (ED) recovery is ill-defined in the research and clinical literatures; the voices of those with lived experience of eating distress are largely absent in recovery configurations. Recovery model proponents argue for person-centered conceptualizations of recovery that attend to systemic constraints. However, biomedical perspectives continue to dominate the way ED recovery is configured. In this dissertation, I take up the question of how people who have experienced distress around food and body and their supporters understand the possibilities, processes, and outcomes of “ED recovery” within a contemporary anglo-Canadian context. I explore barriers and facilitators to recovery, and how systems might better support people in recovery and supporters as they work together to assemble a sense of greater embodied ease. I consider how self-representations of recovery are received by healthcare providers. I conducted a feminist, new materialist thematic analysis of interviews with 20 people in recovery and 14 supporters (chosen by those in recovery). Five of these participants made digital stories (short films) about their experiences, which were screened with 22 healthcare providers, who responded to qualitative pre/post questionnaires about ED recovery.

Participants in recovery explored feeling misunderstood, misrepresented, and mistrusted as they navigated systemic constraints and dominant cultural norms about relationships with food and body, as well as those issued for “how to be recovered”. Surveillance featured in participants’ accounts of both treatment and recovery; more positive experiences of recovery were found amongst highly attuned supporters. Supporters described living at the intersection of
their loved ones’ distress-inducing relationships with food and body. Healthcare providers reported feeling underprepared to treat EDs and expressed a desire for more artistic, person-driven representations of recovery such as the stories they were shown. Participants’ narratives encapsulate interweavings of time, relationality, and space as they enact and perform their recoveries in a matrix of instructions about bodily behaviours. Implicating new materialist, feminist theoretical frameworks complicates a singular, linear, and choice-based logic of recovery. The multiple versions of recovery articulated by participants reveals the need to engage with uncertainty to promote recoveries that do not rely on dominant imperatives to be self-managing subjects.
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Chapter 1: Introduction

What “we” know about eating disorders and recovery depends on who “we” are, and who “we” ask. In an academic dissertation, written by a white, thin, heterosexual, cisgender woman living in a western context, these “we”s take on immediate significance and unmarkedness that is worth problematizing. The voices of those with lived experiences of having engaged in behaviours that have attracted the label of eating disorders have been binarized with the “professional” voices that define and delineate what constitutes eating disorder recovery, at least in the clinical imagination. People with lived experiences of distress around food, exercise, weight, and shape, are not silent about their experiences, or their definitions of recovery. And yet, a read of the literature reveals an absence of these voices in what comes to constitute the “evidence” for what recovery “is”: what it looks like, presents as, and even feels like. There are qualitative studies on recovery; this is not a question of quantitative versus qualitative, but rather an exploration of the positions from which people writing about “eating disorders” write, and for and about whom they are writing. To begin this dissertation with a reflection on this absence is to identify a contradiction even in my own writing: I write from a place of privilege about a subject around which I am expected to hold an “academic distance.” I also write from a place of lived, embodied experience of feeling at odds with my body and having behaviors marked out as pathology; a place of having encountered “the experts” from the “other side.”

Inevitably, in my writing, I will draw on literatures that have contributed to the presentation of eating disorders, and recovery, as singular. I will draw on a body of literature that is profoundly disembodied in writing about embodiment—a paradox feminist scholars across disciplines before me (e.g. Chadwick, 2017; Weiss, 1999) have marked out. I also draw on literatures from feminist scholars who have long critiqued this distancing and tried to imagine the
situated and embodied entangledness of all behaviors, including those around food, weight, exercise, and shape (e.g. Bordo, 1993; 2009; Hepworth, 1998; Malson, 1998; Orbach, 1986; Saukko, 2008). These scholars have chosen various points of entry into exploring eating disorders—some as embodied experience, others as cultural phenomena, many as both—and have built the grounds on which I begin my exploration. As I will remark upon, these literatures rarely come into conversation with those aspiring to cast off the scientific “taint” of bias and enfoldedness into culture. In this dissertation, I will bring these seemingly disparate worlds into conversation, as well as putting them into conversation with the lived, embodied experiences of my participants. I will reflect on my own entangledness in these conversations, including in activist and advocacy work and through my own constantly moving experience in my body. My choices of terminology reflect a desire to build bridges between worlds bearing deeply inconsistent epistemologies, ontologies, and methodologies, and will be critiqued for this. And yet, to me, this is a critical task: a moment of infusing clinical, expert discourse with embodied experiences of at least a small subset of those who have experienced shifts in their bodily experiences from more to less distress. My writing will, at times, mirror that which I critique: the distanced, pathology-focused expert writing that characterizes much of the “eating disorder literature.” This, too, is deliberate. Moving in and out of linguistic conventions for discussing these experiences is an attempt to speak on multiple registers, and perhaps to intervene into dominant codes with alternative ones.

This eclecticism might be framed as a kind of “code-switching,” moving from one lexicon to another in order to be made intelligible, a practice that Gumperz (1962) and others argue has a social function. The “codes” I am working with may themselves be diverse; there are fluid boundaries between them, as well. Not unlike the use of different codes or dialects for
intelligibility and group identification (Auer, 1998), the use of writing conventions tethered to
different disciplines and ontologies presents an opportunity for fusion, but not without
contestation. Blending may lead to the creation of a new form of communication from different
modes of speech (Alvarez-Cáccamo, 1998). Whether or not I have been effective in my code-
switching will be at the interpretation of the reader, but bears mention immediately prior to the
beginning of my work. In this blending, as I will discuss, I am also creating an “assemblage”
(Deleuze & Guattari, 1987); a bringing together of frames, voices, perspectives, stories,
embodiments, and realities to generate a picture of the experiences of eating disorder recoveries
that have existed in particular times and places, and that may be read through various lenses. In
this bringing together, we might also consider the affective spaces of care in which “recovery”
takes place – the way that emotions and sensations operate within the planes of interaction that
comprise recovery assemblages. These “affective economies” (Ahmed, 2004) play out
throughout the corpus of data I consider in this dissertation, including the cartographies of
knowledge, interviews, digital stories, and screening data, and provide evidence for the flows of
power around “eating disorder recovery” and the power of ideas and emotions in shifting
people’s orientations.

In this dissertation, I will explore questions related to the recovery assemblage for people
who have experienced distress around food and in their bodies and their supporters. I will trouble
the lines between recovered/disordered, as well as the language and theories that scaffold those
very terms. The dissertation begins with a review of the literatures related to eating disorders and
recovery from “mainstream” and “feminist”¹ perspectives, the role of families in eating disorders

¹ Both of these terms will be taken up and problematized throughout the dissertation, but act here
as shorthand for the broad bodies of literature considered herein.
and recovery, the recovery model and an anti-psychiatry and mad-studies oriented critique of psychiatric models, and the intersections between these areas. I will map the contours of the sociopolitical spaces around these bodies of literature and explore their uptake amongst those in eating disorder research, treatment, and advocacy spaces throughout. Moving to the empirical studies described herein, I will outline the methods I used in gathering and analyzing data, including interviews, digital storytelling (short-film-making), and screenings of stories with healthcare providers. In total, I spoke with 20 people “in recovery” and 14 supporters (selected by people in recovery). Five participant made digital stories, which were screened with 22 healthcare providers. Thematic and case study analyses of this data were scaffolded in a new materialist feminist approach that implicates the various flows and ebbs of power structures, including both human aspects (e.g. social positioning and perceived social positioning, relationship structures between individuals experiencing eating distress and their supporters and would-be informal and formal supporters etc.) and non-human aspects (e.g. treatment modalities encountered, technologies of care, affect, etc.).

Analyses reveal a complex web of factors that comprise the recovery experiences described herein. As I will discuss, the complex, affective, relational, and dynamic quality of recovery experiences foregrounds a perspective on recovery that configures “it” (or, more accurately, “them”) as similar to life itself. Participants’ experiences with informal and formal supporters and care providers interacted with their spaces of social belonging and embodiments to inform their perspectives on what constitutes recovery, how to get there, and where they fit into broader social discourses on recovery, health, and wellness. Their insights offer us theoretical and practical insights into the ways in which healthcare and other settings might begin to reconfigure understandings of and treatments for people experiencing distress around food and
in their bodies in light of a fraught social landscape of food and bodies. Supporters, too, detailed experiences of tension between personal and relational experiences related to eating distress and broader health discourses that individually responsibilize (or, in the case of a support relationship, relationally responsibilize) people for their own health and wellbeing. In experimenting with affectively attuned ways of being around their loved ones, and in interaction with systemic constraints both tangible and ideological, supporters developed different ways of understanding recovery.

Screening digital stories made by participants with healthcare providers offered insight into the under-preparedness of healthcare providers to attend to complex and diverse needs. Layered onto the fraught experiences many participants had with healthcare systems that mistrusted, misunderstood, and misrepresented them, healthcare provider insights into their learning from the stories reveals how we might shift systems not by prescribing singular solutions or narratives, but instead by opening to the unfinished, the complex, and the relational. Together, as explored in the discussion section of this dissertation, these analyses carry theoretical weight: they speak to the need to engage not only with the “before” and “after” of recovering and recovered bodies, but instead to the sticky and partial meanings that recovery holds for people experiencing it in a broader Western culture and in their own spaces of social belonging. They invite us to build deeper dialogues between eating disorder recovery discourses and other recovery model work, including that which problematizes the potential for a focus on “personalized recovery” to be co-opted by a neoliberal orientation toward individual responsibility for health (McWade, 2015; Morrow, 2013; Poole, 2011). On a practical level, the results open up the possibility of radically trusting those experiencing eating disorders, rather than imposing rigid strictures on behavior; this shift further reflects a desire to turn toward
explanations of eating disorders that do not rely on biomedicalized markers to denote legitimacy. Instead, participants’ stories, and the analyses herein, reflect a desire to open to difference, to trust, and to resist pathologization, while recognizing the ways in which these, too, can speak to people’s need to find legitimized explanations for their experiences.

1.1 Context and Background

1.1.1 “Eating Disorder Recovery.”

“Eating disorder recovery,” despite ostensibly being the “end point” for any treatment or efforts toward combatting a distressing relationship with food, remains poorly defined in both the research literature and the popular canon. Efforts to define eating disorder recovery stemming from academic and clinical contexts, generally in the anglo-western world, have been focused on measuring the absence of symptoms that collectively signal diagnosable eating disorders in diagnostic manuals including the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 2013) and the International Statistical Classification of Diseases and Related Health Problems (ICD) (World Health Organization, 1992). From a clinical perspective, symptom remission often acts as a marker for a person’s readiness to leave treatment or to step down to a lower level of care (e.g. Geller, Goodrich, Chan, Cockell & SriKameswaran, 2012; Yager, Devlin, Halmi, Herzog, Mitchell, Powers & Zerbe, 2005). However, there is widespread agreement in the professional community that symptom remission does not itself constitute full recovery from an eating disorder; it simply means that one is no longer engaging in behaviours codified as psychologically and physically limiting (e.g. Bardone-Cone et al., 2010).

Work is currently underway to establish a consensus definition of eating disorder recovery, building on an acknowledgment within the field that we need a more actionable definition of this phenomenon (LaMarre, Bachner-Melman, Oberlin, Hartman McGilley, de Vos & Dooley-Hash, forthcoming); in some senses, the pursuit of a consensus definition is itself a
technique of power that wallpapers fundamental uncertainty. The need for, practicality of, and likelihood of such a definition is an open question, one that will continue to feature as a tension throughout this dissertation. Further, the establishment of such a definition operates itself as a technology of power much in the way that the DSM and other similar clinical categorizations of “eating disorders” marks some as well and others as ill—often along particular sociodemographic lines. Different stakeholders desire and require such a definition for different reasons – ranging from the ability to compare treatment outcomes to the provision of a “seal of approval” for one’s enacted recovery, and those representing these various interests themselves hold different perspectives on the possibility, utility, and practical use of a consensus definition of eating disorder recovery. As Noordenbos (2011b) notes, better understanding of how and why differences in conceptualizing recovery exist is a key task of researchers oriented toward understanding this phenomenon.

Despite the acknowledgment that the eating disorders field needs to focus on better understanding the “what” of eating disorder recovery (i.e., what it looks like and feels like), the prevailing focus for over twenty years has been a methodological preoccupation with isolating factors involved in reaching recovery; in other words, variables that promote or detract from the achievement of recovery. Further, the factors isolated as helpful in facilitating recovery are largely individual traits, thoughts, or behaviours. If relationships are examined, they are often seen as variables in the model of reaching eating disorder recovery, or mediators/moderators of a linear pathway to an endpoint of recovery – an endpoint that remains poorly articulated. Though researchers acknowledge that eating disorders do not occur in a vacuum or vector, and are in fact produced in particular contexts (e.g. Easter, 2012, 2014; Bordo, 1993, 2009; Burns, 2004; Hepworth, 1998; Malson, 1998; Warin, 2010), eating disorders and recovery alike are often
treated as if they can be understood solely by isolating specific factors or variables involved in their production. What is often missing from research around eating disorders and recovery is a thorough exploration of the factors that people in recovery from eating disorders understand to be important contributors to living their lives and the specific sociocultural and political-economic circumstances in which this living is done, in which theorizing about eating disorders is produced, in which treatment occurs, and in which definitions of recovery itself are negotiated.

There has been an opening to the “recovery movement” within the mental health field more broadly taking place alongside a problematization of the push toward “cure” for variants in mental health amongst critical health psychologists, mad studies scholars, and members of the consumer-survivor movement (Everett, 1994; Nelson, Lord & Ochocka, 2001; Rismiller & Rismiller, 2006; Tomes, 2006). Rather than conceptualizing recovery as a return to some state ostensibly identical to life prior to the state coded as pathology, the recovery movement positions it as a journey toward finding personal meaning in life (Anthony, 1993). This orientation has gained ground amongst those who have experienced mental distress. It is less commonly adopted in eating disorder treatment, though this exclusion not without exception (e.g. Dawson, Rhodes & Touyz, 2014; Musolino et al., 2016). It is most commonly employed when referring to eating disorders deemed “severe and enduring” (e.g., Robinson, Kukucska, Guidetti & Leavey, 2015). Situating eating disorder recovery in a sociocultural milieu replete with troubling relations with food calls for a contextualizing and complicating of recovery. While eating disorders diagnosed using DSM criteria are reported to be prevalent across the lifespan at 1.5-3.5% (Hudson, Hiripi, Pope & Kessler, 2007), eating labelled “disordered” is much more common, with some recent studies reporting figures as high as 10% (Solmi, Hatch, Hotopf, Treasure & Micali, 2015) to 31.1% (Reba-Harrelson, Von Holle, Hamer, Swann, Reyes & Bulik, 2009). These studies may
not capture the full range of distress-inducing experiences around food and in bodies that tend to be taken for granted, considered to be a part of regular self-monitoring and management in a society wherein dictates for avoiding obesity are proliferate (Gard, 2011; Gard & Wright, 2005; Rail, 2012; Rail, Holmes & Murray, 2010; Wright & Harwood, 2009).

To re-situate eating disorders within this complex landscape of affective relationships with food and body, researchers might re-orient toward the question of what constitutes an eating disorder, and how to respond to this kind of embodied distress. For instance, a critical feminist frame places behaviours associated with eating disorders along a continuum, situating eating within a specific cultural context and a particular period of time (i.e., an anglo-western context in the 21st century, in which diet culture is normative and bodily discontent common, if not expected). Using a critical feminist lens allows for a problematization of “normal eating” itself as an unstable construct, one whose meanings shift depending on context (LaMarre & Rice, 2016a).

Re-considering what different people mean when they say “eating disorder” can help to shift perspectives on what constitutes recovery. Recovery is often framed as “becoming whole again” (Jenkins & Ogden, 2012). However, this framing may not always hold if we do not consider the person with the eating disorder to be broken, false, or inauthentic when they are in the throes of what has been coded as pathology (Lester, 2016; Saukko, 2008, 2009). When recovery is framed as a return to wholeness, we assume a) that the person occupied a normative, “unbroken” body prior to the development of distressing relationships with food and body and b) that the desired outcome of treatment is, likewise, a body that is deemed socially (and contextually) normal. Dominant constructions of recovery can render specific bodies “unrecoverable”—particularly those bodies that are not recognized as “legitimately disordered” (e.g., racialized bodies, larger bodies, queer bodies, disabled bodies, etc.) and whose bodies will
remain “abnormal” when normativity is a condition for living (LaMarre, Rice & Bear, 2015).

From a critical feminist perspective, eating disorders can never be isolated from context –
including broader, systemic and political-economic context, as well as more immediate relations
to family, friends, and local cultures (Bordo, 1993, 2009; Burns, 2004; Hepworth, 1998; Malson,
1998; Pirie, 2011). In order to understand distress around food, weight, and shape (and the
experience of not being or not always being in distress around food, weight, and shape), we need
to look beyond the individual and understand how such experiences are produced in and co-
influential with sociocultural surround.

A body of literature outlines the experiences of informal (unpaid) caregivers of those
with eating disorders, who are also typically framed as non-experts (e.g. Bulik, Baucom &
Kirtby, 2012; Sepulveda et al., 2008). Likewise, there are many studies that attempt to ascertain
subjective experiences of eating disorder recovery from a qualitative perspective (e.g. Dawson,
Rhodes & Touyz, 2014; Malson et al., 2011a; Noordenbos & Seubring, 2006; Walsh, 2008).
However, there are fewer accounts of the experience of eating disorder recovery from the lived
experience perspective of informal caregivers or, as they will be termed here, supporters (for
exceptions, see Dimitropoulos & Freeman, 2016; Linville, Brown, Sturm & McDougal, 2012).
Less common still are analyses of recovery that explore how interpersonal differences in
understanding and experiencing eating disorder recovery impact the individual and the supporter
experiences of recovery. Supporter experiences are most often positioned as external to the
individual in recovery, aspects of experience that can be fully accounted or controlled for in
order to isolate specific individual variables implicated in recovery. As Price-Robertson,
Manderson & Duff (2017) note, however, “the messy constellation of people, institutions,
environments and objects on the whiteboard suggests that mental health recovery is hardly the “deeply personal” (Anthony 1993, p. 17) process that it is often presented as” (p. 2).

Further, heteronormative structures of “family” are often left unquestioned in research that focuses on relationships in the lives of those with eating disorders. This literature largely centres the experiences of mothers, assumes a two-parent household in which the mother has the primary caregiving responsibility, and presumes that the person with the eating disorder is young and living at home. In this focus, the literature reinscribes dominant notions about who might develop an eating disorder and about the context in which they might develop or recover from it. In this research, I use the term “supporter” to encompass both those informal caregivers who do occupy mother or father roles (as normatively conceptualized), but also chosen kin including partners and friends. I will expand on this choice in a section outlining research on informal caregiving and family experiences of eating disorders; briefly, the choice reflects a desire to resist normative notions of who is caregiving for whom, but also a commitment to honouring the unpaid, often unseen, and highly gendered labour of those who do occupy more normative caregiving positionalities. I adopt a perspective on recovery that invites us to consider not how supporters might be “resources” for recovery but rather how they might be understood to form an intimate and integral part of the affective, embodied experience of recovery. Here, the “recovering self” is not removed from the social world but always entangled with its flows (Fullagar, 2018).

1.1.2 Research Questions.

The focus of this dissertation is eating disorder recovery. However, in “conceptualizing” recovery, I reposition the concept of eating disorder recovery as an assemblage, looking at recovery not as a static idea or phenomenon but rather a collection of different materialities and
ideas, forces and fixities. I attend to its flows, expressions, affects, relationships, and manifestations amongst people in recovery within their social worlds. These questions are provisional frames to guide the overall investigation of the assemblage of eating disorder recovery in a particular historical time and space: participants’ accounts reflect their embodied experiences of eating disorder recovery in Canada in the 2000s. This geographical orientation may seem limited, but rather than invoking nationalism, the intent is to foreground how recoveries will always be coloured by context, including geographic and ideological locations. Further, in exploring recovery in the Canadian context in particular, we might explore what is present and what is lacking in terms of desired support for people experiencing suffering here and now.

Broadly, I ask: How do people who have experienced distress around food and body and their supporters understand the possibilities, processes, and outcomes of “eating disorder recovery” within a contemporary anglo-Canadian context? In order to situate this work systemically and generate data that will be useful on a policy level, I ask: What barriers and supports do individuals and their supporters experience as they navigate the continuum of care for eating disorders within a Canadian context? How might systems better support diversely embodied individuals and supporters as they work together to assemble “recovery” or a sense of greater embodied ease? Further, I inquire: How do people in recovery and their supporters creatively represent their experiences through digital storytelling? How does viewing digital stories (3-5 min, first person films created by participants) about eating disorder recovery created by individuals in recovery and their supporters impact healthcare providers and their understandings of the recovery assemblage?
I emphasize context because stories and themes are always contextual – not in terms of “context as variable,” but rather in terms of how “environments” flow through data and its analysis. The analysis of these participants’ accounts also reflects my own embodied lens on the stories, as well as an immersion in the eating disorders research, treatment and advocacy spaces over the past 6 years. I relate to the data not as a “knower who knows” in a humanistic sense (Berbary & Boles, 2014, p. 407), but rather a researcher who seeks to “bring the body back in” (Frank, 1990, cited in Chadwick, 2017, p. 54) to qualitative research through “embodied methodologies […] which reflect the multifaceted, contradictory, ambiguous nature of lived experience and the ways in which it defies easy categorization” (Inckle, 2010, p. 27). By this I mean that while I have training in conducting qualitative research, and follow methodologies that allow me to make meaning of experiences, I am not seeking to impose my perspective on the data as a singular truth or fixed reality. I do not have the exact same lived, embodied experiences as participants, and thus my interpretations will always and necessarily be incomplete “knowledge” of the “true” experience of being in these bodies.

The question of how to collect and analyze data in a way that yields insights about embodied experiences that might be leveraged for policy change is an open one. Considering how “stories are told not just about bodies but also through bodies” (Chadwick, 2017, p. 58) I approach these research questions recognizing that answers will necessarily be partial and contextual, but will also reflect the participants’ embodied experiences and a multiplicity of voices that have impacted these experiences – including relationships in their lives, medical systems in which their lives have at times been entwined, and broader social forces and relations of power. “Results,” then, might be considered helpful in structuring more fluid and flexible systems to scaffold recoveries – the ultimate aim of the work – but will necessarily miss the
embodied needs of those not included in the project. This caveat is offered as a way of expressing that the answers to the above questions will reflect not universal experiences of recovery, but always contextual, always embodied, and always intercorporeal flows of recovery for these particular participants in this particular time and place.

1.1.3 Linguistic Specificity.

Before continuing to explore my theoretical framework, the broad aims of this project, and the relevant literature, I will consider the role of language in order to foreground my use of specific terms throughout the dissertation. A major aim of my research agenda is to engage with critical and mainstream perspectives alike in order to build bridges between seemingly disparate theoretical frames and paradigms. A concern I have in reviewing the critical feminist and mainstream literatures on eating disorders is the lack of engagement between more post-structural, critical theory-oriented explorations of eating disorders and applied, often biomedically-based, engagement with eating disorders. Critical feminist eating disorder literature offers much in terms of exploring the political economic, socio-historical and cultural situatedness of eating concerns; yet, these have not been taken up in dominant frameworks, despite ostensibly sharing aims around improving the lives of those who face distress around food, weight, and shape. Perhaps a part of this lack of engagement is tied to how critical feminist work, often from a poststructural orientation, often problematizes the individualizing and universalizing lens most commonly taken up in mainstream eating disorder literature, as well as challenging the types of expertise inscribed upon individuals’ experiences. Doing so may result in those who “speak different languages” about eating disorders (or, in other words, look at eating disorders through different lenses or paradigms) not being able to establish shared understandings of what eating disorders are, what they mean, and how they impact people.
I do not think it is realistic to propose that scholars and clinicians from across disciplines and paradigms should establish perfect agreement about the terms they use, and recognize that calls for linguistic specificity can themselves reinforce a scientism or positivist outlook on “accuracy.” We cannot pretend, equally, that each of our experiential and disciplinary legacies are neutral. As Callard & Fitzgerald (2015) note, drawing on Cooter (2011, 2014): “we are […] co-producers of the very epistemic power from which we claim to distance ourselves” (p. 207). However, for the purposes of this dissertation, I take a playful and improvisational approach to working toward a shared understanding of the terms of engagement that I hope will speak to those speaking and writing about eating disorders from across paradigms. Feminist and poststructuralist scholars have chosen different ways of problematizing the terms “eating disorders” and “recovery,” for instance, modifying the language by adding a slash or a hyphen, or putting the terms in scare quotes. These methods disrupt the expert discourse that marks out and pathologizes certain behaviours, and certain bodies, for intervention. I have chosen not to modify the terms, in order to increase the likelihood of alternative analytic and theoretical approaches to understanding eating disorders and recovery being “heard” by those who use the terms without considering their sociohistorical situatedness. Writing, and speaking, are always necessarily partial ways of exploring embodied experiences – but language is and has power (Foucault, 1970). Critical theory allows us to think outside of “what is,” in part by creating new language that values other types of knowledge and moves away from language that has been inscribed on people and their bodies and that carries traumatic and historical roots. As Olson (1998) points out:

Because the English language is a communal inheritance, the act of using this language to communicate may paradoxically entail complicity with transmitting the manifestations of
racism, sexism, and the like that are embedded in it. Consequently, language is never simply a tool that an individual employs to bring about political and social changes (p. 448).

There exist different strategies for navigating the fraught space of language. The one I employ in this dissertation is to recognize that in some ways, using normate language and a critical feminist frame presents a paradox. There is a danger in using language that has been essentializing and traumatizing; there can also, however, be power in reclaiming this language (Olson, 1998). My attempt in doing so is to speak on multiple registers using the same plane of language (Braidotti, 2015). As a person with lived experience of an eating disorder, I recognize the constraint and freedom that coexist in the diagnostic terminology: the ways in which this language allows access to treatment and resources for some and not others, the relief associated with having a name to put to an experience, and the profound difficulty of escaping the label once it has been applied. Given the political aims of this work, it feels important to use these sticky and troublesome terms as they are used in the policy, research, and treatment work on eating disorders to bring criticality into the mainstream.

Briefly exploring the potential problematics of the terminologies used herein helps us to explore why a challenging of this language might have been needed in the first place. The problematization of the word “recovery” is based on the idea that it contributes to a narrative of cure and suggests a return to a state prior to the eating disorder, which is impossible within a framework that considers subjectivity to be continually in flux (McWade, 2015). From a post-

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2 Not all perspectives on recovery presume that all things can be cured; a recovery model perspective will be explored and discussed, including possible critiques of the perspective. In short, recovery model perspectives foreground the fulfillment of meaningful lives to the individual (e.g. Anthony, 1993).
structuralist perspective, we might question how the term “recovery” implies movement toward some category of experience deemed “normal” (Howell & Voronka, 2012). Normal is not a real or natural category, but rather a (discursively) constructed one – grounded in the search for a “cure” for functioning deemed aberrant, normality is a category that will always be unavailable (and sometimes even undesirable) to some (Davis, 1995). “Re”covery means assuming that there is a normality lurking inside of every individual, clouded by the symptoms of an eating disorder and able to be achieved by shucking off the shackles of pathology. This may enforce the problematic assumption that someone using behaviours deemed eating disordered is somehow false or inauthentic while they are engaged in behaviours marked as eating disordered (Lester, 2016; Saukko, 2008, 2009). Such perspectives on recovery prominent in the eating disorders literature conflict with broader mental health discourses on recovery that will be discussed in more detail in the following section. A perspective on “recovery as both a personal and social experience” (Morrow & Wiessler, 2012, p. 28) repositions recovery as deeply entwined with social inequities and possibilities rather than biomedicalized visions of what it means to be experiencing mental illness and to recover (Morrow, 2013). This contrast reveals the ways in which perspectives on eating disorder recovery lag behind the (still imperfect, and often top-down) perspectives on recovery present in broader mental health discourse.

Critiques of the use of the terms eating disorder (and each of the DSM-approved diagnoses included in this category, including anorexia nervosa, bulimia nervosa, binge eating disorder and other-specified-feeding-and-eating-disorder) and recovery are well taken. Probing beyond DSM categories is a key element of my theoretical approach. Even from a pragmatic perspective, requiring participants to have received a DSM diagnosis immediately excludes from research those who (a) have not sought a diagnosis because of the significant barriers to access
that many face on a structural level; (b) find psychiatric practice to be traumatizing or inappropriate for personal, political, or cultural reasons; and (c) do not fit the “expected” picture of an eating disorder either due to complex social locations or difference uses of food than those recognized as eating disorders in diagnostic canon. It immediately positions research within a well-established body of literature wherein researchers continually lament the lack of diversity in their samples without considering how the very procedures used in the research make their approaches inaccessible to many. Further, categories “tidy up” experiences in a way that immediately makes some experiences seem less worthy, despite the fact that there may be many more people who do not neatly fit into diagnostic categories than people who do (Wonderlich et al., 2007). Nonetheless, the use of the terminology that pervades the eating disorder literature is a pragmatic choice: it allows me to situate this work in direct conversation with the significant debates and tensions in the field.

It can be beneficial to challenge this linguistic convention; doing so acknowledges the power that language holds to label and re-inscribe power upon people with lived experience. However, we are also theorizing about and proposing solutions for distress around food, weight, and shape within a specific system that does recognize certain forms of expertise as inherently more valuable and that may automatically push aside any theorizing that appears to do away with their frames of reference. These systems (and the dominant mode of thinking within them) tend to privilege autonomy, individuality, and unified subjectivities as demonstrations of wellbeing (Blackman, 2007). This may make articulating a recovery beyond “individual achievement” alienating to those who work within dominant paradigms. We might also consider the role of hope for those actively struggling and their supporters, who exist within a paradigm wherein
hope is instilled in scientific cure (Blackman, 2007). At times, participants may endorse perspectives that would be troublesome for those who challenge dominant notions of expertise.

In order to begin to bridge paradigmatic gaps, we might consider how dominant discourses are not simply “bad” or “good” – all discourses are both good and bad; both problematic and beneficial in turns and sometimes both at once (Foucault, 1979). However, some discourses come to dominate, excluding certain people who do not fit the narrow confines of belonging delineated by the discourse. Acknowledging that discourse is neither wholly negative nor wholly positive is not a matter of claiming their power or moral equality—rather, it is a way of understanding that we cannot simply throw away one discourse and replace it with another. Discourses constitute as they are constituted, and create multiple and often conflicting meanings (Weatherall, 2012). An analysis of discourses helps us to see and understand how and why inequalities continue to exist and mushroom despite our awareness of them (Weatherall, 2012). We might also explore how despite the constraints of discourse, people negotiate and subvert discourse with alternatives each day as they live their lives (e.g. LaMarre & Rice, 2016a; Rinaldi et al., 2016).

We contribute to and negotiate multiple discourses at once, and these are not imposed upon us but rather built through interaction (Foucault, 1979; Potter & Wetherell, 1987). As a feminist scholar, I may problematize the inscriptions on subjectivity tethered to the term “recovery” and its biomedical leanings, but I cannot ignore the power that dominant, biomedical, and at-times individualizing discourses hold for some with lived experience (Easter, 2012; 2014; Eli, 2014), and write onto their understanding my own preferred, highly political, understandings of their distress. To engage in an analysis that resonates with participants’ lived experiences, I must acknowledge that participants shape their subjectivities within a particular sociohistorical
setting. Acknowledging this does not position participants as passive consumers of this setting; many can and do push at the boundaries. However, awareness and pushback are not immunity to the sway of social dictates and models of understanding. I acknowledge that some may argue that attempting to engage with both post-structural (and post-post structural) and mainstream discourses and terms leads to problematic eclecticism in research (Allport, 1964). My intent is not to erase difference, but to bring together into an assemblage (Deleuze & Guattari, 1987) different frames and ways of understanding the world – even from an ontological standpoint – that allow us to make more complex accounts and post hoc analyses of experiences that risk losing nuance when approached from a single lens.

For this reason, and due to a commitment to making change from within the power systems we are all a part of and that shift and change, rather than breaking and becoming radically new, I often use normative terms while at once problematizing them and challenging their inscriptive power. I use the term recovery to refer to the movement toward a state of qualitative difference following a period of experienced distress around food, weight, and shape. Although I acknowledge that cure can mean different things to different people using it, I also recognize how cure can itself impose expectations of reclaiming normative embodiments onto those experiencing it. I use the term “eating disorder” to capture a wide array of distress around food, weight, and shape, while also acknowledging that some have experienced this label as traumatizing and inappropriately imposed upon their experiences, as well as the fact that some face barriers to obtaining a label that may have helped them to access the kinds of support they need and desire.

At times, I use the word “patient,” when referring to experiences of treatment, though I do so selectively with the acknowledgment of the historical surveillance of women’s bodies in
particular and how “being patient” in the clinical context carries with it inherent inequities in power that territorialize bodies (Fox, 2011). We might even problematize the term “sufferer” as holding a tone of judgment about how an individual experiences their body during an eating disorder and making that individual passive in relation to pathology. Sufferer is a term that may also reduce the person to pathology—a discursive move that can paradoxically limit the person’s ability to imagine themselves otherwise (Malson et al., 2011a). Others (Weissman et al., 2016) have proposed avoiding the use of “sufferer” or “struggling with an eating disorder” in favour of adopting clinician labels or “less emotionally charged” terms like “treatment-seeking” or “exhibiting an eating disorder or related symptoms” (Weissman et al., 2016, p. 352). However, given that not all participants in this study— or who experience eating disorders in general—claim or feel attached to their clinical labels or seek treatment for their distress, these alternative terms are not necessarily preferable for this study. I have used the term “sufferer” when participants refer to their affective experiences of suffering, to acknowledge their lived experiences. At other times I have invoked the more clinical “person with an eating disorder” or simply referred to the person by (pseudo)name when referring to an individual, and “participants” when referring to the group. Again, given that DSM language has infused personal sense-making (Moncrieff, 2010), if participants chose to label their eating disorders my inclination was to follow this self labelling. In interviews, I explicitly asked participants how they chose to refer to their distress and also to their recoveries, and endeavored to reflect their choices in this work.

It is also worth exploring the use of the word “family” to refer to close others in my participants’ lives. In my dissertation work, I used the term “supporter” to refer to participants’ selected family—those they elected to include in interviews and digital storytelling. Family
theory researchers have long noted the challenge in conceptually and legally defining family (Goode, 1982). The predominance of the nuclear family has marched on relatively unchecked in Western research in particular, despite some notable expansions of which types of people might be included in that (private, bounded) biologically or legally constituted structure/entity (Holtzman, 2008). In the context of eating disorder research, family as entity is rarely defined; while close others in sufferers’ lives may be included in research studies, a perspective of “family” as two parents (or at least one parent) caring for a child looms large in studies of the family role in eating disorders, treatment, and recovery.

In this literature, family is generally considered to mean “mother” and “father,” without unpacking the implications of this framing. For instance, Holtom-Viesel & Allan’s recent (2014) meta-analytic study of family functioning in eating disorders includes comparisons of mothers’ and fathers’ orientations to their child during the eating disorder, without complicating the picture of what a family might be. This conceptualization of family may inadvertently reinscribe stereotypes about who might suffer from an eating disorder: namely, an adolescent, generally white and Western, from a two parent, generally middle-class, heteronormative and cisnormative nuclear family. Recruiting for and obtaining samples of families may reproduce normativity in eating disorder research by immediately excluding those who do not exist in the expected family relationships.

In my dissertation work, I will use the terminology of supporter when referring to the people participants have selected to participate in the work, as these are the people that participants’ *found to be supportive* during their distress. These people sometimes fulfill roles in participants’ lives more commonly associated with “family” – but not always. Unless otherwise noted, I use the term family when I am referring to the “assemblage of heterogeneous
components (e.g., bodies, practices, objects, stories and everyday interactions) that form contingent relations across time to produce an emergent whole with a collective identity” (Price & Epp, 2015, p. 60). Not all familial relations across time are positive, but they are all in some way constitutive of embodied experience. These are not necessarily the relationships that have become the focus of this dissertation. Thus, I use the term “supporter,” a person who may or may not be a part of the family, which connotes a generally helpful relationship – but one that, as will become clear – is not always uniformly positive either. The support assemblage may also be comprised of heterogeneous components, and is made up of contingent relations, temporally bound (Price & Epp, 2015). A supporter may be a part of the family assemblage, but a family member is not automatically a part of the support assemblage. It is my hope that by choosing the term supporter and playing with notions of what constitutes “family” this research might be more inclusive of those whose most important relationships are not held with those to whom they are related by blood or legal documents but rather those with whom they have other affective ties that impact their lives in significant ways. At times, participants’ own choices of terminology dominate, particularly in quotes. In these instances, I defer to participants’ preferred self- and other-labels.

1.2 Literature Review

1.2.1 Eating Disorder Recovery: The Recovery-Etiology Link.

Eating disorder recovery occupies a place of contention within the research literature and within clinical practice (Yu, Agras & Bryson, 2013; Bardone-Cone et al., 2010; Walsh, 2008; Herzog et al., 1999; SteinhAUSEN, 2002). Part of the contentiousness of eating disorder recovery rests on the unfortunate fact that eating disorders themselves remain relatively poorly understood amongst researchers and clinicians. A preoccupation with understanding eating disorder etiology has yielded numerous explanations, nearly all of which end with a concession to the fact that
these disorders are complex, multi-faceted, and multi-dimensional (Strober & Johnson, 2012). Strober & Johnson (2012) highlight how specific models for the genesis and maintenance of eating disorders have come to dominate the landscape of eating disorder research. Eating disorders are increasingly framed as borne of “faulty wiring” or biology, termed “biologically based mental illnesses” (Farrell, Lee & Deacon, 2015; Strober & Johnson, 2012). Some have found that this framing is helpful for alleviating the significant stigma and shame that has accompanied the diagnosis of eating disorder, though this is not universally the case (Easter, 2012; 2014; Farrell et al., 2015). Over the past 10 years in particular, we have seen an expanding body of literature highlighting the biogenetic roots of eating disorders and addressing the brain as a site of intervention (e.g., Kaye, Fudge & Paulus 2009; Klump, Suisman, Burt, McGue & Iacono 2009). This framing is commonly advanced as a means of reducing the stigma associated with seeing eating disorders as borne of volitional control (Crisafulli, Von Holle & Bulik, 2008).

A preoccupation with the biological aspects of eating disorders has arguably been a part of the rise in interventions designed to address brain functioning, for instance and perhaps most popularly, deep brain stimulation (e.g. Lipsman & Lozano, 2014). Those interested in this type of intervention argue “that an increased understanding of [anorexia nervosa’s] neural roots will lead to better treatments” (Lipsman & Lozano, 2014, p. 250). These accounts exist in stark contrast with earlier pathway models for eating disorders, particularly those that emphasize the sociocultural roots of eating disorders. These latter accounts include, most notably, Stice, Ziemba, Margolis & Flick’s (1996) dual pathway model of bulimia nervosa, which has underwritten many approaches to the prevention and treatment of eating disorders. Stice and colleagues argue that eating disorders result from negative affect and dietary restraint rooted in the sociocultural prizing of thinness.
Fairburn and colleagues advance another popular model for eating disorder risk that is largely sociocultural, if more behaviourally-based, than Stice’s model. Fairburn and colleagues wrote several influential papers in the late 1990s advancing the claim that eating disorder risk increases with negative social environments early in life, as well as specific personality correlates like social anxiety (Fairburn, Doll, Welch, Hay, Davies & O’Connor, 1998; Fairburn, Cooper, Doll & Welch, 1999). More recent explorations of causation have sought to establish differences between risk factors across eating disorder diagnoses. Hilbert et al. (2014) reported that bulimia nervosa (BN) shares similar sets of risk factors with anorexia nervosa (AN) and binge eating disorder (BED), sharing perfectionism and dieting with AN and substance abuse, bullying, family overeating and childhood obesity with BED.

Fairburn’s model of risk factors continues to be extremely influential; this cognitive behavioural model also underlies the most-used diagnostic instrument for eating disorders, the Eating Disorder Examination Questionnaire (EDE-Q; Cooper & Fairburn, 1987). This instrument is built on the assumption that AN and BN “share a complex psychopathology that has both specific and general components” (Cooper & Fairburn, 1987, p. 1) able to be measured using a discrete set of questions about eating, weight control methods, and cognitive orientation to weight and shape. It is an interview measure, but notably not a qualitative approach to assessing for eating disorders – it is very much mired in the positivist assumption that there is a “true pathology” that can be detected with the use of specific questions.

Despite the popularity of sociocultural explanations amongst prevention researchers, such models have borne the brunt of criticism amongst those who understand eating disorders to be “biologically brain based illnesses” (e.g. FEAST, 2012). Accordingly, treatment models that target the sociocultural or even cognitive behavioural aspects of eating disorders continue to be
widely practiced, despite some dissenters’ perspectives on these approaches as futile. Indeed, cognitive behavioural therapy (CBT) based on Fairburn and colleagues’ work continues to be a mainstay of treatment programs across the continuum of care. In today’s treatment landscape, enhanced CBT (Fairburn, Cooper & Shafran, 2003) is heralded as “suitable for any form of eating disorder, including anorexia nervosa” (Dalle Grave, Calugi, Doll & Fairburn, 2013, p. R9). Meanwhile, family-based treatment (FBT, Lock, LeGrange, Agras & Dare, 2001) is presented as the preferred method of treatment for adolescents in particular (NICE, 2004).

Establishing effective treatment has certainly not been without challenges – even those treatment models considered “efficacious” boast only 60% “full recovery” (defined as no longer meeting criteria for an eating disorder according to the Eating Disorder Examination Questionnaire and having attained over 95% of ideal body weight; Lock & LeGrange, 2012, p. 19). Studies such as those by Lock & LeGrange often highlight outcomes labelled “recovery” without problematizing the concept; and yet, criteria for recovery used in outcome studies vary so widely to render comparisons meaningless, leading to vast divides in the field around what type of treatment is seen as “best practice”.

Clinicians and researchers continually point out that there is a need for comprehensive, comparable, and clinically relevant criteria that would allow for meaningful comparisons amongst treatments (Berkman, Lohr, & Bulik, 2007; Björk, Clinton, & Norring, 2011; Couturier & Lock, 2006a; 2006b; Jarman & Walsh, 1999; Kordy et al., 2012; Noordenbos & Seubring, 2006; Steinhausen, 2002; McGilley & Szablewski, 2010). And yet, the establishment of such criteria is continually sidelined, deemed of lesser significance to treatment efficacy. Research on recovery is framed as supplementary to work on establishing the what, why, and how of eating disorders – often, the focus remains on anorexia nervosa as first course of action (see ANGI;
Bulik, Duncan, Breen & PGC_AN Work Group, 2017, for instance). The irony here is that without knowing what endpoint they are aiming for, it is challenging for clinicians and researchers to make claims to effectiveness or even to suggest to people how likely it is that they will recover, or what recovery looks like once they “get there.”

What is evident from such explorations is that it is nearly impossible to talk about recovery without also touching on eating disorder etiology and treatment. Whether or not it is named, different perspectives on recovery stem from divergent understandings of how these disorders come to be and how they should best be treated. For instance, if eating disorders are seen as biologically based illnesses, recovery would entail restoring physiological symptoms associated with eating disorders, like weight gain and nutritional status (e.g., in Rance, Clarke & Moller, 2014). If they result from different neurological pathways, recovery might be achieved by “correcting” these pathways by way of, for instance, electrical stimulation (e.g., in Lipsman & Lozano, 2014). Alternatively, if they result from body dissatisfaction and negative affect, learning to view one’s body as it is and working to internalize media ideals to a lesser degree could generate a state of recovery (e.g., in Stice et al., 1996). Using a cognitive behavioural perspective means that recovery would entail being able to identify erroneous cognitive constructions and behaving in a way that challenges incorrect assumptions (Fairburn et al., 2009).

Many critical feminist scholars also argue that eating disorders are tied primarily to a toxic sociocultural surround, but delve more deeply into the structural and systemic precipitants of bodily distress than the more individually-oriented sociocultural researchers noted above (e.g., Bordo, 1993, 2009; Burns, 2004, 2009; Hepworth, 1998; Malson, 1998; Rice, 2014; Warin, 2010). There is no one singular feminist lens through which we might look to understand how
eating disorders come to be; this is an important note given the problematic ways in which “feminism” may be subsumed by those seeking to critique it (or, more accurately, “them”).

Broadly, as far as it is possible to make such a statement, feminist scholars are concerned with locating discussions of eating disorders within specific sociocultural and historical contexts that exert control over people’s bodies (Hepworth, 1998; Malson, 1998). Gender is of primary importance to feminist scholars; for instance, feminist scholars have explored how bodies coded women are subject to a greater degree of control than those coded men, how those coded women have struggled for recognition as human beings capable of logic and reason, and how the feminine is associated with the bodily (Battersby, 1988; Rice, 2014).

For many critical feminist scholars in particular, the very term “eating disorder” is questionable, calling out as it does a location of pathology (Malson & Burns, 2009). Pathologization is seen as problematic as it may act as another way of controlling women’s bodies (e.g., Bray & Colebrook, 1998; Jacob, Gagnon & McCabe, 2014; Sherwin, 1998); indeed, critical feminist eating disorder scholars may question the use of the DSM in practice, arguing that the manual creates arbitrary lines and boundaries around which types of eating are labelled “normal” and which are deemed “pathological” (e.g., Bray, 1996; Rice, 2014). Many prefer to call distressful relationships with food “eating dis/orders” (with a slash) or other altered versions of the term, particularly postmodern feminists who consider discourse (language and linguistic practices) to be themselves powerful mechanisms of social control (e.g. Malson & Burns, 2009).

Notably, and as the terminology example illustrates, feminist scholars use different terminologies and concepts in their analyses. There are multiple “ways in” to illustrating the patriarchal relationships between bodies, distress, and the social surround.
Another example of these multiple paths to unpacking the intertwining of bodies and worlds is “the gaze,” and how various feminisms conceptualize and explore the impacts of patriarchal gender norms, experiences of looking and being looked at, and the intersection of these experiences. Many use the lens of self-objectification to explore the links between bodily distress and the sociocultural surround; this framing suggests that internalizing the (sexually objectifying) gaze can generate experiences of body dissatisfaction and contribute to the development of eating disorders, among other negative outcomes (e.g. Calogero, 2004; Fredrikson & Roberts, 1997). A significant body of feminist literature is devoted to exploring the relationship between self-objectification and eating disorders (e.g. Brown, 1987; Calogero et al., 2005; Ludwig & Brownell, 1999; Meyer, Blisset, & Oldfield, 2001; Moradi, Dirks & Matteson, 2005; Noll & Fredrickson, 1998). Understanding self-objectification helps to identify problematic gendered patterns in society: for example, the commodification of women’s bodies on a grand scale (e.g., in mass media). This perspective has helped to identify the pathways through which internalizing thinness ideals can occur, and how this internalization comes to impact on people’s embodied experiences of body shame and disordered eating (Calogero, et al., 2005).

Solutions to self-objectification are intended to be sociocultural; indeed, as Calogero et al. (2005) note, “it is imperative that we challenge these experiences at a social and cultural level” (p. 49). If self-objectification and its corollary, sexual objectification, are viewed as systems, their dismantling would lie in a dismantling of the systems that uphold them (Calogero & Tylka, 2014). However, in some reductionist uptakes, the impetus for change may be

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3 Note that researchers exploring self-objectification may acknowledge the tensions inherent to exploring the impact of the gaze on corporeal manifestations of distress. They may complicate what is often presented as a causal relationship between consuming media and being subject to
paradoxically reinscribed on the “victim” of this commodification – “solutions” to objectification come to focus only on methods individuals can use to bolster their self-image and guard against the gaze (or at least, against letting the gaze seep in; e.g. media literacy approaches, see Wilksch & Wade, 2015 and others) rather than on altering the social milieu from which the gaze emanates. This may be a positive interim step toward reducing body shame and experiences of body dissatisfaction, but may not alone make major shifts in the prevalence and impact of eating disorders. Further, we might extend and complicate self-objectification theory to explore how the gaze may be experienced as desirable by some women (Rice, 2014).

Other accounts explore the relationship between the gaze and/or objectification in more post-structuralist terms, configuring eating disorders as an attempt to avoid the gaze – in other words, “appearing to disappear” (Malson, 2009; cf. Bordo, 1993; Chernin, 1985; Orbach, 1986; Rice, 2014). Here, an eating disorder may be considered to be a way of distancing oneself from a feminine body, or embodying at least in part the masculinized control and rationality expected of productive bodies under neoliberalism (Bordo, 1993, 1999; Burns, 2004; Gremillion, 2003; Grosz, 1994). These theories highlight the need to explore how people are active in the construction of images, as well as their internalization (Coleman, 2008; Malson, Halliwell, Tischner & Rudolfsdottir, 2011b). There is more to the picture than looking/being looked at; as Malson et al., (2011b) suggest, “the relationship(s) between bodies and images might thus be best understood not in terms of ‘media effects’ but of bodies becoming through their constitutive

the gaze (see Calogero et al., 2005 for an example of this more complex application of self-objectification theory that acknowledges the non-causal relationship). However, in popular (for instance, media) uptakes of such work, nuance may be lost, leading to the problematic assumption that eating disorders are borne of vanity and/or desiring to be desired, an idea refuted by Bordo (1993, 1999) among other critical feminist researchers, and by Grosz (1994) on a philosophical level: she suggests that eating disorders might instead be “precisely a renunciation of these ‘ideals’” (p. 40) to which those gendered woman may be expected to adhere.
relationships with images” (p. 8). The concept of self-objectification and poststructuralist theories of gaze-avoidance/attraction/construction might be productively integrated to highlight how the root of the issue lies not at the level of the individual but in the systems that sustain gendered relations of power that subject women’s bodies to scrutiny, which they may reject or be drawn toward (or both). Perhaps most importantly for the purposes of this work, self-objectification and gaze theories inform discourses of surveillance and self-surveillance, which can be strongly related to the neoliberal societies in which the participants in this study live that urge continual self-monitoring not only of appearance, but of health itself (Rabinow & Rose, 2006).

The implications of self-objectification for non-heterosexual individuals have been minimally explored, with studies demonstrating that lesbian women experience similar levels of self-objectification as heterosexual women (Hill & Fisher, 2008); heterosexist discourses might be internalized regardless of personal sexual orientation (Haines et al., 2008). However, in some accounts (e.g. Fabre, 2014) the gaze is rendered male, the gazed-at rendered female, and eating disorders are rendered a way of attracting heterosexual attention. The importance of engaging consciously and critically with self-objectification and other gaze theories becomes paramount in light of pervasive myth that lesbian or bisexual women do not get eating disorders; that they are somehow immune to bodily distress (MacDonald, 2011; Jones & Malson, 2013). The presumption that queer women do not get eating disorders is tied to an assumption of body acceptance within queer communities – particularly those comprised of individuals who identify as women (French, Story, Remafedi, Resnick, & Blum, 1996; Lind, Kotow, Rice, Rinaldi, LaMarre, Friedman & Tidgwell, 2018; Herzog, Newman, Yeh, & Warshaw, 1992; Rinaldi, et al., 2016; Rice et al., under review; Share & Mintz, 2002). If “sexual minority” women are seen as
having distressful or distressing relationships with their bodies, these are assumed to be tied to living in a body that is out of the norm—particularly if the woman is fat (Rinaldi, Rice, LaMarre, McPhail & Harrison, 2017). If an eating disorder is suspected, it is assumed to be tied to overeating (e.g. Heffernan, 1996). Queer women’s experiences are often collapsed into a single category, homogenizing queer women’s lived, embodied experiences and how these relate to their social locations (Lind et al., 2018; MacDonald, 2011; Rinaldi et al., 2017). Specifically in relation to self-objectification, despite evidence to the contrary (Haines et al., 2008, Hill & Fisher, 2008), some suggest that queer women are unlikely to internalize the gaze, which is seen as explicitly heterosexual; therefore, they are seen as less likely to aspire to bodily ideals of thinness implicated in the genesis of eating disorders (Brown, 1987; Ludwig & Brownell, 1999; Meyer, Blisset, & Oldfield, 2001).

Evidently, this assumption of immunity amongst queer women is significant and problematic, particularly as some researchers have suggested that eating disorders are actually more common amongst LGBTQ+ folks (Austin, Nelson, Birkett, Calzo, & Everett, 2013; Koh & Ross, 2006; Wichstrom, 2006). The use of a heterosexist matrix in coding eating disorders—in other words, the idea that one is or is not at risk for an eating disorder based on their sexuality and thus vulnerability to the male gaze (Rinaldi et al., 2016)—is not the only problematic assumption advanced about who is and who is not vulnerable to eating disorders. This is an area in which critical feminist critiques of mainstream models of eating disorder causation, maintenance, and (possibly) recovery can instruct us about how to expand our perspectives to better understand bodily diversity as it interacts with distressing relationships with food, weight, and shape (Rinaldi, LaMarre & Rice, 2016).
Queerness is but one example of the axes along which stereotypical portrayals of eating disorders are proliferated – and inform perspectives on who is “recoverable” (LaMarre, Rice & Bear, 2015). The experiences of women of colour, for instance, may also be elided in non-intersectional feminist accounts of disordered eating. As early as 1996, Thompson illustrated how black women’s experiences are not be captured in the narrow ways of understanding eating disorders that we have at our ready disposal. Dis/abled folks (Roosen, 2013; 2017), those from lower socioeconomic statuses (Gard & Freeman, 1996), those in larger bodies (Lebow, Sim & Kransdorf, 2015; Rice, 2007; Rinaldi et al., 2016; Lind et al., 2018) and those experiencing many other axes of marginalization may be presumed to be immune from eating disorders in an optic that presents desirability or internalization of ideals as the primary contributing factor to the development of these disorders. In reducing “culture” to mean internalization of Western media ideals, we engage only on a superficial level with the complexities of multiple and intersecting identities, social power, and eating (Lee, 2004). Implicitly advancing the hypothesis that culture is equal to media and thin ideals leads to a glossing over of how eating disorders are indeed tied to sociocultural milieu, but media is but one aspect of ever-changing and shifting society, among socioeconomic, political, and historical pressures that further situate bodies in nexuses of surveillance, control, and tension (Becker, 2004; Lee, 2004; Lester, 1997, 2007).

Feminist perspectives, no matter which terminologies and conceptualizations they use, have not been popular ways of understanding eating disorders. Many who have experienced eating disorders are offended at the inference that their disorders reflect political protest, for example. Those who refute perspectives that situate eating disorders in socio-historical and political-economic context tend to argue that presenting eating disorders as a feminist issue means understanding them to be conscious and deliberate choices, or that this perspective means
ignoring men’s experiences of eating disorders. What is arguably missing from these critiques is (1) that there are significant divergences in feminist approaches to eating disorders and (2) that in general, such accounts are not intended to be read onto any one person’s experience of an eating disorder but rather to identify broader social issues that may be implicated in the genesis of any kind of subjective experience of distress, no matter how that distress is acted out. On the issue of “don’t men get eating disorders too?” we might consider, for example, how gender binaries are no longer (or perhaps never were) helpful for people of any gender. Dismantling gender binaries is helpful insofar as it instructs us about how by unbinarizing our accounts we might value and understand the experiences of those who relate to the concept of gender in myriad and multiple (even shifting) ways. Gender, as a sociocultural construct, is a fascinating point of departure for analysis of behaviour, subjectivity and materiality, not in its fixity but in its fluidity and difference (Butler, 2004).

1.2.2 Perspectives on Recovery.

Divergent perspectives on what causes eating disorders subtly underlie recovery research, and are not always named, sometimes perpetuating the belief that studies of recovery can be atheoretical or detached from broader understandings of eating disorders themselves. Dissent amongst treatment professionals about the best way to go about reaching recovery may be harmful for clients, who may also feel that their own preferred articulations of recovery are marginalized versus those of professionals in the field (Yu, Agras & Bryson, 2013). Even in studies that take a qualitative approach to recovery, certain assumptions about what recovery is and how best to get there may limit individuals’ ability to articulate their own versions of recovery. In research studies researchers must often define what constitutes recovery in order to secure participants that are deemed “recovered” who are able to reflect on their experiences.
Despite its commonness, this approach automatically delimits the range of topics and experiences counted within recovery discourse.

This is not to say, of course, that qualitative (or quantitative) research on eating disorders and recovery does not have value. Quantitative approaches have revealed how treatment outcomes lag for eating disorders and how eating disorders are a significant issue in many societies, for instance (e.g. Rome et al., 2003; Schoemaker, et al., 1997; Treasure & Russell, 2011). Qualitative researchers have explored the personal meanings former sufferers have made of their experiences, unearthing recovery processes for sub-groups of people (e.g. Arthur-Cameselle & Quatromoni, 2014; Dawson, Rhodes & Touyz, 2014; Granek, 2007; Hay & Cho, 2013; Jenkins & Ogden, 2012; Lamoureux & Bottorff, 2005). Presenting eating disorder recovery as multidimensional (Hay & Cho, 2013) or as a process of “becoming whole again” (Jenkins & Odgen, 2012) helps us to understand that simply righting the physiological aspects of recovery will be insufficient for scaffolding a lasting recovery. We might situate this within the culture that Braidotti (2013) describes as continually setting up a striving relationship, wherein we are always out of step with that which is supposed to bring us prosperity and happiness. Within this context, people may need to hold multiple versions of themselves—their subjectivities—in order to reconcile wildly conflicting desires, access, and achievements (LaMarre et al., 2017). Many such accounts ask participants to describe what recovery is like for them; for instance, Federici & Kaplan (2008) note that participants found that a key part of recovery was being able to manage emotions and challenges without resorting to eating disorder symptoms. Looking at the differences between clinician and client perspectives on recovery, Noordenbos (2011a, 2011b) found that clients often described recovery as rediscovering a sense of self.
However, even these more lived-experience-oriented accounts tend to present with two key issues: (1) they subtly replicate, to a certain extent, an individualizing and responsibilizing discourse on health that asks those suffering to “pull up their socks” and achieve normative health and (2) relatedly fail to acknowledge how the prescriptions offered to those in recovery ask sufferers to act in direct opposition to normative dictates for health (LaMarre & Rice, 2016a). People are asked to change within a set social context; broader social change is rarely addressed as a key support for recovery. It is widely assumed that the types of treatment on offer will universally appeal to a homogeneous group of “people who suffer from eating disorders” despite significant evidence that this group is far from homogenous. Indeed, there are seemingly endless variants in eating disorder symptomatology (Herzog et al., 1999; Yu, Agras & Bryson, 2013) and people from diverse social locations experience distress around food, weight, and shape (Algars et al., 2012; Becker, 2004, 2007; Becker et al., 2010; Cachelin et al, 2001; Thompson, 1996; Lind et al., 2018). Despite this acknowledged diversity within this “group,” a set of unmarked and underexplored assumptions undergirds calls for increased rates of recovery.

While establishing a consensus definition of recovery is an admirable—if lofty—goal, and one that I am contributing to, my focus in this dissertation is to better understand the meanings people make of their experiences (and the experiences of their loved ones) of recovery. Even the term recovery may itself be perceived as unimaginable (Malson et al., 2011a) or as alienating (LaMarre & Rice, 2016a) when it rests in the social imaginary as some special place of perfection. Those with eating disorders may not only ask if it is possible to recover from an eating disorder in general, but if it is possible for them, particularly if their disorders were never seen as legitimate to begin with (LaMarre et al., 2015, LaMarre & Rice 2016a). Better understanding of recovery is therefore critically important not just to support stronger
comparisons amongst treatments for eating disorders (Noordenbos, 2011a; Steinhausen & Weber, 2009; Von Holle et al., 2008; Walsh, 2008) but to address: (a) how structural conditions limit the possibility of attaining some category of “recovery” for diversely embodied people, (b) how recovery occurs in relation to other people and to these structural conditions, and (c) how recovery may not in fact be a unitary or singularly definable construct but rather a contextually-nuanced and irreducible relationship between person and world. Some feminist writers have explored the importance of “developing shared understandings of recovery” (Musolino et al., 2016), but there has yet to be significant feminist theorizing around ways of reconciling a desire to push for consensus around what recovery means and how to get there with a desire to attend to the lived, embodied experience of recovery in a way that centres difference and resists the pull of homogeneity.

1.2.2 Recovery Model.

Some researchers have begun to explore whether eating disorder recovery might be conceptualized using a “recovery model” framework, oriented more toward people’s subjective experiences of wellbeing rather than any discrete categories of symptom reduction or remission (e.g. Dawson et al., 2014; Musolino et al., 2016). This approach is fairly controversial in the field, where markers of symptom remission and bodily restoration continue to be the predominant criteria for discharge from treatment programs and indicative of movement toward wellness. While researchers and clinicians occasionally accept more “harm reduction” style outcomes in eating disorder recovery, this is generally only the case for anorexia nervosa deemed “refractory” – that is, non-responsive to treatment and long-term – as opposed to all eating disorders (Hay, Touyz & Sud, 2012; Munro et al., 2014; Touyz & Hay, 2015). In general, eating
disorders lag behind other mental illnesses in terms of conceptualizing a recovery that might be experienced in subjectively different ways by those who seek it.

While recovery models implemented in other mental health services are far from perfect, they warrant comment here, as they are largely consumer-driven and present us with alternative ways of thinking about recovery. Importantly, these models remind practitioner-researchers that in order to facilitate recovery for more diverse individuals, there is a need to think at a systems level. As Leamy, Bird, Le Boutillier, Williams and Slade (2011) write: “orienting mental health services towards recovery will involve system transformation” (p. 451) – focusing on individuals is simply insufficient for scaffolding major change. Recovery model practices are based on the idea that we need to move beyond models that primarily focus on medicalized and pathology-centric formulations of illness and move toward individual definitions of recovery (Price-Robertson et al., 2017). Uptakes of the recovery model are anchored in different worldviews, including anti-psychiatry, which is predicated on a suspicion of the way that psychiatry can reduce people to a pathology (e.g. Rissmiller & Rissmiller, 2006). Positioning the individual as agentic and active participant in their recovery, but also constrained by systems of power that constrain individual action suggests a post-structuralist perspective that urges a deconstruction of dominant and singular perspectives on what it means to be recovered (Howell & Voronka, 2012). These models are promising, as will be described below, but are not without their critics – particularly around the lack of definitional clarity that has plagued recovery model practice as it has infiltrated healthcare systems (Andresen, Oades & Caputi, 2011; Craig, 2008; Price-Robertson et al., 2017).

The UK is arguably a leader in embracing consumer-driven recovery models for the treatment of mental illness, at least in theory. Since the 1990s, service user involvement has been
recognized at a policy level as an area for improvement in mental health services in the UK, driven largely by pushback from consumers who have experienced challenges at systems levels when seeking treatment for their illnesses (Department of Health, 2012; Tait & Lester, 2005). Prior to this recognition, the anti-psychiatry movement had been operating in North America since the 1960s, as Thomas Szasz (1971, 1972) and colleagues critiqued certain practices within psychiatry (Morrow, 2007). From early on, the movement bore a liberatory flavour, highlighting the capacity of those who have experienced psychiatrization to live their lives independently from psychiatric intervention (Tomes, 2006). These movements have not been without their dissenters; as Tomes (2006) writes:

the idea of according consumer/survivors a privileged role in policy making has prompted expressions of concern: worries that the ‘wrong’ consumer perspectives are being accorded too much policy weight, that their views are insufficiently evidence based; and that they are contributing to the fragmentation that besets mental health policy (p. 721)

Tensions and divisions within the movement have proliferated as it has progressed, including varied perspectives on the goals of the movement, the best approaches to intervention and support, and the involvement of families, among other issues of divergence (Tomes, 2006). Despite these divisions, recovery has featured as core tenet of these movements, deployed as a framework and concept to counter the significant stigma faced by those with mental distress (Frese & Davis, 1997). Moves to integrate recovery-model thinking are underpinned by a push for policies that embrace a version of recovery defined by those with lived experience, a version that includes recognizing how “unpacking these notions [of the benign nature of recovery and resilience] can reveal the ways in which they are powerful tools in the governance of those
deemed mentally ill, and also by extension, all citizens” (Howell & Voronka, 2012, p. 4).

Recovery becomes much more complex than a simple restoration of normalcy; it is “grounded in a focus on survivor rights, peer support and recovering from the oppressive effects of being a mental patient” (Poole, 2011, p. 15, cited in Howell & Voronka, 2012, p. 4). To establish this kind of orientation toward recovery, those who have “been there” must necessarily be involved in policy and decision-making. But how might this be achieved?

In the UK, policy makers have given lip service to “patient and public involvement”; however, intentions to involve service users have not always translated to actual increases in involvement by those most impacted by the quality and character of mental health services (Tait & Lester, 2005). As Tait and Lester describe, user involvement in practice has generally stopped at mutual support for recovery and stigma-fighting campaigns, rather than deep involvement of users across the continuum of service decision-making and delivery. This shortfall of actual involvement may be linked, they suggest, to a number of barriers, including lack of information, costs, and resistance from professionals hesitant to relinquish their expert status in the name of user involvement. Craig (2008) further questions whether recovery has simply become a buzzword, used to satisfy calls for evolution of mental health treatment systems.

In response to these barriers and challenges, others in the UK have sought to lay out conceptual frameworks for enacting a recovery orientation. Conceptualizing personal recovery “as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles... a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness” (Anthony, 1993, p. 527), researchers, practitioners and policymakers have highlighted how systems might facilitate recovery. Shepherd, Boardman & Burns (2010) set out a model to help mental health services classify their recovery orientation, from engagement, to
development, to transformation, where transformation is assessed with reference to a number of indicators about user inclusion, environmental/institutional change, and support. Often, these enactments of the recovery model are underpinned by a perspective on mental illness that views it as tenacious but modifiable; something that impedes full participation in life.

To a certain extent, a recovery model and definition of personal recovery offered in accounts that still position mental illness as individual pathology replicates (by necessity) a neoliberal frame of reference that is worth interrogating. It is worth noting that not all of those who endorse a recovery model framing adopt this perspective; in fact, one could argue that positioning and understanding mental illness as such represents a problematic departure from the liberatory origins of the recovery model (Howell & Voronka, 2012). In some uptakes of the recovery model, recovery is defined with reference to the degree to which those in recovery are able to live a contributing or productive life even when they are experiencing “symptoms” of their illness (e.g. Anthony, 1993; Shepherd, Boardman & Burns, 2010). Even when tempered by the assessment of an individual’s subjective experience of living a meaningful and satisfying life, the focus on productivity firmly situates recovery within a framework where workforce contribution remains a marker of the individual’s status.

I have an uneasy relationship with the subject of my research inasmuch as it is, to a certain extent, predicated on exploring “recovery from” eating disorders; the recovery literature to which I contribute often highlights “problematic neoliberal individualist principles including hope, empowerment, self-determination and responsibility” (Howell & Voronka, 2012, p. 4) in the name of promising the resumption of normality. For Pilgrim (2009) and others (e.g., McWade, 2015), recovery is “polyvalent,” contextual, and multi-layered. McWade (2015) expands on the recovery model by understanding recovery to be “a site of socio-political struggle
over what lives are deemed liveable in the context of global neo-liberalism” (p. 244) – tied to
discourses of time and space. To explore recovery models in a way that does not simply replicate
a bring-people-in to neoliberal time logics approach, then, we might explore differential access
to the “enabling resources” (Duff, 2012, p. 1389) that constrain or open recovery. Recovery –
and hope for recovery – is not achieved by individuals, but rather by collectivities (Bird et al.,
2014) and maintained in a relational network, in time, and in space (Duff, 2016). Rather than
simply trying to recuperate lost (potential) productivity along a timeline defined from outside, we
might attend to people’s individual and relational needs in recovery.

The lack of interrogation of the various tensions inherent in the use of this terminology in
the sociohistorical, cultural, and political-economic climate in which we research, treat, and write
about mental distress is a limitation of the literature on service-user involvement in mental health
care, and the increased interest on developing a national (e.g., Kirby et al., 2003; Mental Health
Commission of Canada, 2009) focus on recovery as guiding framework for mental health care.
As Morrow & Weisser (2012) note, recovery has (at least) three shades in the literature: recovery
as personal journey, recovery as social, and recovery as problematic concept imbued with
psychiatrizing discourse (p. 31). In the eating disorder context in particular, we might also add to
the picture the uneasy ontological alignment between eating disorders and other conditions
labelled mental illness. Suggesting that it might be possible to conceptualize eating disorder
recovery without attending to body weight or, possibly, symptom elimination, is still incredibly
contentious.

Further, people with eating disorders may themselves take vastly different orientations
toward the recovery model, given the unique place that eating disorders occupy in relation to
other mental illnesses – a kind of claiming of the status of mental illness from a biological,
physiological perspective (i.e., through the framing of biologically brain based illness) while also resisting against the kinds of strictures implied in this orientation. Some with eating disorders and in recovery themselves cling tightly to the biomedical model (Easter, 2012, 2014; Eli, 2014); more so might the parents of those with eating disorders. Accordingly, biomedical markers of recovery and (certain types of) clinical expertise might not easily be traded for a deep respect for the lived experiences that drive a recovery-model orientation. I explore these questions and orientations to recovery as a part of this dissertation work, in order to better understand the landscape of possible responses to the systems-level shifts required to build a better, more comprehensive treatment continuum for eating disorders. It is, of course, possible for a treatment continuum to both include service-user involvement and diverse orientations toward recovery – pragmatically, researchers and practitioners will likely need to move past a hope of obtaining complete agreement or consensus when it comes to defining what we are aiming for and move toward a nuanced understanding of the possibility of diverse recoveries as we consider how best to support people.

1.2.3 The Family Context.

Typically, researchers have been more interested in how families may contribute to the development of eating disorders than in exploring how they might help to facilitate eating disorder recovery, much less their perspectives on eating disorder recovery. In her work on eating disorders in the 1960s, Hilde Bruch wrote a now much-maligned text that implicated families in the genesis of eating disorders (1962). Family systems theory (Minuchin, Rosman & Baker, 1978) is another common framework through which eating disorders in the family context have been viewed; again, parents today take issue with the fundamental tenets of these theories, which strongly implicate family members in the genesis of eating disorders. Minuchin, Selvini-
Palazzoli, and Bruch all explored the “psychosomatic family,” which is described as a “rigid, inflexible system” (Fishman, 2006, p. 507). Such families are described as having significant deficits in nurturing, as being low in empathy expression, and as having difficulties supporting children’s separation and individuation (Killian, 1994). Families where eating disorders are present are described as having high levels of criticism and rules, focusing a great deal on weight and appearance, endorsing thin ideals, exercising coercive parental control, holding rigid patterns of interaction, and having low levels of family cohesion (Gillet et al., 2009). These earlier analyses of this family environment, however, may fail to take into account that eating disorders themselves are often highly disruptive of family systems (Robin et al., 1999).

It is worth exploring, for a moment, the gendered component to this familial focus. In suggesting a “nurturing deficit,” we can consider who—particularly at the time this theorizing was taking place, but continuing today—is generally considered to be “in charge” of nurturance and care work. Reading between the lines of the elements of “the psychosomatic family,” we might observe who is blamed for various components of a “problematic” family dynamic. Mothers face the burden of blame when deficits of nurturance are said to exist; fathers might be blamed for coercive parental control. Here there is also a heteronormative assumption—that mother and father will be present and enacting particular gender roles in order to assure “proper family cohesion.”

Within the early canon on eating disorders in families, there is a strong reliance on the attachment literature. Researchers and clinicians invested in this perspective argue that all children seek attachment to their primary caregivers (traditionally, in the literature, mothers) (Dallos, 2001). Those who do not receive the expected or desired responses from caregivers develop insecure attachments; in the context of eating disorders, these are seen as contributing to,
for example, an adolescent’s inability to become an autonomous individual (Steiner-Adair et al., 2002). Accordingly, work with families in treatment tends to focus on assisting family members in re-establishing appropriate boundaries, enhancing communication skills, and re-calibrating family systems by inducing crises and exploring alternative mechanisms for handling conflict (Fishman, 2006). Clinicians may also focus on domains of attachment functioning such as “interpersonal style, affect regulation, coherence of mind, and reflective functioning” (Tasca, Ritchie & Balfour, 2011, p. 257).

To a certain extent, family-focused approaches to treatment have been helpful in de-individualizing responsibility for eating disorders; instead of being a matter of individual choice, eating disorders are situated within dysfunctional systems. On the other hand, these perspectives tend to (at best) ignore the social construction of developmental pathways and the embeddedness of families within broader social structures and (at worst) blame families (and especially mothers) for causing children’s eating disorders. While it is, of course, important to acknowledge that some people with eating disorders have experienced mistreatment at the hands of family members (May, 2005), it is important to avoid universalizing experiences or assuming that all families of people with eating disorders are somehow dysfunctional. Given the history – and continued existence – of discourses placing mothers in particular in the role of caregiver in the home, these accounts tend to most deeply blame mothers for causing their child’s eating disorder, which has generated significant pushback from many mothers active in the eating disorders advocacy world. Importantly, mother blame discourses have not been limited to sociocultural attributions for disease and disorder; biological research may contain language that constructs women as to blame for all manner of disorders from the moment they conceive (Winett, Wulf & Wallack, 2016).
The idea of a prototypical “anorexic” or “bulimic” family may support a family blame perspective. Establishing causation for detrimental family dynamics is no easy task, particularly “deficits” observed in such families may possibly stem from the eating disorder itself (Robin et al., 1999). We might also question whether it is possible to a) have and b) observe a “normal” family dynamic, when family dynamics might themselves change upon observation. Further, approaches such as these tend to rely on the idea that there is a “normal child” or normal subject and a presumption of a universal developmental trajectory; this approach foregrounds “developmental appropriateness” and Others that which does not fit (Burman, 2008; O’Dell, 2015). Treatments often focus on re-establishing this normal developmental pathway, suggesting, for example, that in order to be seen as recovered, children must become appropriately individuated from their families (Lock et al., 2001). While there is nothing inherently wrong with proposing a developmental pathway, this presumption does underwrite some common assumptions about the kinds of people who might “get eating disorders” and their families. There is little room in such pathways for systemically enforced marginalizations and other differences that can constrain participation in “recovery as expected.” Perhaps most notably, there is little acknowledgment of how seeking to assist eating disorder sufferers’ rejoinder to normal developmental pathways subtly reinforces broader societal power structures, most notably neoliberalism. Moreover, these theories carry shades of ableism in the assumption that the non-normative is dysfunctional and thus in need of correction.

The family is not simply a “black box” that maintains an internal homeostasis, as Selvini-Palazzoli (1974) would have it. Instead, the family environment is itself inextricably tied to broader systems of power; indeed, families are one medium for cultural messages to trickle down, but these cultural messages do not inhere solely within the family context (Haworth-
Hoeppner, 2000). Families face a significant burden of blame and responsibility for eating disorders; those in caregiving roles, including, often those engaged in mothering, may face the dual pressures of blame and burdens of care. Recent data indicates that women caring for a child, for instance a child living with a mental illness, spends 65 hours per week – versus 35 for men – caring for the child – a significant difference (p<-.05) (Turcotte, 2013). Combined with the history of mother-blame in eating disorders (McNab & Kavner, 2001), women caring for loved ones with eating disorders may find themselves in challenging binds.

Importantly, family members are also in thrall to the same biopedagogies that govern society: messages about how to self-manage in regulation with social dictates in order to be healthy and productive citizens (Wright & Harwood, 2009). In a society wherein biopedagogical teachings around how to enact healthy and productive bodies inscribe surveillance, particularly around food, weight, and shape, engaging in restrictive practices around food may even be considered normative (Bell, 2006; LaMarre & Rice, 2016a; Rinaldi et al., 2017). Further, as media literacy is presented as immunity from eating disorders (LaMarre et al., 2017) and families are exhorted to conduct themselves in a “proper” way that would protect their children from developing issues with food, weight, and shape, a family with a child (no matter their age) who develops an eating disorder risks significant shame and stigma. They are expected to promote resilience, regardless of circumstance (Rose & Lentzos, 2016). Blame may be compounded by the assumption that a child who develops an eating disorder was raised in a household that was not doing a good enough job inoculating the child against the pernicious effects of media.

This shame and stigma can lead to significant challenges for caregivers, including substantial distress and disrupted social functioning, and lowered overall quality of life (Haigh & Treasure, 2003; Perkins et al., 2004). It may also prevent families from seeking needed support
Caregiver burden is a significant focus of emerging models of family-based treatment, as researcher-clinicians become aware of the real challenges of implementing highly family-involved forms of treatment. A move toward family involvement in treatment has been important for moving away from models in which family members feel removed from, shut out of, and misunderstood by treatment (McMaster, Beale, Hillege & Nagy, 2004). As family members may react to eating disorders in unhelpful ways out of confusion around the best ways of supporting their loved ones (Brown & Geller, 2006), it is incredibly important to build systems that support family involvement.

However, even with this upswing in interest in the subjective experiences of caregivers and concern with supporting caregivers, there is still very little in the way of research specifically exploring family members’ perspectives on recovery, their expectations for recovery, and how these coincide (or do not coincide) with those of their loved ones. Where this research exists, researchers have tended to focus on the families of those with anorexia nervosa who are seeking inpatient treatment (Dimitropoloulos & Freeman, 2016) or on the role of social support specifically as a facilitating factor for recovery (Linville et al., 2012). These are both interesting orientations to the family system and recovery, and certainly offer perspectives on how to clinically intervene in ways that will allow for more complex analyses of the roles of families in treatment processes. Interestingly, however, the limited literature on families and eating disorder recovery continues to offer accounts primarily from the perspectives of individuals in treatment, projecting their families’ perspectives through their own experiences (e.g. Dimitropoloulos & Freeman, 2016).

Further, the vast majority of studies on families and eating disorders in general focus on families of those currently or fairly recently seeking inpatient or other hospital care for their
eating disorder; often clinically significant anorexia nervosa and less often bulimia nervosa. The samples in these studies are predominantly white and are presumably able to seek insured care for their disorders. There is less attention given to the experience of those whose disorders have long gone unrecognized or dismissed, perhaps by both family and medical professionals. There is less emphasis placed on the sociocultural complexities of various family arrangements and the cultural norms that may preclude a recognition of conditions labelled mental illness within the family; or, conversely, that may discourage seeking help for “problems of the mind” *beyond* the family (e.g. Chen & Mak, 2008; Chiu, 2004; Taylor, Sherman, Kim, Jarcho, Takagi & Dunagan, 2004). The stigma associated with mental illnesses may not be the same in non-Western societies; as Kirmayer (1989) points out, in societies in which there is less focus on individualism, stigma may not be a personal matter, but rather a familial one. The decision to seek—or not seek—treatment thus becomes a collective one with implications for the entire family unit; alternatively, if it is taken as an individual decision, it may engender conflict in the family system. As previously noted, the nuclearity of the family is also presumed within the family literature, limiting researchers’ ability to meaningfully explore other important relationships in the lives of those with eating disorders and in recovery.

Beyond concerns about the nuclear family being the predominant kind of family represented in the literature, there is also a presumption that the individual who is experiencing the eating disorder is the child. The voices of parents with eating disorders are significantly missing from explorations of eating disorders in family contexts; experiencing an eating disorder when one is a carer carries its’ own complexities and challenges (Stitt & Reupert, 2014). To attempt a move beyond the reductions that exist in configuring “family” in eating disorder research, participants within this study identified their own supporters for participation. This
helps us to acknowledge that while we must challenge the replication of family blame in eating disorders, we need to also avoid assuming that families will be uniformly supportive; some people with eating disorders do consider their families to have contributed to the development of distress, and/or have histories of trauma within their family contexts.

Given that families and loved ones are situated within the broader sociocultural milieu, it is logical to assume that their perspectives on recovery would also be at least partially mediated by dominant assumptions and/or a lack of articulation around what recovery is and how to get there. The prevention research realm has taken up a call to research in more ecological ways – that is, understanding the embeddedness of systems in order to address change at all levels (e.g., Haines et al., 2006). I propose that a similar shift is necessary within the recovery research realm as well. Like work that interrogates dominant perspectives on recovery more generally (e.g., Duff, 2016; McWade, 2015; Poole, 2011; Howell & Voronka, 2012), it will be important to explore what meanings loved ones make of recovery in order to understand the individual’s experience, but also to understand the complex workings of power and bodily surveillance in, through, and around intersecting individuals. This work builds on the efforts of feminist and critical researchers who encourage a deeper consideration of the contextual embodied worlds of individuals and kin (e.g., Rice et al., 2016; Riggs & Peel, 2016). A shift to exploring the roles of supporters, rather than those related in a nuclear family structure, will also help to bring caregiving experiences and orientations toward recovery into relief. This shift also promotes a broader consideration of the complexities of families’ lives that may contradict an expected orientation toward help-seeking that presumes that supporters will suspend their entire lives in order to provide support—an assumption that may even preclude their involvement, or their loved one’s involvement, in treatment.
1.2.4 Supporters in Context.

As noted, families do not exist in isolation from broader sociocultural and historical environments – environments that also impact family members’ lives and interactions. In part, the biomedicalizing trends described above in relation to adopting specific orientations to recovery are grounded in broader social commitments to the individualization of risk and responsibility within neoliberal culture. Normative “practices of the self” (Rabinow & Rose, 2006) exhort people to take responsibility over their lives and their health in order to be the best that they can be. While on the surface this does not seem at all problematic, a potentially troubling ramification of this orientation is the proliferation of expectations that, performed correctly, life will generate certain types of bodies. Power circulates through this call to self-governance: not a top-down, juridical power where people act out of fear of consequences, but pervasive power at the biological level – biopower (Foucault, 1979).

Specifically, exploring biopower in the context of eating disorders means exploring biopedagogies, or the subtle and diffuse messages that circulate everywhere in society and tell people what they need to do in order to be healthy, happy, and productive citizens (Wright & Harwood, 2009). Perhaps the most obvious example of biopedagogies in the contemporary Western social arena is the uptake of anti-obesity discourse. Some suggest that we are seeing a moral panic around fatness; fat bodies are more than stigmatized – they are de-humanized and degraded (Granberg, 2001; Saguy & Ward, 2011; Saguy & Riley, 2005; Rice, 2014; Rice 2015). Morals are tied to bodies, but this is not a new trend; different bodies have long faced marginalization (Davis, 1995). Those in larger bodies are told they are unfit on a physical level and also on a moral one (e.g. De Brun, McCarthy, McKenzie & McGloin, 2014; Puhl & Brownell, 2001; 2006; Puhl & Heuer, 2009; Teachman & Brownell, 2001; Rice 2009). Health is
read into body size, with the assumption that corporeal form can instruct us about how well one is measuring up to societal standards (importantly) not just of appearance but of productivity.

These assumptions about whose bodies fit – and whose bodies are fit – serve to reinscribe a thin zone of normality in which bodies should fit: one must be not too fat, nor too thin (Lupton, 2013). Such assumptions are also inflected with “healthism,” wherein people are judged to be more or less morally valuable on the basis of their achievement (or lack thereof) of a particular version and vision of health (Crawford, 1980). Under this optic, people’s bodies are used as “proof” of their attainment, or lack thereof, of idealized health. The practices assumed to result in “healthy bodies” are based in white, middle-class cultures, and include exercise and dietary behaviours that may be incongruent with other cultural practices (Brown-Bowers, Ward & Cormier, 2017). At the same time, consumer capitalism marches on, peddling products to fix all social ills. Most recently, a particular type of marketing that some have come to call the “female lifestyle empowerment brand” (Diels, 2017) has become proliferate: companies have been tapping into the insecurities of women in particular (though of course those who identify with other genders are not exempt) in order to sell products. Building on a Dove (Unilever) brand of sellable “body confidence” (Rice, 2014), the predominant sentiment sold in such advertising is that it is right and normal to dislike your body, but that this is not an unfixable matter – it can be solved by eating this cereal, or buying that cream. Of course, when such initiatives fail, people are left without recourse to alternative strategies for living in their bodies which are still non-normative and were perhaps never “curable” to begin with. Alternatively, a new commodity becomes the item du jour; the new necessary purchase that will assure health and happiness – we are never fully in step with the marchings-on of advanced capitalism (Braidotti, 2013).
It is for reasons such as these that some have noted that eating disorders may even seem like a logical coping mechanism (Aprhamor & Gingras, 2009). As Aprhamor & Gingras (2009) note, bulimia nervosa in particular exemplifies an attempt to toe the line between consumption and restraint. Indeed, Burns (2004) notes that until it bulimia is “discovered,” people with bulimia often receive praise for their corporeal forms, fitting as they often do the narrow dictates for what bodies can and should be. As she argues, it is the (commonly resulting) form of extreme restriction (coded anorexia nervosa) that elicits concern and intervention, whereas it is the uncontrollable flows (i.e., vomit and other methods of purging) of bulimia that call others to intervene (Burns, 2004). Those with eating disorders often receive praise for their disorders in their early stages; particularly problematic is the way in which those whose bodies do not become marked as eating disorders because their corporealities do not match stereotypical understandings of what it means to be “eating disordered” are often dismissed by ill-informed medical professionals (Sim, Lebow & Billings, 2013) who fail to recognize that weight is not the only marker of a serious eating disorder (Lebow, Sim, & Kransdorf, 2015).

Biopedagogies are implicated in the production and reproduction of the surveillance over bodies that, while it does not necessarily yield eating disorders, neither helps those who are struggling (particularly those who are also marginalized in other ways) nor makes it easy to recover. Once an eating disorder is recognized, people are not free from social sanction – pervasive myths and stigmas circulate around those who suffer from eating disorders and, notably, their loved ones. Eating disorders are commonly understood to be matters of choice (Stewart, Keel & Schiavo, 2006), which is perhaps unsurprising given the degree to which each of us is made responsible for all aspects of our health (Novas & Rose, 2000; Rabinow & Rose, 2006). People are often blamed for their eating disorders (Crisp et al., 2000; Roehrig & McLean,
Crisp et al. (2005) report that up to 1/3 of laypeople in the United Kingdom endorse this point of view. Myths and stereotypes circulate around the ease of recovery as well, not helped by media presentations of linear, highly privileged recoveries, for example those of well-known celebrities (O’Hara & Clegg-Smith, 2007; Shepherd & Seale, 1999). Poor understandings of eating disorders serve to perpetuate such myths, exacerbating stigma (Rodgers et al., 2015), though people with eating disorders may also self-stigmatize (Holliday, Wall, Treasure & Weinman, 2005).

Supporters are not exempt from being subject to and/or perpetuating both biopedagogies and stigma. Building on a long legacy of parent blame related to eating disorders often linked to Bruch’s (1962, 1978) work wherein eating disorders were located in poor interactional patterns, many parents of those with eating disorders have eagerly adopted a biological framing (FEAST, 2012) with the aim of legitimizing eating disorders (Easter, 2012, 2014). Parent blame is not unique to eating disorders, however, in this society bent on shaping and molding bodies into submission. Parents are, in general, held responsible for their children’s bodies; anti-obesity rhetoric very commonly calls parents to account in managing their children’s health (measured by their children’s size)(Tischner & Malson, 2011; Wilson & Woolhouse, 2017). Family members doubtlessly live in a society rife with internal contradictions around consumption, the pressure to contribute to the economy and to be productive and to manage individual health in a way that minimizes risk.

Biopedagogies do circulate in and through families as well as in society more broadly. To say this is not to blame family members for unhelpful behaviours around food, weight, and shape – we are each implicated in upholding (as well as sometimes challenging) systems of power and patriarchy. There are doubtless things that family members can do to make problematic relations
with food, weight, and shape less likely, but families do not exist in Petri dishes any more than do individuals. Where family members might better be enlisted is in understanding the subjective experiences of their loved ones who have experienced eating disorders as they seek to recover.

Of course, the above commentary has not yet implicated culture and other differences. “Family” itself, and relations to others in society and to dominant (Western) cultural messages, is not a unitary construct but one that needs to be explored in relation to different sociocultural and historical specificity. Cultural differences and structural locations inform the degree to which mental health is seen as an issue to be discussed at all, let alone outside of relational contexts. Indeed, techniques of treatment typically employed for eating disorders (most notably, cognitive behavioural therapy) are not always congruent with cultural norms, which may impede sufferers from seeking treatment (Burgess, 2012; El-Jamil & Ahmed, 2015; Patel & Reichert, 2016). Issues of acculturation and divides between culture of origin and local culture may also weigh heavily on those who seek to fit a dual set of norms, particularly around success and productivity. For instance, Rice (2014) highlighted how expectations about success and productivity informed Southeast Asian women’s experiences of their bodies; likewise, Bordo (2009) notes how eating disorders are far from a “white girl’s” disease – they may simply present in different ways amongst those who have different cultural experiences.

It is not new to highlight how the stress of immigration or other cultural disconnects might feed mental distress, but it is an important point for situating eating disorders within a non-homogenous perspective on “family” and “culture.” Too often, “culture” is reduced to media in studies of eating disorders, which neglects the significant roles that other parts of an ecology can play in building lived, embodied experiences. Further, studies exploring family experience in eating disorders have seldom focused on the experiences of marginalized families. Importantly,
for the purposes of this research, differences in familial and cultural experiences can inform experiences of recovery. The stereotypical presentation of “eating disordered person” (i.e., as white, middle to upper class, young, woman) pervades treatment models and current perspectives on recovery in very subtle ways that may render this construct inaccessible to people seeking to recover and may further complicate familial relationships. For example, dietary preferences rooted in ethnocultural specificity may be seen as “strange” or disordered in treatment settings not designed to accommodate cultural variety (LaMarre et al., 2015). Class may play out in the expectation or requirement that sufferers, or their parents, take time off work to devote themselves full time to recovery. Those in treatment and families may be asked to provide variety in food selection, which they may not have the resources to provide.

The very concept of recovery may be inaccessible particularly to those who do not fit the expected mould of eating disordered person. Paradoxically, in order to claim recovery and be legitimized by the biomedical psychological complex, the diagnosis of eating disorder needs to be conferred to begin with – and this is one of the few places in which the significant barriers associated with being a marginalized person with an eating disorder are recognized in the research canon (Thompson, 1996). Still, these barriers have largely been articulated in terms of their impacts on individuals. What if family members do not recognize eating disorders as legitimate, or see recovery differently? This will likely have an impact on the individual’s experience of recovery; again, people exist in complex and embedded contexts. Isolating singular barriers to recovery and applying them across the board is no more likely to yield long-term solutions than is unquestioning accepting the “truth” of diagnostic categorization. Exploring supporter articulations of recovery is paramount for advancing what we know about recovery as embodied and contextualized. Importantly, I consider “family” to be defined by the person with
the eating disorder – biological ties are not the most important factors in deciding which people “matter” for this relational nexus. The term “supporter” is used as a way of untethering relational supports from the assumptions made about family in eating disorders – positive and negative.
Chapter 2: Methods

In order to understand recovery differently, we need to employ different methods. In this dissertation research, I used a combination of qualitative and “post-qualitative” methods to explore participants’ embodied experiences and to attempt to deepen understandings of eating disorder recovery assemblages. Post-qualitative methods go beyond centering lived experience through engaging participants in meaning-making activities like interviewing that are central to a qualitative approach and toward “rethinking the thinking that underpins the ‘doing’ of research practice” (Fullagar, 2017, p. 247-8). So, while I engaged in more “traditional” qualitative approaches, I also took an improvisational and theory-driven approach to collecting and analyzing my data that interrogates not only the data collected but the ways in which it was collected.

I conducted semi-structured interviews with all participants (people in recovery and their chosen supporters) and made digital stories with a smaller subset of participants from both of these groups. Moving beyond individual perspectives on recovery, and exploring how situated experiences of recovery are heard and interpreted by those implicated in the production of eating disorder recovery discourses and biopedagogies, I screened digital stories with groups of healthcare professionals across disciplines. I approached these three sources of data with a perspective on eating disorders and recovery also based on naturalistic observations of the field of eating disorders via my own involvement in advocacy, treatment, and research communities. I thus also engaged reflexively with the data sources and situated analysis within the broader landscape of eating disorders and recovery that operate on a societal level. I implicated my own “embodied self” (Sandelowski, 2002, p. 108) in the analysis but do not foreground my own lived experience – and selectively disclosed it in research settings, as I will discuss – in order to avoid
marginalizing participants’ experiences in favour of foregrounding my own (Rice, 2009).

Nevertheless, I cannot ignore how my own body impacts my research (Burns, 2006; Chadwick, 2017; Ellingson, 2006; Rice, 2009; Turner & Norwood, 2013) – particularly laying claim to the contested territory of recovery. My awareness of the tides and turns of the cartographies of knowledge that exist around eating disorders also sociohistorically and contextually locates my analysis and inevitably impacts the meanings I make in my analysis.

2.1 Recruitment and Exclusion Criteria

I obtained ethics approval to conduct this research in July 2016 through the University of Guelph Research Ethics Board (REB). Subsequently, I recruited 20 individuals in recovery to participate in qualitative interviews about eating disorder recovery. I aimed to recruit people with diverse embodiments (i.e., of diverse ethnicities, socioeconomic statuses, body sizes, etc.); I was less successful in obtaining a diverse sample than I wished to be, as will be detailed in the results section. I recruited using Twitter, Facebook, and list-serve posts. As recruitment was straightforward, I did not need to use physical posters to supplement these strategies. I created an online shareable poster that specifically asked for people whose stories had not been heard, and specified that a diagnosis was not required for participation.

After I had interviewed 15 participants who were largely white, I used a targeted recruitment strategy to try to attain more diversity in my sample. Recruitment criteria for participants included being over 18, self-identifying as having overcome an eating issue or being significantly improved in terms of subjective experiences of distress, not currently in intensive treatment for their eating issue (excluding continued talk therapy), residing in Canada OR having resided in Canada during the time of their eating disorder. Diagnosis was not used as an inclusion criterion due to the significant exclusions inherent in recruiting only those who have
been diagnosed with eating disorders. I did not pre-suppose a definition of recovery, as the goal of the work was to better understand participants’ orientations to the construct of recovery; as such, imposing my own value judgment or an “objective” measure of recovery felt not only overly delimiting but also counter to my theoretical framework.

Following their interview, each participant was asked to select 1-2 supporters to participate in qualitative interviews. My aim was to interview a total of 15 to 40 supporters, based on the assumption that each person would nominate at least one. However, not all participants were able to identify a person who had significantly supported them. The implications of this will be discussed in the results section.

All participants from this larger pool were then invited to participate in a digital storytelling workshop. Due to participant time constraints, I offered participants several options for participation in the workshop, held in winter 2017: in-person attendance, one-on-one work, guiding me through the creation of a story, or participation via Skype with independent video production. Offering choice was intended as a measure to open up the possibility of participation to those who may face additional barriers not only to eating disorder treatment but also to involvement in eating disorder research.

Healthcare provider audiences were recruited using existing connections and through snowball sampling. Providers were offered choices for when and where they would watch the stories. The majority of these providers watched the films in a screening together at their medical school.

2.2 Data Collection

Data collection took place between July 2016 and June 2017. I conducted semi-structured interviews with 20 people in recovery from eating disorders and 14 supporters. Interviews with
people in recovery ranged from 30 minutes to an hour and a half, and interviews with supporters ranged from 25 minutes to 2 hours. Interviews were conducted mostly over phone or Skype (29), with a few interviews conducted in person (5). Participants were all offered the option of preferred interview location. I conducted all interviews myself, for consistency. I followed a semi-structured interview guide, but followed participants as they shared their stories; some participants needed more prompting, while others told their stories mostly unprompted and answered questions before I had the chance to ask them explicitly.

All participants, both people in recovery and their supporters, from this phase of the research were invited to participate in a digital storytelling workshop at the University of Guelph. Nine participants (8 participants in recovery, 1 supporter) indicated interest and availability to come to Guelph for a workshop or participate virtually; 2 participants (supporters) expressed interest were unable to come to Guelph to conduct the workshop. One participant elected to take part via Skype, as she had existing video editing skills and was located outside of the province. Three participants dropped out just prior to the workshop due to personal circumstances. Two of the participants who had been interested could not attend the chosen weekend and participated in a mini-workshop later on.

The initial digital storytelling workshop took place on Saturday, January 28th, with two people in recovery and one supporter. All three participated in the half-day story circle; one participant remained for the whole day to make her story with me. One participant (who was attending via Skype) made her story on her own after story circle. The third participant left after story circle and came back to Guelph on Friday, April 21st to finish her story with me. The second mini workshop took place on Sunday, February 12th with two participants in recovery; these participants elected to do a story circle and record voiceovers and to have me assemble
their stories with images in the days following the workshop. I sent these stories to participants following their creation to ensure that they matched participant’s vision for the story; they did not ask me to make any changes and confirmed that their stories were captured as they wished.

My intention was for the digital storytelling workshops to follow the digital storytelling methodology developed by REDLAB mobile media lab (University of Guelph, led by my advisor, Dr. Carla Rice) and adapted for use in my Masters’ thesis (completed in 2014). These workshops are traditionally 3-day intensive workshops wherein participants construct their stories. Workshops typically include a curriculum, based around the topic of interest (eating disorder recovery, in this case), a story circle (a chance for participants to share their stories and receive feedback), technical tutorials and work with the video editing software Final Cut Pro, and a final screening. Participants develop 150-300 word scripts that act as their primary storyline; these scripts are read aloud and recorded in the sound booth.

Because of the geographic dispersion of participants and logistical challenges (e.g. participants with jobs on the weekend, transportation challenges, accessibility), I elected to adopt a more fluid version of the typical REDLAB/Re•Vision method. This choice was also based on my experience of facilitating more than 10 digital storytelling workshops over the past five years and the challenges of technological accessibility that can accompany these workshops. Often, participants feel overwhelmed by the learning curve of a) breaking down a life story into a 3-5 minute version; b) audio-recording their voice; c) learning how to use a Mac computer and d) learning how to use video editing software. However, I did not want to lose the workshop setting entirely; as I observed in my Masters’ work that the story circle is a powerful moment for generating story (LaMarre & Rice, 2016b), I offered the option of participating in the story circle and then taking one of several options for story creation:
1. If participants were interested in using the lab computers, I supplied MacBook Pro computers available for use in the workshop space. Participants were offered the option of borrowing overnight if they wished, and/or providing me with "post-production" notes to me if they did not finish the story by the end of the workshop or if there were things to be tweaked after the workshop was done.

2. If participants preferred to use their own computers, they were offered the following free video editing software options: iMovie for Mac; Windows Movie Maker for Windows; Hit Film for Windows; Filmora Video Editor for Windows or Mac. If you choose this option, you can begin editing at the workshop and finish it at home on your own time.

3. If participants were interested in telling their stories but not doing the editing themselves, they were able to talk with me about their ideas, and I offered to do the editing in Final Cut Pro after the workshop. This option still involved attending the workshop and taking part in Story Circle, recording an audio track, and choosing images – just not the hands-on video editing.

4. If participants were unable to be at the workshop physically, they were offered the option of participating in Story Circle virtually and creating the story on their own during and after the weekend.

While one participant chose to create her story independently after story circle, the most popular option was to attend story circle and either work with me one on one or have me create the story after the voiceover stage. Two participants chose each of these options. The process itself was not analyzed in and of itself; however, a discussion of process from the perspective of the researcher is explored in the analysis section.
In order to understand the impact of viewing stories on healthcare provider audiences and their understandings of recovery, I screened the stories for several healthcare provider audiences. Healthcare providers answered pre and post questionnaires to assess their perspectives on the stories and the extent to which they found the stories impacted their perspectives on eating disorder recovery. Pre-screening questionnaires asked which healthcare field they were from, whether they had prior experience treating eating disorders, and what eating disorder recovery means to them. Post-screening questionnaires were comprised of questions about the feelings the films brought up, whether and what they learned, what eating disorder recovery means to them, and who, if anyone, they thought would benefit from watching films like those screened in the workshop.

2.3 Data Analysis

To analyze interview data, I used a theory-driven thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2014). As I progressed through analysis I also realized that it was ethically important to me to separate, rather than relating, the data sets, to ensure a greater degree of confidentiality for all involved. Thus, the results section is comprised of several different sections: analyses of interviews with people in recovery, analyses of interviews with supporters, analyses of digital stories, and analyses of healthcare provider responses. Following Braun & Clarke’s (2014) call for more theoretical approaches to thematic analysis, I elected to use an approach that would allow me to engage with themes not as discrete entities signaling an inner reality, but rather from a more open, new materialist perspective – as parts of broader assemblages. Digital storytelling, in particular, has presented an analytic challenge; while digital

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4 In the following section on reflexivity, I detail the privilege of holding stories and participants’ investments in their relationships with each other, which drove this choice
storytelling itself offers a new, more experience-close way of *generating* data, there are few examples of analyzing digital story data in a way that transcends the typical limitation associated with any data analysis technique. The aim, in analyzing arts-based work, might be described as one of bringing in “the visceral, emotional and visual elements in research creation and dissemination” (Hodgins & Boydell, 2014, para 10). Re•Vision researchers have approached stories as both artistic renderings and as evidence, blending qualitative and post-qualitative approaches to analysis (e.g. Lind et al., 2018; Rice et al., 2016; Rice et al., 2015; Rinaldi et al., 2016; Rinaldi et al., 2017). Accordingly, I chose to engage in methodological eclecticism in analysis of the stories, interviews, and healthcare provider screening responses as a way of “doing research differently” (Berbary & Boles, 2014, p. 408). I draw upon more “traditional” forms of analysis (thematic analysis) for the interview data, while taking a close read of the digital stories as artistic productions and research evidence. I reflect on my own embodied relationships with the data and integrate a contextual analysis to situate this work.

While my approach is termed thematic analysis, I am aligned with perspectives that acknowledge the power of language and discourse – not as a route to some inner reality, but rather as a site of power (Fairclough, 2001). Discourse analytic approaches, including Foucauldian discourse analysis, have often been used to explicitly unpack the power bound up in and reproduced through language. Foucault holds that: (a) discourse is not a route to reality, but is rather culturally produced and mediated; (b) power and knowledge are constructed *through* discourse; (c) discourse simultaneously opens and constrains possibilities for subjectivity; and (d) discourse illustrates the pervasiveness of power; how it flows in, through, and around human and non-human subjects rather than being imposed. Foucauldian discourse analysis allows us to identify how “regimes of truth” (Foucault, 1979) are built and reproduced. Because discourse is a
social construction, an analysis of discourse provides us the means of examining how power circulates in society, in interaction.

While critical discourse analysis is a productive way of theorizing how power flows through interactions through vocalized exchanges, it is arguably insufficient for conducting a deeply embodied analysis. As Chadwick (2017) remarks:

Bodies and fleshy, embodied experience are always already there, in our qualitative data. Instead of ‘getting beyond’ language, perhaps the goal of embodied methodologies should be to try and find new theoretical and methodological ways of approaching, tracing and representing the bodies already in our qualitative data and analyses (p. 58)

Theory might be used, Chadwick suggests, to think about subjectivity as simultaneously embodied (i.e., expressed through non-verbal cues, felt in fleshy ways by researcher and participant alike), and ideological (i.e., tied to power discourses typically configured as “external to” subjects, as in discourse analytic approaches). Moving beyond discourse allows for an analysis of excess – of that which is contradictory in research data, expanding upon the ways in which Foucault and other discourse-oriented scholars have acknowledged that people are not simply passive vessels upon which language (and power) are written. Research is itself an assemblage, here – an amalgam of “the bodies, things, and abstractions that get caught up in social inquiry, including the events that are studied, the tools, models, and precepts of research, and the researchers” (Fox & Alldred, 2015, p. 400).

I thus used thematic analysis (Braun & Clarke, 2006) as a methodological tool to code segments of text from transcripts, identify which pieces of data cohere, and create a framework for drawing conclusions about themes that traverse the data set. This thematic analysis, however, was driven by new materialist theories and at times lay in tension with post-qualitative
methodological leanings. To reconcile the potential challenges of using a qualitative methodology while aspiring to enact post-qualitative inquiry, I attended to the semiotic echoes of themes: “the energies, rhythms, forces, and corporeal residues necessary for representation” (Grosz, 1989, p.43 cited in Chadwick, 2017, p. 59). In Braun & Clarke (2006) this corresponds with a latent-level thematic analysis, rather than a semantic approach, which would address themes at face-value. This means understanding that while the data may be marked by patterns of meaning that become themes, these themes are not abstracted from the context in which they are produced. As Grosz (1989, 1994) explicates, in order to understand how these “themes” surface, we must also explore the set of practices and contextual echoes that lead to their expression in this time and place.

On a practical level, analysis consisted of first having interviews transcribed verbatim, including pauses and verbal tics. I then listened to recordings alongside the transcripts in order to check the transcriptionist’s work and explore the non-verbal cues that exceeded what I could remember from conducting the interviews. I transcribed 5 of the interviews myself to ensure that I was connected to and familiar with the data; all of these were interviews with supporters, as I had not spoken with any supporters of people with an eating disorder in the context of research prior to this project. I then coded the transcripts using MAXQDA software, a data suite designed for qualitative and mixed-methods data analysis. I coded inductively, creating my coding system as I proceeded through the transcripts. I made memos throughout the process when pieces of text struck me as different from other parts of the story, when I found particularly insightful accountings of how power works in and through bodies, or when something impacted me on an affective level, or I remembered it doing so during the interview itself. I did this separately for the interviews with people in recovery and for supporters.
I coded all of the interviews from people in recovery first, followed by those of supporters. I then collapsed similar codes into themes, for clarity and conciseness. About halfway through the coding process, I explored the themes in relation to the excerpts I had coded, and found that there were several key thematic areas that recurred across the data set in terms of their conceptual centrality to the experiences described by participants (time, embodiment, and relationality); importantly, this was not about these themes being most-mentioned, but rather about how central these patterns were to understanding the whole of the experiences participants described. In the remaining transcripts, I was attentive to the operation of these themes. I also revisited earlier transcripts through this lens to ensure that my increasing clarity on the central themes had not been missed in earlier readings.

After all of the transcripts were coded, I explored the cross-codings (places where the codes overlapped) to look for intersections between codes and generate additional meaningful themes. I looked not only at the number of times a particular code was mentioned, but also the contextual surround, how often a participant mentioned the same theme within their transcript, and the contribution of the code to the overall understanding of the issue. For instance, while the code “non-disclosure” only appears 43 times across the data set, it is brought into salience in relation to the code “stigma and stereotypes.” That is, here participants described their experiences of choosing not to talk about their eating disorder and recovery because of the stigma surrounding eating disorders within their close (i.e., family) or more distant (i.e., medical settings, broader societal) contexts. I exported documents with important cross-coded excerpts and analyzed these excerpts in more detail, looking for participants’ accounts of the construction of their subjectivities as eating disordered and/or recovered. Again, time, embodiment, and relationality became frames for analysis and helped me to locate where and how participants
evoked, negotiated, and/or contested dominant constructions of their own eating disorders and/or recoveries, as well as those of imagined others. In supporters’ accounts, these analytic frames also helped me to explore relational complexities around disclosure, help-seeking, and in action in relation to systems.

I elected not to specifically link participants’ accounts to those of their supporters. This choice was made for a number of reasons. First, not all participants were able to identify a supporter to be interviewed for the project: of the 20 people in recovery interviewed, only 11 identified a supporter to be interviewed; 2 of these people identified more than one person. In one case, supporters were interviewed but not the individual with the eating disorder; this family unit responded to the interview request as a group, and the individual in recovery later decided not to participate. Nine participants in recovery did not identify a person who significantly supported them during their recovery or did not follow up with me when I sent a reminder asking them to identify a person who had supported them. This represents a finding in and of itself; as one participant named, when asked to nominate a supporter: “unfortunately, I don't think that I have anyone that would feel comfortable doing that.” Another participant remarked:

I really want to help as much as possible, but this is a tricky one for me. My parents are really the only ones in my life at the moment and it's more out of necessity rather than my feeling like they are truly "supportive". My doctor has been great, but that's not really a relationship beyond the monthly check ups. I think I mentioned to you that my therapist, who was also more like a mentor or even a surrogate mother in a way, kind of abandoned me about 6 years ago and since then I have been reluctant to seek out any other support. As for friends...when you have been sick as long as I have, people get tired of trying to help and move on. I don't blame them one bit. I am attempting to reconnect with some of
them, but that will take time. I guess the bottom line is, I don't really feel like there is anyone at this point.

Responses like these constitute a kind of data attuning me to the landscape of support beyond what is normally seen within the literature on support relationships in eating disorder recovery and also call for more nuanced understandings of support relationships – understandings that I will tease out in the results section. These responses have been included in the analysis section to illustrate part of the broader contextual analysis of the themes within the interviews; a part of the landscape or cartography of knowledge used to understand the situated and embodied experiences of those in recovery.

This idea of building a “cartography of the present” (Braidotti, 2003) helps to thicken the thematic analysis I performed with the data. It draws on a Deleuzian social cartography, which entails “map[ping] individuals on a plane of immanence”, and operates on multiple levels, mapping “any given thing in terms of the internal composition of its parts and its powers for affecting and being affected” (Gatens, 2000, p. 63-64). This technique of seeing has its roots in philosophy, though it is inherently a trans-disciplinary approach (i.e., an approach that does not congeal to a single disciplinary perspective). It entails looking at participants’ “power locations” that inform their interactions (Braidotti, 2013, p. 164). It is not about seeking some truth in discourse or an objective reality, but instead about exploring how people already enact “affirmative alternatives” through their interactions with others and with the world (Braidotti, 2013). Engaging in affirmative politics does not mean denying or ignoring the ways in which human and non-human actors constrain human action, but rather “starting from micro-instances of embodied and embedded self and the complex web of social relations that compose subject positions” (Braidotti, 2011, p. 76) as sites of potential resistance and moving outward.
Constructing a cartography of the present, or a critical cartography, means looking not only at discourse or the discrete themes presented within the data but also at the material conditions in which people act: the systemic factors and non-human elements that may constrain (or enable) action and discourse (Braidotti, 2003, 2005, 2013). In this particular case, this involved a deep survey of the representations of eating disorder recovery that inform and are indeed produced by those in recovery, their family members, healthcare providers, and others. It involved understanding the paths people take to their particular experiences including the range of possible paths not taken (Rose, 2009). Undertaking a cartography of the present allows us to get closer to embodied subjectivity by unpacking the idea of “choice” by de-centering the focus from the human subject to take into account that which is not present in discourse (Braidotti, 2005; Gatens, 2000). It is similar to, but different from, a genealogy, which “trac[es the] discursive formations of power and control, by assembling a strategically organized ensemble of historical knowledges that will be capable of opposition and of struggle against the coercive power of social scientific discourse” (Hook, 2005, p. 7). While a cartography of the present entails analysis of concepts and the contexts in which they are constructed, as does genealogy (e.g. Hook, 2005), it focuses primarily on the ways in which concepts and systems are constructed in the present (as opposed to those “ensembles of historical knowledge” Hook notes) – not ignoring the past, but exploring its manifestation in the present.

Situating thematic analysis within a cartography of the present helps to unpack how the master and counter-narratives – or themes – present in participants’ accounts are not “new,” and perform specific functions for participants and for power relations. A cartography of the present allows for contextualization of “found” themes against broader discourses, exploring the multi-layered concept of power and master narratives or dominant discourses (Braidotti, 2005). A
cartography of the present moves toward a nomadic – or, de-centered, starting with difference, post-humanist – perspective; one that considers not only knowledge and power as built of language but also the affective ties to discourse that are generated in collectivity (Braidotti, 2005). It calls for “renewed and constant attention to the shifting grounds of socially mediated power-relations” (Braidotti, 2003, p. 60).

2.3.1 Digital Story Analysis.

Digital story analysis is not well documented. For visual methods in general, including photovoice and photo-elicitation, thematic or content analyses appear to be among the most popular. Boydell, Gladstone, Volpe, Allemang & Stasiulis (2012) also consider creative methods and their analysis for health settings, including digital methods that envision research as more than a process of uncovering some inherent truth to experience. When the data is only visual, we can find an array of analytic approaches (Knoblauch, Baer, Laurier, Petschke & Schnettler, 2008). From a qualitative, social science perspective, video analysis approaches tend to focus on setting, whereas photography analysis focuses primarily on the “symbolic structure” of the image (Knoblauch et al., 2008). Grady (2008) proposes that when interpreting visual data, researchers must explore both the perspectives of the picture maker and the viewer; he suggests that the benefit of using visual data is the ways in which it opens up routes to emotion, variations over time, and the co-constitution of relationships. Bohnsack (2008) focuses on an analysis of visual data beyond the “iconic” or representative quality of images and encourages an analytic approach wherein the researcher would explore patterns of structure across multiple photographs. Others, like Goodwin (2000), take a more ethnographic approach to the generation and analysis of images. Goodwin draws on conversation analytic approaches to understand images as another form of language – “an analytically distinct subfield of a more encompassing science of signs”
that “can only be investigated by taking into account a diverse set of semiotic resources and meaning-making practices that participants deploy to build the social worlds they inhabit and constitute through ongoing processes of action” (2000, p. 157). The focus here becomes less on the image itself, and more on how the image is constituted.

It is here, rather than through methods that propose a focus on the image itself, that we find a route toward digital story analysis. In my Masters’ thesis, Dr. Rice and I began to experiment with data analysis techniques, including narrative thematic analysis (LaMarre & Rice, 2016b). The challenges presented with digital story data include a) the centrality of the setting in which and process through which the stories are created to their “meaning”; b) the coexistence of visual and voiced “data” within the stories, and lack of prior methodological work delineating ways of bridging the gap between visual and linguistic data; and c) the individual differences in stories that preclude a “true” thematic analysis aimed primarily at collapsing meaning into discrete and cross-cutting themes. Digital story data is in excess of our limited frames of conducting qualitative enquiry; like an embodied approach to transcription, they preserve “bodily eruptions in speech” (Chadwick, 2017, p. 59) that become hard to flatten into text format. In previous work on digital story analysis, we have also conducted analysis as a group process to preserve individually situated themes in digital story data (e.g., Rinaldi et al., 2016; Rinaldi, Rice, LaMarre, McPhail & Harrison, 2017; Rice et al., 2016; Rice et al., 2015; Rice et al. 2017). Conducting analysis in a group has allowed for the emergence of thick description of the themes contained within and cutting across both visual and voiced data. However, the analysis for this dissertation was undertaken independently, and thus not subject to the same co-presencing and discussion that has yielded deep discussions about data.
To build on and enrich the overall analysis present in this dataset, I elected to analyze the films using the same thematic analytic, theoretical approach as I used for interview data; however, as noted, this manifested differently given the thick nature of the stories and their individuality. Using the same theoretical frame helps to thicken both sets of data about participant experiences, allowing me to engage with the multivocality (Gilligan, Spencer, Weinberg & Bertsch, 2003) of participants’ stories: how participants construct themselves on multiple registers, for multiple audiences, and in and through time. For digital stories, I approached the stories primarily as case studies, with less integration across cases than interviews. In the discussion section, however, the stories are more deeply contextualized against each other, the context in which they were made, the audiences they were made for, and the broader context of eating disorders research, treatment, and public discussion. Because they were generated for the purposes of screening, aspects of film production, including representational power, audience, and selection of images become important sites of analysis. I have also explored how the context of the filmmaking seeps into the stories; as the stories are produced in a group context, we might, for example, explore which themes are held in common between the stories and those which transcend categorization.

I created a summary of research results for lived experience and supporter data and sent these to the respective groups for feedback and review (see Appendix). Digital storytelling participants who had requested it were also given a copy of my analysis of their film for review. These steps constituted a member check (Doyle, 2007); rather than seeing this as only a technical procedure to “validate” my results, I communicated to participants about the importance of their voices to the project and encouraged them to provide feedback if they had the time or inclination (Birt, Scott, Cavers, Campbell & Walter, 2016). Several participants replied and were positive
about the results; one offered an additional point to add to her film analysis but no other modifications were sought by participants.

All of the analyses for this dissertation were conducted within a theoretical frame, described below. Perhaps most importantly, while the theoretical approaches I have used critique dominant modes of power, and their operation, they also offer a “politics of possibility” (Braidotti, 2013) – a starting point for movement and change. Addressing “bodies as permeable and co-implicated in nature-cultures” (Fullagar, 2017, p. 255) as I will describe in my theoretical framing allows us to unpack the normative ways in which human agency is construed and gesture toward ways to scaffold ways of being that open to – instead of foreclosing – difference.

When researchers “use theory to think with their data (or use data to think with theory)” (Jackson & Mazzei, 2013, p. 261), there is an increased recognition of the always-provisional and always contextual nature of data and “truth.” I have challenged myself, as Braidotti encourages, to think about themes not as concepts, but processes. While I have collapsed meaning into themes to satisfy convention and for intelligibility, I see these thematic categories as partial, provisional openings rather than objective and enduring truths.

2.4 Theoretical Framework

Particularly in a dissertation aiming to un (or perhaps re) tangle the complexities of embodied recoveries, outlining my theoretical perspective will help to situate this work in the vast landscape of existing work in the field. I take a critical feminist, embodiment-focused approach to analyzing eating disorder recovery. Importantly, and as I have briefly commented upon above, there may appear to be a disconnect between my use of the term “recovery” and this theoretical

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5 This participant had been diagnosed as being on the Autism Spectrum in the months following the digital storytelling experience, which helped her to make sense of her experiences of the world and that she wished me to include in the story analysis.
framework. For many critical feminist scholars, particularly those using a post-structuralist frame, the term recovery may be seen as incongruent with a perspective on eating disorders that sees them not as a reflection of pathology but rather on a continuum with other eating behaviours. For post-structuralist scholars, diagnostic labels do not reflect “real categories” but instead serve to reify boundaries around normal and abnormal conduct with food, weight, and shape – discursive categories that may be experienced as harmful or even traumatic by sufferers (e.g. Malson et al., 2011a). These categories may be doubly problematic insofar as they also restrict people’s access to desired or needed treatment and/or legitimize or delegitimize people’s lived experience on the basis of their fitting or not fitting externally-imposed criteria for eating pathology.

Responding to calls from post-qualitative researchers such as Berbary & Boles (2014), Jackson & Mazzei (2013), St. Pierre (2013) and Fullagar (2017, 2018), I have aimed to “think with theory” and data in my analysis, acknowledging that my knowledge of participants’ accounts is and will necessarily be partial. Ontologically, I position myself as embracing an “experimental ontology of becoming” (St. Pierre, 2013, p. 652) that aims not to represent as real, but rather to explore openings. Broadly, I align myself with thinkers who propose that biology and culture are inextricably linked and co-influential (e.g. Grosz, 2004, 2011; Editors of Interstitial Journal, 2013; Rice, 2014). This perspective allows me to at once acknowledge the potential issues with using language that may be seen as problematic from a discursive feminist lens (e.g., the terms “recovery” or “eating disorder” themselves) while also acknowledging that this language holds currency in policy settings.

Understanding that we are all – researchers, clinicians, supporters, people without named relations to eating distress, people with lived experiences, and those who occupy more than one
of these categories – part of broader systems of social control and resistance yields an approach to analysis that might be termed posthuman in its focus on exploring relationality and co-constitutiveness (Braidotti, 2013). Like those who subscribe to nomadic or posthuman theorizing (i.e., Braidotti, Barad, etc.), my ontological orientation gestures to how humans’ embodied experiences are not singular; they are entwined with other people, other things, and other forces (Fullagar, 2017, 2018; Pyythinen, 2016). Exploring relationalities and flows, and how our systems of making meaning and experience are tied together and to the systems generally considered to be our “surround” may be a productive way of moving beyond theories which continue to reproduce boundaries between categories that are fundamentally overlapping – including those of eating disordered and recovered, clinician, researcher, supporter, and person with lived experience, and more.

An approach that opens to the deeply contextualized – to the point of being inseparable – nature of becoming bodies also permits me to value lived experience. This valuing extends to taking a more generous read of perspectives that I do not necessarily endorse on the nature, causes, and correlates of eating disorders. For instance, there has been a recent focus within the eating disorder field on establishing evidence for the biogenetic roots of eating disorders. Some, notably many parents (e.g. F.E.A.S.T., 2012) may see such attributions as useful for minimizing stigma and shame (though I will discuss the limitations of such approaches in this work as well; see also Easter, 2012, 2014). Failing to acknowledge the currency that biogenetic attributions hold in policy level discussions of eating disorders and recovery would be to ignore the lived experiences of many or to write onto them a particular ad-hoc sociocultural explanation rooted more in my own critical feminist perspectives. However, we must equally acknowledge the potential limitations of such framings; taking an embodied, “becomings” (Grosz, 2005, 2011;
Rice, 2014; St. Pierre, 2013) perspective allows for nuanced navigation of co-constitutive biological and sociocultural intertwinings. There is nothing inherently incommensurate between a critical feminist frame that proposes that we value the perspectives of those who have an embodied experience and a perspective that suggests that biogenetic explanations might be persuasive for minimizing stigma. The difference lies in the recognition that no single framework will be useful for all people in all contexts, and the insistence, from a feminist perspective, that each explanation will necessarily be impacted by sociocultural flows.

The ultimate aim of this work is to better understand eating disorders from a systemic perspective: systemic encompassing supporter, cultural, and socio-political and economic relationships in which people are embedded and which people help to create. About half a million people in Canada suffer from eating disorders (NIED, nd). Yet, the Canadian continuum of care for eating disorders is severely lacking; there are few inpatient beds, insufficient affordable independent therapy, and fewer still community-based supports for those with eating disorders. The community supports that exist, such as Sheena’s Place in Toronto, rely on private funding and are continually in danger of losing funds. Many people with eating disorders seek help in the United States, either by securing limited-time funding through provincial health plans or by paying out of pocket or with semi-private insurance. Those who do not fit the narrow expectations for what it means to have an eating disorder (for example, those who do not obtain a DSM diagnosis due to barriers to access or traumatic experiences with treatment systems on offer) are left with no support at all; they are left “unrecoverable” (LaMarre et al., 2015) and unaccounted for in even the most generous estimations of the number of people suffering in this country.
In order to provide those who are suffering with a picture of how life might look after they work through their eating disorder, researchers and advocates need a clearer picture of the kinds of recoveries others have experienced. Without a nuanced understanding of the lived, embodied experience of recoveries and the diverse shades recovery can take, it is more challenging to establish much-needed support to assist people on their journeys. Though eating disorders can be isolating, people with eating disorders are also embedded in systems; people in those systems have their own experiences of eating disorders and recovery; equally, their reactions to the person in recovery contribute to shaping that individual’s experience of recovery. Moving beyond seeing individuals as sole actors in their own, self-dictated, and autonomous paths to recovery is an essential step in generating accounts of recovery that are reflective of the messiness and differences inherent to life.

This approach is a departure from earlier feminist theorizing around eating disorders specifically but builds on the work of other feminist scholars interested in bodily matters. For instance, Fullagar (2018) uses Barad’s agential realism to explore the materiality of practices of knowledge and the ties between materiality and discourse in women’s experiences of recovery from depression. She uses theories of embodiment (e.g. Lather, 2015) to explore the medicalization of depression and to describe recovery as being something beyond transformation. Using Barad’s idea of “diffraction,” Fullagar moves beyond “research [that] produces the phenomena it seeks to know” (2018, p. 5). For instance, Fullagar explores health in terms not only of things that are considered “variables” in much of health research (e.g., amount of physical activity, calorie intake, etc.) but also in terms of environmental pollution. As she notes, policies designed to enhance the former may lead to more exposure to the latter. Thinking intra-actively about health, then, requires an analysis of how these seemingly disparate areas
converge and interact (Fullagar, 2018). In so doing she recognizes the shades of grey within practices normally represented as black and white.

For Barad, “difference is understood as differencing: difference-in-the(re)making. Differences are within; differences are formed through intra-activity, in the making of ‘this’ and ‘that’ within the phenomenon that is constituted in their inseparability (entanglement)” (Barad, 2014, p. 175)(for another example of this uptake of Barad’s differences and diffraction, see Fullagar, 2018). Hor, Godbold, Collier & Iedema (2013) similarly seek to situate patients within healthcare contexts and draw on Fox et al.’s (2005) elaboration of bio-responsibilization (making people out to be responsible for their bodies, including at the cellular level). They remark upon the inseparability of patients and power, describing power as not able to be removed, resolved, or “shared” with patients because of its complete infusion into systems (Hor et al., 2013). These accounts and others recall a Foucauldian approach to biopower – where power is diffuse and operates on, in, and through people – but extends this beyond its humanist tetherings to offer insight into the experiences of people managing their bodies in relation to other people and to the things, affects, and meanings people create. In other words, conducting analysis in this way sees as power and agency as not only inhering within humans but rather circulating in and among people, things, and meanings.

The use of an expanded theoretical frame, in concert with the linguistic choices described above, is driven in part by a reflection on trends within the eating disorder field to date and a desire to do things differently. A significant body of excellent critical feminist work on eating disorders highlights considerable systemic and structural concerns that maintain environments in which it is incredibly challenging to recover from an eating disorder. Innovative work by Malson et al. (2011a), for example, highlights how those in treatment may not be able to imagine
recovery; many others have identified how and where eating disorders fit within social relations with food (e.g., Burns, 2004; Warin, 2010). However, despite the significant contributions of feminist scholars, this work has rarely been taken up or engaged with in the mainstream eating disorder literature. Placing mainstream and critical literatures into dialogue offers us a unique opportunity to blend research focusing on the individual aspects of eating disorders and those that theorize the sociocultural surround in which those with eating disorders live and, thus, must recover. Recognizing the co-constitutive nature of social phenomena (Grosz, 1994; Rice, 2014, i.e., how both biology and environment are important to the genesis of and recovery from eating disorders, recognizing that people are always engaged with their social worlds) allows for innovative theories of recovery that acknowledge diverse embodiments of eating disorders and recovery. In an ideal world, in which the power imbalances that exist within the field are acknowledged and addressed, this would also engender more fruitful debates within the field that bring together, rather than polarizing, opinions about what eating disorder recovery is, how to get there, and the problematics therein.

Ontologically, I do not believe that there is necessarily a singular or real truth to recovery, some universal construct that can be advanced with a set of criteria or markers that those with eating disorders must reach in order to claim “recovery.” Instead, I see recoveries as necessarily enacted in specific spaces of belonging and as differently experienced based on a person’s unique embodied positionality. Taking an embodiment perspective on recovery means exploring how one’s body acts as a precondition for living in and experiencing the world (Merleau-Ponty, 1996[1964]; Overton, 2015). Rather than treating the body as simply a physical structure or collection of cells and flesh, it is a dynamic and evolving vehicle for engaging with the world (Overton, 2015). The body cannot be perceived like any other object by virtue of also
being the object with which one perceives the world (Merleau-Ponty, 1996[1964]). It is built (and continues to build) in concert with both historical and relational contexts and conditions; that is, the experience of the body can shift and change by virtue of being with others (Weiss, 1999). The body is not a *tabula rasa* to be written on by culture, but rather also constructs culture (Grosz, 1994). The brain is also a part of the body, unable to be completely isolated and studied as a discrete entity (Braidotti, 2011). Looking at the body in all of its difference and complexity allows us to move beyond surface level explanations of eating disorders and recovery and to explore how mind, body, and environment entwine to create experience, often in unpredictable ways (Braidotti, 2015).

I analyze eating disorder recovery by creating an assemblage of theories that weave together perspectives on bodies, affects, and time. These come together to build understandings of recovery as always co-constituted, intercorporeal, and more-than-human (Braidotti, 2011; Weiss, 1999; Grosz, 1994, 1999). It may be unconventional or challenging to engage with the more-than-human, by which I mean discourses, flows, and material trappings that impact our experiences of the world: social media postings, our physical environments, comfort objects, pets, medical and other knowledges that come to matter to us as we all negotiate our realities and shape ourselves as we shape the world. However, the task of doing so allows us to move beyond a person-centered analysis characteristic of social science—and particularly psychological—research and practice in a neoliberal age (Sugarman, 2015). I centralize bodily materiality as a dynamic, becoming, particularized, and intercorporeal site of analysis. I see differences (e.g., sexual difference, ethnic difference) as “real” to a greater extent than do those whose analyses are more discursive; however, I see discourse as another flow with which bodies interact. In a
sense, discourse, here, is also material. Subjectivity, then, lies in “between the practices of culture, discourses, ideology, and the body” (Chadwick, 2017, p. 59).

Participants’ accounts reflect not realities that are fixed and forever, but openings to different ways of understanding recovery. Theorizing these accounts, in all of their situated entangledness and complexity, requires nimble use of frameworks from post-structuralism to post-humanism. Levy, Halse & Wright (2016) invite qualitative researchers to “think diffractively,” again drawing on Barad’s metaphor of diffraction to theorize the interaction between subjectivity, discourse, and bodies. They adopt MacLure’s (2006, p. 731) “baroque method,” to open to uncertainty, take multiple perspectives, and avoid foreclosing expertise and knowledge (Levy, Halse & Wright, 2016, p. 185). Similarly, I take what might be termed an eclectic approach to my theorizing in relation to eating disorder recoveries. I seek, as Braidotti would encourage, to “engage in affirmative politics, which entails the creation of sustainable alternatives geared to the construction of social horizons of hope, while at the same time doing critical theory, which implies resistance to the present” (2011, p. 268). I engage with theory as deeply and inextricably political – unable to be untethered from the forces it helps to create in, through, on, and beyond bodies. Theory drives, and is inextricable from, my analysis.

2.5 Reflexivity

As a critical feminist researcher aiming toward new materialist and post-qualitative approaches to inquiry, I acknowledge that the assemblage of recovery involves not only the sets of instructions offered to people in recovery, the embodied experiences (sensations, affects, stories, relations, etc.) of people in recovery, the relationships with other humans and things that comprise recovery, but also my own implicatedness in the “object” of my study. While I am aware that being reflexive risks overshadowing the stories of participants, a brief commentary on
how I am entangled in my data and its production and analysis is worth brief comment. I offer
my experiences as neither a representation of my bias nor my absolution from subjectivity.
Instead, I reflect on my past, present, and potential future relationships with eating disorder
recovery assemblages to foreground the importance of the material to me, part of the lens I am
using in my analysis, and the forever-incomplete, unfinished understandings researchers build
about any phenomenon of interest. I also discuss, in this section, my embodied reactions to
participants’ accounts, as I recorded in reflexive memos throughout the process, and what this
reveals about the experience of doing research in a post-qualitative frame.

When I began working on eating disorder recovery as a phenomenon of inquiry, I was
much more certain what I was looking for. I entered my Masters’ 4 years into my recovery from
an eating disorder not otherwise specified, for which I had been partially hospitalized at a large
hospital in Mississauga for eight months. I recovered primarily by following the rules of the
treatment program. In many ways I was a model patient; I resisted the program in subtle ways –
for instance, by still stretching in the evenings despite warnings that any physical activity might
push me over the edge to death’s door – but largely adhered to the program. My resistance was
much more subtle than the resistance I observe in the literature: here, resistance is framed as
cookie-throwing, water-loading, physical fights, and more. I remember only one such incident in
my journey, a particularly fraught panic attack in which I wrestled my mother to the ground as I
attempted to procure my running shoes to get out the door. I was otherwise “compliant,” if
uncomfortable, in the treatment setting.

My own eating disorder story largely fits the “told” story of an eating disorder. I am
white, middle class, heterosexual, cis-gender woman, mostly able-bodied, and my “natural body
size” or setpoint has been relatively thin. Where my eating disorder journey diverges, it has been
cleaned up in its retelling. I was diagnosed with eating disorder not otherwise specified because I did not fall below the weight threshold; my behaviours being mostly oriented around exercise, my body was very muscular upon admission. I have recently noticed that when I return to speak about my experiences at the treatment centre, my psychiatrist calls my disorder anorexia nervosa and speaks about it as if I had been hyper-emaciated. Because of my relative privilege and continued thinness, my story is easily re-written to fit the stereotype to an even greater degree than it already did.

I was not always as aware of the stereotypical portrayal of eating disorders and recovery as I am now. Previously, I accepted the standard perspectives on recovery as easily as I never questioned my whiteness; because I did not experience marginalization, I assumed that it was not a significant issue. While I waited on a wait list for upwards of 4 months, most of my delays in treatment seeking were due to my non-acknowledgment of the need for more intensive support. And while I believe that the support I received was ultimately key to my recovery, I am still undoing the inscribed rigidity borne of my treatment experiences, including limited flexibility over meal timing and composition. Nonetheless, I emerged from treatment mostly unscathed by the experience. Unlike others who have reported significant harms associated with treatment – or who just could not adhere to the rigidity it inscribes and were thus forced out of the system – I entered and exited treatment only once. I am deemed recovered by the medical psychiatric complex and clung wholeheartedly to this label myself until I began to unearth the complexities and privileges associated with claiming this label.

During my Masters’ work, I explored experiences of eating disorders and recovery in a broad way. In openly asking participants about their experiences, I discovered the complexity of recovery. While participants endorsed recovery as a possibility, few were willing to claim that
label for themselves. They questioned their own recoveries when they compared them to the pristine versions of recovery encapsulated in representations of recovery – pristine versions of recovery I myself bought into and reproduced. I realized, in writing my Masters’ thesis, the possibility that representations of recovery might themselves foreclose its possibility for some people. I recognized my own complicity in upholding systems and frameworks that made this category unattainable for people who faced marginalization or even just life complexities that made it difficult for them to perform recovery in the same way that I did. I was simultaneously writing for a popular blog about eating disorders, and in this context, I encountered many people who told me that the blog and my writing about this subject made them feel more able to pursue their lives in ways that made them feel well, rather than trying to live up to others’ standards.

This discovery propelled my PhD work, as I was curious to learn more about the recovery landscape beyond the research studies. I became curious about how stories – my own and others – simultaneously challenged and upheld standards of recovery that essentially asked people in recovery to be held to a higher standard than others who live in a world firmly bent on molding peoples’ bodies into pictures of health pre-determined for them. I began to recognize in the research literature a parallel tendency to find what the researcher was looking for: often, researchers pre-determined recovery standards before recruiting; in so doing, they procured stories of recovery from those who oriented to recovery in the same way that they did.

Of course, as is evident from this reflection thus far, I too have my own ideas about recovery borne of prior research, personal experience, research literature explorations, and experiences in the advocacy space. How to recruit for people that might expand the definition of recovery without simply confirming my own perspectives became challenging; adding to the general challenge of finding people who have not told their stories and who often do not feel
they have the space or scope to do so. I acknowledged this challenge from the start of my research and elected to ask for people who “felt that they had something to say” about recovery. I did interview people who shared my perspective; I also interviewed people who took more normative perspectives on recovery, as well as people who challenged me in new ways – particularly with the perspective that the eating disorder was, for them, “just a phase.”

I found myself most personally challenged by and emotionally impacted by interviews with supporters of people in recovery. I conducted many of these interviews late at night while travelling in Europe, and found myself sobbing following accounts of physically moving loved ones to treatment spaces, of the deep love that drove their hope for recovery, and of the ways they were able to reconcile their dislike of monitoring their loved ones’ behaviours with the need to provide intensive support in the absence of significant structural assistance. I often thought about my mother during these interviews and gained a new appreciation for the challenge of navigating treatment systems when you have an adult child. I was also astounded by and grateful for interviews with young men who supported their partners through the process of eating disorders. I became even more attuned to the importance of listening in the recovery relational process; something participants in recovery often found only in their chosen supporters.

I navigated self-disclosure on a case-by-case basis. I often found that participants asked me questions about my research and about the state of affairs in eating disorder research and treatment. Supporter participants in particular often wanted to know if what they were doing was “right” – I answered their questions as much as I could in an open and uncertain way while trying to satisfy their desires to know; I used research data, experiences across the treatment-research continuum, and personal experience to respond. I did not tell my story in detail when I disclosed; I noted that I had experienced eating disorder treatment, that I had been diagnosed
with eating disorder not otherwise specified, or that I had a mixture of normative and “different” experiences within and beyond the system. I named that I held privilege in recovery because of my whiteness, my size, my heterosexuality, my visibly able-bodiedness, and more. I commiserated about the lack of services for people with eating disorders and their supporters and shared what I knew about ongoing efforts to change this. My disclosures were thus not always related to my embodied experiences of distress; sometimes they were related to my experiences of advocating for change. I am very open about all of these experiences in my work and online; if one were to Google my name, they would be able to find out very quickly that I had these experiences. Thus, disclosure did not feel like a personal risk. The balance was to maintain a focus on participants’ experiences of and perspectives on recovery and to not let the conversation become sidetracked with my own experiences.

Some participants knew about my experiences prior to being interviewed; for some, it was on this basis that they decided to be interviewed. Many participants were familiar with my work, which they described as a reason for participation; they were interested in having an open conversation about recovery. While this knowledge of me and my perspectives and story may be considered a bias, it yielded particularly rich data in which the interviewer-participant relationship became less hierarchical. In a way, I am a participant in my own data; however, I would argue that researchers, and their bodyminds, are always present in their data. Because of my awareness of the conversational nature of my interviews, I was also aware of how often participants said things like, “I hope my answer is useful” or “I hope this is what you’re looking for.” Statements like these demonstrate the ways in which participants orient to research and presents the continual challenge of how to navigate power relationships in research. Participants
are, in a sense, offering a service to researchers. And yet, the researcher is usually the one who dictates the terms of engagement.

During analysis, my challenge became not disentangling my own points of view from the data – the themes stood out to me in a way that scaffolded a relatively coherent central argument, if with variations on themes due to different social positionings and personal perspectives – but identifying what aspects of the entangled recovery experience to focus on. My desire for the work to be “useful” inevitably drove these choices; I was undoubtedly attuned to participants’ articulations of gaps in the system and their difficulties in navigating these. Disentangling my own version of recovery from those of recovery was actually made easier by my awareness of my perspectives on recovery. I have spent a significant amount of time understanding how I relate to recovery—as an incomplete, non-linear, imperfect, and contextual process—which allows me to identify moments in which participants’ stories remind me of my own and moments when they do not. Often, participants’ stories challenged me to acknowledge the ever-partial perspective I (and others who’ve recovered) will inevitably take on recovery. We are only able to experience recovery in and through our own situated bodies; while others might tell us stories, even when we share similar experiences we do so partially and incompletely.

Each participant’s story shared aspects of mine, and every participant’s story contained differences. I watched my reactions using memos after interviews, noting moments when I found interviews challenging – for instance, when a supporter said that they did not think that people in recovery should become therapists, a perspective I disagree with – and when I found them engaging. I noted my embodied reactions to doing several interviews in a row – the migraines and body aches, the tears, the need for physical touch following several of the interviews. Taking stock of these embodied experiences also alerted me to how participants’ stories transcend the
voiced aspects of their accounts. If I was having these reactions as a researcher, I imagine that
the telling of the story was a visceral experience for some, if not all, of the participants. It is also
worth noting that very few participants cried or became visibly upset during their storytelling.
For some, telling the story was something they were very used to; many participants would be
used to telling their story to doctors and other healthcare providers. I was encouraged that my
questions moved beyond their “by rote” stories when most participants paused for thought when
I asked, for instance, what recovery meant to them.

By the end of interviewing supporters, I began to feel that I was holding a lot of stories. I
felt this way particularly because many of the supporters I interviewed had never shared their
stories with anyone before; this was their first experience of opening up to another person about
their loved one’s eating disorder and how supporting that person had felt for them. The main
reasons participants articulated for this were that they did not wish to breach their loved one’s
privacy. Partners of people in recovery were particularly conscious of the privacy of their loved
ones; they did not share experiences with friends because they often shared friend groups and
their partners were not always open about their experiences. Thus, I became the vessel for these
untold stories. Stories can feel heavy, particularly when they involve frustrating experiences of
being underserved by a system of bureaucracy. The heaviness of these stories drove me to
become even more committed to their telling; the generosity of participants—and their feelings
of safety in disclosing their stories to me—made me more optimistic about the research
encounter as one not only laden with power inequities, but rather one that can, in some cases, act
as a moment of disclosure under the expectation that this story can become a part of movement
to make change.
It is worth noting that during my PhD studies, I became involved in a relationship that made me still more aware of the relational dynamics of eating disorder and anxiety recovery. Observing the “abnormality” of my own behaviours around food—which still largely mirror those prescribed in treatment—made me even more attuned to the challenges of navigating both food and emotions in relation. Supporters’ stories—particularly those of young men who were partners of young women in recovery, were crystallized against my experiences of suddenly noticing the ways in which my own anxieties impact my partner’s well-being. These experiences impacted my writing and made it necessary to engage more than ever in memo-writing to explore my reactions to the stories participants were telling me, and my interpretation of them, in light of my lived experience. I would not claim any of my writing to be free from bias, but in disclosing my deep identification with the stories participants shared, I hope to provide insight into my affective relationships with my “data.”
Chapter 3: Analyses – Interviews

3.1 Demographic Information

Demographic information was obtained by asking open-ended questions about self-identification, in order to avoid foreclosing categories onto participants. I interviewed 20 people in recovery from eating disorders. The average age of participants in recovery was 28 (range 19-41). 14 participants identified as heterosexual; the remaining six identified as pansexual, bisexual, or sexually fluid. 19 identified as women and one identified as gender nonconforming. 11 participants self-identified as white; two identified as white but specified French Canadian; two identified as white but specified Italian; one identified as Greek. Four participants identified as Asian (East Asian, Singaporean, Japanese, and Punjabi). Two participants resided in Quebec, one in Nova Scotia, one in BC, and 16 in Ontario. Nine participants had graduate degrees, eight participants had bachelor degrees, college degrees, or part thereof, two had high school diplomas, and one had completed part of high school. Not all participants had received diagnoses for their eating distress, nor had all experienced formal treatment for their distress. They identified with a range of diagnoses and symptoms, including binge eating, purging, restriction, over-exercise, and a fixation on particular ways of eating. Participants were also asked which terminology they preferred to use to refer to their disorders; the majority chose the language of “eating disorder,” regardless of diagnostic status. In terms of amount of time recovered, as will be explored in the results and discussion, timelines were challenging for participants to articulate due to the entanglement of behaviours coded as “eating disordered,” clinical encounters, relationships to the recovery terminology, and other factors in their lives. Some discussed their eating disorders as recent (i.e., within the past year) whereas others described their disorders as being much further in their past (i.e., 15 years ago).
14 supporters participated in qualitative interviews. The average age of these participants was 38 (range 20-61). Seven identified as men, and seven identified as women. All identified as heterosexual. Two identified as Greek, one identified as Chinese, eight identified as white; two identified as white but specified French Canadian; one identified as white but specified Italian. 12 had started or completed undergraduate education, one had a graduate degree, and one had a high school education. Two participants resided in Quebec, one in BC, and 11 in Ontario.

### 3.2 Themes

Themes are sub-divided into those from participants in recovery and those of supporters. While the results intersect to generate understandings of recovery, dividing the results into those themes most relevant to participants in recovery and to supporters helps us to understand the specificities of these different lived experiences. Following these analyses, a case-study style analysis of digital stories consistent with the approaches to digital story analysis described above is presented. Finally, results of healthcare provider screening data are presented.

#### 3.2.1 People in Recovery.

##### 3.2.1.1 Misunderstanding Matrix.

Participants described the widespread misunderstandings that circulated around eating disorders and recovery in settings ranging from doctors’ offices to specialized eating disorder treatment settings to the media (mainstream and social media alike) to family contexts. The misunderstanding matrix was underscored by a number of subthemes pertaining to these various spaces and the limitations they imposed on participants’ bodies and the possibility of understanding themselves as a) deserving of help and b) worthy and capable of recovery. These subthemes included: untrustworthy illness; choices; the non-equivalence of weight and health.

##### 3.2.1.1.1 Untrustworthy Illness.
Participants described being framed as untrustworthy even after they were no longer in acute distress. This construction was particularly evident in medical contexts, where participants articulated that the diagnosis of “eating disorder” coloured doctors’ interpretations of their behaviours, thoughts, and attitudes. This persisted into participants’ recoveries in a way that re-entrenched power differentials between those with lived experience and medical professionals. This also contributed to participants feeling that they lacked voice, sometimes leading to avoidance of medical follow up or opting out of engagement with medical settings as their lives progressed. This experience was also gendered and raced: as Jameela, a Punjabi-Canadian participant, described, going to the doctor’s office explicitly placed her in an under-powered role, an experience she links to her gender, as well as to her race.

When I go to the doctor, I feel like they don't take me seriously. And I don't know if it's… I think it's also a societal thing, because in my culture, like women are just seen as not as intelligent, and you know, they're like "unless you're married, you're pretty much seen as a little girl.” Like I'm 24 and my doctor still sort of treats me like a little girl sometimes. And other health professionals have done that too, and sometimes I think that they do discriminate me based on my race and my gender, and it makes me feel like my voice isn't being heard, and then, you know, add an eating disorder to that and people just sort of don't take me seriously. (Jameela)

Jameela’s articulation of an encounter with a family physician exemplified an attitude many participants described as persisting regardless of their “objective” state of illness or wellness. The stigma and stereotypes directed toward those with eating disorders — including the idea that they are not to be trusted — continue into recovery. For Jameela, this skepticism was linked to her experiences of being a child of immigrant parents diagnosed with an eating disorder. In her
Punjabi-Canadian community, being diagnosed with an eating disorder signalled selfishness, lack of control, and conformity to a White Western ideal. She notes that this experience is not unique to her encounter with her doctor (who is also Punjabi-Canadian); she describes not being taken seriously by “people” in general, and how her voice has not carried as much weight in diagnostic and other medical conversations because of her multiple and intersecting identities.

The skepticism Jameela describes was common amongst participants whose pathways to care were not straightforward: those who had not been diagnosed by medical professionals, who had not pursued traditional types of treatment, or whose recoveries did not align with a standard medical articulation of recovery (i.e., complete symptom remission). Lived experiences were dismissed or treated as implausible when they did not embody dominant medicalized constructions of the path to recovery. Kathryn, for instance, describes how she rarely shares her story out of a fear of others being skeptical:

> I think for a lot of people, those assumptions about how you get to being recovered are maybe a little bit… stronger… I think, than people who haven't experienced that or maybe people who are a little bit less knowledgeable about eating disorders, in some ways might be a little bit more, I guess accepting of like different ways of getting there, like I think if I were to talk to like a doctor or something like that about my experience, I think they'd be, to be honest, I think they'd be a little bit skeptical (Kathryn)

Contrary to the assumption that those who have years of experience treating eating disorders or who have specialized education in eating disorders might be more accepting of various types of eating disorders, Kathryn describes how those who “are a little bit less knowledgeable about eating disorders” might actually be more accepting of her story because they do not have pre-conceived notions about how one might go about attaining recovery. Kathryn was diagnosed
with anorexia but did not pursue formal treatment for her eating disorder, instead finding recovery by turning to informal support.

Participants in recovery struggled to be taken seriously for both their recovery and other medical issues because of their history; this is particularly striking because it was often hard for participants to attain diagnosis in the first place. Particularly for those who did not embody the stereotypical presentation of eating disorders, obtaining clinical recognition was described as one of the most challenging aspects of the road toward alleviating distress. Participants reported that doctor read their bodies as proof that they did not have eating disorders, which delayed the help-seeking process. As Julia describes,

I wish they took people who don't look – quotation marks – like they have an eating disorder, you know, like not like what's portrayed in the media, you know, like a skeletal kind of person. I wish that they knew that anyone can have an eating disorder and to really look out for those signs when they have someone come in, and not to dismiss anyone, really, when they talk about these things. 'Cause even if they look like they're fine or quote-unquote healthy or whatever, you don't know how much someone struggles and they're… I just, I really wish there was that because I think even with the doctor that saw me, I think maybe if I looked sicker, maybe they would have done something sooner, you know, and that's not right at all (Julia)

For those whose bodies were never clearly illustrative of the stereotypical eating disorder, such comments could exacerbate their eating disorder. In general, only those who “proved” their illness through their bodies — for instance, by losing a significant amount of weight and becoming emaciated and/or by exhibiting other signs of illness through blood levels, cardiac incidents or other side effects of starvation — were immediately taken seriously and deemed
“sick enough” to warrant help. Those whose bodies do become emaciated are simultaneously taken seriously and dismissed; attending to the physical ramifications of the disorder is seen as the top—and sometimes only—priority. Participants explored this dilemma in relation to the misunderstandings they encountered from the medical psychiatric complex and reflected on how their own understandings of their experiences differed markedly from those of the medical professionals they saw.

Participants often found themselves at the mercy of doctors who neither believed them nor knew what to do with them if their bodies did not match eating disorder stereotypes. Beyond not believing patients, participants described doctors as clueless about eating disorders and their various manifestations — and seemingly hesitant to admit to their lack of knowledge and seek out help from others who might know more.

Well my impression, after talking to her very briefly that one time, was that she didn't know anything about it. Like she relied on stereotypes of what a person with an eating disorder looked like, and I think she was probably thinking of anorexic people who are, you know, a year or so in it, so really skinny, really, really skinny, sickly people, and I did not fit that description, I was maybe 125 pounds back then? So I looked really healthy and so she didn't see that I wasn't well. And she didn't believe that I wasn't well. Because I didn't fit her mental image of what I was supposed to look like. So, I guess, what I would have liked was that if you don't know about something, admit it? (Cora)

Cora avoided contact with medical professionals and pursued recovery independently after early negative experiences with healthcare providers; she described doctors refusing to seek help themselves in understanding eating disorders. Participants described encounters like these with
doctors as reflective of a lack of willingness to abandon their position of power, knowledge, and expertise.

Those with specialized knowledge about eating disorders were not exempt from the problematics associated with imposing clinical judgment on patients without making significant room for patient perspectives. Returning to how health professionals exacted judgments of illness on participants’ bodies, some participants also reflected on the impact of diagnostic fluidity and the ways in which this fluidity changed their own orientation to the category of “sick enough” to warrant specialist interventions. There was also, in these reflections, an acknowledgment of how doctors hierarchized treatment levels based on the bodily ramifications of the illness – and the diagnosis they proffered. For instance, in the quote below Emily describes how her body, and her diagnosis, received different responses over the course of her illness. She crystallizes this change in relation to a doctor’s recommendation of day treatment over inpatient, which impacted her understanding of the seriousness of her illness.

I think for me, I had always identified as an anorexic, and so it was this idea of like the minute I started binging and purging, it was this idea of, you know, I can't even starve myself well. Like I'm just, I'm now, eating, overeating and there's all that shame that goes with that and I think throughout treatment as a bulimic, I struggled with that. It was that idea that (the second mental health facility)... well I didn't meet like the weight category, so I didn't need a bed, and it was that whole idea... even the medical community didn't seem to understand that you could be just as sick and be a normal weight. I shouldn't say just as sick, I do understand that someone extremely emaciated needs to be re-fed, but it was that idea of like someone that's normal weight can be making themselves sick fifteen times a day, and or like totally using laxatives, and it was just odd that, that that weight
was, was what kind of deemed you as like "okay, critical inpatient" or "you know, day
treatment" (Emily)

The “untrustworthiness” of those with eating disorders and in recovery that participants
described was also perpetuated by would-be supporters, others in recovery, and those in the
general public. Here again, we see the uneasy rubs between those who imagine and/or follow
“treatment as usual” paths and those who devise their own solutions, treatments, and recoveries
in line with their personal orientations to health, bodies, and illness. Participants reported that
their families often watched them eating, even long into recovery, to ensure that they were
complying with treatment protocols. Particularly for participants who had been admitted to
treatment many times, each subsequent admission was subject to increased surveillance and
disbelief—essentially, treated as evidence of the “eating disorder voice” still being dominant.
The person in recovery and the eating disorder continued to be dichotomized as people around
them feared a backslide. In some cases, this led participants to distance themselves from those
who configured their experience in this way, as a way to shield themselves from the experience
of being watched and disbelieved.

As selfish as it might sound, actually protective of myself, too, because I don't want the
police scene all over again and the badgering me and oftentimes even when I don't do as
well or they notice that I'm struggling more, or I haven't finished a meal one day, I kind
of get the cold shoulder from my family. I can tell that they're upset with me because I
didn't eat what I should have eaten, or... and I know that it, that it's just frustration on
their part, because they've lived with this for so long, but it makes me feel like their love
and support is conditional for me. (Zoe)
This continued surveillance and “police scene” described above was also tied to bodily performance; when participants were read by others as being “too thin,” they experienced extreme skepticism from loved ones who knew of their histories of struggling around food, weight, and shape. This was linked to a paradoxical experience: instead of feeling supported and protected by the surveillance, some participants described how this environment could lead them to enact more eating disordered behaviours. As Anna noted thinking: “well if you aren’t going to believe me, I might as well be anorexic” (Anna). This perspective might also be tied to a discourse of autonomy: in a society in which autonomy is lauded as a hallmark of ideal personhood, expressions of autonomy might be found in unexpected places when a person is under threat of lost autonomy from multiple angles (e.g., through extreme surveillance).

3.2.1.1.2 Choices.

Participants’ accounts were inflected with various framings of “choice”; their eating disorders were often perceived as choices by society in general or by close others in their lives, a framing they contested. Participants described how this assumption impaired their relationships with potential supporters, medical professionals, and others in their lives.

it's like there's like still very much that like mentality that it's a choice, you know, or it's, you know it's something like you chose, or just any number of stereotypes that there are. I think health care providers, a lot of them still have that. (Julia)

they didn't understand, they thought it was selfish and it was a choice, and that I was a bad person for making it. (Robyn)
Here, participants Julia and Robyn consider how both healthcare providers (Julia) and parents (Robyn) interpreted their eating disorders as choices, which limited the empathy they received from these others.

A choice-based framing had a nearly uniformly negative impact on participants’ experiences of being heard. They highlighted how even those who “should know better” — including those who knew them well (like their parents and close friends) and their doctors — misattributed eating disorders to choice. This led, according to participants, to a lack of compassion for those with eating disorders:

And maybe to be like more compassionate, because a lot of people with eating disorders are already feeling really, really ashamed about it. (Jameela)

Not only does the framing of an eating disorder as a choice impede possibly supportive relationships during the eating disorder, but so too does the assumption that recovery itself is a choice that can be freely made in the absence of a consideration of contextual factors. As Julia describes, recovery is often described as a choice, and in terms that configure this choice as a black and white one: you are either actively choosing recovery every day, which would be made visible—or performed—by continued weight gain and movement toward a place of clinically defined wellness, or you are shrouded by your eating disorder to the extent that you are deemed incapable of making this choice, or unwilling to do so. Asked to describe what she wished healthcare providers knew about recovery, Julia said:

I wish they knew how hard it was, you know? I wish they knew that even if we're not being compliant or whatever, or if we're not, basically, if we're not being perfect in the recovery process, it's not that we're trying to be difficult, it's that we're really, really struggling and we're fighting but it's hard and I wish there was more… I wish there was
more empathy, I wish there was more understanding — we're not rebelling, we're not acting out, it's just really hard. (Julia)

Framing eating disorder recovery as a choice risks making those who are taking steps forward and back feel as though they are not “doing recovery” well enough. Taking “actionable” steps, for instance increasing caloric intake, decreasing physical activity, engaging in self-care, and more are presumed to correlate with the subjective experience of recovery and moving toward wellbeing; however, as participants illustrated, this correlation may not be straightforward. This dynamic has the potential to entrench tensions between healthcare providers and those in recovery as the prescriptions for recovery may not (at least immediately) result in a subjective improvement in quality of life. This framing can, further, perpetuate the idea that someone can simply “snap out of” an eating disorder by coming to a realization of what the eating disorder is doing to their life, rather than understanding the ways in which the psychological, social, and other contextual factors in an individual’s life can complicate this “choice.”

my parents, they were sort of aware of the situation, but I don't think that they really understood exactly what to do or how to help? I think for them, they just don't have a lot of understanding about eating disorders, and you know, what they are. I don't think they really understand that it's really an illness and that it's not something that you can kind of decide all of a sudden to stop doing (Kathryn)

Some participants, like Kathryn, negotiated and rebutted this framing by suggesting that eating disorders belong to a category of medical illnesses, thus not something one can suddenly stop having. This framing aligns with the biomedicalized framing advanced by many to draw attention to the seriousness of eating disorders. This device is notably used in public advocacy
campaigns around eating disorders to gain recognition, empathy, and compassion for or toward those with eating disorders within a system that codes health with rationality.

3.2.1.3 The Non-Equivalence of Weight and Health.

Participants described wishing that doctors had listened to their stories regardless of how their body looked. They explored the non-equivalence of weight and health both in relation to their bodies-in-distress and their recoveries. They also expressed more general concerns about the way that society focuses on weight; specifically, the potential drawbacks of a societal focus on the “obesity epidemic” and what that means for understandings of the seriousness of eating disorders versus obesity as public health concern — something that they described as impacting the way that healthcare practitioners had interacted with them.

they're so common, and we are freaked out about obesity, and we don't even ask "okay, so of all the kids who are underweight, how many of them are trying to lose weight". I now find it harder for us. (Cora)

Cora describes how common eating disorders are and how commonly they are missed amidst the focus on the “obesity epidemic” that pervades public health discourse. Her description of the questions not asked in public forum — in the specific example she offers, the school context — reveals the ways in which keeping a focus on the need for slimming leads to an under-noticing and under-reporting of eating concerns, particularly when they occur in the context of those who are deemed in need of weight loss. Weight loss is categorically described as a “good thing,” something that led many participants’ eating disorders to be missed in their early stages.

because I was heavy and I was losing weight, it didn't show on me. You could tell that I had lost weight, but nobody really knew that what was going on in my head was really, really, really bad, and deep down inside I knew someone really bad was going to happen,
but because I was losing weight, people were kind of like "oh my god! you look great! Keep going, keep going!" And it was like, okay! Sure! (Catlin)

As Catlin describes, her weight loss was seen as positive by those around her because she had begun severely restricting her food intake at a weight socially framed as higher-than-desirable. The social reinforcement for her behaviours led to their exacerbation, much as it did for other participants whose weight loss was praised as their thoughts continued to spiral in a direction that led them to a deeply distressed relationship with their bodies.

In an extended conversation about not being heard when one’s weight is not commonly associated with an eating disorder, Abigail explored how those whose bodies neither exceed nor undershoot societal norms for weight are ignored — and how this trapping of normalcy can mask embodied distress.

A: I just read stories about like women who've lost a lot of weight, or people who've lost a lot of weight, and like they're better now, but I dunno, it's kind of weird with that, because even if you're considered overweight by like a doctor, that doesn't define your health or how well you are, because when I was underweight, or even at a healthy weight, I wasn't well. I didn't feel good, and I was sick. But now, I'm still considered overweight, but I feel good.

I: Yeah.

A: And, I just think, maybe, that should be touched on more, like in social media, 'cause not everyone understands that.

I: Yeah. Totally. ‘Cause there's this kind of representation that like "oh, you can be, a certain weight, but once you're over, or under that, that's a problem, but –

A: Yeah.
I: nobody thinks about it if you're kind of in this in-between space, they don't ask how you're feeling.

A: Exactly.

During her interview, Abigail and I explored how her experiences of weight conflict with dominant readings of health present in the (dominant, White, Western) cultural imagination. Interestingly, her reflection imposes a certain skepticism about the wellness of others who have pursued weight loss; because of her lens on the situation (i.e., having been at a “healthy weight” while simultaneously struggling with distress) she questions the validity of wellness amongst those who have pursued significant weight loss and been framed as “better now.” She juxtaposes her own experiences of feeling good despite fitting into a category of “overweight” with her experiences of being unhappy at a lower weight to offer evidence for the fallacy of reading weight as health.

Jameela commented on how discussions about weight compounded with cultural and racial assumptions about desired embodiments in her Punjabi-Canadian community; her experiences demonstrate the challenges of toeing the thin line between acceptable and unacceptable forms of embodiment, as well as the impossible standards of demonstrating “proper” appetite and eating patterns and norms for body size within multiple contexts at once (i.e. within diasporic racialized and dominant white cultures).

They put a lot of… in my culture they put a lot of your value into the way that you look, especially if you're a woman. So if you don't look a certain way, then no one's gonna marry you, and if no one marries you, then that it's like this total shame-fest that they put on, and that's always really annoyed me and irritated me, and in terms of eating disorder, because my culture expected me to eat a lot and be healthy, but stay… if I'm not eating,
people say to me all the time in my culture, 'cause they don't understand eating disorders; they don't even understand, understand mental illness, they're like "you know, do you even eat roti?" Like they just say that to me like I'm really dumb, and it, it'll be like the first thing that they say to me when they meet me. Relatives or whoever, they're like "do you even eat, like do you even… you're so thin now! You've lost, you've lost so much weight!" Or they just say these sorts of things to me that really make me really ashamed. And I don't even ask them for these comments, they just say it. So. (Jameela)

Jameela’s account also reveals how people volunteer comments about weight and eating — and the assumed connections between the two — without being invited to comment. The caught-in-between experience she describes as specific to Punjabi culture also reveals the gendered and racialized nature of this discourse. These uninvited comments have implications not only for the ways in which she is valued as a person amongst her Punjabi relatives and community and in white western culture but also in terms of what they mean for her marriageability. Her corporeal form — and the nourishment she provides it — become emblematic of her worth as a woman on multiple levels. As someone who identifies as gender fluid and non-heterosexual, Jameela’s embodied experiences are at odds with the ways in which she is binarized, not only in terms of a fat-thin and over-nourished-under-nourished dichotomy but also in terms of a woman-man, married-unmarried dichotomy. It is assumed within the statements made by her relatives and acquaintances that she will be seeking out a marriage with a heterosexual man and that in order to do this she needs to embody a slim margin of acceptable womanliness.

While recovery was described as being about more than weight gain, the person’s orientation to the weight gain was also wrapped up in more or less desirable terms — the
expectation to love your body all of the time flies in the face of the social messages people receive about how their bodies are “supposed” to look.

I was also thinking a lot about ensuring eating disorder is where it is to me, you know people post before-and-after photos, which is not helpful at all. I mean, yeah, they talk about "oh, like you know, I'm so much better", which is great, but I don't know, I just, I wish they talked more about how hard it is instead of like fixating on the physical aspects, like weight gain, for example, or like the before-and-after photos, but the person at their lowest state and now. I don't know, I just I wish there was more talk about… also I feel like a lot of people think that recovery is going from you all the disorder behaviours to something like being in love with your body like every single day, every moment, under every circumstance and I don't think that's… I don't think that's real. (Julia)

As Julia describes, eating disorders themselves are misunderstood as being wholly about weight and food. Further, recovery is from eating disorders is misunderstood as being a process of before and after that can be measured through observable bodily changes – weight loss, then weight gain. It is also worth noting that Julia engages with the idea of “real” recovery: to her, unconditional and constant body love is not synonymous with a “real” recovery, a dynamic echoed by many participants. Linearity in recovery was described as expected in medical and dominant cultural contexts, and yet not resonant with a personal experience of “reality” in life and recovery. Participants’ accounts thus complicated the linear experience of recovery and explored it in relation to love-your-body discourses, an imperative that often felt unrealistic or hollow.
3.2.1.2 Surveilled Spaces to Safe Spaces.

Participants’ accounts frequently configured their bodily journeys and comfort, as well as their sense of being heard, in terms of their relationships with time, space, and other people. The complexity of embodying eating disorders and recovery in this sociocultural context are crystallized against participants’ accounts of surveillance around their bodies and behaviours prior to, during, and after the acute phase of distress. Issues of power, gender, and embodiment were interwoven with reflections on the passing of time and the spaces in which participants felt safe and/or watched. This theme was underscored by several subthemes: being watched; being listened to; and being liminal.

3.2.1.2.1 Being Watched.

Participants described experiences of surveillance in the context of treatment, which interacts with self-imposed surveillance in the context of the eating disorder. Emily describes self-imposed surveillance that went on unchecked until she hit what she described as a breaking point: “I thought I really enjoyed my life the way it was, and I don't think [it was] until after the fact that I realized I had really been living in a very specific type of prison I had built for myself.” For Emily, the eating disorder itself was a “prison”—a space typically associated with intense scrutiny and surveillance. Her words highlight how she was only aware of the degree to which this operated when she became aware of what her life had been and could be. This later awareness reflects a certain degree of comfort in the self-surveillance wrought by engaging in eating disordered behaviours in this sociocultural context. Here, self-surveillance is internalized as an imperative; this surveillance becomes routinized and aligns in many ways with socially-sanctioned self-discipline endorsed by dominant health pedagogies.
Some participants noted that the rigidity of their treatment environments provoked more deeply entrenched surveillance by imposing it from the outside as well, compounding and/or conflicting with eating disorder-set rules:

I think they were very... I mean I'm very stubborn, and specific, I, not that I don't like authority, but I don't think, I don't like it when I feel like my voice isn't being heard. And a lot of the times, I feel like there was very little patient autonomy or concern, it was kind of like "this is how we do it, and this is how we deal with eating disorders, this way, using this approach," and I didn't like that. I struggled with the idea that it had to be so all-or-nothing, when I feel like, in life we're taught about balance. (Emily)

Participants also commented on how in the context of the treatment unit they positioned themselves as “not like the other” patients, reveals perceptions of how people with eating disorders relate to surveillance and “resist treatment” even amongst those with eating disorders. For instance, some participants attributed their ability to get better to not being like the other patients – they noted how they wanted to recover, opposing themselves to an Other that did not want to get better (something they inferred from other patients’ vocalization of wanting to lose weight after treatment, for instance). As Lenore remarked:

I think I really did believe that I was not like the other people there. There was certainly a part of me that wanted to get better, it just wasn't the part of me that I listened to all the time. I felt like a lot of the other people there, I looked at them, and I mean, you would hear them say things like "you know, I'm just gonna lose all the weight when I get out, anyways, they can't force me" and maybe it's 'cause I was such a people-pleaser, I tried to be, you know, "oh, yes, I understand, this is, this is a big problem, I don't know how it happened, and I'm gonna do my best to get better, I'm gonna cooperate with you,” but
other people were very uncooperative and I didn't identify with that. You know, those were the sick people, I was the good one who was doing what I was supposed to, and not intentionally thwarting other people's intents to help her. (Lenore)

In positioning herself as the “good patient” Lenore leveraged her people-pleasing tendencies to discursively position herself as not fully eating disordered, even within the treatment setting. Her account reveals the common positioning of eating disorder patient as uncooperative. Further, it reflects a postfeminist sensibilization of being “not like other girls” that allows dominant discourses of femininity or, in this case, gendered discourses of girls with eating disorders, to persist.

Participants also spoke about things that were seen by other patients and not by staff on the units and how these contravened the rules on the unit in a way that became problematic for them.

We had contracts that we had to sign saying that we would not self-harm in (the residential facility). For example, we could be discharged for self-harm behaviour, but in children's, everyone in there was self-harming, so it was almost normal but everyone was doing it behind the staff's backs (Ellen)

The complexity of surveillance is revealed in Ellen’s account of behaviour on the unit. She found the prevalence of self-harm on the unit to be problematic; equally, she described mealtime behaviours that she believes would have been avoided by keeping a closer eye on patients. Unexpectedly, Ellen calls for increased surveillance on the unit, arguably revealing an internalization of ideas about how eating disorder treatment “should be done” and what accountability looks like in this context. In another quote, she expands upon her views about how to keep an eating disorder treatment environment healing-oriented:
I: Is there anything that you wish that doctors in general, or doctors specifically in eating disorders program, knew about eating disorders and recovery, that you think would help them make that space better for people?

E: That you need to keep a closer eye on people, especially during mealtime.

I: Yeah?

E: Like, we had a mental health worker, who would ask us what like the lowest fat percentage was in like yogurt was and stuff.

I: What?

E: 'Cause he knew we'd know!

I: Oh my God.

E: But, it was one of those things, I was like, "why are you asking us this?" [...] So, I feel like staff in inpatient facilities having a better understanding and almost not giving as much freedom. Whereas I feel like the freedom helped me more in (the residential facility), whereas in an inpatient facility, I feel like that freedom isn't helpful at all.

Ellen’s account also speaks to issues around staff self-surveillance. Through her account, Ellen describes how staff would ask patients about their knowledge around food content, drawing on patients’ considerable knowledge about macronutrients and weight loss. Her account suggests that while dynamics of surveillance/non-surveillance impact patient care in terms of how much patients are watched, there may also be a need for more staff co-surveillance, where staff themselves are held accountable for their actions. This further illustrates the ways in which conflicting and opposing biopedagogies for eating disorder treatment and general health choices materialize in the treatment environment, comprised as it is of people who attract the label of eating disorder and those who are expected to treat them. Her reflection also complicates the
freedom/surveillance divide. She describes the differences between hospitalization in an inpatient facility, where staff attempted to create a trigger-free environment, and yet incidents like the ones she described (related to self-harm and related to staff members offering patients the opportunity to obsess over nutritional content) were common, and her stay at a residential facility, which she describes as trying not to foster a “trigger-free environment.” This account demonstrates how imposing too much rigidity and rule-boundness in treatment settings has the potential to lead to acts that become framed as rebellion. In the other environment, patients were offered the opportunity to work through things that triggered them with staff members, helping them to make sense of reactions.

Surveillance featured not only in accounts of having and being treated for an eating disorder but also appeared in recovery. Participants described surveillance as playing a role in whether or not they disclose their experiences of having and overcoming an eating disorder with others.

R: It's something I've debated a lot in my head as to whether or not I should openly disclose what I've been through or just continue to, you know, keep it under wraps and the way that I do. 'Cause I think of what you do, you own it, and it's awesome. And I wish I could do that. But I just, I can't. For me, I grew up in an oppressive little town. It was not okay to be gay, it was not okay to have a different colour of skin, it was not okay to be different. And I was different. And everyone knew it, because it was announced in my classes, and then like people would taunt me on the school bus and be like "so are you ever gonna eat a cookie again? Like, what do you eat?" Um, and like there's an added layer to it for me now of like, do I want people to… you know what I mean?

I: Yeah.
R: And then there's the layer of... people stigmatize you. They make assumptions, and they expect certain things, and then they watch you. They watch you, what you're eating, and they judge. And I don't like that. So for me, the decision to tell someone is always a really big deal and based on: is this gonna change the way that we interact? Are you suddenly going to start interacting with me weirdly, and is food, if we go out for a meal, is that gonna become weird?

I: Yeah.

R: So, I don't tell people, just 'cause it's not within my comfort zone to do it.

I: Yeah. Yeah. And it's not for everyone, for sure. And there is that degree of surveillance that accompanies it.

R: Yeah. And I don't like that surveillance. I survey myself enough. (Robyn)

Robyn describes the surveillance that can accompany public disclosures of having experienced an eating disorder. She notes that sharing her experiences is “outside of her comfort zone” and fears that telling others about what she had been through would lead to people judging and scrutinizing her intake. It is worth noting that Robyn experienced inpatient treatment and felt stifled in an environment that watched her every bite. This tendency was notable amongst many participants: treatment-imposed rigidity informed their present-day experiences. Those who had been hospitalized for their eating disorders often enacted recovery in relation to this experience, which worked more or less well for them depending on their frame. There was not one ideal way to be recovered, and some found the continued presence of “monitoring” devices like meal plans to be important in their lives. For others, however, the lingering presence or fear of surveillance led them to be cautious about who they would share their experiences with, particularly any lingering concerns around food, weight, and shape:
I want them to understand more and to kind of, to know what I've gone through, what I'm going through. But at the same time, my mom, I feel like she would either be really, really worried or she'd be really controlling, like constantly watching me like a hawk. (Julia)

Bodies in general are subject to surveillance, watched to ensure that they do not cross the line into too thin or too fat corporeal territory. Because of the ways in which our food “choices” and behaviours are assumed to correlate with our corporeal outcomes and reflect psychological well-being, this surveillance often pervades social situations that centre around food. Participants articulated this surveillance well into their recoveries, noting their awareness of who they were with when they ate and how much these people knew about their histories.

3.2.1.2.2 Being Listened To.

While participants often felt watched, at times they also felt deeply listened to by others in their lives, ranging from healthcare providers to supporters. They described safe spaces, either in terms of physical locations or ideologically safe spaces. For some, this involved being offered a safe place to live. When asked what was most supportive about one of her primary supporters—a teacher—during her eating disorder, Robyn reflected “she gave me a safe place to live.” Participants described the challenge of living in circumstances where they felt misunderstood by those who shared their living spaces. Physical relocation was sometimes necessary in order to move beyond the eating disorder. For Carrie, this move entailed also separating herself from a religion that her parents adhered to.

My parents were part of this like super religious subgroup and I left that religion and moved out on my own and I think a lot of the concepts was kind of coming from that for me, so just kind of making this huge change in my life and then, you know making all
those changes, and then being like "oh, okay, like I still have this thing to deal with, I'm still like super anxious, I'm still not able to eat." So I remember making a decision, when I was just terrified of like moving out, 'cause I didn't, I preferred to eat something, and I was like "I can't just, I can't be this girl who like starves to death and it's just, I can't, I can't be that person, that's not who I'm supposed to be." (Carrie)

Carrie’s account also highlights how problematic living situations and unsafe spaces can become the focus, as opposed to the eating disorder. For Carrie, the problem that needed to be dealt with in the immediate term was living in a situation that was not in line with her orientation to life. It was only once she was able to get out of this immediate threat to her wellbeing that she was able to recognize the ways in which her eating disorder impacted her life. Before this move, the distress caused by the eating disorder was entangled with other aspects of her life in a way that shrouded the eating disorder-specific distress from view, and hence from help.

Sometimes safe spaces were not physical but digital. In order to find these safe places, participants often needed to distance themselves from less helpful spaces and people in their lives. For instance, Sherice found that her old social networks were no longer helpful to her as she moved through her binge eating disorder.

S: I also did like a social media purge at that time too, so that was also so helpful.
I: Yeah. Just getting rid of people who were kind of reinforcing the things you were trying to distance yourself from?
S: Exactly, yeah.
I: Was it hard at all to do that, or was it mostly just freeing?
S: It was hard at first, 'cause I felt bad because I knew some of my friends are nutritionists and so I'd want to support them, and especially on things like Instagram. I
stopped going on Facebook completely and that was difficult, too, 'cause I felt—I realized, wow, that's how we get all of our information, people just assume that you know what’s going on because they posted it on their Facebook.

Sherice’s comment reveals the tenacity of the digital space for either helping or hindering recovery processes. She explores digital spaces as having been variously helpful and unhelpful to her in her pursuit of a life without acute distress around food, weight, and shape. Having been a part of Paleo and other nutritional communities, Sherice reached a point at which the messages perpetuated on these communities did not provide her with the support she needed to enact the kind of relationship with food that she wanted to have. This process of distancing was not easy, and the online space became as “real” as a physical location; the reproduction of digital relationships represented material interactions where social norms entered into decision-making about being in or being out of these spaces. Severing ties with these no-longer-helpful communities entails unliking or unfollowing unhelpful people and accounts—a decision Sherice describes as challenging.

The specific character of the accounts Sherice felt she had to unfollow reveals a deeper complexity around individual participants’ preferences for types of support. Eileen also found the holistic health movement to be problematic for her. Even when others in her life dismissed claims advanced within alternative health dictates as unscientific, the discourses of bodily control and cure held within these were persuasive to her in a way that she recognizes upon reflection as problematic. For her, not only did she become averse to eating for weight loss support but the phobia of food ran deeper and felt contaminating; she describes these perspectives as “bogus” retrospectively but identifies that the hold they had on her at a time in her life was extremely strong.
I got into natural health. I went to see a natural health practitioner, and she did these, I think bogus tests telling me that I had these parasites and that I should be on this very limited strict diet, and the book is called "Cure for All Diseases", which I mean, just in the title, you can tell it's not very valid. But at that age, it really affected me, so I was, it's like I was susceptible to these theories. And my sister had the same experience, we both went to see her, and she just thought "Oh, that was a bunch of bullshit, or whatever", whereas I became very phobic about the foods that she told me I was supposed to avoid. And then it just went from there, like any health food… there was the "eat right for your blood type", and these foods are toxic like nightshades, like tomatoes and potatoes and peppers, like they might be causing you to feel like you have toxic symptoms and I just became… anytime there was a theory, I would pick it up, and I would become phobic of that food […] I really thought that what I was eating was contaminated and that it was making me sick. Huge phobia of pesticides. (Eileen)

While Sherice and Eileen needed to distance themselves from digital and physical vestiges of extreme dietary control—like those present in the Paleo, “clean eating,” or holistic health communities they had been a part of—others found solace in these communities, which they described as helping them to reconfigure their relationships with food and health. Here, it is important to avoid making value judgments about styles of eating and what they mean about a person’s recovery. For Robyn, the very communities that Sherice described as detrimental were helpful.

R: I had some scary symptoms that no one was helping me figure out, there was a neurologist working on it, and I was waiting on MRIs, and I was combing the Internet for non-scary options, and I came across this website where like a support group and one of
the things, one of my symptoms was that I had horrific night sweats. I was getting up multiple times a night, I was wringing my pyjamas out, I was wringing my hair out, the sheets were drenched, our bed was stained, and I'd already been checked for early menopause and all of those things, and someone said, "this happens when I eat gluten". And I started going "Oh, that's interesting – when I eat gluten that's one of the reactions I have.

I: So that was a very clear sign to you?

R: That was a clear sign to me that I should experiment with taking it out and see whether it made a difference, and it made a huge difference in so many things.

I: Yeah. So it sounds like for you eliminating gluten actually made the eating disorder related stuff better?

R: It did.

Under some articulations about what it means to be recovered, a person with an eating disorder who decides to adopt a gluten-free diet might be regarded as “less recovered” or replacing one “addiction” with another. For Robyn, however, finding out about her individual reactions to gluten—and finding a supportive community who could help her figure out things that she could eat that did not contain gluten—made her feel heard, supported, and understood, as well as improving her physical symptoms, which she described as “scary.” Regardless of whether or not the gluten was causing her physical symptoms, it is worth exploring how being listened to functioned in Robyn’s experiences. When Robyn had suggested food-related reactions to doctors in the past, these had been brushed off as related to her eating disorder, subsuming all of Robyn’s subjectivity into her eating disorder. Here, instead of being told she was making something up or others assuming that all of her choices around food here linked to her eating disorder, Robyn was
validated and heard. Being listened to, and being offered the opportunity to make decisions about food in line with her preferences for health, resulted in her physical symptoms resolving, as well as the psychological relief of being listened to and having an explanation for physical symptoms.

Safety and safe spaces were not always described in relation to physical or digital locations; they also manifested as people in participants’ lives who were able to help participants in the ways they wanted to be helped. A quote from Cora exemplifies how people did not need to be experts in eating disorders to be “safe people” – more important was a lack of judgment and an openness to learning and listening.

I didn't feel judged by my mom. I could see that she was struggling with it, and that she didn't really know what to do, and she just wanted me to be happy, and well, but I don't think, and I didn't, yeah, she did kind of feel guilty, I think, about it all. But throughout all of it, though, I didn't feel that judgement and because of that, that helped a lot. (Cora)

The importance of being listened to resonated throughout participants’ accounts, unveiling the critical importance of having a say in the kind of support one is receiving.

Safety was not always configured positively in participants’ accounts, however—at times, participants described the problems with feeling overly safe in rigidly structured environments. For instance, the hospital context could become a familiar one, limiting their ability to move beyond the behaviours that kept them sick. Elizabeth described the double-edged sword of the safety of an inpatient unit: “I felt really safe in the hospital, and safe getting help for depression. I wanted that safety again, so I wanted them to do something about it.” She had been hospitalized for depression before her eating disorder, and when her eating disorder began to spiral out of control and significantly impact her life, Elizabeth craved the feeling of being taken care of that had been cultivated in her first hospital stay. Lenore also described the strange sense
of safety that came with the hospital context, a space in which she had felt looked after and cared for in a way that she hasn’t previously experienced at age 11 when she was hospitalized:

everyone was really, really nice there, and I was able to talk to people and have a lot of really positive interactions with people. I mean, it's funny. Going to the hospital shouldn't be… I mean of course it was a bad experience, in a lot of ways, but I guess it was good in some ways too, 'cause I was really struggling with something before, and now I sort of had attention and help and my family came in a lot, like my extended family was really supportive, and in the days when I first got there, they stayed overnight every night and I had tons of visitors. I think, I felt really supported once I was in there. (Lenore)

Evidently, for some participants, structure and rigidity were safe; this safety might be deconstructed not in terms of the desire for rigidity or structure being problematic or pathological but one orientation to a system in which all individuals in Western, biopedagogical societies are placed in the position of needing to make choices about our health that are seen as directly dictating our outcomes and having long-term ramifications for our health—and, by corollary, our morality. When acutely distressed, this “choice” imperative becomes even more challenging than it is in the best of times. Some participants described how under these circumstances, rigidity became desirable, and they did not wish to be judged for this desire.

I can't really say enough about meal planning for me, I know that for some people, it can be too rigid, but for me it's completely helpful with calming my anxiety and knowing that this is right and this is what I need to do and this is what someone told me I need to do (Isabel)

For Isabel, having a certain amount of structure—for her, around food—provided her the mental space she needed to do the work of her life.
Participants did not always find safety in expected places—particularly not in structured treatment contexts. Many negotiated different pathways to recovery, perhaps best illustrated through the example of several participants who had experienced intensive treatment and later relapsed. Upon relapsing, they opted not to re-enter clinical settings for help, but rather to explore their recovery pathways with the knowledge they had gained and external support. This pathway provides evidence for not only a re-valuing of whose voices are heard—and where participants perceived the possibility of being listened to to exist—but also a questioning of the extent to which knowledge is “enough” to pursue recovery and the conditions under which recovery can take place.

Isabel had found hospital treatment to be helpful when she first experienced extreme distress around food, weight, and her body; however, upon relapsing, she was unwilling to return to the suspended space of the treatment centre, putting the rest of her life on hold for treatment. She described herself as adamant about doing recovery differently the second time around, with the help of those she described as supportive providing the kind of support she desired: to be heard and worked with, rather than on.

I was really adamant about not wanting to go back to the hospital, because I had a job, and I had a boyfriend, and I was living in (a large city), so I continued to see my therapist, and what actually helped make it better was working more with my mom. So I knew that the hospital meal plan was what I needed to be doing especially to gain the weight back that I knew I needed to for my brain. (Isabel)

It would be easy to frame Isabel’s decision to not return to treatment as demonstrating that people can choose recovery if they only have enough awareness about what is going on. And, indeed, many participants reflected on the key of being aware of signs of a relapse or backslide
into illness, as well as the ways in which knowledge about their eating disorders and about ways of staying healthy had helped them to recover. However, Isabel explicitly situates her ability to follow through with the meal plan and recovery path within a relational context, noting how her access to supportive others allowed her to make this choice.

it was really hard. I just asked my mom to basically play hospital with me, and I went home there, for like a week, and we talked about how we could do meal planning, so for like a year I made meal plans for the week with my mom over the phone, and she would bring food down for me and I just made myself stick to it. (Isabel)

Isabel’s account demonstrates the importance of support, as well as her awareness of the intensive work required on her part and her mother’s in order to enact treatment support. She later reflected on the nature of this privilege and how uncommon this unconditional support is for those seeking it, and how she feels fortunate to have been able to enact her recovery in this way in order to avoid the problematics of treatment as she had experienced it, as comparative and often distress-worsening space.

Participants noted the ways in which eating disorder treatment was rarely on their terms, in their spaces, or facilitative of a re-engagement with their lives, which acted as impetus toward pursuing recovery outside of a clinical space.

they were like "you should probably go either residential or the day hospital", and neither of which were in (my area). I remember the biggest dilemma that I had at that point in time was that I really wanted to stay in school, um, but all the treatment programs were in (other cities) and it just, it wasn't feasible at all. (Julia)

For Julia, pursuing recovery by moving to a different city and suspending the rest of life did not seem like a feasible decision that took her preferences into account or allowed her to learn how
to balance the challenges of her life with her move toward recovery. Julia and others complicated the idea of “motivation for recovery,” noting that decisions to not pursue formal treatment were not necessarily tied to not wanting to get better, but rather about balancing major foci in life and not seeing the eating disorder as the single most important challenge they needed to face.

Other participants also took what they could from treatment and did not return there, as the treatment space was not commonly configured as consistently therapeutic; participants who did return to treatment multiple times also reflected on the changing nature of their relationships with the program—the more they returned to the treatment program, the less they felt heard there. Participants rarely attributed program deficits and the lack of voice and trust they felt in treatment to individual staff members, generally referring to the problems with treatment as systemic.

I think the staff is wonderful. I think it's like a program construction problem. (Zoe)

I hated treatment. I mean, it saved my life, and it was necessary, but I hated it. (Robyn)

Referring to the intensive treatment space as a problematic one was not mutually exclusive to recognizing the ways in which this space could also be necessary; particularly in the absence of the supports described above, participants might sacrifice voice and choice for treatment that they thought could save their lives. But, they noted that this should not need to be the case—participants’ desires for collaborative, patient-oriented, community-based and respectful treatment were nearly universal. Participants were honest and lucid about their own privileges in being able to seek either or both of formal or informal support, and the challenges that the current system poses in terms of access to treatment at all, let alone treatment that takes participants’ voices into account:
There's a huge financial barrier [...] not all families are equipped to do this whole re-feeding process and to take a year off from work and do this thing. And the clinician said "well, we just tell them, you have to. It's life-or-death, you have to do it." And you know, I'm thinking, you can tell them that, that still doesn't make them able to do it, if they're experiencing significant mental health issues, trauma-related issues themselves. So. telling someone to do it, that's not the end of the story. (Carrie)

E: A lot of people just don't have that support, either family support or financial support, and I just feel so fortunate and appreciative that my family stuck around.

I: Yeah. And it's interesting because, I mean, even with all of that support, it doesn't mean that recovery is at all easy, right?

E: Yeah. And I think like, I mean my family is very good at reminding me of that, like it does take hard work as well, but I mean I just feel like I was given all the chances of recovery and some people don't have, like I remember hearing about the number of psychiatrists that specialize in eating disorders, and you probably know this statistic better than I do, but it's like 11 in Canada or something? (Emily)

Carrie and Emily’s quotes are two of many that reflect an awareness among participants that recovery is scaffolded by not only individual work, as a neoliberal rationality might purport, but a number of privileges including sociocultural recognition, financial access, and social support. This systemic awareness helps to complicate a linear narrative of choice in recovery. Even with significant privileges, many of the participants in this study struggled to reconcile lessons learned in treatment and support given with their personal life experiences and orientations to recovery and had trouble being listened to in treatment contexts. This illustrates how recovery is linked to
systems, and the need to enhance systems to scaffold access – and sustainable recoveries. The tension between participants’ reflections on the need to bolster systems of support and their reflections on the individual work they had done to attain recovery also illustrates the need to at once provide voice and “choice” to those in recovery while chipping at the systemic context in which recovery is performed if we wish to not only build space for recovery but for recoveries.

3.2.1.2.3 Being Liminal.

Participants’ accounts reflected the challenges of being in-between—time on wait lists, time pursuing recovery while engaged in other life activities and necessities, time between treatment and home. The in-betweens and tensions associated with these states might be termed, following studies from health anthropology, “liminality” (Eli, 2014; Lester, 2007). Isabel described her experimentation with therapists and dietitians while she endured a six-month wait for treatment:

In between that referral and going to the hospital, I tried a counsellor, as well as a dietitian, which I know are pretty similar things and they were extremely unhelpful […] So, I guess, I'm not sure, yeah. If I hadn't gone to the hospital, that would definitely be a barrier […] the counsellor clearly had no experience with someone who had had an eating disorder, and didn't really… everything I said seemed like something brand-new to her. She would just listen, and didn't really have any helpful things that I could take action on, which I feel like are pretty important when you're trained to aberrant behaviour, or even DBT, there was none of that. It was more just me talking and I needed more than that at that time, and then the dietitian was just like a total joke, looking back at it. I remember, I remember so clearly that they asked me to keep like a five-day list of what I had been eating. (Isabel)
Experiences of liminality converge with general lack of knowledge amongst non-specialist eating disorder clinicians and converge with structural issues in accessing treatment to build a barriered experience of liminal space, wherein participants felt stuck and without helpful options. Further, the perspective Isabel shares—that the dietitian and counsellor are “pretty similar”—reflects a blurring of the roles of those providing support for people with eating disorders. Like Isabel, other participants experienced attempts at stopping eating disorder behaviours during this liminal phase between diagnosis and treatment.

Once participants had reached out for support, disjuncture could occur in expected timelines and trajectories for recovery, as well as preferred mechanisms for support, that thrust participants into confusing matrices of illness and wellness.

About three weeks after that, I had a therapist appointment, so I went in and I sat down and I said "I'm ready for help. Make your referral for me to go to inpatient." So, it was a bit of a wait, and I eventually had my appointment, and the nurse said "I think outpatient would be better for you". (Ellen)

Ellen described having made the difficult choice to drop out of school and attend treatment; a struggle several participants described, as they were often asked to “put the rest of their lives on hold” for treatment for their disorders—in a sense, momentarily leaving their developmental trajectories in order to later be expected to rejoin them. Ellen’s experience also demonstrates power dynamics in decision making around treatment levels, and the impact of not having a say about the type of treatment. Disjunctures between clinical decision making and personal assessment of the severity of illness, and the kind of treatment that would be most helpful, impacted participants’ sense of liminality.
Treatment decisions were also sometimes based on feeling liminal – feeling like there was no other choice, no other way out, as opposed to a strong desire for recovery. For instance, Zoe said, upon being asked why she decided to enter treatment, “I felt trapped, I felt like there was nowhere, no way out.” Her treatment decision was as much linked to the sense of there being no safe spaces—in or outside of treatment—as it was to the idea that treatment would somehow be the key to her recovery. The choice here is less an active decision to get better than a surrendering to another uncertain space.

Another key moment of liminality was the transition from hospital to “real life.” As described above, highly surveilled hospital settings could be simultaneously negative experiences and comfortable ones—spaces in which decisions were largely made for participants and schedules kept quite rigid. Participants often reflected on the lack of transitional support, particularly in adolescent treatment, and how this led to vulnerability and uncertainty for them. This was perhaps most clearly articulated when participants left care as adolescents and found themselves over eighteen and thus pushed into the adult care system. Robyn was one such patient, and reflected on being left without significant support:

I received no follow-up care because I was now an adult and I had been treated in a paediatric facility, which was something that they knew going in and they toyed with where they should admit me and ultimately they admitted me in the paediatric hospital because they could keep me in there and they couldn't keep me in an adult facility […] when I came out, I did not know how to eat, and so I started starving myself again.

Robyn’s account exemplifies the role of power in the medical context, the complications in the systemic nexus of adolescent and adult treatment systems, and the extent to which each of these systems is able to enforce rigidity—or, at least, the ways in which they do so. While adolescent
units are better able to exercise external power over residents of their programs, for instance through “keeping them” as Robyn describes and pursuing supplementation and/or nasogastric tube feeds should the person not eat, adult systems tend to discharge patients when they do not follow their meal plans or other program rules. Moving between these two systems, adolescent and adult, and their respective configurations of choice, can induce a sense of liminality or suspended life in between.

Sometimes the lack of transitional supports described earlier led to a false sense of wellness that later led to relapse, as it did for Emily:

I went away for university without giving my eating disorder a second thought and thinking I didn't need any care there, because I was re-fed to a certain amount and so I think like it just, it never got really dealt with underlying issues, and, and then just unraveled from there. (Emily)

Without being equipped for the possibility of relapse – and simultaneously not being equipped with alternative tools for managing distress once re-feeding has occurred, participants sometimes felt like failures upon relapsing. Because this possibility, and the possibility of altering an assumed linear trajectory to recovery, were not discussed, relapses were framed as individual problems, to be addressed with individual solutions.

Even the spaces in between treatment and home during intensive treatment could induce a disconnect of caring that Julia described as troubling, noting “In my program, it was kind of like once the program is done for the day there wasn't really support that I could access.” The treatment space operates, in day hospital-style programs in particular, as a kind of suspended reality (see also Eli, 2014, 2018 and Lester, 2007 for more on liminality in eating disorder treatment).
3.2.1.3 Recovery is Life

Recovery might be conceptualized as life itself—not in a way that presumes that it is the central focus, but in the acknowledgment that there is no singular way of understanding what recovery is, will be, or looks like across diverse groups of people. Participants were unsatisfied with prior descriptions of recovery and how to achieve it from healthcare providers, the general public, family members, friends, and others in their lives—this experience circulated around a subtheme of responses entitled Unguided Pathways. Some participants reported an experience of recovery not being the defining aspect of their personality, contrary to prior research highlighting the centrality of recovery to the identity of people who had experienced eating disorders—these experiences fall under the subtheme of Not Only Recovered. Participants’ discontent around dominant representations of recovery further crystallized around some of the aforementioned misconceptions, misunderstandings, and stereotypes associated with eating disorders; under the subtheme Not All Sunshine and Rainbows, participants’ accounts speak not only to their challenges in relating to representations of recovery, but also how this challenge of relating to dominant representations related to their interpersonal relationships and how they were understood in the world. Finally, participants articulated the what of recovery through reflections on the Life of Recovery—that is, how recovery featured in their lives, not as the only important aspect of themselves, but as one experience among many that constitute their identities. The “arrival” at this place was tenuous at times, not a conscious choice, and inscribed with relationality. Participants articulated their recoveries in a deeply entwined way, reflecting on their recoveries not in isolation from their social spaces of belonging but in relation to them, and to the discourses on recovery they had encountered.
3.2.1.3.1 Unguided Pathways and Embodiment.

This subtheme relates to the experience of being uncertain about timelines, but also about how this relates to the bodily experience—and bodily memory—of eating disorders and recovery. Participants distrusted their own versions of their recovery timelines and discussed their enduring distortions, which can be tied to bodily experiences of being in/out of time. Many participants explicitly described their own timelines of recovery as fuzzy or foggy, which contradicted the information they had been presented around “how long it would take” to be fully recovered. This was due to being treated multiple times, the length of time since they had thought about their eating disorder and recovery journey (i.e., difficulty remembering details in the interview context) and/or the fog associated with some of the techniques they had used to cope, including but not limited to eating disorder symptoms. For instance, Emily reported how her drug use and drinking made it difficult to remember the exact trajectory of her recovery timeline:

That’s the thing, my timeline is always so gray because a lot of that time, I was drinking, and then shifting I was also, I was using marijuana too, as a way to escape (Emily)

This attempt to escape from time was not uncommon amongst participants. Some relied on their supporters to help them piece together their recovery trajectories, and to remember what they had been like during the time of their eating disorders—and how different this was from how they are now. Reflecting on her discussions with her fiancé about her eating disorder and recovery, Isabel noted how memories entwine and intersect to generate her overall picture of her pathway.

He remembers things very vividly and I don't have as strong of a memory from that time about things I did, or what I looked like, or how I acted. So he'll bring it up from time to time about how, how far we've come and what the experience was like for him and us—and then, I think I tend to bury it a lot because like, and I don't know if this is common,
but I almost have like flashback-style memories of things that'll happen just randomly [...] and I barely remember being there but I can remember it like very vividly, certain things. (Isabel)

Isabel’s account reveals how not only treatment but also the eating disorder and the recovery process can place participants out of time. This experience might be put into context against physiology and psychology. The flashback-style memories Isabel describes speak of memory disjunctions linked to the physiological experience of starvation, to draw on a biomedical discourse; it makes sense that time and memory might be processed differently in an under-nourished brain. Beyond the physiological processes of the brain when it is not adequately fed, however, it is worth considering the potential for the eating disorder to function as a numbing device for anxiety over life circumstances, and what that does to the experience of being in time, and remembering that time. That Isabel describes her flashback style memories as a) being triggered by her interactions with her partner and b) being vivid tells us something about the intensity of the emotion likely associated with the memory, and the degree to which she might have wished to not think about them. Only in interaction did the memories “come back” fully; left out of relation, perhaps those memories might not have been accessed.

Thinking about eating disorders and recoveries as out of normative time allows us to probe this relationship beyond simply exploring the self-protective mechanisms of the body and instead look at intercorporeality, memory and time as they work to constitute recovery. Taking Isabel’s case as example brings to light corporeal changes in time; during her actively ill phase, Isabel and her partner were in relation. Isabel described him as a supportive other, who was observing her wasting body “from the outside.” She described how for her partner, the changes to her form reside primarily at the level of images, allowing him to access a catalogue of the
shapes she has taken over the course of their relationships and reflect on perceived differences between these various images. Isabel sees these reflections as more accurate than her own, perhaps because she has a distorted sensation of her body in space and the image of her body, but also because of the (likely countless) times she has been told that as someone who has been diagnosed with an eating disorder, she is unable to accurately judge the shape and size of her body. The “other” on whom she relies to inform her perception of her body is not only her partner, who presents a positive perspective on her bodily changes, but also the generalized compendium of eating disorder specialists who present a persuasive message about what the brain of a person with an eating disorder does—which could itself impact the function and processing of the brain when it encounters its own image, the body and the environment are configured as a Mobius strip (Grosz, 1994) of mutual entanglement across space and time.

The distortion of body image was described by many participants as something that persisted into recovery. Some participant wished to change this, while others accepted it as a part of their lives. These divergent orientations on the desire to “move beyond” (and, associated, a belief in the likelihood of this being possible)—as well as the mutability of this distortion—are found below:

   my reflection has always been distorted when I look in the mirror, like I always just see myself as a monster, or like back then, not as bad now (Abigail)

The relationship between recovery and body distortion or body image bears deep exploration in relief against accounts of legitimacy, truth-telling, and reflection. This debate cannot be distilled down to a simplistic articulation of those with eating disorders do/do not/will not always/will forever experience body image distortion. Individual orientations to the concept of body and distortion “before,” “during” and “after” eating disorders is further complicated by how time
itself is present in/out of participants’ accounts. Given the fuzzy/foggy logic of time in relation to recovery, and to the trajectory of the distress itself, determining the before/during/after of distortion becomes illogical. It is challenging, for instance, to use a memory to identify how one felt in their body prior to the development of an eating disorder when: a) the participant may not be able to identify a clear “moment of onset” for the eating disorder, b) their supporters and clinicians may identify a different starting point for their eating disorder, and c) body image and embodiment are felt as much as seen or remembered; recalling visceral body experiences may not easily be articulated in language. Participants’ accounts of the body image work done in treatment reveal how current approaches to “body image” work may overlook certain aspects of embodied experience that cannot be neatly categorized into before and after and that capture only certain aspects of participants’ embodied experiences.

The body image stuff is really tough for me, because—and I don't wanna sound like a cliche or like that I haven't realized that I did have body issues—but it only became a struggle for me to be in my body when I was looking back at a healthy weight and trying to figure out how to stay there. I hated my sick body, I didn't connect with that at all, so, that is actually another thing that was tough for me in treatment, because I felt like we did a lot of worksheets and stuff about our bodies and I just like… I look at womanly bodies and think that those are beautiful, and always admired really strong women who like play sports and things like that, so that was really tough for me, and that's what I don't like about those fluffier recovery ideas. (Isabel)

This quote complicates the idea that people with eating disorders are not aware of the categorization of their bodies as malnourished or sick when they are acutely ill. She describes hating her sick body, which made it hard for her to complete the activities presented in treatment.
that were based on the assumption that all patients wish to stay in a “sick body.” Her “body issues” were not tied to distortion in the expected way; she describes an affinity to more “womanly” (curvier, coded with normative femininity) bodies as opposed to her more emaciated form when she was in treatment. The recovery prescribed in this setting was presumably “fluffy” in its reliance on the achievement of a “love your body” orientation—the idea that proof of recovery would take place through the embracing of a womanly form. And yet, Isabel already loved womanly bodies, and hated her “sick body.” In terms of her orientation to her body, she might be described as being at a time point ahead, not expressing the expected eating disorder-to-recovery trajectory for which treatments have been designed. This poses her experiences as disjointed from treatment trajectories that aim to correct nutritional deficits, then to “right” “wrong” body images and distortions held by patients.

Addressing body image is common in eating disorder treatment programs; all participants who had attended eating disorder treatment programs reported having explored body image in treatment. When they had not experienced body image issues in the expected way, they noted this contributing feeling like they did not belong in treatment.

for the longest time, I kind of just felt like I don’t really belong in this program, because I'm not really afraid of gaining weight, even though I do have my body image insecurities. (Jameela)

Several participants described body distortion as beginning prior to the onset of their symptoms, but there were also participants who reflected that until they had developed their eating disorders, they did not have significant body image distortion. Reflecting on her childhood, Julia noted: “I never had any kind of like body image issues, or anything.” Later in her interview, Julia qualified that body image distortion is now something that she struggles with and that she
suspects will persist. Accordingly, she defined recovery as not acting in accordance with her negative thoughts about herself, while positioning body image distortion as persistent: “I think there's always those thoughts I still have, you know, a lot of like, body image issues, there's always still that.”

Though some participants’ accounts ran counter to narratives of body image distortion leading to eating disorders, others reported what might be regarded as a more “typical” account of body image, adhering more closely to the expected trajectory. For instance, Robyn noted: “one of my earliest memories is looking in the mirror as a toddler and seeing fat.” In a society in which fat is coded as immoral, it is easier to make sense of this experience of feeling that one embodies societal ills leading to an eating disorder. Still, even when eating disorder trajectories embody the normative, participants described approaches to addressing body image as doing little to attend to the deeper, embodied function of eating disorder coded behaviours they used to manage their emotions. A quote from Cora helps to explore the experience of what she felt like in her body: “it was pretty much just always, I was always focused on how, physically, how fat I felt and how I felt physically also had a lot to do with what I had to eat that day.” Cora does not describe what it felt like for her to see her own appearance, focusing instead on the sensation of “feeling fat” as existing in a circular relationship with what she was eating. Whether or not they felt that body image played a major role in the development or sustenance of their recovery, participants nearly uniformly felt discontented with the idea that eating disorders were primarily tied to normative definitions of body image.

3.2.1.3.2 Not All Sunshine and Rainbows.

While some participants longed for a vision of the reality of recovery as they pursued it—and felt that they had been underprepared for the realities of recovery when they were in
treatment (if they did)—others wanted to ensure that any articulations of recovery reflected a deeper understanding of the realities of living in a body in a world that does not accept all bodies and one that in fact is often explicitly exclusionary of certain bodies. Many participants preferred more “realistic,” imperfect versions of recovery to an illusion of perfection that they may not feel able to live up to. Julia describes how not having an image or vision of what recovery would be like impacted her disorder, making her feel like recovery was impossible and like she would live with her eating disorder forever. Her account also reveals how she wishes she could go back and offer herself a glimmer of hope, not that life is perfect in recovery, but that there are aspects of recovery that are worth aspiring to:

in a lot of ways, I was almost like resigned to just living with it for the rest of my life, which is really sad, but it just goes to show how bad it was. I just wish I could like almost give myself back and give a glimpse of what life was like now, like it's not by any means sunshine and rainbows, it's not a million times better, but it is a life, you know? (Julia)

That Julia’s vision of recovery entails going back and speaking to herself about what recovery would be like is a detail that adds complexity to the idea of role models in recovery. Given the differences in individual recoveries, participants were often unsatisfied with representations or performances of recovery, sometimes even questioning the validity of accounts that represent recovery as a place of peaceful perfection with bodies. This questioning lies in tension with the general distrust of those who experience eating disorders so often explored through the accounts in general. Participants were often either skeptical of others who presented themselves as always happy with their recoveries or questioned their own recoveries as not good enough because they did not fit the shiny, happy images of recovery they saw. At times participants articulated both orientations in their accounts, often not wishing to claim the label of recovered because it
represented something different than their lived experience. Enacting a “perfect” recovery sometimes felt so false to participants as to play into silence around struggles and postpone seeking help during relapse, as Emily describes:

I guess I went from eating disorder to "I'll have a perfect recovery" and so I followed the meal plan. I wasn't against it, I've always loved food, so I enjoyed all the different variety I was then allowed, and the different desserts, and the snack. The only thing I didn't like was the Ensure that I had to have and I didn't like that I couldn't be active […] I went for my final year of high school, kind of seeing the medical doctor out of the (local university hospital) program, and we never addressed the underlying psychological issues, I think, and that was my own surface-level treatment of everything. Like "everything's fine, like I'm happy.” (Emily)

Participants also described the “love your body” imperative to be unattainable and frustrating, complicating their experiences of being recovered and at times imposing other standards they needed to live up to in order to perform fit femininity and demonstrate that they had achieved recovery.

The Dove commercials, that are like "all women should feel beautiful all the time!” and, and I'm like "that's fucking bullshit, why don't we just all feel like ourselves, and feel human, and feel like smart, or caring", like they shifted the focus from "okay, so you, most women should feel ugly" to "women should feel beautiful." But they're still making us fixate on how we look as the most important thing about ourselves.

I: Mm-hmm. Yeah. And then there's almost this imperative to feel beautiful.
C: Uh-huh. Exactly. And if you don't feel beautiful, then you suck as a human being.

You're supposed to live in this world and always feel beautiful in the skin you're in, no matter what you look like, and if you don't, then again, the problem is with you (Carrie)

Carrie’s quote reveals that the issue with this discourse is not necessarily its positivity. Participants were generally displeased not with the content of the messages but who was made responsible in the love your body discourse. Rather than attributing responsibility for bodily discontent to marginalization of certain bodies, the responsibility for feeling good about your body comes down to the individual. Perhaps particularly for those in recovery from eating disorders, there is an impetus to make the “choice” to love one’s body—to prove that one is recovered by showing that one can align with this prominent discourse and enact “normalcy” in that way. However, upon deeper examination, those in recovery in this study were skeptical of anyone who expressed total, unconditional body love. They also explained the sense of being held to a higher standard than others in society in general, who might be “allowed” minor back-steps in their body love journeys. For those who were known to have had eating disorders, proving body love becomes a way to immunize oneself against the skepticism that other might express about the lives of those with eating disorders and to be seen as “normal.” This could at times result in the hyper-performance of perfection described above, or a general awareness of the different levels and kinds of surveillance to which those in recovery are subject.

I think a lot of like conversations about recovery almost hold people who are recovered to a higher standard than people who haven't ever experienced an eating disorder, so and I think almost this perception that you have to have really great body image to be recovered. I’d say that my relationship with my body is pretty average, so like I have good days, I have bad days, but I don't actively restrict my food, exercise for me now is
something that's really enjoyable and it's not something that I do to lose weight, and I
don't think about numbers in the same way that I used to. So it's just, it's not really
something that occupies a huge part of my life anymore. (Kathryn)

Kathryn’s quote exemplifies how those in recovery are not actually asked to perform “normal”
health behaviours and care about their body, but super-normal behaviours about bodies and an
indisputable body love that does not falter. This imperative reflects that what is being prescribed
in eating disorder recovery may not actually be “normal” eating or “normal” body image but
actually ideal eating and ideal body image. Social dictates for body love while also maintaining a
very specific type of body run in opposition to how people in recovery are tacitly expected to be
happy with any kind of body. This also relates to promises often issued in treatment that the
person will “not get fat.” This subtle stigmatizing of certain bodies permits—and even requires—
unconditional body love while simultaneously dictating the terms of what kinds of bodies might
be worthy of this love, similarly to how body love discourses have been co-opted by consumer
capitalism to suggest that body love can be bought.

Participants’ accounts contradicted each other in terms of what someone in recovery eats
and what they do with their bodies, which is itself illustrates multifinality in recovery. This could
be coded as “levels” of recovery, but I hesitate to code participants’ accounts in this way.
Participants’ recoveries were lived in relation to their own histories, in relation to the “normalcy”
enacted in their family environments and their social contexts more generally. Just like loving
one’s body perfectly is not something that participants felt was realistic, nor was eating with
reckless abandon necessarily something participants aspired to. Robyn described her relationship
with food and its relationship to recovery as follows:
I don't envision recovery look like eating McDonald's; that's just not who I am, that's not, doesn't jive with my philosophies on life and health; but like not having to think so much about food and not being so afraid of what my body will look like if I was to just not think about food and not control so much and like eat a cookie if I feel like having a cookie, a gluten-free cookie (laughter), versus you know having a salad for lunch every day and that kind of stuff. (Robyn)

Similarly, Caitlin reflected on how she might occasionally experience total “freedom” around food, but this was not a consistent reality for her.

People think that everything is gone, you're fine, you're great, you can go to a restaurant and order a burger and fries and a milkshake and eat it and everything's great, and everybody's happy and like that's not really, that's not really reality. It's not reality constantly, it might be reality once in a while, but it's not reality. I think, that people think that now it's like, well you can just go on and live your life, and it's like none of this ever happened and that's not true. (Caitlin)

Regardless of the nutritional content of what they were eating, the imperative to eat in accordance to, on the one hand, treatment prescribed meal plans and, on the other, societal expectations around what a “healthy person” eats could feel oppressive and overly surveilled, to participants. Similarly to the expectation that participants would feel at ease in their bodies all of the time, this pressure had a tendency to backfire. Out of fear of being labelled as still struggling, some participants hesitated to express any misgivings about what they were eating.

I'm unable to really voice any sort of concerns that I'm having or if I feel like I'm slipping a little bit or I'm having one of those days where I can't finish this meal because I'm really struggling with it, I can't go to them and say that, because I feel like they're going to flip
out and then get all "Oh my God. We need to put you in an inpatient program" and all of this kind of stuff that then freaks me out, so. (Zoe)

Exploring the experiences of those whose supporters did not require them to enact a perfect recovery to presents possible alternatives to the “perfect recovery” trap. Elizabeth contrasts the experience of speaking with her partner about her recovery to that of speaking to her parents, exploring how “hysterical” reactions only make her feel worse, whereas openness and listening provide her with support and understanding, rather than expectation:

My partner is very good about it. I can talk to him about it no problem, and he's supportive […] my mom tends to be a bit hysterical sometimes so I just want to prevent that, I don't want to burden them with anything. (Elizabeth)

Elizabeth noted that her method of interacting with her parents about her eating disorder was to not talk about it at all. The risk of setting off a cascade of concern was too great, whereas her partner would listen without judgment. This preference for measured responses and desire to be heard, rather than “fixed,” was common among participants who preferred to envision recovery as imperfect and ongoing.

The need to avoid the perfection trap was also articulated in relationship to the perfection some felt was required of them from their eating disorders. For instance, Ellen described what her eating disorder promised, and how this impacted her need to not look at recovery as perfect:

It [the eating disorder] promised me that I'd be closer with all of my friends, which I learned that in order to be closer, you have to be vulnerable with people. Which my eating disorder was not letting me do, and now that I'm able to do that, I feel like I'm closer with everyone. And it told me that everything in life would work out perfectly if I
listened to it. Which I guess, hasn't come with recovery either but I'm now able to realize that nothing in life is perfect.

For many participants, recovery was about the idea of letting oneself be imperfect, and moving beyond the assumption that life would be perfect—and recovery would be perfect—was a key moment for them in accepting life-as-usual in the “after” period following acute distress.

I think for me right now my biggest thing that I'm working on is just being compassionate towards myself, and for me that means not, heh, letting myself not be perfect and not, everything doesn't have to be done in a certain way. (Sherice)

Exploring recovery beyond perfection required participants to let go of the perfect image of recovery peddled to those in recovery—which is not easily done, particularly when so few visions of recovery are made available to those seeking them. As described above, having more openness in supportive relationships was an important first step in pursuing a life outside of performances of perfection.

3.2.1.3.3 Not Only Recovered.

Participants did not always consider their eating disorders to have been the single most important part of their lives. For some participants, the eating disorder was one among many experiences that shaped their subjectivities. This perspective is largely absent from existing accounts of recovery, which primarily focus on recovery as central to a person’s life, embodied experience, worldview, and subjectivity.

Alina configured her eating disorder as one of several life events that had occurred to her in her teenage years. Asked about how she would refer to her experience after the acute distress around food, weight, and shape, she noted: “I would never call it recovery, I feel like I don't want to like dramatize it too much… it's just one of many dumb things that I did.” This might be seen
as a blame inducing or choice reinforcing statement; by framing the eating disorder as a “dumb thing” that one “did,” the eating disorder might be seen as a choice. However, this might be reframed: in discussing her desire to not “dramatize it too much,” Alina may also be distancing herself from some of the aforementioned assumptions made about people with eating disorders and in recovery. Alina did not configure her recovery as a choice, either, and only upon looking back on the eating disorder did she realize how much it had impacted her at the time. Moving beyond distress, for Alina, was largely a function not of a choice to engage differently, but moving forward in other areas of her life that made sustaining an eating disorder impossible.

This unconventional view on recovery might be controversial for its potential for choice-based framing, but may not actually represent a brushing off of the severity of eating disorders. It simply represents a different trajectory toward a better life where healing meant not focusing on remedying the eating and body related distress, but other underlying distress that perpetuated the eating disorder. Alina was not the only participant to not seek formal treatment, and to heal without focusing solely on the eating disorder itself. Other participants reflected on disengaging with the identity of having had an eating disorder because they disliked the associations that accompanied being someone with that history.

I'm just tired of educating, I guess. So, I'm expecting that if I tell people that I have recovered from an eating disorder, that they might have more questions than anything else? And that's... I just don't feel like I'm there anymore. I'm not in the educating kind of headspace, anymore [...] I think that's it. So I don't really have a really good reason, it's just more I don't feel like it anymore, I'm tired, that's what I really wanted. I put that thing to sleep a while ago. (Cora)
Cora’s quote also reveals how those in recovery are so commonly called upon to educate those who have not experienced eating disorders, and how sometimes “real recovery” entails not being in that space of educator anymore. For Cora, recovery means, in part, not needing to continually correct the persistent stereotypes about eating disorders that continue to circulate in social media: the eating disorder, here, becomes configured as a part of the past, as opposed to a core part of continued identity.

This configuration might also be considered in light of the collapsing of the identity of those with eating disorder histories as solely linked to their eating disorders and be understood at least in part as resistance to this attempt at collapse and delegitimization. This might be a particularly persuasive approach for those who are delegitimized along other lines in their lives, marginalized, infantilized and/or misunderstood for any number of reasons including race, class, gender, sexuality, etc. Elizabeth described this relationship to identity, reflecting on wanting to continue to identify as recovered from an eating disorder while also trying to move beyond this identification:

A big thing for me is not making it my one and only. Because then I feel like I want to hold onto it more, and I feel like it's more a part of my identity. But I really don't want it to be a part of my identity. But a part of me does, you know.

In order to, as she also phrased it, “get on with her life,” eating disorders—and eating disorder recovery—needed to become less of the focus in her life. Along the same lines, eating disorder recovery, or the impetus to “get there,” was sometimes articulated as a reaching for the future. Elizabeth expanded on the need to move beyond the eating disorder/eating disorder recovery identity as core to her being by reflecting on her larger life goals and how those interacted with her eating disorder:
I'm tired of letting things get in the way of what I want to do. And I'm just not willing to let them anymore, so if someone has a problem, like whatever. I have goals that are bigger than you, so I'm gonna pursue those.

Recovery, for Elizabeth and some others, was thus enabled by focusing on other aspects of her life; which then led to a desire to move beyond that part of subjectivity. This also led, as is evidenced by this account, to a reclaiming of her own perspective on her recovery versus external evaluations of her perspectives. This reclaiming of power comes, in part, from framing those who define her recovery differently than she would, as “small”—taking away some of the power of their discourse on recovery.

3.2.1.3.4 The Life of Recovery.

The diversity of participants’ perspectives on recovery reflected the diversity of their lives. As participants’ accounts attest, the task of defining a singular recovery feels not only a challenging task, but also a potentially harmful one. Inevitably, any version or definition of recovery forecloses what researchers are looking for in research. Participants exist not only in relation to others’ (e.g. supporters, healthcare providers, etc.) definitions of their recoveries but also in relation to the research enterprise itself. Participants’ self-reflexivity in relation to the research they were participating in became clear throughout the research, to the extent that it became in and of itself a defining theme for the dataset.

Participants’ lucidity around their storytelling task revealed itself through a collective concern over offering the researcher a “story worth telling,” which in and of itself speaks to the idea that there might be a “correct” story of recovery. Participants were asked why they decided to partake in the research, and many noted that they wanted to give back to the eating disorder
community and/or that they had done research themselves and recognized the challenge of recruiting. As Alina noted,

I like helping with research—I’ve done two Master's degrees myself and I know it’s useful to have sometimes hard-to-get participants and it sounded like sort of a unique person that you were looking for? And I thought it sounded like I fit the criteria (Alina)

Participants’ concerns about giving the answers that I might want transcended the idea that they fit the criteria I was seeking; even when they thought they likely fit the study criteria, participants often sought reassurance that they were giving the answers that would help me to conduct this research. If they had offered a long answer, participants sometimes qualified or apologized for this “ramble,” for instance saying “sorry, I know I gave you a lot of long-winded answers” (Jameela). They might also note that they hoped that their responses would be “useful,” aligning with the desire to give back described above; “I think hopefully you can use at least something of what I've given you” (Emily).

These participant responses might be explored in relation to how they referred to their stories and their recoveries as unique. One of the most common responses to the question of what recovery meant to them was that it was a unique process, and that “recovery” was challenging to definitively delineate for all people at all times. The question of whether it was even desirable to develop a definition of recovery to govern the recovery space also emerged in participants’ accounts. Ellen, for instance, noted that her version of recovery was “just something I made up on my own.” Caitlin remarked, similarly, that rather than looking to role models in recovery, she acted as “her own role model” and that her other role models were not those who had experienced eating disorders, but rather her family members as they lived their lives unencumbered by significant distress around food, weight, and shape.
I was kind of my own role model and I, because I had such a great, a strong family. It was great to have that constant support and those constant role models behind me the whole time as well. (Caitlin)

Others echoes similar sentiments, insisting that recovery for them be evaluated in relation to their own experiences and embodied spaces of belonging.

And yet, in these calls for an individualized definition of recovery to illustrate their own recoveries, a persistent sense of there being another version of the recovery story or a “right” definition loomed in participants’ accounts as well, which was evidenced by the way that they, at times, contrasted what recovery was for them versus what it might look like for someone else. Despite some participants suggesting that they had made their own definitions of recovery, there was also a sense of the interactional accomplishment of this definition as participants reflected on the versions of recovery they had encountered. Whether their definitions aligned with a more “mainstream” or dominant idea about what recovery is, their definitions of recovery and the collective sense of the need for individual definitions speak to the existence of multiple standards and prescriptions for recovery that manage the category or phenomenon of recovery interactionally in society.

That these standards and participants’ experiences of incompleteness exist in relation to the told story of recovery invites reflection on the key importance of listening in addressing and determining recovery.

I think it's that idea of everyone's eating disorder is a little bit different. And the importance of you know, listening to the individual. And I think asking the individual what they see as recovered, what recovery looks like to them. (Emily)
I need a recovery program that is client collaborated—goals are collaborated with clients, not everybody has the same goals in recovery, and sometimes it's really difficult to sit there and follow rules to achieve a goal that maybe not something you want to achieve to actually get into recovery. (Zoe)

Regardless of the actual content of participants’ statements about what recovery “is,” the agreement on the need for others to listen to them and believe their versions of recovery and buy into their goals was expressed as a critically important part of getting beyond distress was held in common by participants. This might also be tied to the need to be seen as more than the eating disorder, and to express one’s subjectivity in all of its complexity. The paradox of recovery appears to be that by focusing too much on the eating disorder, the person is missed, dismissed, and unheard. Their identity may then become so tied to the eating disorder—to recovery—to be offered the time and space to flourish.

Recovery was not only tied to discourses of what recovery “is” but also to the intercorporeal relationships participants had, have, or are building in their lives. Participants strongly oriented to—and nominated for participation—supporters who were able to balance their own predisposed ideas about recovery with the desires of the participant. The difference between these orientations to structure in supporting someone toward recovery operates at an affective level. Describing supporters who provided a kind of structure that imposed surveillance and generated resistance, participants often described how these supporters had directed anger toward them.

My mom was pretty concerned, ’cause she knew I was losing weight, and I think she was aware that this is something that affects teenage girls a lot. She’s a medical doctor, and
she was always like asking me to eat more. Yeah, she was concerned, I mean she'd kind of get mad with me. (Alina)

When my parents found out that I was self-harming, they like did not take that well, and they did all the wrong things, were very accusatory, and so I've been very scared to reach out to my parents, and it was the same thing… I remember sitting at a table and instead of having two slices of bread, I was having three slices, and they were just like "Only two slices." (Abigail)

My dad kinda like pretended it wasn't a thing… he pretended it wasn't a problem. My mom was just … she was extremely, extremely worried, and I think, because she reacted so badly, in a way it made me not want to talk about it with them. And so I never really, I've never had like a heart-to-heart with them or anything about what it's been like what I'm going through. That made it a lot harder to get treatment because I think having a solid support is so important when you're going through treatment and I didn't have that (Julia)

In the quotes above, family members demonstrated concern that participants read as accusatory, angry, or unapproachable. The affective response of fear—whether for their own safety or for their parents’ well being and mental health—led to a strategy of moving forward in that relationship by not talking about the eating disorder. If participants decided to seek out additional help, they did so without involving the supporters; some reported that they still did not talk about the eating disorder and/or recovery with those they had hoped would support them but who had
reacted in a way that led the eating disorder to be framed as something other than a topic of discussion.

Some participants described their parents as unhelpful and found that in order to move through their eating disorder they need to move forward in their relationship by not talking about the disorder, as illustrated in Elizabeth’s account above. Importantly, this did not mean they thought their parents were bad parents or they necessarily blamed them. As Elyse reflected:

They were good parents and they still are, and so now I don't want to talk to them about it, because I don't want to bring these issues back, and my mom crying, I don't want to get into that again—so I'm more like, let's just, I don't want them to feel guilty for that, because it's not their fault, and I kind of moved on too, and now I don't feel guilty about it anymore, so I don't want them to feel guilty, and I know my mom will, even though I tell her not to. (Elyse)

Guilt, here, is configured outside of volitional control—Elyse noted that her mom would feel guilty “even though I tell her not to,” highlighting the intricacies of managing an eating disorder within a family context.

Affective responses that elicited sharing responses from participants generally tended to be characterized—if not with total understanding—with warmth, openness, and empathy. These responses provided participants with evidence that being honest about struggle was welcome and that recovery could be imperfect without fear of reactions that would themselves not be generative to peaceful relationships with their bodies and emotions. Isabel noted this tendency and how it helped her to engage with her supporters:
working with my mom was what, what ended up helping, and I think it had a lot to do with being honest about exactly what I'm experiencing with the people who care about me so they can help. (Isabel)

When relationships with supporters were consistent “before,” “during” and “after” the eating disorder, participants also felt better equipped to engage in “life as usual” into recovery. This was particularly important for bridging the divide between the suspended time and place of intensive treatment and the liminal space of transition from treatment toward “recovery.” Not feeling the need to tiptoe around supporters facilitated continuance in relationships; some participants even described their supporters’ roles as playful and experimental, in line with their desires for their lives in recovery.

My family's relationship with food was always so good and they never blamed each other, never blamed me, and we're always open, and we're always open to trying new therapies. Like, okay, let's all go to group therapy. Okay, now we're going to try family therapy. Okay, now apparently we have to go to some like random chanting therapy and everyone was kinda like "Uh, alright! Let's go do this!" So I think the fact that they were always open to trying new things was really helpful as well. (Caitlin)

As relational and interactional as recovery is, recovery again did not mean uniformly shouting about recovery and body love from the rooftops—this publicness and focus on the recovery process as pivotal was far from a uniform one for participants. Orientations to the category of recovery varied enormously. They ranged from seeking and then later giving peer support in recovery, as Carrie did, and described as connecting her with a community of people living lives that were so much bigger than the isolated one she linked to her eating disorder:
the thing that really pushed me forward, too, was being this community girl, and seeing people who had been really ill who are doing great and live fantastic lives and making their decisions and just feeling that sense of connectedness, so that whole peer support piece. I felt like I was part of a community, we supported each other, we understood what we had gone through and that was just, like that was what helped me, so if it was really one thing, it was that. (Carrie)

Carrie describes having experienced others’ skepticism around her involvement in the peer support community:

I've read a lot of literature, I'm not a psychologist but I've studied this intensely for 20 years, and I think that peer support piece so powerful around eating disorders and we've been so afraid of it. In a larger community, there's just been "oh, if you put two people together in a room, like aaah! They're gonna both get sick and die!" Its just so much trepidation around it, that I found to be so powerful, and hopeful for both. (Carrie)

Carrie’s experiences exemplify a double bind in which those in recovery may become stuck: on the one hand, eating disorder recovery is described as an incredibly powerful aspect of people’s lives in the clinical, research and popular literature around eating disorders. Making meaning from eating disorder recovery is an expected outcome. Those with eating disorder histories are also, as has been described in earlier themes, often unable to escape this history as a lens through which others view them. Yet, there is a simultaneous trepidation to “allow” involvement of those with lived experience in the eating disorder treatment and research community. Advocacy is, at times, delineated as a “safe space” for their engagement; those with eating disorder histories are expected to “give back” (and may wish to do so, as is evidenced by the responses many participants gave to the question of why they wished to participate in research) but expected to
do so on the terms of those who define the boundaries of eating disorder treatment continuums.

There is little space for people who wish to engage in the community on their own terms, like Carrie, who advocates for peer support models. The resistance to this engagement reveals how those in recovery may be expected to move beyond the eating disorder while simultaneously holding onto the power of recovery as a very particularized aspect of self.

Participants viewed supporters as not uniformly helpful or harmful in participants’ lives and in hearing them and orienting to their recoveries, of course. Acknowledging the dynamism and co-constructed nature of supportive relationships is important to avoid subsuming potential helpers into the categories of “good” or “bad” supporters. Participants identified that some supporters began as helpful, providing a listening ear to participants where they had not found it before, but later becoming less helpful as they experienced their own struggles or developed a sense of antipathy toward the possibility of recovery, as Robyn described:

he was super supportive in the early years, he listened, he knew exactly what to say and how to comfort me and like within the past probably since 2008 or 9 like something changed and he just, he doesn't, he doesn't get it anymore, he doesn't know what to say, and he always says the wrong thing and he always makes it worse, and we just, I just, for the most part sometimes I still try and talk to him about it, but I always end up more upset than I began, and so for the most part I don't. (Robyn)

The disjunctures in support might at least partially be explained by the temporality of recovery. If eating disorders and the recovery process operate on a different time scale than normative time, and supporters’ lives largely align with normative linear trajectories, disconnects might occur. Following a linear time logic, a person in recovery might be expected to move forward toward the end goal of recovery (as articulated in line with the supporter’s personal definition of
recovery, perception of the person they are supporting’s definition, and awareness of clinical and popular definitions of recovery). Certainly, supporters might be aware of or even expect setbacks or a forward and backward motion in attaining recovery, but these forward and backward steps are assumed to be dialectical moments that will resolve toward an ultimate end. For the person experiencing the distress, time might move in fits and starts, suspensions and hyper-forward motions that belie a linear trajectory. The goal of recovery might even be explicitly defined as returning to a state “before” an eating disorder, which is presumably impossible given this forward motion. In a way, the person might at times be considered to be seeking the past, which can complicate the pathway. Logics of time conflict in a way that affectively tires both members of the relationship.

The alternative possibility existed as well, within participants’ accounts—some described supporters learning and growing with them and becoming better supporters for their needs over time. Participants described resolving relationships with supporters in terms of co-learning and growing together; this was a decidedly interactional process through which all parties reflected on their changes and challenges.

I’m happier now and how they feel like they can have a conversation with me without me turning around and yelling at them about something. Because I feel like every time we'd have a conversation, it would end up in me like running into my room crying, or yelling at them about something. Which now, I don't do that. (Ellen)

Relationality and the tetheredness of recovery to life trajectories persisted beyond supportive relationships participants had experienced toward current or future interactions and relationships participants had or envisioned. Several participants expressed recovery in terms of learning to not only express needs to others in their lives but to themselves.
I want to be able to live a certain way without concern. I don't think I am all the way there yet, with respect to just not caring so much what other people think, or suggestions of others, or meeting the needs of every other person. I think that recovery for me is knowing and listening to what I need, which sounds really selfish, I think, but just like little things too, I think recovery for me is living really independently, and being able to, you know, have a little puppy, like those are the sorts of little rewards and things that I hope to someday achieve and being able to care for another. I hope someday that I can either have a child or adopt a child, but again I want to ensure that my head's on right before I try and raise another. (Emily)

Boundaries in recovery thus functioned not as a way of shutting others out but of making sure that one’s needs were met before opening up to others’ needs in a way that would allow a person to develop caring relationships that did not deplete them but rather filled them up. Building effective boundaries could be considered self-work but was also done in relation with others in participants’ lives. Enacting recovery in relation—including the vulnerability and openness many described as key to engaging with the support available to them—meant also identifying those with whom these boundaries could be built.

3.2.2 Supporters.

Following and in light of how participants in recovery described and related to treatment systems, the experience of eating disorders, supporter relationships, and the idea of recovery itself, supporters accounts build out the relational and contextual experience of eating disorder recovery. Supporters explored what it means to be recovered, articulating different perspectives on the im/possibility of recovery. They articulated recovery in the context of the time and space required to achieve it, and against a backdrop of clinical, personal, and societal imaginings.
around eating disorders and recovery. They expressed the challenge of enacting surveillance and themselves being surveilled, expected to enact hyper-normalcy around food and act as role models for loved ones in recovery. This experience at the boundaries of eating disorder recovery prescriptions and dominant discourses on health presented supporters with both the unique opportunity to develop a sense of comfort in their embodiments while simultaneously proving challenging in terms of enacting “proper care.” At times, they had to shift their own preferred modes of embodying care to meet the needs of their loved ones, and/or to provide care consistent with clinical discourses on recovery. Accessing treatment also placed strain on supporters, who often had to invest significant amounts of resources—financial, time, and relational—in supporting their loved one. Despite the inaccessibility of treatment, particularly to supporters, supporters expressed gratitude for the (often little) support received, revealing significant gaps in our continuums of care for eating disorders.

3.2.2.1 The Im/Possibility of Recovery.

Supporters’ articulations of recovery varied significantly depending on a number of factors, including their relationship with the person who had experienced eating distress, their own orientation toward health and what they feel constitutes a good life and the amount of time that they perceived as having passed between the eating disorder and the time at which we spoke. Many supporters acknowledged the heterogeneity of recovery, and articulated a general sense of believing that recovery is possible:

I'm already aware that it means different things to different people, I mean, in my view, the ideal situation is that is she can just kind of eat and not think about it, but I know that that… I don't know, I don't know how it goes for other people, like I know that there are people who recover from eating disorders (Ted)
There were several participants who articulated that they did not believe that full recovery was possible, making it difficult to ascertain consensus about whether or not “supporters” find recovery possible; this is also more challenging still in light of the different relationships between various supporters and people in recovery and the contexts of their lives. Jeremy, a husband, for instance, does not believe full recovery is possible:

true recovery, as in "this does not bother me anymore", I don't think exists. Can they live with it? They find ways. The ones that survive it find a way to live with it. I think that's what recovery is to me, finding a way to live with it. (Jeremy)

This resonates with the orientation of many participants in recovery to the idea of full recovery being a state of not ever thinking about the eating disorder. Supporters often described recovery as an ongoing and multi-layered process:

I would say it's multi-leveled, you can look at it from a physical standpoint and say, okay, we're re-fed, the scale is say that there's enough weight on this person, so in terms of a physical recovery; but there's ongoing recovery, ongoing acceptance […] recovery is like an ongoing thing, there's that level of, these things are stable, and then there's that area where it's an ongoing development, it's never, you're never really recovered, I don't think. (Jane)

While supporter participants often referred, as noted above, to some “other” person attaining recovery (much like participants in recovery did), descriptions of recovery were generally tied to their observations of their loved ones. Supporters’ perspectives on the possibility of their loved one reaching a state of full recovery were contingent on their definition of full recovery; most participants did not describe their loved ones as fully recovered, often qualifying that they would tell me this but would be less likely to tell their loved one:
The thing is when you say the term recovery, I think it means the total end of the problem [...] she's not there yet [...] I don't know if that's really a possibility, and with (daughter)'s history [...] I don't really know if it's possible for her to end it. But that said, I probably would never say that to her, because to be so fatalistic is not really a good thing to do with someone who has a mental health problem. I sincerely hope that she would be able to get over it one day, because it's not something that she's happy about. (Scott)

Time featured prominently in supporters’ accounts, and the relationship between time and legitimacy of recovery was notable in the way that supporters oriented to their relationships and recovery, for instance through the “always in recovery” perspective described above. Supporter and individual timelines and expectations around recovery complicated the triadic relationship between supporter, people with eating disorders, and recovery. An intervening discourse here was the set of clinical guidelines offered to supporters around how long it would take their loved one to recover from their eating disorder. If and when recovery did not play out in a linear fashion and in the timeline anticipated, supporters often felt let down by the experience and misled by those who suggested that recovery would look a certain way or follow a certain path. Looking at recovery from “the outside” but also entangled in recovery in terms of the ways the eating disorder impacted their lives and relationships with their loved ones, supporters often felt disillusioned by recovery trajectories that were non-linear; further, when the trajectories were non-linear, they showed a skepticism about the possibility of recovery being at all possible. Recovery expectancies, tied to clinical and popular discourses about what recovery would look like felt incomplete and unsatisfying for supporters, who again explored how recovery ended up being something that “other people” could achieve, but not them – there was a sentiment of
“what about us” expressed by some supporters who highlighted the catch-22 of wanting some hope and role modelling from others who had been through the experience but also did not want to feel misled:

The facts are very confusing, 'cause they're there to make you feel hope, but then when you don't meet those benchmarks, you're also left wondering, "oh, well, what about us?"

[…] They're great if they work in your favour, but if they don't, you're like "okay, well, what about us?" (Alexis)

Recovery was not necessarily contingent on a certain amount of time elapsing, but time also acted as reassurance in recovery: as time went on, supporters felt more comfortable withdrawing from the roles in which they’d been placed in treatment as either primary or second enforcer of normalcy. They also, at these moments, felt more comfortable reflecting on recovery with their loved ones. The idea of normalcy in relation to eating, body, and relationships was another key feature in the accounts of recovery offered up by supporters, who simultaneously enforced and pushed against dominant framings of what it means to be recovered, what it means to be healthy, and what constitutes wellness. Supporters accounts reveal complex tensions between taking care of self and taking care of other, as well as a strong thread of love toward the person they are supporting that they described as helping to sustain what they also described as a challenging process. The tension between being alone and being supported also fluctuated in and out of supporters’ accounts: this tension was undergirded by the need to balance disclosure and privacy, reaching out and reaching in, and feeling misunderstood (and watching a loved one be misunderstood) by healthcare practitioners and/or society in general. These tensions, needs, and desires will be described in more detail in the following sections.
3.2.2.2 Surveillance and Normalcy.

Supporters’ accounts reveal the complexity of existing in between and in relation to the person in recovery and dominant discourses on healthy and normalcy simultaneously. Supporters’ accounts demonstrated an acute awareness of the intersection between dominant discourses for health and prescriptions offered for recovery. Though most supporters had no prior knowledge of or experience with eating disorders, interactions with their loved ones while they struggled revealed to them the paradoxical nature of what is prescribed for people in different bodies. This experience was an abrupt one for supporters; they often described feeling uncomfortable negotiating this space in between and needing to take on and take in new roles and information as they supported their loved one. Supporters were often expected to step up and take on the role of primary supporter after acute treatment was completed (if the person had pursued intensive treatment). They simultaneously perceived a need to tread lightly around matters of food and weight with the person they were supporting. From within, they felt the pull of specific definitions of what “normal eating” and normal ways of being might look, drawn from family and broader cultures and informing what they anticipated recovery would look like for their loved one. They themselves sometimes felt watched or surveilled, by treatment providers and by the person in recovery, complexifying the surveillance matrix. Interestingly, though they often felt called to watch what their loved one was doing with their body, they also resented the externally-pressing comments and watching of their loved one’s behavior. Some perceived the role and associated rights fell to them, particularly given the lack of information most people have around eating disorders.

3.2.2.1 Watching/Being Watched.

Supporters often described feeling both responsible for and uncomfortable with the experience of watching over what their loved one was or was not eating. Many of the supporters
constructed themselves as people who were not the type to dictate ways of being to others; they were often, however, asked and/or expected by treatment providers to take charge of their loved one’s eating when the person returned home from treatment. A “good supporter” is expected to push the person in recovery to eat “normally,” but little attention is paid to how “eating normally” might be differently defined in different situations, cultures, and individual relationships to food. Many supporters described how having a loved one with an eating disorder made them think about their own relationship with food; they wanted to model eating for their loved ones and thought about how this also might model “normal eating” for others in their lives as well. In this sense, not only did supporters feel that they needed to watch their loved one’s eating, but their own as well. This “role modelling” is articulated in the quote below from Jay, whose girlfriend had experienced an eating disorder:

I definitely try to be as good of a role model as I can when it comes to food—I try and be normal, I try not to be overly cautious and, cause she’s not stupid, she’ll know if I’m acting. So I just try and be normal and I would say that she — before I met her, when I was younger there was a time period when I was more of a healthy eater — I don’t know if healthy is the right word — just, I didn’t eat as much you know ice creams and snacks as I do now and when I met her I just felt like, I didn’t want to do that in front of her so, and actually it made me a better person too in a sense because I think my relationship with food is better now, just trying to be a good example for her. But yeah like I just try and be normal. (Jay)

Jay’s account reveals the complexity of “normal eating” in a society that has a very particular vision of what “healthy” means. Reflecting on his past, he notes that he was a “healthy” eater, and then pauses to problematize the meaning and choice of this word. He
chooses normal to describe his current relationship with food instead, reflecting on normal as something that entails occasionally eating what might socially be framed as indulgent. This account and others reveal the multi-directionality of surveillance and definitions of normal; it is likely that Jay’s definition of normal changed as a result of the eating disorder recovery dictates for normalcy he encountered in his relationship.

Jay was not the only supporter to be impacted by a loved one’s understandings and articulations of normal; several supporters described their increasing problematization of social dictates around food as a result of their encounters with their loved ones. Another boyfriend, Elliot, said:

I think I have a relatively normal and healthy relationship with that. I guess actually like through struggling with [loved one] I am a bit more aware of making sure that I’m eating regularly and healthily and just remembering that, just trying to be positive about your body image. And I think I’ve always had a pretty normal relationship with that but even after struggling with [loved one] I’ve come to be more aware of it as well (Elliot)

The ways that supporters defined “normal healthy relationships with food” also informed the recovery expectations they had for their loved ones. While they generally claimed their relationship with food as their own, they also recognized the complex entanglements of health and food in the way they talked about food normalcy. Like the accounts of the two young men above, they caught themselves thinking differently about food in light of their loved one’s struggle, which helped them to notice the contradictions expected of their loved ones at times during recovery. They also recognized the abnormality of the normal eating as prescribed in treatment in relation to what they saw as “true” normal eating —though they did not always pinpoint the origin of this prescribed “abnormal normalcy” as being the treatment context. The
ways in which prescribed rigidity around food played out in their lives speaks to the multiple webs and standards of eating to which those in recovery are held — as well as the relationality of food and eating.

Role modelling also took the form of embodiment, not just eating. The ways in which supporters talked about their bodies also reveals the distinction between normative body image struggles and eating disordered body image struggles. One participant was the sister of a person with an eating disorder, and reflected on her body history and the fact that she had not engaged in any extreme measures to alter her body:

I just go through the regular struggles that women go through, probably. Always wanting to lose a few pounds here or there, but never anything extreme. I've never been inherently unhappy with my body image, looking at my body, so I haven't done much to change it. […] Or done anything extreme to change it, maybe. (Alexis)

As evidenced in this extract, there is a described difference between what “women” as a group might experience versus what someone with an eating disorder would do. In this excerpt in particular, the difference is described as being in the action, the intensity, and the degree to which it impacted the rest of life. For Alexis, the body image struggles she has experienced are normative insofar as they are not described as being debilitating or significantly interfering with the rest of her life. This also gives us clues to the ways in which eating disorders are framed by those who are not experiencing them, but who are seeing loved ones experience them. If the difference driving the extreme behaviour is the intensity of the feelings of body distress, then the supposed contributor to disordered behaviour is the centrality of body distress to self-concept. This speaks to dominant models of eating disorders wherein body distress is causally linked to the development of eating disorders, but also reflects subtleties beyond a simply causative
model. We might consider the lack of deliberation or choice in the behaviour — in the excerpt above, Alexis is not blaming her sister for engaging in extreme measures to alter her body, but recognizing that her embodied experiences of distress have never been intense enough to warrant alteration for body peace and acceptance. Interestingly, the aesthetic form of the body and the acceptance of what one’s body does feature in Alexis’s descriptions of her sister’s recovery, as evidenced here through the use of the terms “body image” and saying “looking at my body.”

Looking at another excerpt from Alexis’s interview this dynamic is evident, in terms of the proof she uses to evaluate her sister’s wellness status:

> I’m able to compliment her on her body more and more, which is I think a really good thing. And tell her, like "Wow, you know, your legs look amazing, you look great!" And rather than her think "I look fat", she's like "Oh, I look great". That's really positive. So I think that's kind of giving her a different, like a good association with body image, and what you can look like and still be healthy, still be fit. (Alexis)

Alexis’s excerpts reveal the ways in which people without a history of an eating disorder negotiate body norms in light of observing this confronting difference between what society deems acceptable and what they are learning might be a different way of being in a body for those with a history of an eating disorder. Being healthy and fit is highly valued in white western society, and is not always easily disentangled from being thin, given the moral injunctions associated with bodily existence in modern western society. Looking great is not a neutral term. Alexis’s explanation of her reassurances to her sister — and her sister’s ability to accept them — might be seen as unduly focusing on the body image aspects of eating disorders, often maligned by those attempting to draw eating disorders away from body image in order to have eating disorders recognized as a serious mental illness with extreme possible consequences. And yet, it
is arguably important to consider how people with eating disorders themselves and their supporters explain their disorders and their recoveries, and whether body image is salient to them. Body image is highly socially salient in a world that does imbue bodies of various sizes with various morals. Further, those in eating disorder recovery exist at the precipice of expectations for embodiment, caught in between dictates for recovery and dictates for health issued to the population in general. Tied up in this nexus, their bodies are interpreted differently by people who know more or less about their history of illness. Interviews with supporters revealed that those closest to the person in recovery might act as intermediary as well, themselves also existing but perhaps not as entangled in this middle ground.

Some participants more explicitly reflected on the challenge of moving from environments of not having any choice around meals to needing to make all decisions for oneself – and being expected to make these in a way that would maximize both recovery and health in general. A mother of a participant who had experienced an eating disorder explained that she saw her daughter’s recovery in relation to her ability to eat intuitively, but recognized the challenge of moving to this “intuitive” place given how rigid rules around food had been in the treatment context.

She has her life back now, she can eat, she can go to restaurants, she can eat with friends, she can eat all those scary foods, she can intuitively eat, she can eat on her own. […] You know, it took her a long time before she would intuitively into the fridge to even get, like, a drink, right? ’Cause she was just so used to it for so, for probably like three, I'd say at least three and a half years of complete having someone else to be in complete control of her meals. (Elizabeth)
Elizabeth herself had been one of those “someone else”s involved in the preparation and delivery of her daughter’s meals, and was able to observe the difference in her daughter who could now “intuitively eat.” The issue of intuitive eating in eating disorder recovery is itself coloured by assumptions around desired ways of eating and different opinions on whether people in recovery can ever move beyond the meal plan at least as a rough sketch of meals to be eaten in a day — and people in recovery and their supporters differed markedly in their relationship to the idea of intuitive eating and meal plans. Some found the continued use of a meal plan to be helpful in bridging the divide between the choice-free environment of treatment and the choice-intensive space of home. Importantly, whether someone “ate intuitively” or followed a meal plan seemed less important to supporters than how the person related to their food.

Perhaps because of the social tensions involved in determining what “good eating” means, the experience of trying to be a good role model for a loved one in recovery and negotiating the need to be a good supporter in the time following treatment was not an easy one for many participants. Many described the need to watch their loved ones as uncomfortable or out of character, not a role they’d have expected of themselves. This switch in the relationship and requirements of surveillance were coloured by the ways in which treatment systems framed eating disorders, the people who experience them, and the way that those experiencing eating disorders might encounter food. This was generally done by externalizing the eating disorder to make it something that the supporters and treatment providers could align against; calling it Ed or describing how it has taken hold of the person. On the one hand, this helped supporters to differentiate between their loved one and the illness, for instance being mad at “Ed,” not the person. On the other, this ask also framed the person as fundamentally untrustworthy—an orientation that risks framing the way the person is perceived into recovery and once again
complicating the choice/surveillance discourse. Participants in recovery described this as potentially problematic, as outlined in the results section for those in recovery. One father’s account of a shift in his parenting style and “waking up” to what the eating disorder was doing to family life helps to illustrate the complexities of externalization and framing of people with eating disorders. William describes the moment at which he experienced a shift in his orientation to his daughter and her eating disorder: “Up until then, it was just, you know, (my daughter) was playing me. You know, I'm just trying to be, you know, the good dad and everything, and you know, more like her buddy. And I was just giving in easier.” He went on to relate this shift to what he described as a positive interaction with healthcare providers — and his increasing alignment with the perspectives of these providers as his daughter continued in treatment:

W: It may seem like they're being mean, but it's just like "okay, I can understand why they're doing it." And they were very good at explaining why they would do things. There are a lot of times you would be sitting there having dinner, and she’d throw things on the floor, and I’d get really upset, and the nurse would come and sit with me, right, and say "It's not your daughter. Just remember, this is all part of it." [...] they're not being mean, they're helping. They're trying to help her, and at that point, it was like "Yeah, you kind of gotta get like this.

I: It's hard if it's not in your nature to, to be that way, though

W: Yeah, no, and that's not my nature.

I: Yeah.

W: Right? So, yeah. It's hard to do.

I: Yeah. Definitely.

W: But when it's like your daughter's life involved, you kind of just, you just do it.
In aligning with the healthcare providers, William was encouraged to understand the behaviours that upset him as attributable to the eating disorder. This is a common orientation to eating disorders amongst those treating them across modalities — externalization features in modalities from narrative therapy (where it originated) to family-based treatment. In FBT in particular, parents are to align against the eating disorder, and externalization is used as a tool to enable parents to take action where it would otherwise feel even more uncomfortable — in circumstances when they need to act against their child’s expressed wishes. William’s account reveals the toll that acting against the child’s wishes can take on a parent who is inclined to take a more allied stance with the child as a general rule; it also reveals what the stakes of countering the eating disorder are — he describes the stakes as his child’s life. This framing also reflects the ways in which supporters may need to orient to eating disorders in order to be able to reconcile their love for their child with actions that provoke extreme distress in their child.

3.2.2.3 Recovery Time, Family Time.

Even when supporters had loved ones who had been treated in formalized treatment settings or who they described as having “good outcomes,” they reflected on how they might improve the treatment continuum. Primarily, this meant ensuring that everyone (not just their loved one) with an eating disorder had access to timely and appropriate treatment for their eating disorder. The need for more readily accessible and desirable support loomed large in supporters’ accounts of the experience of accessing treatment. This desire for improvement coexisted with a gratitude for support delivered — no matter how problematic the support was, in some ways. This illustrates an interesting relationship with systems, and systems of power, wherein participants were grateful for support that they did not always like, simply because it was available to them. Despite wait lists and disagreements with treatment providers, the inability to
access the type of support they wanted for their loved one, and the red tape that surrounds access
to treatment, as well as some negative healthcare provider experiences, supporters expressed
their thankfulness for the supports they had received. This does not mean they were completely
satisfied and saw no room for change, but the fact that all supporters expressed gratitude for
treatment at some point in their interviews reveals an interesting — and slightly distressing —
reality of the treatment continuum: support is so scarce that any treatment is seen as better than
none.

Time while waiting for treatment took on a very specific character for supporters — these
were the worst of times, watching a loved one get worse and knowing that support was not
available for a significant amount of time. Sally described the pain of watching her daughter, in
her words, “slip away”:

I: What was that like for you, like, to watch that all happening, and to see your, your
daughter just slipping away?
S: That was… there's not really words to describe it, I don't think, that can clearly
describe the pain involved. Because — knowing how painful it is for them that are
suffering. To feel like that unworthy of being able to do the right thing for yourself, that
was the pain that, that I, I did through, because you know that they're suffering so much,
right? And, yeah, so there's not really, like a good adjective to describe other than just
painful, incredibly sad, concerned, I was really determined that this — you just don't
leave any log unturned, they're gonna get the right help here.

As Sally noted, there are not adequate words to articulate the pain of watching a loved
one suffer without being able to help. This feeling of powerlessness in the face of lacking
support was shared by many supporters — and perhaps informed their aforementioned
skepticism about the possibility of full or sustained recovery. Regardless of whether or not their loved one was interested in getting support, the lack of desired support in a time frame that worked with their lives seemed, at times, an insurmountable issue. Sometimes the loved one knew they wanted help, and hoped that the supporter would help them get it; this weighed heavily on supporters when they were unable to help their loved one get the kind of support they wanted. More often, there was a period of time during which the loved one with an eating disorder fluctuated between wanting help and not wanting help; sometimes this time involved multiple doctor visits, appointments with specialists in nutrition, therapy, or other allied professions, and ultimately wait lists. Jane described the time prior to intensive treatment for her daughter as a negotiation and waiting game:

[Her doctor] put her on a wait list, actually she wouldn't even agree to go to (a local hospital) or have any type of an assessment done for… I'd say probably a couple, maybe six weeks of going back and forth to our doctor, and then she wasn't getting better, she was just getting worse. In that time frame she saw a nutritionist, she saw a cognitive behaviour therapist, and you know, with the hopes of trying to kind of nip it in the bud, and it… it just spun out of control, it just got hold, and she just became very, very ill and mentally — she was just being able to, the doctor would just kind of prescribe her a minimum amount of calories, and that's all, they just talked, it was soothing for her while she got on a wait list for (a local hospital) to go for an assessment. That was a four-month wait. (Jane)

Aligning treatment-system time with the rest of family life and with the fluctuating orientations to illness and wellness that people with eating disorders displayed was a challenge supporters negotiated as they attempted to take action. While on wait lists, supporters helped
loved ones reach different possibly helpful resources. Often, these measures were a stop-gap between desired and available treatment; however, they were commonly unhelpful and sometimes even exacerbated the issue. Descriptions of time featured heavily in supporters’ accounts of this time-in-between, as they made sense of their timelines aloud in the recounting of their stories. Similarly to people with eating disorders interviewed for the study, they did not always feel comfortable recounting a solid timeline — the time-in-between in particular was described as fuzzy, blurry, and full of gaps.

Canada’s healthcare system is regularly praised around the world as exemplary, held up for its ‘universal’ nature and low cost. However, as participants remarked, access to treatment was neither guaranteed nor always free. Only some treatments are covered and follow up or additional care is usually not covered. Care that is covered by provincial healthcare is commonly accompanied by the significant wait lists described above — and the concordant attempts to try anything that might possibly help the loved one recovery in the meantime. This liminal time was filled with often-futile attempts to promote recovery in the absence of other treatment — attempts that often come at a cost premium. This demonstrates the time-money tradeoff and situates recovery attempts within a framework of two-tiered healthcare that privileges those with financial resources.

Supporters’ own experiences with healthcare systems and attempts to seek support were also coloured by lack of access and the time-money tradeoff nexus. These attempts to seek support interestingly mirrored the experiences of participants in recovery, who often found that they were unable to access any support at all if they were deemed “not sick enough.” As Scott remarked:
one thing that I know, and also with my own experience with, in the mental health system, like it's really hard to get, counselling. Like if you want to get free counselling, you pretty much have to either have a very serious mental illness, a mental illness that you could potentially go on ODSP for, or you have to be at a suicide risk. And so it's really hard to find free services. I went for counselling at (a local university) for a bit, and eventually you use up all your tokens, and they say "we can't give you counselling anymore, but here's the number of this therapist that costs $100 an hour". (Scott)

Supporters’ experiences of not being able to access desired support that was covered under provincial healthcare plans represented a significant barrier and often exacerbated distress. Once again, these barriers and the strain associated with them was expressed in relation to both money and to time, as is evidenced in Jane’s quote:

The expense of private therapy was really… it was a big commitment. It was, almost, well, it was about $1,000 a month. Because we were driving (to a large city farther away), and I would drive her in and drive her back out. It was, emotion-focused family therapy, so the two of us [parents] would go in, and then it was just [our daughter] for a while, and then it was the two of us again, so it was, you know, most of the time I was driving in with her, but it was, that was like a three and a half to four hours out of, you know, the week, once a week, plus parking, plus the therapist, and it was a lot for four or five years. (Jane)

In describing the hours, weeks, and years that went into this carework, Jane observes the relationship between caring and time. Finances were one part of the nexus of carework; additionally, the time described represents time that was not spent doing remunerated work or other family work. It is notable that within neoliberal, capitalist society, monetary framings and
metaphors infused supporters’ talk, becoming a proximal way of dictating expectations about how, and within what time frame, people are expected to recover.

3.2.2.3.1 Relational Loops.

The ripples of lack of support were evident throughout participants’ accounts—particularly for those who were in romantic relationships with the person in recovery. For these participants, they were not only the main supporter for the person in recovery, but this person was also their primary supporter. When their loved one was not doing well, they also suffered from a lack of support. These loops of lacking support were made more challenging by the lack of access endemic to systems of support rooted in a wait list and tiered, hierarchal, triaged system. Personal strain was exacerbated when neither the person in recovery nor the supporter were doing well, emotionally, mentally, or physically:

So she was in a terrible mood. And I was in a very bad mood also. So it was difficult to deal with at that time, because I would have liked to reach out to someone for support and she's my only person to talk to. She's the only person that I can talk to about stuff like this, because my parents are not always very understanding. My mom will get too worried, and my dad will basically be insensitive, so I just have anyone to talk to except for her (Scott)

Amanda similarly pushed her own struggles aside to support her best friend as she navigated recovery; Amanda’s own past struggles with food became less important in the moment as she helped her friend, who she perceived as more in need of help:

I would really try and obliterate my own self and say – shut up she needs you right now, she really needs to see you eat and not care, not care about what you’re doing. (Amanda)
Loved ones’ eating disorders were not the only factor in supporters’ lives that could impact their mental state—and other experiences commonly exacerbated the strain inherent in caregiving. Supporters sometimes felt the need to put aside or bottle up their own feelings or emotional needs in favour of supporting the person with an eating disorder.

I want to do 100% of what I can to help her and all that, sometimes I, at the detriment of my other stuff, but I'm good at handling it, I think. I mean, so, basically, I kind of wish she had some more people in her life that were helpful, but yeah, she doesn't seem to have much in that regard. (Ted)

Supporters often described stepping up to fill gaps in care — gaps related to the lack of other supportive close others or by systems; systemic gaps, therefore, impacted not only those acutely struggling with distress around food, weight, and shape, but those in close relationships of care with them. The lack of options felt discouraging to many participants; as Jill noted: “very discouraging, the types of support there is for eating disorders. Like, very discouraging.” The systemic gaps were evident to supporters who spent years navigating a system that not only did not provide them with enough support, as supporters, but did not cater to the needs of their loved one. Not being able to find adequate support imposed additional strain on carers, who often desired but were not able to legally or practically provide loved ones with the access to systems that would provide meaningful and long-lasting support:

no amount of online support groups are going to help some of these girls—like they just need therapy and they need doctors on their side and they need society on their side. I read an article about how CAMH doesn't even… they're so not wanting to deal with eating disorder that the article is that they're almost deliberately shooting them down.

(Alexis)
Supporters became intimately familiar with navigating systems; but, this awareness did not change their access. They discovered ways of working within a system they described as broken, becoming strong advocates for care for their loved one. This was particularly true for parent supporters; for instance Elizabeth, who discovered that people were more likely to be admitted following emergency room visits:

E: What they told us was, they'd told us at both (local hospitals) and (far away) is that if someone comes in from emerg, so this is what I learned, if someone comes in from emerg who needs a bed, they get the bed. So right after, every time she'd have like an episode, a psychotic episode, or she tried to, you know, hurt me or my husband, I automatically called 9-1-1, and got them to come. 'Cause I thought, "you know what? It's the only thing that's gonna save my daughter's life. Because no one's admitting her into the hospital. No one's getting her a bed. So maybe if an ambulance brings her in, maybe they will."

I: How many times did you end up doing that?

E: Well, she was never taken away in an ambulance, the only time she was taken away, we were, well we took her twice to emerg, to (two different hospitals), then I think it was two occasions, we took her, we called 9-1-1, uh, the police came, first responders and they took her in a police car.

Needing to take measures outside of the expected trajectory to care in this context (i.e., instead of visiting the family doctor, getting a referral, and following up, opting to call an ambulance to seek emergent care) demonstrates further gaps in the system, and had affective impacts on supporters who needed to engage with systems in these roundabout ways. The refrain of “by any means necessary” resonated through accounts of getting loved ones into full-up, over-taxed treatment programs.
3.2.2.3 Thresholds of Care.

In general, supporters expressed a great deal of empathy toward their loved ones’ struggles. There seemed to be, however, a threshold over which the burden of caring became too much. Several carers explicitly mentioned feelings of overwhelm, often after years of repeated attempts to support their loved one.

We had, we had a near, not a near relapse situation, but a situation where I saw the relapse could have very well been coming. And I was tired of like "you'll be fine." I'm like "Okay, you know what? That's fine, you're an adult, it's your future, if you want to throw everything away for this thing that you love so much, that's your choice." My father's like "You can't be mean to her like that." I'm like "Dad, she's gonna be 30 in 2 years, like. I'm tired. I'm very very tired." (Alexis)

I care about her. I mean, that's number one, I love her, she's my wife. And, you never want to see somebody that you love suffer. So, I mean, there's that to deal with. But, we also live in very close proximity to each other. I don't necessarily have a short fuse, but if you keep hitting me with the same thing over and over again, I start to get frustrated, or irritated, and I feel guilty about that every time it happens. Because I know why she's doing what she's doing, but it's a fight. It really is. I'm not complaining, I refuse to complain about it, because I care about her and I want her to be happy. In the back of my mind, I still know, all she needs is someone in her corner and she's gonna go light years under her own power. I've never forgotten that. So, it's a tough act, I was gonna say a tough act to follow, but it isn't—it's walking a razor, sometimes. When things are hard, when she's struggling with something, it's hard not say, "oh, this again?" But, you need to, you need to filter that out, and be there for her, and at the same time find a way to let
that go, whether you have to vent it through, my favourite is video games, which is slowly driving her insane, but you know, if we have something that we're dealing with and we get frustrated with each other, um, you know, we'll eventually resolve the conflict, but in the meantime I go and play Fallout 4 and shoot people in the face for a half hour. And they're sprites, and nobody gets hurt, and I'm happy. But yes, a little vent. I'd say, as a support, I need to find the time and space to find those vents without carrying it over and taking it out on her, because it's just a double whammy. (Jeremy)

Exhaustion, guilt, and frustration cohere in the excerpts above and in other accounts from supporters that demonstrate the challenge of caring for someone with an eating disorder. These emotions and embodied sensations do not operate outside of the context of deep love and care; they might actually be interpreted as side effects of the deeply relational experiences of loving someone and seeing them suffer. As Jeremy noted, “you never want to see someone you love suffer.” The impact of observing this suffering for long stretches of time is strong; coupled with the inability to access support themselves, this weighed heavily on supporters and impacted their own state of mental wellbeing.

These rippling impacts of the eating disorder, in its relationality, stretched out into recovery. Some articulated the continued emotional impacts in terms of post-traumatic stress. Working within systems and seeking to help a loved one recover “at any cost” often, in hindsight, left supporters feeling like they should have taken greater care of their own emotional needs; as exemplified in a prior theme, supporters often pushed these aside in favour of enacting care and support for a loved one.

We've—you know what? We have sucked the life out of our health care system. I'm telling you right now. We sucked the life out of them. And you know what? I honestly
can say is, I mean, it's hindsight, right? But, from a parent perspective, we didn't have
time to do our own self-care. I should have been seeing someone. I was too busy seeing
doctors and psychiatrists and stuff with my daughter, because it was family-based
treatment. And I mean, don't get me wrong, I'm overjoyed that my daughter's doing well,
and she's alive, but the thing is, is at what price? Right? What price, when now she sees
her parents, right? And now we're having to go through and now, I know that she
probably feels some shame and guilt, right? You know what I mean? Like it's a total
snowball, right? (Elizabeth)

This excerpt further demonstrates the complexity of exploring residual emotions of guilt and the
feeling of exhaustion. Rather than identifying the cause of the continued ramifications of the
carework as systemic, Elizabeth notes how she “should have been seeing someone” without
explicitly identifying the reason why she was not seeing anyone. She does identify that she was
busy, engaged with systems of care; however, she situates the blame within herself for not
engaging in proper “self-care.” She also explores the impact of her not having cared for herself
in relation to her daughter’s experience of her (Elizabeth’s) continued suffering.

This hesitancy to blame systems was emblematic of supporters’ accounts; even when
supporters had expended significant time and money on systems of care that they described as
problematic at best and traumatizing at worst, participants often expressed gratitude toward
healthcare systems.

And if, if we, you know, I mean, what if we hadn't been able to afford any therapy, like
what, what would've happened? I don't know, like and there's lots of families that can't.
You know, I kind of imagined, we'd go to see (the therapist) maybe six times, twelve
times, had no idea it was going to be years and years, so. But it worked! So I don't resent it. I sound like I'm a bit resentful. I'm not resentful. (Jane)

In such accounts, participants reflect on their privilege in accessing systems; in a way, this is a roundabout critique of systems that people in society are not told they are able to critique in an open way. The fact that they accessed treatment at all feels like a privilege in a system that denies treatment to those with less access.

3.2.2.3.3 Finding Connections.

Given the limited amount of support available to supporters, supporters often found solace by gathering as much information they could, often online and/or in groups. Supporters rarely had significant experience with eating disorders prior to helping their loved one recovery and often described the experience as a trial by fire. When they did find people who had similar experiences who could form communities of support, they tended to see this experience as surreal:

I spent probably a year every Monday going to (a mother's support group). And sitting in on those conversations, you know, it was very surreal that our bond was that we had these beautiful, intelligent, vibrant daughters who all shared the same problem, that they were basically killing themselves. Odd. Very, very surreal. (Jane)

Supporters who were in partnership with those in recovery had a particularly challenging time finding groups of people who were able to provide them support; not only did they not have access to resources through treatment programs, but they also felt that to seek out support would be to breach their loved one’s privacy. Resultantly, many sought out information online.
I was kind of like, "okay, I really have to figure out what I should do or not do or whatever, so I went, I went Googling looking for like 'what should you do when you're dating someone with an eating disorder'" (Ted)

Regardless of their relationship with the person with an eating disorder, supporters attempted to find out as much as they could about eating disorders, which often fell far outside of their personal experiences of food, eating, and bodies.

I eventually talked to the doctor, and, um, and she basically, you know, confirmed that she felt that she had an eating disorder, and it's a mental illness, and it's not gonna be an easy haul. So, from there, I just, you know, started to go crazy with information overload.

Whether it be the Internet or just trying to talk to the right people and get the right information and begin, started to be, educate myself. That was number one. Education for myself and then I could figure out how to, how to help her better, because she was slipping away. (Alexis)

Participants were aware that they would never fully be able to get into the headspace of the person with an eating disorder, and commonly tried to listen to their loved ones as much as possible to learn from their experiences and provide tailored support that would meet their needs — particularly when this kind of support was significantly lacking outside of the home.

The thing is that I, I've always approached this in the same way, like there haven't been any insights that affected the way that I behaved towards her, so I don't know if there is any piece of information that I gleaned, that, you know, was particularly helpful. I just like I obviously, living with someone who has an eating disorder, you naturally have more respect and understand for people who have eating disorder, because it's not, as I said before, an isolated thing. Like there's a lot of other stuff and like the person cannot
really help sit there doing, like they're going through with that type of behaviour, because the behaviour serves the purpose linked to a greater whole. (Scott)

Listening to, and living with, their loved ones often made supporters attuned to the needs of people with eating disorders; to have empathy for and relate to experiences very distant from their own. This attunement featured in participants with eating disorders’ accounts as one of the main reasons for which they were selected for participation in the study. For those in recovery, it was important to have people in their lives that created the space for them to be at ease in their own version of recovery. While supporters did not necessarily wholeheartedly and completely share the person in recovery’s definition of and orientation to recovery, they were able to engage with the person in recovery in a way that enabled them to live in a largely positive affective relationship with this person. Supporting someone in recovery became less about surveilling or even envisioning a recovery that was exactly alike, but rather making space for fluctuating, not always conventional, and individual ways of embodying and living recovery.
Chapter 4: Analyses – Digital Storytelling

In this chapter, I outline my reflections on the experience of the digital storytelling workshop, to provide background and context on the experience of storytelling with these participants. I then offer a deeper analysis of the resultant stories. These analyses might be read, following the prior thematic analyses of participants in recovery and supporters’ accounts, as situated case studies tied in to the broad overarching thematic concept of recovery as life itself: dynamic, contextual, relational, intercorporeal, and temporal. Following these analyses, I present data from the healthcare provider screenings, where healthcare providers watched and reflected on these stories.

4.1 Workshop Reflections

At first I was very disappointed that so few people were able to attend the workshop. As the cancellations came in, I took them quite personally. I wondered what it was about me and my approach to the workshop that meant that people didn’t want to come to the workshop. I thought about how despite my best efforts to make the workshop accessible, people were still not able to come. This made me seriously question whether people really wanted to tell their stories; whether I was forcing people to go places they didn’t want to go. Once the workshop was underway, I realized that my attendees were deeply engaged and invested. One was Skyping in from another province, another drove from an hour and a half for half a day, and the third was a supporter who drove in from an hour away. Her sister had originally intended to come but could not because she was sick. The conversation we had in the morning went to deep places that the supporter thought she couldn’t have gone if her sister-in-recovery had attended. She was able to explore in-depth the experience of supporting someone through an eating disorder—the good, the bad and the ugly.
The supporter reflected on her family as a team, and how they have all felt—deeply—the pain of her sister. She noted that she would follow her sister anywhere that she had to go, to make sure that she was ok. She would, basically, follow her to the ends of the earth to protect her. She said things that I normally might frame as problematic—such as that she watches her sister like a hawk—but that, framed in the way that she framed them only made me more appreciative of her work. Because while she watches her sister like a hawk, she also spoke about her wanting others to stop watching her sister like a hawk; this was something she could do because she wanted her sister to live the best life she possibly could. She spoke about watching her sister get multiple hip fractures from running upwards of 20km a day – something I used to do regularly. She spoke about the pain of not being able to travel, of watching her sister literally crumble to bits while claiming vehemently the space of recovery. This made me think a lot about this performance of recovery that is expected, and what it takes from us; how in being made to believe that being recovered means being invulnerable, we have to hide the parts of us that struggle. How in being expected to toe that line between “too thin” and “too fat” we’re required to enact a very specific version of healthy that draws simultaneous praise from those who don’t know and watchful eyes and sighs from those who do. About how the kind of support provided in treatment systems is simply not enough – not enough to teach a person more than how to eat well in a hospital.

We also talked, as a group, about how the search for underlying cause becomes a hunt that ignores the emotions of the person suffering and their family. About how while sometimes there’s a marked trauma, sometimes eating disorders are borne of nothing more than starting down a dietary rabbit hole, faced with a society that does not welcome some bodies. This is striking to me in light of those who prefer to frame eating disorders as biologically brain based
illness. I wonder if a part of this framing comes from a frustration with the seemingly endless need for people to find an original, time-stable cause for eating disorders. Of course, in resisting this, people often repatriate it—in avoiding searching for an original social cause, they inscribe an original biological cause. It seems that people need reasons for things; if not sociocultural, then biological. In the search for a cause, blame often becomes implicated—blame of sufferer, blame of supporters, blame of media. We’re all looking for someone or something to blame.

Another striking moment of connection related to the idea of people with eating disorders and in recovery being emotional super-feelers. One of the participants reflected on how she felt like the canary in the coal mine—when anything is off, it hits her. She also noted that for her, recovery didn’t begin in treatment, where they only provided information about how to eat, and talk therapy, where she could intellectualize her experience. It wasn’t until emotion was able to enter into the picture that she was able to get to the heart of how to recover, and to see recovery as about more than just performing the perfect patient, but really exploring what it means to be in her emotions and to be in her body. The Skype participant reflected on similar themes of feeling disconnected from her body, though she framed it in a slightly different way and noted that she wasn’t able to go there until she was re-fed. For her, things were a bit different because she never felt like she had an eating disorder until people kept diagnosing her or accusing her of having an eating disorder – and then she thought, well, I’ll do that then. In all of these cases, people were unable to get the kind of support they wanted because of “complexities” in their cases – being unable to find an origin story, being able to perform recovery perfectly in but not outside of the treatment space, being thin but not afraid of getting fat. These complexities made it hard for participants to find the support they needed, when they needed it.
We had a discussion at one point about calorie counts on menus, and I feel like I learned something from this discussion. The sister noted how she loved the calorie counts on the menus – not for herself, but for her sister. She said that for her sister, the calorie counts allowed her to be able to eat more options, because she trusted the calorie counts. Whereas before she was only able to eat a few things that felt “safe,” she is now able to eat a wider variety of foods. This really interested me, because I think my main point about the calories remains—essentially it can tether people with eating disorders to the number of calories in something. But this could be framed, as here, as a harm reduction measure. While it isn’t necessarily in the service of a full recovery as expected, it can support the person in eating something. This makes for an interesting dilemma around the social and individual meanings of food and how we relate to food. I worry sometimes that intuitive eating and the idea that we shouldn’t follow a meal plan at all, ever, or know how many calories we’re taking in is an unrealistic expectation for those in recovery.

While it might be ideal, knowing the calories in something can be a pragmatic intermediary step. It can be, in a way, freeing in terms of the range of actual foods eaten, if not truly in the service of a lasting recovery. Over the past few years I’ve changed my frame around ideas of surveillance and considered how in dictating what “counts” as recovery, there is also an imposition of surveillance; this complicates my petition against calorie counts on menus as well. Because if, for some, these menu counts give peace, who am I to say that’s wrong? Who am I to say that everyone needs to enjoy food for food’s sake as opposed to viewing it as food? Further, we seem ok with having those who haven’t experienced eating disorders count their calories—we even encourage it. And yet for those with eating disorders, this is always problematized. Sometimes it may be necessary to count calories or follow a meal plan to make sure you’re
eating enough. The problem is not necessarily the existence of calorie counts on menus, but rather the enforcement of their presence on restaurant menus.

I have reflected more recently on how I often don’t know how many calories are in what I’m eating, now, and I’m getting better at not caring. I’m also working on not caring as much about how much protein is in something, and how “balanced” it is. It is interesting to think about the complexity of rigidity inscribed in the treatment systems we have available to us and what they mean in terms of the lives we live after treatment, especially in the context of the lack of transitional support that exists for eating disorders. In treatment, there’s an imposed rigidity that impacts how we are able to eat and how much we are able to be ok. And yet, once we leave treatment we’re expected to cast that off. There is a surveillance that almost becomes comfortable in the treatment system but that is made more complex by relationships. It feels ok to be watched by some people and not others. We’re ok with some people checking our plates, and having others do so makes us want to scream and cry and throw the table. This continues into life after treatment; siblings or parents might watch us and we might like their reassurance or ask for it – but if someone we don’t know as well or who doesn’t know about eating disorders does so, this is stifling, embarrassing, and stigmatizing.

Overall, what stood out to me in the workshop was that eating disorders and recovery are always relational. In regard to the surveillance discourse, it was also interesting to understand the supporter experience of actually being a part of the other person. This boundary blurring would normally be framed in the biomedical as enmeshment, but this could also be understood in relation to gender roles and the feminization or care, and I can look at similarities and differences in terms of the roles that women supporters are configuring their relationships as opposed to the men I’ve interviewed – there are some interesting and complex relationships there in terms of
gender roles, where the men are taking on feminized roles—but are not socialized to know how to do this or to know how to ask for help; in a way, however, this not being able to or wanting to ask for help was also true for the sister who participated in the workshop. The fierce protectiveness might also be framed as the sister stepping into a role that represents a part of her struggling sister that she sees as presently being in need of support— that part that fights back against ED. It’s interesting to think about the difference, then, between having someone fight that fight for you and having you fight that fight yourself. In making two people fighting for one (or many more people fighting for one) can we reconfigure subjectivity as relational? Is this problematized only because in our neoliberal society we expect people to step up and manage themselves? Is it a problem or is it beautiful? Is it both? How can people help each other access their emotions and manage their distress without creating an unequal relationship and without neglecting their own needs? Who do we call upon to do this work, and who is never asked to do this work? If someone is asked to do the work who’s never been socially asked to do so, how can they be expected to hold the other’s story?

4.2 Digital Story Case Studies

4.2.1 Meghan.

Meghan’s digital story was made in bits and starts; as a part of the original mini workshop, over the course of emails exchanged, and in person for a one-on-one workshop. She was enthusiastic about making the story, but acknowledged that her editorializing side tended to stop her creativity. I re-evaluated her consent to participate several times over the course of the interaction around the story, to make sure that she was still willing to make it; I feared that she felt she had to because she had signed up to do it. Initially, Meghan had planned to make the story at home with the help of some friends after participating in story circle in the group workshop. However, she found that this was challenging: abstracted from the container of the
workshop, it was hard to figure out how to convey a story that spanned over ten years and that, as she noted, didn’t really have a natural end. She noted that she also feared creating a representation that was the told story – one that would make recovery out to be something idyllic, which it was not. In the end, we decided to work together to create her story.

She came prepared to the workshop day. She began by sharing an excerpt from an article she’d recently read wherein a chef who teaches her students to cook intuitively encouraged her pupils to eat and taste, and repeat. The chef noted that at the end of the workshop, participants always asked for the recipe even after they noted they enjoyed the more intuitive approach. People yearn for recipes, even when they know that there is not one perfect way to do things. Meghan’s entrance into the story space with this metaphor set the stage for the creation of a story that is decidedly non-linear. Her story contains three short poems: one a Sanskrit proverb from a collection of poems designed for those in recovery from alcoholism, one a poem she wrote about recovery, and the last a letter to her younger self.

The Sanskrit poem configures time as non-linear, acknowledging the enfolding of past, present, and future. The poem, in noting that “For yesterday is but a dream, and tomorrow is only a vision, but today, well lived, makes every yesterday a dream of happiness and every tomorrow a vision of hope” is reminiscent of Ricoeur’s configuration of the two-way marching of time; the traces of the past that seep into the future and the backwards-constitution of the past (Felman, 2000). As Hemmings notes, “all history takes place in the present, as we make and remake stories about the past to enable a particular present to gain legitimacy” (2005, p. 118). While the poem might be read as a utopic rendering of the hopeful future or a vision of the past made rosy, the interest of the poem lies in the call, therein, to acknowledge the present.
This call might be read as neoliberal, too—impelling the subject to act in the present, unencumbered by circumstance. And yet, within the digital story it tells a different narrative of eating disorder recovery than one completely controlled and idyllic. Following the poem, Meghan reads a poem she wrote, saying:

Life is no longer about survival. I have choices today. It’s like I was living with blinders, tunnel-vision forcing a narrow view of life. I still resist, the pull toward the grooved ruts of habit are magnetic. But ruts are drudges. Isolating places with steep walls on either side. Keeping me constrained. It’s lonely.

We might consider the use of the word “choice” as, again, a term rooted in a neoliberal optic that responsibilizes individuals for their health, happiness, and wellbeing. Stories are in part artefacts of their contextual creation—and those in eating disorder recovery are no less impacted by discourses surrounding the power of choice. In Meghan’s story, the choice becomes between the narrow vision of her past and the uncertainty of her future. She describes the continual pull of “ruts,” while simultaneously acknowledging their undesirability. This acknowledgment crystallizes a theme that emerged from the interviews: that those with or in recovery from eating disorders are not simply unaware of the problematic potential outcomes of their behaviours; these behaviours simply exert different magnetism on them depending on the rest of the context of their lives. Interestingly, Meghan’s ending clause—“it’s lonely”—is not necessarily associated with the constrained place of isolation, but perhaps also tied to the push-pull of navigating recovery, particularly when representations of recovery leave one wanting.

The final part of Meghan’s narrative is drawn from her experiences of emotion-focused therapy, wherein she was asked to speak to her inner child. As an image of her as a child materializes on the screen, superimposed over her slowly moving back, she says: “Dear inner
child. I’ve got life from here. You’ve done what you’ve needed to, but I can take it from here.” She noted that this was a mantra that she repeated to herself when she found herself pulled toward the behaviours that felt magnetic, as described in the previous excerpt. In sharing the image of herself as a child, smiling and wearing a bikini, standing in water, Meghan references herself as a small child, ostensibly before the onset of her eating distress, without trying to return to that state. The returning to that state, in fact, would be undesirable – and was something that she found led her toward behaviours that brought her further distress.

Time and space feature in Meghan’s narrative and images of recovery. The story is visually simple in construction – layered images of her walking, and then sitting and stretching, along a table in front of a window, trees blowing outside, rendered in dream-like tones. Superimposed above, her hands clasp and unclasp. Meghan asked that this clasping be present in her story to represent one way she thinks of her recovery: like clasping her hands in the opposite configuration than she usually would. While the images – and, arguably even the narrative – primarily represent images meaningful to Meghan, the story reveals something about eating disorder recovery that is not captured in words alone, or in interview data wherein she answered questions specific to her eating disorder recovery. Interestingly, she never specifically names “eating disorder” or “recovery” in the story. Instead, the story is about life and time; wandering in and out of relation with distress, reconciling but not revisiting the inner child, clasping one hand over the other – carrying on.

4.2.2 Catherine.

Catherine’s story was made in a single day – the day of the initial mini-workshop. Catherine was the sole supporter to attend the digital storytelling workshop, and wanted to make her story about the experience of supporting her sister through recovery. Her sister had intended
on attending the workshop but was ill on the day of; resultantly, her sister become consultant on
the creation of Catherine’s story, sending photos and talking to Catherine over text throughout
the workshop. Following discussions in story circle about the unfinished nature of recovery and
the need for more realistic understandings of the ongoing, entangled, and relational nature of
recovery, Catherine created a story that details her family’s unfinished recovery story.
Immediately, Catherine’s story is about relationships. She opens with a description, both verbal
and drawn, of the members of her family. She describes her family as a “squad,” and shows
several pictures of the squad throughout the narrative. She externalizes “Ed” (the eating disorder)
as an unwelcome addition to the squad, noting that they “basically refuse to leave.”

While verbally, Ed is externalized, Ed does not feature in the images in the story – either
in pictures Catherine brought to the workshop or the figures she drew in the workshop. Instead, Ed features only in the voiced narrative. We discussed, in creating the story, possibly having
“Ed” floating above certain images. Catherine was adamant that Ed would not be pictured in the
story – thus, despite his refusal to leave, his unwelcomeness is configured in his visual absence
in the digital story. Instead, Catherine visually and verbally constructs a team family facing Ed
“head on, despite Ed’s omnipresence and persistence in our lives.” Compellingly, Catherine’s
words describe a challenging and ongoing struggle to extricate Ed from the picture, while the
images she chose show a smiling and cohesive family. Again, the spectre of Ed haunts the story
in the mismatch between the emotional tenor of the words she is speaking and the largely
positive images she shows. While her sister is visibly thin in many of the images, one might not
automatically associate the images with challenge.

The one visual clue that the eating disorder presence haunts the family is the
superimposition of letters from her sister while she was in treatment over images of the family.
In these notes, the words “calories” and “sucks” and “miss you” stand out, revealing the challenge of separation from the family while her sister was pulled out of family time into treatment time. Catherine also notes that the time following treatment was not rosy: “after she left treatment, we found very few options available to us – at least not those that come without a big price tag.” At mention of the price, a bill for services hovers on screen. Instead of pursuing costly options, she describes, the family decided to pursue recovery as a team – or an “army of four,” in her words. Later in the story, she explains that treatment had “helped my sister get better – or, gain the weight back.” She uses a skeptical tone here, further clarifying that this occurred ten years ago. While the family continued to support recovery, they distanced themselves from treatment systems after that point.

Catherine’s continual use of the word “we” while configuring action in the singular reveals the bondedness of the family in her story – something she understands to be integral to the support of her sister. Her sister is firmly a part of the “we,” a member of the squad, team or army – but plays a different role; one protected by the family and a whole. This provides an example of how externalization might be used sensitively and affirmatively to fight against the eating disorder, not alienate the person. Her sister’s fiancé is introduced as a “full-fledged member of the squad,” an additional team member enrolled in support. Rather than describing recovery as “easier,” Catherine elects to call it “more supportive,” highlighting again the centrality of support to the experience. Further, while she details a number of challenges: confusing options, not knowing where to find support, and more. Catherine’s story is not without hope; she describes her sister’s law school graduation and engagement as bright spots in the experience. She once again uses “we” to construct the family’s involvement in these positive events as well; for example, saying “now we’re planning a wedding.” The story ends as it began:
with support. The externalization of Ed continues through the story, a way to ensure that once “Ed” is gone, the support will remain. In saying “but not even after Ed leaves will we walk away—we’ll be with her forever, we just hope Ed won’t,” Catherine firmly embeds the family support as non-contingent on the presence or absence of the eating disorder.

The interaction between normative and non-normative notions of family and support operate throughout the story in ways that reveal the complexity of eating disorders and recovery. Throughout the story, Catherine’s sister is ambiguously ill or well. It is unclear—and unimportant—whether or not she is acutely ill or recovered at the time the story was made. What is more interesting, arguably, is the space of support that Catherine vehemently constructs, as well as the relational alignments that pervade the story. Catherine presents in image and in words the cohesiveness of the unit and the inextricability of their shared experiences. This support is non-contingent, but is made complicated. She resists a solely negative story by inserting examples of moments of joy in their family life, using these as the scaffolding for a loving and supportive relationship she configures as forever. In a way, this contrasts with the ambiguity of recovery—while recovery is ambiguous and perhaps illusory, the support is enduring.

4.2.3 Amy.

Amy’s story is told primarily on the visual level through her pen and ink drawings, drawn “furiously,” as she notes, during the time of her illness and in recovery. The etchings reveal intricate cages for small figures, bodies contorted to fit within the confines of larger structures. As these drawings slowly move across the screen, Amy narrates a poetic story of being made smaller by constraining expectations for behavior around food felt foreign to Amy after her immigration to Canada from Singapore. Amy explores themes of not quite fitting and enacting
belonging through shrinking herself—including her artistic expression—as well as exploring what it means to be normal and not normal in between multiple spaces of belonging.

Amy begins her story by noting that she “blames no one but herself” for the development of her eating disorder. She goes on to complicate this seemingly individualizing statement, situating herself in relation to “her,” a nameless figure who floats above the story to the viewer less familiar with her story. In story circle, Amy shared that her relationship with her stepmother was fraught, as she attempted to appease her expectations while asserting her own independence and culture of origin. This floating “she” may also refer to the eating disorder itself; throughout the story, Amy does not name the “she,” leaving the viewer to interpret it as they wish. As Amy discusses how she was “more than a series of psychological treatises on motherless children,” Amy situates herself not only in relation to her stepmother and her eating disorder, but also in relation to dominant psychological discourses that inscribe abnormality onto those with non-normative familial structures. Here, she shows an image of a figure with arms and legs wrapped around a face with horns, shielding its eyes and crying. Behind the figure, smaller figures and eyes are positioned, perhaps images of the narrator growing up.

The relationship between normalcy, choice, and agency figure throughout Amy’s story in a way that complicates the dominant narrative of eating disorders. While generally a choice-based framing of eating disorders is framed as problematic and stigma inducing in the literature, here it lives in relation to a continuum of food choices that people in Western societies make. Amy positions herself as an actor in the development of strategies that would later be read as eating disorders, noting that she “decided to be normal to convince the world that I could change into anything. I, in a way, killed my soul in an act of spite.” Faced with continual accusations of
“not being normal” around food, Amy enacted food practices that were restrictive, which helped her attempts to “mould herself into a shape that [she] thought was fitting.”

Amy’s repetition of the words “civilized person” in reference to her behaviours around food invite the viewer to consider dominant cultural narratives around what it means to eat. In configuring her eating practices, surveillance is omnipresent: she is performing “normal” for an audience, which rather than bringing her peace further distances her from her connection to her body/mind. As she describes the paradoxical pain of becoming less “distorted,” for instance through her bodily positioning, Amy shows an image that strikingly positions a small body atop an open skull, being pulled into the mind. This image foregrounds the Cartesian dualism so present in contemporary Western thought that would suggest that we might all master our bodies by exerting our mind’s control. Amy’s body rebelled:

My body would give itself away. The fingers and hands fidgeting uncontrollably, the mouth convulsing, emitting a string of confused syllables in a mixed tongue. I could, all the while, feel her omnipotent gaze on my back—dissecting, othering, putting order to everything that spilled out.

The “she” in the story “trimmed and pruned” back the leaks and flows of Amy’s body, exerting surveillance and control over that which she considered to be in excess.

For Amy, recovery stemmed from a “seed, dormant in the deepest recesses of [her] soul,” illustrated poignantly through an image of a feminine figure with ribcage exposed, shrouding several smaller figures enclosed within. Recovery was not easy, however—Amy describes her abject relations with the nature of herself that she remembered, describing it as monstrous and grotesque. When Amy describes her attempts to recover, she refers to the reconfiguring of her own history through the eyes of others. This description mirrors the revisionist history of eating
disorders, wherein their timelines and specificities are configured and reconfigured by different actors who play a role in their constitution, often leaving little room for the person themselves to trust their account. Amy explicitly names this dynamic:

My history would reconfigure itself again and again in my eyes, under the flickering lights of another’s gaze, so that what I remembered would be covered in sediment or worse, erased, leaving but a phantom trace on a template of my soul.

As she reflects on this phantom trace, Amy shows an image of a feminine figure holding a picture frame or x-ray machine showing an anatomical heart. She pauses, then continues to reflect on how she stopped drawing during the time of her illness; in her containment and attempts to bound herself up in “normalcy,” art, too, became something that bubbled out in bits and starts, abject and uncertain.

Amy closes her story by asking whether it was her fate to be defined by a series of deletions. In not closing her story, she leaves the viewer unsure about the conclusion, or whether recovery occurred. This uncertainty may act, however, as an intervention into the normative, packaged recovery story, wherein solace is found in enacting “normalcy”—which Amy found so constraining. In the time since making her story, Amy has also come to be placed on the Autism spectrum; in reading the account I wrote of her story she noted that she would add that this new category of belonging adds to her reflection on and understanding of her experiences. As she wrote: “my narrative can be read as trying to fit into certain social and human protocols. In that light, a lot of my invisible struggles makes sense, because it did feel like learning another alien language.”
4.2.4 Gina.

Gina’s story speaks to the ways in which negative interpersonal experiences can impact not only the onset of disordered eating behaviour but also the course of one’s life. Beginning with a photo of herself as a child in a school classroom cooking class, Gina reflects on how “love has always been something [she] seek[s] out,” but that she did not have much of, growing up. All the other children in the photograph are engaged in the cooking, while Gina looks directly at the camera. She speaks about how she sought to replace feelings of love with food; this was not about intentionally changing her body size, but more of a coping strategy to fill up the deprivation she felt.

Moving to a class photograph in which Gina stands in the middle, again distant from the other children, Gina speaks about how she quickly gained weight, becoming the largest kid in her class. She says: “I needed to fix that, fast.” The language of fixing lies in line with dominant discourses on what is to be done about larger bodies in society; these bodies are automatically assumed to be problem bodies, bodies that fall outside of the narrow confines of what an acceptable body is. For Gina, “dieting and hyperfocusing on food” became levers to gain social capital, as evidenced by her “feeling likeable and in control.” This control was linked to but not explicitly about the control of food; it was a control of her self-presentation, one always provisional and contingent on the continued engagement in restriction. Gina reflects on the emptiness of the control, saying that she “still lacked love,” calls her journey a destructive one, and notes that she was not well.

Like other storytellers, the recognition of not being well was not enough to suddenly make a change. Contrary to the dominant narrative that people with eating disorders are not aware of their struggles or the problematics of their behaviour, Gina’s story reflects the certainty that she had that her behaviours were destructive. Of course, it is impossible to know whether
these details and this awareness exist primarily in the retelling. However, it is worth noting that Gina’s next step was to seek medical help—help that ended up further entrenching her ill health rather than salving the wound, as she had hoped. The “plethora of pharmaceuticals” she was prescribed were detrimental to her overall wellbeing.

Gina moves to a description of her abjection via mirrors, superimposing an image of herself onto a mirror as she describes feeling unable to leave the house and being disgusted by the image of herself. As she notes that she “felt like [she] had lost [her]self completely,” Gina’s story fades to black. To make the change needed, Gina felt that she needed to take her health into her own hands, stopping her medication and focusing on her wellbeing from a non-medical standpoint. While this approach might not fit for everyone, for Gina it allowed her to move beyond the continual quest for external validation afforded not only by those in her social circle but also from medical professionals. The love that Gina found, as she notes, had to come from within.

It is important to complicate the notion of agency and self-help within Gina’s story to avoid simply advocating for the kind of rugged individualism characteristic of neoliberal approaches to health. While the major shift in Gina’s recovery occurred through the self-management of her disorder, we might consider this self-management in relation to the narrow approaches currently offered for eating disorders within the medical psychiatric complex. Gina found little other than medication offered to her, as she was never formally diagnosed with an eating disorder. Because of her diagnosed comorbidities and her larger body size, Gina’s behaviours were not diagnosed as anorexia. It was only upon later reflection with a holistic physician that Gina found her eating disorder legitimized; until then, years after the main struggle, doctors had met her distress with the offer of pills and dismissal. Faced with the binary
option of pharmaceutical treatment or no treatment at all, Gina elected to pursue her own approach to health. This was not a solely agentic and singular decision, despite the way in which Gina describes it. Agency is complex and entangled with social discourse, such that even acts of self-perceived agency may be entwined in social structures (Lavis, 2011). Societal contexts act in, on, and through people in a way that makes it impossible to fully disentangle personal agency and choice from context. It is through this lens that we might make sense of the choices and modes of recovery expressed in Gina’s film—and work to intervene into these contexts.

4.2.5 Kay.

Kay situates her relationship with food in her own history, beginning in childhood. Setting up a contrast from the start, she reflects on her relaxed relationship with food: “I didn’t analyse the food I ate, I happily ate nearly every food my mother presented to me.” The childhood photo Kay chose to illustrate her relaxed food relationship is a close-up; she stares into the camera with a half smile, holding a pop tart in her hand. Moving to a description of her mental illness symptoms, Kay reflects on what she constructs as preceding her eating disorder, choosing a very different kind of photo to illustrate what is described as obsessive compulsive disorder, anxiety, and depression. In this photo, she looks off into the distance, facing the opposite direction to the crowd in the photo.

Kay uses the example of eggs to illustrate her now-fraught relationship with foods, following the onset of anxiety, OCD and depression. She describes “noticing the subtle tastes and textures of food”; this noticing is not the usual kind of food abjection present in descriptions of eating disorders, which configure people as living in a defiant relationship with food. Throughout her story, Kay continually reflects on her relationship with food as one characterized by a close scrutiny of the items she was to eat, first based on taste and texture and later based on
their potential for contamination. This purity/contamination discourse may be more common than previously explored for those with eating disorders, as Megan Warin’s (2010) work on anorexia illustrates. Abject relations with food may not always be tied to the potential for food consumption to result in changes in corporeality, but rather the possibility that eating food will result in literal bodily contamination. In contemporary Western society, fatness and contamination have, however, come to be synonymous, a dynamic that warrants deeper exploration in relation to eating disorders.

As she describes a visit to an alternative healthcare practitioner, Kay once again shows a photo of herself facing directly toward the camera. Unsmiling, she describes how she went undiagnosed and felt she could not function; she ascribed her illness, including the anxiety, OCD and depression that kept her stuck, to the mainstream food supply, which she saw as “totally unsafe.” Seeking help from a therapist was key in addressing core issues; and yet, Kay’s mental health continued to suffer. Contrary to Gina, Kay found psychiatric medication to be one key element in her recovery. This different dynamic underscores the complexity of individual requirements in recovery.

The final photo in Kay’s story features her holding a cat and smiling at the camera. Rather than wrapping her story up in a neat conclusion, Kay reflects on how “years of trial and error” resulted in some movement toward wellness. For Kay, a biomedical perspective on her mental illness experience was helpful in reducing self-stigma; this framing allowed her to not feel responsible for her years of struggle. She describes her illness as “real,” further underscoring this commitment to a biomedical perspective. She describes her relationship with food as “not completely conventional,” reflecting on, once again, the diversity of approaches to food and living that may or may not work for different people in recovery.
4.3 Healthcare Provider Screening

Digital stories were screened to a total of 22 healthcare providers (HCPs): 14 medical students, six physicians (non-psychiatric specialty), and two physiotherapists. Of these, 13 had received no training in the recognition, prevention, treatment, or referral process for eating disorders. Seven had received training of some kind, and a further two indicated that they were unsure whether or not they had received training. HCPs filled out a qualitative questionnaire about their perceptions of recovery prior to seeing the films and after seeing the films, as well as their reactions to the films, what (if anything) they felt they had learned, and who (if anyone) they thought the films should be screened to. Overall, though not without exceptions HCPs found the films impactful on a personal level and thought that the films contributed to or had the potential to contribute to stigma and stereotype reduction around eating disorders by sharing personal experiences of diverse experiences of eating disorders and recovery. The script for the screenings is provided as an appendix.

4.3.1 Understandings of Eating Disorders and Recovery: Nuancing “Cure”

While HCPs were not explicitly asked what they thought eating disorders were or the best ways to address them, understandings of and discourses around eating disorders surfaced in HCPs’ responses around what eating disorder recovery means. HCPs generally understood that eating disorders were complex and multifaceted illnesses, even before viewing the films and despite not having received training. Eating disorders were also positioned as completely consuming an individual’s life; in other words, a serious and challenging mental illness. For instance, one HCP reported:

I think that an eating disorder encompasses so much more than simply meeting diagnostic criteria. The disorders are insidious in that they co-opt the individual’s entire life force, and remain like a backseat driver that won’t shut up (HCP 1)
Eating disorders were often described in terms of the harms they cause, a construction inherent to the framing of moving from one state to another in the recovery process. Recovery, here, was constituted as “progressing from a state in which one’s relationship with food leads to physical and/or psychological harm, to a state in which one’s relationship with food can lead to a healthy physical and psychological state” (HCP 2). This harm and complexity based framing leant itself to a cure-based understanding of recovery, particularly in the pre-screening data. Some HCPs referred to “fixing” components of the eating disorder and to the need to define recovery at least in part through “objective measures.” While these cure-based discourses might be problematized, HCPs in this study tended to accompany these statements with a recognition of the individual nature of eating disorders, and to question the possibility of arriving at a singular “cure” for all:

I do think there’s a need for some objective standards of recovery (e.g., around the severity of interference of behaviours and thoughts with functioning, and maintenance a healthy weight range [on average]), especially given that denial and biased perception can be inherent to the illness itself. The challenge is that a definition is only as useful as its ability to accurately represent a concept and be confidently applied, and much of recovery is an internal experience. (HCP 9)

Most HCPs were concerned with balancing the “necessary elements” of eating disorder recovery with the contextual aspects of recovery that might not necessarily be able to be prescribed in a universal way to all. Interestingly, these nuanced perspectives on cure were present even in pre-screening data and in the absence of ED specific training. It is worth mentioning, however, that the med students who comprised the primary sample, were students at a medical school oriented toward problem-based learning and that does not require all students to
come from “pre-med” or even science-based backgrounds. Thus, it is possible that these medical students are less inclined to take a purely positivist or biological perspective on human behaviour. Further, as viewing the films was voluntary, people with an existing interest in eating disorders were likely more inclined to come to the screening. While HCPs were inclined to cite “medical stabilization” (HCP 16) as a part of the process of recovery, this might be done in the same sentence in which they would specify that recovery is a journey, as did HCP 16, who defined eating disorder recovery as “an ongoing journey toward medical stabilization and healing the thoughts associated with the eating disorder.”

HCPs reported that viewing the films either confirmed their suspicions that eating disorders and recovery were diverse and multifaceted, or taught them about this diversity. Sometimes, the recognition of diversity marked a departure from a more textbook-seeming definition of recovery in the pre-screening data. For example, prior to screening, HCP 3 defined recovery as

a journey where someone is re-defining their relationship to their body image, weight, food, and societal expectations, with the outward result being that they continually move toward not having an eating disorder anymore.

Following screening, the same HCP noted that

Eating disorder recovery means many different things and is unique to the individual. It is often related to the individual’s story of how they developed disordered eating. Etiologies and solutions are therefore extremely varied.

Here is a shift, not only in the uniformity of the definition (applied to individuals versus noted as a singular definition) but also in the way the HCP defined the precursors and responses to eating
disorders. Again, throughout the responses there is a significant interlinkage of how HCPs defined and understood recovery, etiology, and treatment.

The shift was not always so striking; some HCPs reported that viewing the films did not necessarily change their pre-existing definition of recovery. This was true particularly, though not exclusively, for those who reported either training or significant interactions with people with eating disorders. One physician captured how the films did not necessarily teach her about eating disorder recovery, but reconfirmed their commitment to viewing the process of recovery as individual and multifaceted:

Having been a physician to dozens of people (male & female) with eating disorders, I don’t believe that I learned from these films. But I am reminded of depth, complexity, struggle/distress and resilience of humans in their journey of life and for those with eating disorders, their journey to recovery, whatever that is for them. (HCP 20)

Further, while they did not note a major shift in her definition of recovery, they added that “what it means must include the person with the ED; every recovery journey is different/unique.”

Overall, HCP responses detailed the necessity of moving beyond simply seeing a singular cure for eating disorders. HCPs negotiated the dominant medical perspective on attaining certain “objective” criteria for recovery by acknowledging that recovery was as multifaceted as eating disorders themselves. Following the film viewing, this likely already existing tendency to see the person rather than the illness was bolstered by having seen multiple versions of what eating disorders and recoveries might look like for different people.

4.3.2 Emotional Impact: Empathy and Powerlessness.

The stories were impactful for most HCPs who viewed them. HCPs primarily reported empathy, sadness, and powerlessness upon viewing the films. Interestingly, several also noted
the relatability of the films, having experienced eating disorders or disordered eating themselves at some point in their lives. HCP 4 reported a mix of empathy, sadness, and relatability, writing that the stories evoked “a sense of sadness, empathy, knowing/relation to certain moments.” That HCPs self-disclosed their own experiences suggests that it may have been worthwhile to include not only a question about whether HCPs had been trained in eating disorders, but also about whether they had experienced or known someone close who had experienced one, to more completely assess the state of their knowledge and experience with eating disorders. HCP 8 also reflected on their own experiences and how this impacted the viewing of the films:

They invoked a sense of familiarity. I could understand what the individuals were saying as I’ve suffered from an eating disorder of my own. They also made me feel understood because others have gone through the same experiences. They brought back feelings of sadness because it got me reflecting on how many individuals suffer from an ED and how much their lives are impacted. (HCP 8)

The last sentence of HCP 8’s account reflected a general sense of powerlessness reported by several participants upon viewing the films: essentially, they became more acutely aware of the struggles faced by those in recovery and their supporters, but unsure what they could do to help change the situation. HCP 22, for instance, noted that the films evoked “sadness, empathy, frustration for lack of supports”; similarly, HCP 1 noted: “These films evoked empathy in me and a feeling of powerlessness. For although I, as a med student, aspire to “fix” my patients, illness changes them in ways a healer cannot change.” Leaving aside the discussion of fixing and cure, explored above, these quotes reveal the limitations of viewing stories in the absence of material ability to shift systems.
Despite evoking powerlessness, HCPs noted value in the stories, particularly their ability to broaden perspectives on what it means to have and recover from an eating disorder. HCP 10 wrote: “I feel like I learned more about what it’s actually like for people to go through eating disorders and the process of recovery.” Further, many reflected on how viewing the films either taught them about or reminded them of the strength of those in recovery: “The films evoked interest from me, as well as understanding of the strength these individuals had. I became more interested in the background contexts of each story and was intrigued at how different they all are” (HCP 3).

All HCPs suggested at least one audience for screening: 13 suggested that the stories be screened to healthcare providers across disciplines, 10 to people with or in recovery from eating disorders, 9 to supporters, 6 to the general public, 6 to healthcare provider trainees, and 5 to younger audiences (e.g., highschool and undergraduate students). The primarily reasons for screening were to share personal experiences of eating disorders with an aim of reducing stigma, humanizing the experience, and reducing the singular narrative of eating disorders tied to misconceptions about the experience.

4.3.3 Wanting More: The Limits of Diversity.

Though HCPs reported that they learned about how diverse eating disorders and recoveries were through viewing the films, several also noted that they would have liked a) more representations of different kinds of eating disorders and/or b) longer or more detailed films. This expansion would have helped them to better understand eating disorders and recovery, as well as helping them feel confident that the films cover the wide range of experiences many reported being aware of.
With respect to the desire for more diverse representations, several HCPs self-disclosed prior histories of eating disorders, either personally experienced or experienced in relation. One HCP noted that her history of a non-anorexic eating disorder made her yearn for more representations of her particular experience; she reported “some disgruntlement at the lack of representation for other EDs (as a non-anorexia ED survivor) and worrying that these stories will be the only stories/types of EDs that people will learn from” (HCP 4). Though I had clarified at the beginning of the screening that not all participants had been diagnosed, and not all had experienced anorexia, the stories did lack a certain degree of diversity. As such, this HCP encouraged framing around the films to ensure that people did not assume that all participants had experienced anorexia.

The desire for longer and more detailed films was shared by many HCPs, which is perhaps unsurprising given that the stories were mostly quite short (ranging from a minute and a half to five minutes). HCPs reported interest and curiosity that led them to desire fuller descriptions of the participants’ struggles, contexts, and recoveries that would have allowed them to connect more deeply to the stories. As HCP 3 noted:

The films evoked interest from me, as well as understanding of the strength these individuals had. I became more interested in the background contexts of each story and was intrigued at how different they all are. (HCP 3)

Several participants also expressed a preference for more concrete stories over more “artistic” ones, suggesting that they were seeking more instructional stories: “some of the more artistic ones made me want to hear more – I felt that they were opening up but in a way that was difficult to understand without context” (HCP 6). This should be taken in the context of others who found the artistic representations to be emotionally compelling, for instance HCP 8 who
noted that “the last video with the drawings was probably my favourite as it allowed me to more closely get acquainted with the author’s mindset.”

Evidently, one type of film will not be desirable for all audiences. However, the desire for longer films was shared by those who preferred “concrete” and “artistic” videos. HCP 9, who was compelled by the last, very artistic rendering of recovery reported: “I didn’t feel “drawn in” by most of the clips, but I did find the last clip to be evocative – it really conveyed the turmoil of her experience. The other videos felt a bit clipped/short and superficial as a result.” HCP 8 noted “I think there would be more benefit if the videos were longer/more in depth,” similarly, HCP 13 wrote that “I feel like longer videos may be more impactful to hear their stories; it allows viewers to connect with the storyteller.”

Thus, while the digital stories were a helpful start, a deeper look into the perspectives of people with eating disorders and supporters would have been appealing to this audience. The films appeared to be a promising conversation starter around eating disorders and recovery, but would require framing around the diversity of eating disorders and recoveries to achieve their fullest impact.
Chapter 5: Discussion

The analyses described above reveal the complexity of the recovery assemblage. They speak to the ways in which experiences of care and support, both formal and informal, are tied to the experience of recovery for both people in recovery and their supporters. Interviews with people in recovery reflect how being mistrusted, having all subsequent experiences attributed to the eating disorder, experiencing dictates related to physical bodies and health and well-being, and facing social, emotional, ideological, and physical barriers to support impacted the embodied experience of recovery. They described the potential for the label of recovery to itself carry the assumptions so often associated with eating disorders and recovery in discourses both popular and clinical. The experience of recovery for participants in various stages of relationship to body, food, health, and wellness, were also fundamentally shaped to their relationships with would-be and actual supporters, whose affective responses to distress and to wellness impacted the extent to which people in recovery felt that they could enact their recoveries in the ways they desired.

On the part of supporters, assisting in the recovery process was also fraught with internal and external surveillance and a desire to provide the best support possible for a loved one. The constraints of a system that excludes some bodies from receiving help and/or prescribes only very narrow “solutions” for eating disorders weighed heavily on supporters, who often felt alienated from care systems. The continued gratitude for even these flawed systems reveals another complexity in the care landscape: the scarcity of resources and reliance on limited avenues of support creates an indebtedness to a system that is simultaneously recognized as flawed. Supporters’ responses reveal a kind of affective attunement to loved ones’ needs and desires in recovery that exemplifies the relational nature of recovery and the ways in which time and space might be configured in the recovery assemblage to enable ways of being that feel nourishing.
In digital storytelling workshops, these themes of relationality, dynamism, and space and time converge to further complicate singular and clinical accounts of recovery. As participants worked through their experiences in artistic ways, it became impossible to conceive of recovery as a simple before-and-after, or an isolated, singular, and capped-off experience. Instead, the affective intensities of recovery were revealed in the deeply dynamic and relational experiences participants described—of both the genesis of their disorders and their recoveries. Stories were, further, tinged by awareness of the sociopolitical surround of eating disorders and recovery: the expected trajectories and “results” of recovery. This self-reflexive and socially-inflected vision of recovery implicates an awareness of the power of “recovery” as term that can itself carry problematic—or emancipatory, or both—meanings. Screening these stories with healthcare providers helped to begin a conversation about the dynamic and multiple nature of eating disorders and recoveries with those who are or one day will be in a position to encounter people with eating disorders and in recovery.

5.1 People in Recovery

5.1.1 Untrustworthiness.

Participants’ narratives encapsulated the complex interweaving of time, relationality, and space as they enacted and performed their recoveries in a matrix of biopedagogical instructions about bodily behaviours. Certain flows pressed up against participants’ corporeal experiences, delimiting the spaces and times in which they were able to lay claim to the status of recovery. These flows were inextricable from framings of eating disorders and those who experience them in general; the subtle and implicit articulation, for instance, that people with eating disorders are untrustworthy (cf. Lester, 2016; Root, 1990) and eclipsed by the voices of their illness (cf. Eli, 2014; Malson et al., 2004; Malson et al., 2011a; Saukko, 2009) persisted into participants’ embodied recovery experiences in ways that rubbed up against their gendered, raced, and classed
experiences of the world. Participants’ bodies were also continually read by those with whom they were in relation, impacting their own understandings of their subjectivities and choices around food, weight, and shape.

The persuasiveness and dominance of the medical frame—and its uptake into dominant discourses around health (Novas & Rose, 2000) have led to people understanding themselves in medicalized terms (Moncrieff, 2014). With respect to eating disorders in particular, these constructions may delimit the extent to which people are able to understand their subjectivities as “recovered” (Malson et al., 2011a). Those who are marginalized along other lines—for instance, racialized people, people from lower socioeconomic statuses, women, etc.—live in bodies that are pushed to the margins, limiting access to a category of recovery that hinges to a great extent on the ability to perform respectability and body normativity (LaMarre & Rice, 2017). People in recovery as illustrated by the accounts of participants in this study, are not always framed as trustworthy witnesses to their own health. The absence of clinical consensus on what constitutes recovery (Bardone-Cone et al., 2010) also means that even those who do pursue formal treatment for their eating disorders may never receive confirmation of recovered; the diagnostic “certainty” of pathology does not extend to recovery. The construction of the untrustworthy and resistant person with an eating disorder persists into recovery, particularly when the individual has not sought out diagnostic labels or treatment or been deemed legitimate by diagnostic and treatment processes for eating disorders.

Eating disorders continue to be socially constructed as disorders of the young, vain, and privileged (O’Hara & Clegg-Smith, 2007; Shepherd & Seale, 1999). Further, those with eating disorders are assumed to be wholly consumed by thoughts related to the eating disorder, and thus unable to make decisions, commit to treatment, or follow through with recovery outside of strict
and surveilled clinical environments (Boughtwood & Halse, 2010; Malson et al., 2011a; Ryan et al., 2006). This construction delimits the degree to which those with eating disorders are believed while actively suffering (Root, 1990) or, as these participant accounts demonstrate, after they have recovered. Not only does this framing lead to a feeling of not having a voice, but it also places some in the position of materially not having a voice or a say. These voices are missing from representations of what eating disorders are, what the best course of treatment is, and what recovery looks like because once they are voiced they are immediately met with skepticism or shut down as remnants of an eating disordered point of view.

It is also here that we see the possible negative ramifications of some uptakes of the externalization of eating disorders as monstrous constructions wholly controlling their victims. The original intent behind the use of externalization for eating disorders is to, as White (2011) remarked: “assist people to characterize whatever problem they are dealing with” (p. 87). Creating a “thing” to target helps to minimize the invasiveness of the problem—the way that it infiltrates all aspects of a person’s being and actions. White (2011) suggests that externalization be done in concert with the person, and in a way that ensures that “a rich, externalized characterization of the problem” (p. 88) is developed; this is not necessarily finding a singular name for a singular problem. With respect to eating disorders in particular, White clarifies: “people do not have identical experiences of whatever anorexia nervosa is,” (2011, p. 88) and thus the “problem” to be externalized is not always “Ed.” If the eating disorder is externalized in a haphazard way, for example by adopting the label Ed without much attention paid to the person’s preferences and choice of how to externalize (which can be the case in treatment settings), the individual’s agency risks being removed, as all choices become framed as those of the eating disorder (Saukko, 2008; 2009).
Of course, this move to externalize can be a pragmatic clinical choice, particularly for assisting supporters and individuals themselves feel less to blame for the actions they take while in distress and redirecting action toward combatting the eating disorder. Indeed, participants in this study often also framed their eating disorders in externalizing terms, referring to this as a helpful strategy for moving toward recovery. As is the case with numerous eating-disorder-treatment related constructions, however, the danger of externalization lies in its oversimplification and is crystallized in the liminal space between eating disorder and recovery. If the eating disorder is an external force acting on the person with the disorder, speaking through them, there is a case to be made for making decisions about that person’s treatment and about what their goals are without enlisting their voice—which is often deemed “too entangled” with the eating disorder to be trusted.

This runs counter to the aims of narrative therapy, which are largely focused on empowering the person to re-write their story and consider the ways in which the externalized problem impacts their life (White, 1986, 1989, 2011). Even when the person is no longer struggling, and they and their supporters attest to this movement toward recovery, a lingering sense of skepticism remains, re-inscribing surveillance into the recovered space. Though the person is deemed “whole again,” (Jenkins & Ogden, 2012) the externalized spectre—Ed—looms over the ways in which the person is believed and heard. The family may be taught to not “give in” to the eating disorder voice (Treasure, Sepulveda, MacDonald, Whitaker, Lopez, Zabala, Kyriacou & Todd, 2008); again, this may be a pragmatic way of engaging family members in the treatment of the eating disorder and uniting against a common foil, but may not be undertaken in a way that allows for the person’s voice to be heard. Unlike White’s perspectives on narrative therapy, which held a deep sense of respect and empathy for a person and their story (Gallant,
2008), a haphazard externalization risks lacking long-term benefit for the person beyond the eating disorder.

Perhaps ironically, the general lack of trust of young women’s accounts of their own embodied distress can act as a barrier to obtaining the very diagnoses that might allow them to later be considered “legitimate” in the medical industrial complex. When participants’ bodies are read as healthy – or “overweight” – despite their internal experiences of distress, this can act as a barrier to obtaining the kind of treatment that might allow the person to obtain a diagnosis and an approval of recovery (Lebow, Sim & Kransdorf, 2015). Illness—and recovery—must thus both be “proven” through one’s body. When participants’ bodies did not match the expectations healthcare practitioners (who are often poorly trained in eating disorders, see Girz, Robinson & Tessier, 2014; Mahr et al., 2015), they faced misunderstanding, misdiagnosis, and labels that further pushed them to the margins, including “atypical” or as having “disordered eating” (e.g. Mulholland & Mintz, 2001). Training alone was not enough to buffer against the operation of power in the eating disorder and recovery assemblage; healthcare providers were categorically assumed to know best what eating disorder a patient had, how best to respond, and what constitutes recovery. In some ways, as participants’ accounts illustrate, being trained and respected as an “expert” made healthcare providers even less likely to abandon their position of power and knowledge in favour of listening to and honouring participants’ embodied experiences. Interestingly, these perspectives on and experiences with healthcare providers differed markedly from the open and individual perspectives on recovery expressed by healthcare provider participants in this study. This may provide a hopeful perspective on the possibility of more open and welcoming healthcare environments than those experienced by participants. Alternatively, as most of the healthcare provider participants were in training, their
scope and ethics of practice may not yet have been circumscribed by the systems and discourses in and under which they must operate.

Particularly when participants had varied diagnoses over the course of their eating disorder experiences and/or their bodies changed significantly while in distress and in contact with specialists, performances of eating disorders through their bodies impacted the degree to which they felt heard and taken care of in eating disorder clinical contexts. Doctors, even when specialists, sometimes misunderstood participants, their behaviours, and their visions for their lives, seeing behaviours and/or thoughts as tied up in their eating disorders and in their bodily presentations in ways that did not resonate with them. This is not to say that participants had categorically negative encounters in treatment; some noted that treatment was the first time they felt truly understood—by fellow patients (see also Eli, 2014), or by doctors and other staff on units. While, as Boughtwood & Halse (2010) articulate, treatment contexts might be places in which the role of patient is performed, this performance may also become familiar, and then become challenging to break out of. Equally, simply having access to treatment did not guarantee participants access to effective services that met them where they were, allowed them to have a voice, and understood them.

The issue of being constructed as untrustworthy by healthcare practitioners with and without eating disorder-specific training was deeply entangled with power and role within healthcare encounters. Participants described how at times they felt as though there was no room for variability in treatment, which reinforced feelings of being untrustworthy or completely in thrall to their disorders. Simultaneously, the healthcare providers may be framed as untrustworthy, but this perspective remains unspoken in the treatment context. Those in treatment may be resisting in subtle ways throughout their treatment in part because of this
distrust of healthcare providers who do not trust them; this is fundamentally “a power relationship that can generate an ‘us versus them’ mentality” (Boughtwood & Halse, 2010, p. 87). They may not feel comfortable expressing their struggles for a fear that these struggles may be used as leverage to remove them from programs they need.

Malson et al. (2011a) describe how patients are often constructed, in specialist eating disorder care, as wholly subsumed by their eating disorders, which impacts their ability to see recovery as possible. Participants in this study expressed that in the treatment decisions made for them, they experienced a lack of autonomy and choice. Here it is worth again considering the pitfalls and positives of externalization of eating disorders and probe its use in practice as participants described it. In some treatment contexts, the eating disorder was not necessarily externalized as a way to help participants re-story their experiences, as would be the approach in narrative therapy (Maisel, Epston & Borden, 2004; White, 2011; Zimmerman & Shepherd, 1993). Instead, the eating disorder, haphazardly externalized, becomes configured as a way of dismissing patient decision-making and preferences in more highly surveilled treatment contexts. Externalization strategies serve, here, pragmatic rather than therapeutic ends, providing a practical justification for the obfuscation of the opinions of the person with the eating disorder. Instead of opening up possibility for them to articulate an alternative self, the externalized eating disorder here forecloses the possibility of patient contribution; the eating disorder is constructed as much more powerful than the person in the moment. In other words, the agency of the eating disorder is placed in higher regard than that of the person in recovery. Regardless of whether or not this reflects any “truth” of the power of the “eating disorder voice” versus the person’s voice, it reveals interesting tensions around a) the perception of the identity/subjectivity of those with eating disorders amongst those treating them, b) the lack of training in methods of integrating
narrative approaches like externalization into eating disorder treatment, generally practiced from a medicalized/psychologized perspective, and c) the lack of understanding or grasp of the epistemologies that underlie narrative therapy.

In terms of the identity/subjectivity tension, consider how in eating disorder literature from prevention to recovery, a “good” subjectivity is presumed to be a whole one—one that does not have dissonance, that is fixed over time, and that is not “vulnerable” to shifts over time (LaMarre et al., 2017). This assumption also carries with it explicitly neoliberal overtones and justifies the individual responsibilization of health by assuming that there is one “right” way to perform eating disorder, patient, and recovery. The neoliberal eating disorder subject is not a fluid one: methods of moving beyond the eating disorder are imposed on the individual and are highly directive, dictating the terms of engagement with treatment and with recovery. The person is made responsible for engaging in treatment and following the rules, and not believed to be a credible consumer with opinions about what might improve their outcomes (as they would ideally be according to consumer/survivor and recovery model approaches to healthcare, see Anthony, 1993; Dawson et al., 2014). The fixity around their subjectivity might also offer clues about the continued disbelief that accompanies medical discussions with the patient into recovery. If the fundamental belief is that the individual has a fixed identity over time, then they would always be (vulnerable to) following the eating disorder voice that is seen as inhering within them. There is some room for slight variations, but the person’s voice is always assumed to be one that might be overtaken at any moment by the eating disorder voice.

There is, of course, an uneasy rub here between the imposed fixity of identity and the externalization of eating disorder—and with it, the idea that there might be more than one way of orienting to the same stimuli or experience held within the person. This rub is inadequately
accounted for by the lack of training in narrative therapy for those in the position of treating eating disorders. Externalization has been readily adopted into the mainstream arsenal of eating disorder treatment, commonly employed alongside psychological techniques drawing from a positivist or post-positivist ontology that presumes that thinking can be “corrected” to generate a healthy subjectivity for the individual that will, then, endure. And yet, a post-modern ontology underpins the use of narrative techniques like externalization. Narrative approaches presume that all people are made of stories (deliberately in the plural) and that we each have multiple, ongoing, dynamic relationships with them (Drewery & Winslade, 1997; White, 2011). We do not tell one story (representative of our dynamic subjectivities) for all time, in all places (McAdams, 1985). These stories are necessarily generated in interaction and may be “re-storied” to generate stories that work for the particular context.

The ideal of fixed subjectivity without dissonance lies in uneasy alliance with a perspective that values openness and change and does not presuppose that a story will endure across circumstances. The value of externalization in narrative therapy is that it allows the person to imagine their story otherwise or in different relationship with the externalized “issue”; not that that issue would be completed removed from their experience forever or that there were not aspects of that issue that might be functional at one point or another (Saukko, 2009; White, 2011). A fundamental characteristic of narrative therapy, further, is that the person receiving therapy is, ultimately, the expert and author of their own story—there is not a right or a wrong way to write that story; only preferred and dispreferred alternatives at different points in time (White, 2011). White’s reflections on the “drift” of externalization also emphasize how important it is to sit with the person and hold space for the multiple and co-existing stories that comprise their lives (Gallant, 2008; White, 2011). Rather than positioning the individual as
expert and author and encouraging them to re-write their own story in a therapeutic way (White, 2011), externalization may be used to discredit and discount the person’s authority over their own experiences. Mainstream treatment approaches thus seem to adopt narrative techniques in a way that first subsumes the person’s identity into their eating disorder and then completely divorces them from the eating disorder—the eating disorder becomes “real” in a way that it can either be wholly representative of the way the person is—who they are at their core—or not present at all (see also Saukko, 2009).

Discourses of disbelief issued by medical professionals who tend to take positivist and post-positivist perspectives on health, identity, recovery and eating disorders as phenomenon, persist into evaluations of recoveries that a) do not follow the expected pathways to recovery and b) do not demonstrate clear before/after pathology as measured using metrics of eating disorders, remission, and recovery devised by psychometricians. But these discourses did not only emanate from healthcare providers; they were also issued by family members and other would-be supporters who themselves live in relation to flows of information about whose bodies fit and what recovery looks like. Participants built their recovered subjectivities in relation to these supporters and negotiated disclosure, non-disclosure, and embodied behaviour in relation to others in their lives.

5.1.2 Choosing Your Choices.

In the scholarly and popular discourse on eating disorders, there is much made of “choice”: a significant part of efforts to minimize stigma and stereotypes about eating disorders has been devoted to debunking the myth that eating disorders are choices (e.g., Hudson, 2016; Fogarty, 2016; Sherman-Lazar, 2017). A common problem with the framing of eating disorders commonly debunked by eating disorder researchers, clinicians, activists, people with lived
experience, and others, is the myth of choice (i.e., the idea that people choose to have eating disorders). And yet, this myth persists. Commonly, the idea of choice and eating disorders is (arguably wrongly) associated with a second-wave feminist framing of eating disorders that positions eating disorders as born from cultural stimuli (Holmes, 2017). But, as Rosalind Gill (2007) points out, people are not passive and ignorant vessels to be persuaded by any media imagery. Indeed, ramped up efforts to promote media literacy have not resulted in concordant decreases in eating disorders or body dissatisfaction; if anything, they have simply driven bodily discontent underground or portrayed under a guise of health (Boepple & Thompson, 2016; Simpson & Mazzeo, 2017). Youth in particular now know that they are not “supposed” to emulate thin runway models or believe everything that they see—to “buy in” to this cultural milieu is seen as uncool or passé.

The argument raised in public discourse against campaigns focused only on thin-ideal internalization for eating disorder prevention becomes that people with eating disorders may be raised in highly media literate, feminist households and still develop eating disorders—which is certainly the case at least some of the time. But in calling out the objectification of women and suggesting that there is a need for more realistic representations, second wave feminists were not simply highlighting a process wherein young girls became prey to media imagery (Bray, 1996; Holmes, 2017). At the heart of this work is an ethic of addressing the need for wide-scale systemic change (e.g., Calogero et al., 2005) that has not been wholly taken up. Certainly, there was at times a glossing-over of the intersectional complexities of bodily identities in early feminist work about eating disorders that perhaps unintentionally fed into stereotypes about who gets eating disorders. It is important to acknowledge that feminist scholars as early as the late 1990s noted how people with eating disorders might be alienated by the way that others talk
about their disorders (Eckerman, 1997) and have disliked perspectives on eating disorders that place media in the seat of blame (Boughtwood, 2005). Malson (2009) further notes that when eating disorders are framed as problems of body image, other cultural forces that generate inequities are glossed over. This does not mean that critiques of media standards of beauty cannot or should not be done; however, it must be done in a way that acknowledges both culture beyond “thin ideals” and the discursive framing of eating disorders themselves—including how sufferers are framed as always feminized, always vulnerable, and always irrational (Bray, 2005; Holmes, 2017).

The work of critiquing media standards of beauty can be done concordantly with debunking the discourse of choice when it comes to eating disorders. Debunking the discourse of choice also bears deeper elucidation in relation to the experiences of those with eating disorders; simply shouting “eating disorders are not a choice” into social media outlets has done little to dislodge the tenacious stereotypes about eating disorders that continue to pathologize, stigmatize, and Other those with struggles around food. As Musolino, Warin, Wade & Gilchrist (2015) point out, “postfeminism, neoliberalism and healthism represent a constellation of contemporary forces which have created an environment for disordered eating to flourish” (p. 2). Eating disorders occur in an environment in which global beauty brands have co-opted the language of empowerment (Gill & Arthurs, 2006) and in which weight is framed as mutable and deeply tethered to morality (Trainer, Wutich & Brewis, 2017). The idea of “not being a choice” must, then, be grounded in an exploration of what “choice” means in a neoliberal consumer capitalist society.

In light of analyses of postfeminist sensibility (Riley et al., 2017), the question of choice and recovery bears deeper exploration, particularly in terms of how participants described the
impact of the “choice” stereotype on their lives. A postfeminist sensibility articulates the contradictions surrounding the encouragement of women to be empowered and “choiceful” while their actions are limited by discourses of consumerism and a system that maintains structural inequities (Gill, 2007). Postfeminism is affective in the way that it structures emotion; within a cultural moment, people orient toward subject positions or ways of being not only on the basis of material reality but also the less tangible feeling they have toward actions, places, behaviours, and more (Riley et al., 2017). Under a postfeminist sensibility, the primary route to empowerment is through bodily and consumer choice (Riley et al., 2017). Applying this to the question of eating disorders, recovery, and choice, we might explore how the framing of recovery as a choice is not necessarily empowering—at least not equally and for all.

For participants, the idea of choice and eating disorders has implications beyond public misunderstandings of the disorders and bears contextualization in participants’ lived experience. When participants’ behaviours were framed as choices, they received limited empathy from others in their lives, whether these others were medical professionals or close others. Under a neoliberal optic on health and bodily control, all people are expected to make choices that optimize our health (Rail & Jette, 2015; Rose, 2009). Following biopedagogies for health entails toeing a line between restraint and excess that allows us to perform health and contribute productively to society (Evans & Rich, 2011). Neoliberal rationality concordantly (but subtly) asserts that we are all equally free to evaluate options and make choices that optimize our health; it “gets into our minds and our souls, into the ways in which we think about what we do, and into our social relations with others” (Ball, 2012, p. 18). Biopedagogies, for all that they circulate around and are filtered through our bodily subjectivities, paradoxically ignore contextualized bodily realities, as well as affect. They obscure the complex intertwinnings between our bodies
and our worlds, wherein there is a mutually influential relationship between environments and biology (Grosz, 1994). Within this perspective, it is assumed that all people in all bodies will be able to make the “right” choice (as it is assumed that there is a singular, right choice), and this choice will lead to identical outcomes for all. We are all assumed, here, to assert logical dominance over our bodies. Negative outcomes, then, are ascribed to poor choices for health in general and eating disorder recovery in particular.

Given the pervasiveness of a neoliberal and biopedagogical outlook on health, it is not surprising that people in the lives of those with eating disorders might interpret their behaviours that result in distress and ill health as attributable to choice. This has less to do with a conceptualization of the stereotypes around eating disorders as the purview of vain, young, white, heterosexual, cisgender, able-bodied, upper-class women and more to do with a general perspective on what it means to be healthy and a healthy productive citizen. Thus, attempts to overcome a choice discourse by simply decrying that eating disorders are not a choice and that we know this because a particular example of a person with an eating disorder did not emulate thin runway models does nothing to dislodge the broader societal brush with which all humans are painted—one in which all people can rationally assert control over our bodies and exact health outcomes. This might help to explain why years of public awareness campaigns designed to explore eating disorders beyond body image as an effort to dislodge stereotypes of choice and volition have had little to no effect; participants’ stories gathered for this dissertation in 2016 and 2017 resemble literature on eating disorders from the 1990s in which participants speak to being misunderstood by friends and family who presume their disorders are a choice (e.g. Thompson, 1996). And while the picture of eating disorders as related to body image has significantly changed over that period of time, there has not been a simultaneous attempt to dislodge dominant
rationalities and pedagogies of health; if anything, biopedagogies and strictures over bodies, as well as the discourse of perfect rationality and ability to be “mind over matter” have only intensified. Perhaps researchers and advocates have been targeting the wrong driver behind a discourse of choice.

Participants also negotiated the choice-based framing of recovery. While framing recovery as a choice foregrounds agency and aligns with a recovery model framing (Anthony, 1993), it does not necessarily encapsulate the complexity and contextual nature of this “choice” within the aforementioned system that forecloses which choices are correct (Morrow, 2013). Equally, seeing recovery as a choice does not account for the multiplicity and relationality of recovery, entwined with other affects and flows in participants’ lives. Imagining recovery to be “a site of socio-political struggle over what lives are deemed liveable in the context of global neo-liberalism” (McWade, 2015, p. 244), we might consider how discourses of “choosing recovery” allows the biomedical psychiatric complex to co-opt liberal individualism to promote an version of recovery not available to all (Howell & Voronka, 2012; Morrow, 2013; Poole, 2011). This framing might be re-imagined as an interesting example of how people are working within a system that ultimately traps them and codes their behaviour as better or worse choices to make shifts in people’s understandings. What is evident through exploring the pervasive stereotypes and continued need for such justifications, however, is that these accountings are not necessarily strong enough to gain significant traction in making change in the framing of both eating disorders and recovery as choice and thus increasing compassion for those with eating disorders and creating material changes in the systems ostensibly designed to serve them.
5.1.3 Bodies of Proof.

Misunderstandings about eating disorders crystallize around the assumption that one’s health status can be determined using the proxy of weight. Participants described this assumption as having detrimental impacts on their experiences of being recognized as suffering, as well as being determined to be well. From assumptions about “not being sick enough” to warrant intensive treatment from doctors to family and friends assuming that recovery was achieved as soon as any weight lost had been gained, weight was a significant topic of conversation—and axis of judgment—in participants’ lives. This finding can be contextualized against a society wherein weight is seen as something completely under humans’ volitional control; weight and health are seen as choices (Bordo, 1993; Trainer et al., 2017), and as markers of internal processes that cannot be seen. Despite our ability to measure health with other proxies (i.e., cardiac function, electrolyte levels, etc.) and our recognition of the failure of weight status to capture “health” (Flegal, Caroll, Kit & Ogden, 2012; Flegal, Kit, Orpana & Graubard, 2013; Kassirer & Angell, 1998), weight remains a persuasive measure used by many to determine the degree of illness or wellness. It is worth noting that participants troubled other “objective” markers of health and illness, illustrating their complex embodied relationships and how subjective suffering is underpowered in medical contexts. Lab results being normal had a way of significantly setting participants back in their journeys—and this was exacerbated should their weight be deemed “normal.” Seemingly objective measures of wellness and illness compounded to create evidence in the clinical eye for the degree of treatment participants required.

Participants wished that weight could be disentangled from health, while simultaneously endorsing some of the taken for granted ideas about health that circulate in our thoroughly biopedagogized society. There is, of course, a degree of clinical pragmatism to take into account, here—under our current system of managed care, clinical decisions must be made on some basis,
however flawed (Lester, 2007, 2016). Market logics infuse medical spaces, particularly as medical services are presented in similar ways to other commodities (i.e., competitively priced, etc.) under consumer capitalism (Logan et al., 1989). Participants similarly took up monetary and consumer metaphors in describing healthcare encounters, illustrating the ways in which market logics infuse and intersect with logics of care (Lupton, 1997) despite the differences between healthcare and commodity goods (McDonald, Mead, Cherarghi-Sohi, Bower, Whalley & Roland, 2007). Creating space for participants’ stories to be honoured as compelling evidence for their state would require a complete overhaul of systems of care that attempt to align treatment level and approach as neatly as possible with available clinical research evidence and markers of illness severity. We might start with one marker continually called out by participants as a flawed indicator of their state of being—and one that lacks significant research clout as a marker of wellness: weight.

Social reinforcement of eating disorder behaviours when a person’s bodily presentation does not match their degree of distress is not a new insight (LaMarre et al., 2015; Woods, 2004). While this may reinforce behaviours coded as eating disorders, in this study, many participants described knowing “deep down inside” that their behaviour was not healthy for them. This is an important distinction in terms of framing participants’ experiences as other than ignorant or vain. Though there was significant social payoff for the weight loss behaviours in which they were engaged, they did experience a degree of dissonance between this feedback and their internal sense of wellness. Commonly, in the literature, those with eating disorders are—again—described as being wholly consumed by their eating disorders (Eli, 2014; Malson et al., 2004; Malson et al., 2011; Ryan et al. 2006; Saukko, 2008; 2009). At least on reflection, and notwithstanding the editorial capacity of participants to re-imagine their reactions upon retelling,
participants reported an awareness of the unhealthiness of their actions. This further speaks to the complexity of choice and recovery—simply knowing something was not healthy was not enough for participants to make a move toward recovery, particularly when their bodies were not read as eating disordered by those around them.

Participants’ embodied experiences of disconnections between their own and others’ bodily presentations and the way that society perceives bodies were not only felt on the level of attractiveness or even social acceptance along the lines of size and shape alone. Instead, these experiences combined with other axes of bodily marginalization, including culture and cultural assumptions about preferred body sizes. Participants from immigrant families, for instance, described feeling caught in between discourses about size, gender, and usefulness or productivity in their familial and broader cultures. Weight, here and elsewhere, is not only a marker of health but also worth (Bell, McNaughton & Salmon 2011; Greenhalgh 2012; Herndon 2005; LeBesco 2011; Rice, 2007; Saguy 2014; Tischner & Malson, 2011; Trainer et al., 2017). The intersection between weight and recovery reveals tensions between “sick enough,” “well enough,” and surveillance in dominant—and marginalized—cultures. The reading of weight as indicative of health further complicated recovery trajectories by imposing finality on the experience of recovery upon the attainment of a weight determined as “healthy” by medical professionals. While the medical professionals assigning the weight category may themselves be aware of the complexities of weight and health status, gaining the seal of approval from the medical profession to, for instance, leave treatment was read by potential supporters as evidence of work in recovery being done—and yielded an expectation of “normal behaviour” and “normal thoughts” accompanying “normal weight” (see also Malson, Clarke & Finn, 2008 and LaMarre & Rice, 2016a for peoples’ understandings of what constitutes “normalely” in relation to health,
weight, and behaviours in eating disorder treatment). These performances of normality gain importance when we consider the social meanings of weight and how it is socially linked to morality (Saguy, 2011; Tischner & Malson, 2011).

Despite social pressures to embody a normative form post-recovery (reinforced by clinical guidelines that articulate recovery as between a BMI of 20 and 24; Gotovac, LaMarre & Lafreniere, forthcoming) those in recovery are expected to be happy with their bodies no matter what it looks like. This orientation toward fleshiness is an expected sign of recovery—the expected transcendence of societal messages of morality. Participants contextualized “love your body” discourses against the unlikelihood that one can move through life in such sharp contrast: moving quickly from engaging in behaviours that indicate bodily dislike (whether that dislike is oriented toward appearance or other aspects of a person’s life) to loving one’s body no matter what, no matter where. Participants accounts exemplified an untethering of mind from body that pervades popular accounts about eating disordered bodies and bodies-in-recovery and more deeply entrench discourses of choice and mind-over-matter. In expecting people to be able to overcome bodily sensations of discomfort as well as societal dictates about bodies, people in recovery are expected to be able to exert mind strength that would discipline their bodies in accordance with social standards, as well as controlling emotions about corporealities deemed not to fit. If they “cannot” perform a normative body, the next targets of attack are emotions, once again framed as outside of logical rationality. The exercise of bodily control goes double in recovery—first over one’s fleshy form, and secondly over the other markers of excess—emotions about and visceral reactions to fleshiness.
5.1.4 Surveillance.

Aligning with prior feminist work on the ways in which eating disorder treatment systems can act as surveilled, panoptical spaces (e.g. Bell, 2006; Boughtwood & Halse, 2010; Gremillion, 2003), many participants reported on the challenges associated with being underpowered in treatment systems. Participants detailed the treatment space as one that put them back into the position of an untrustworthy child, regardless of their age at the time of treatment. An orientation to treatment as a place where all choices are made by others persists, despite an increasing acknowledgment that offering increased choice may yield longer-lasting results (Vandereycken & Vansteenkiste, 2009). While not all participants had experienced inpatient units, those who did often subtly or more explicitly commented on the surveilled nature of this space. Generally, and importantly, participants did not attribute their dislike of these spaces to individual clinicians. They did not have “a bone to pick” with clinicians for asking them to give up their disorders—in fact, participants spoke favorably about most individual clinicians. However, they described the challenges of being subject to the gaze within the medicalized treatment unit. This gaze emanated not only from health professionals working in the space, but also from fellow patients. In addition to the gaze from without, there is also a gazing from within; as Bordo (1993) describes, those with eating disorders become very adept at self-management. In this study, this bore out in terms of the ways in which participants embodied not just the physical trappings of ideal healthy citizenship but also the active self-work encouraged by health biopedagogies and healthism (Shea & Beausoliel, 2012; Trainer et al. 2017). Perhaps because of their normative social framing, these behaviours were rarely marked as problematic until reframed after the fact; that is, participants were encouraged to, or praised for, “following the rules” in treatment contexts (contexts that health anthropologists have
described as a “greenhouse,” bubble (Eli, 2014) or “aquarium” (Eli, 2018)), but once “back in the real world,” these behaviours became subject to scrutiny (LaMarre & Rice, 2016a).

The imposed rigidity of treatment contexts raises questions about the sustainability of the ways of eating and being imposed in treatment—difficult questions that are largely unanswerable and that speak to the challenge of teaching “normal eating,” particularly in a society in which normal eating is actually abnormal (LaMarre & Rice, 2016a; Musolino, Warin, Wade & Gilchrist, 2016). Treatment systems are faced with the impossibility (or extreme challenge) of at once breaking rigidities patients may have around food, and equipping patients with alternative ways of nourishing their bodies. To break patients’ rigidities, treatment settings may inscribe new kinds of rigidity that take their place; some have described this re-inscription of rigidity in the treatment context as “feeding the disorder,” rather than the patient (Padrão, Barbosa & Coimbra, 2013). Everyone must eat to live, but whose version of eating is the “best” one? Patients voices are generally, once again, framed as untrustworthy in the negotiation of a style of eating that will match their lifestyle post-treatment. This is not necessarily done in a malicious way, but more likely in a protectionist one: eating disorders can and do result in death for some (Steinhausen, 2002). Malnourishment, left unchecked, may lead to literal wasting of bodies (Fairburn & Harrison, 2003). But too often, this fear of wasting—that likely stems from a humanist ethical perspective advocating for logic, reason, and universal moral values (Dierksmeier, 2016; Kant, 1787)—reflects a fear of wasting productivity—the impetus for treatment becomes less about saving lives and more about recovering productivity.

The way that participants described themselves in relation to others in their treatment environments raises interesting insights into the uptake of post-feminist perspectives and eating disorders as they are constructed as disorders of the rebellious (Burns, 2004) or at least resistant
(see, for example, Fassino & Abbate-Daga, 2013 for a discussion of resistance to treatment as a critical challenge to overcome in eating disorder treatment). For instance, some participants described “not being like the other girls” when they described wanting to adhere to treatment protocols and/or wanting recovery. This framing presupposes that others with eating disorders do not wish to recover and in so doing constructs “good” and “bad” patients. Participants further described the behaviours that some on the units enacted or “got away with” and occasionally called for increased staff surveillance to counteract this possibility. When there are strict rules for what is allowed in a treatment setting, the issue becomes what to do when a rule is broken or breached (cf. Lester, 2007). Particularly in the adolescent context, punishment is the common approach—in the adult context, patients are commonly removed from programs upon breaching a rule. The surveillance in this context ends up dictating who is able to be in treatment. When there are few beds available and when those with eating disorders are commonly framed as treatment resisting, there is a dilemma around what to “allow” in treatment contexts. The need to balance protection with re-imposition of rigidity is not an easy line to toe. As participants’ accounts reveal, being subject to continual surveillance is not always as effective as intended, particularly when patients align to push back against imposed rigidity and seek methods of coping when their regular coping mechanisms (e.g., eating disorder symptoms) are removed (Boughtwood & Halse, 2010).

Surveillance, and the experience of being watched in general, was not unique to the treatment context. As Allison, Warin & Bastiampillai (2014) note, “young people (and young women in particular) learn from an early age that their bodies require constant surveillance,

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6 This resistance may be based in fear (Vitousek, Watson & Wilson, 1998), rather than representative of a rebellious anti-healthcare attitude, as it is sometimes represented.
modification and improvement” (p. 116) particularly in relation to food and exercise practices. That our bodies are subject to surveillance from within and without is not a new observation; critical scholars have acknowledged for years the extent to which we are constantly under surveillance—a kind of surveillance we also begin to enact on ourselves as we continually strive for productivity and usefulness (Foucault, 1979; Rose, 1999). Further, critical theorists have explored the role of the gaze, “a complex affective assemblage [comprised of] simultaneous feelings, intentions and desires, pleasure, competition, strategy, envy, eroticism, friendliness, understanding, inclusivity, among others” (Winch, 2016, p. 906). It is not surprising, then, that participants who had and had not experienced formal treatment for their eating disorders also reported feelings of being watched. Being surveilled in food intake and body also featured in descriptions of recovery. Ongoing self-surveillance has been a feature of recovery models beyond the eating disorder context in their emphasis on people’s need to manage themselves and their bodies such that they reduce the risk of relapse (Price-Robertson et al., 2007). Coupled with dominant biopedagogies for health that encourage constant self-management around food and bodily practices (Wright & Harwood, 2009) and discourses of discipline and management of feminine bodies in particular (Gill, 2007; Rice, 2014), the sense of surveilled recovery that surfaced in participants’ accounts knits neatly into the social fabric of internalized control characteristic of late capitalist society.

The sense of being watched while performing recovery led some participants to not disclose their eating disorders to others or ever talk about them publicly, for fear of people changing their perspectives on them or their behaviour. This suggests that the well-documented stigma associated with eating disorders (Crisafulli, Von Holle & Bulik, 2008; Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Easter, 2012; Roehrig & McLean, 2010) may continue into
Participants described vastly different ways of “being recovered” — ranging from following what might be termed “rigid” meal plans to eating intuitively to not considering the eating disorder to be a relevant part of their self-framing and thus not describing their current eating patterns. These varied practices of recovery lie in opposition to the predominant perspective on what constitutes normal eating in the treatment context and in tension with the often-unnamed ideal of eating in recovery (Olwyn, 2012; Eating Disorder Hope, 2012; Fowler, 2015). The idea that others might be watching to observe issues with the recovered person’s behaviour is problematic. In a society in which all bodies are subject to surveillance and to biopedagogies (Wright & Harwood, 2009) and these biopedagogies unduly impact those living in “bodies of risk” (LaMarre et al. 2017; Rail & Jette, 2015), it makes sense that one might not wish to invite greater surveillance and scrutiny, particularly if one is living in a body already called out along lines of oppression. The amplitude of surveillance is only increasing in a society in which all consumers are now made aware of the caloric content of food. Everyone becomes a possible surveilling agent, and target of surveillance, in this social nexus (Nayar, 2015; Peterson & Bunton, 1997; Rose & Novas, 2007; Trainer et al., 2017). Indeed, supporters also discussed the experience of being surveilled and expected to perform support in a particular way, which had often-negative impacts on both their own relationships with food and their perceived ability to interact with and support their loved ones.

5.1.5 Being Listened To.

In contrast to experiences of being watched, participants also described times at which they felt that their voices were deeply listened to by medical professionals, by others in recovery, and by supporters. This could occur within commonly surveilled contexts; wherever these experiences occurred, they lead to participants feeling legitimized in their struggles and allowed
them to develop a sense of community and support. The experience of being listened to was linked to the concept of safe space – space in terms of physical location and in terms of social and psychological connection to others and the world around them. Whether being listened to occurred in typically structured surveilled environments or not, participants’ experiences revealed how aspects of supporters’ interactional styles and desires for safety for their loved ones helped them to cultivate the openness and honesty many came to associate with a recovered style of being.

One way of framing this safety is in terms of affective spaces of care, or “affective economies” (Ahmed, 2004). In an affective economy, “emotions do things, and they align individuals with communities – or bodily space with social space – through the very intensity of their attachments” (Ahmed, 2004, p. 118). They connect people and things, rather than being, like emotions, inherent to people. In describing the active character of emotion, Ahmed continues on to choose the term affect to more dynamically configure the sensed, felt intensity of relational and social experiences. Configuring safety in relation to the care relationship in eating disorder recovery, we might consider which affective conditions enabled participants to connect and be open with some people and in some places and not others. Participants’ perceptions of supporters’ attunement to their needs, in connection with the safety of spaces created a situation in which participants were able to experience a shift in their own capacity to affect—and thus to be affected (Massumi, 2015). They could experience a greater degree of freedom, particularly if we think of freedom through an affective lens, where it is “not about breaking or escaping constraints. It’s about flipping them over into degrees of freedom” (Massumi, 2015, p. 17-18). In reflecting on how constraints may not be escapable but can be transformed (“flipped over”), Massumi explores the contingencies of freedom and their ever-tethered nature. Indeed, these
spaces and relationships may well have constraints—but constraints that participants experienced as more liberatory than closed and contingent.

Safe spaces were sometimes physical locations; many participants spoke about how they were unable to recover in spaces that felt stifling, that held remembrances of past trauma, or that were risky in terms of personal safety. Participants’ experiences of safety were contextualized against their individual social locations; there was not one single space all participants experienced as “safe.” “Being safe” took on a sometimes-unconventional character but was nearly uniformly associated with the sense of being listened to, not being judged, and being understood. Affective attunement—that is, the attunement to the particular needs and desires of participants in line with the particularities of their recoveries—scaffolded these emotional planes, enabling participants to change in subtle ways toward a place of greater subjective wellness. Participants could move, in these spaces, from being clinical objects to agents through different “affective enactments” (Lester, 2016, p. 2).

Sometimes safe spaces were physical; others found solace in safe digital spaces. Safety was configured by moving away from or toward more generative and inviting spaces from the perspectives of those seeking help. What was safe for one participant—for instance, meal plans—was unsafe for others. It is also worth troubling the implications of the term “safety.” Within the eating disorders literature, safety is often described as undesirable: making “safe” food choices in the treatment context, for instance, seen as playing into the eating disorder (ANRED, nd; Hart & Royster, 2016, Rollin, 2015). However, given the challenges of life, we can question whether perhaps there is a degree of safety that might help to protect people from needing to completely overhaul their relationships with food and their bodies completely from one day to the next. The sudden removal of coping mechanisms in overly rigid treatment systems
has the potential to lead to behaviours coded as rebellion rather than a commitment to recovery (Boughtwood & Halse, 2010; Malson et al., 2011a; Warin, 2006, 2010). This tension also featured in the subtheme of being watched. However, there is a fine balance between rigidity and freedom; participants’ responses indicate that rigidity *that matches their desires* can help to provide a degree of (positively construed) safety that allows them the freedom to explore other aspects of their recoveries beyond food.

Participants did not always find what they were looking for in treatment, particularly when they did not feel heard, respected, or believed. To reach a place of wellness, participants commonly needed to negotiate treatment protocols and pathways to meet their needs. Often, this resembled a piecemeal approach to treatment that brought together personal orientations to the eating disorder and to goals for recovery with clinical requirements for recovery. Participant’s pathways to recovery were “self-directed” in multiple ways: for instance, some were self-directed in deciding not to pursue treatment in clinical settings (see also Woods, 2004), while others described their experiences in formal treatment settings as self-directed, particularly when they perceived treatment as primarily about re-feeding or getting their weight up to a certain place and then leaving them to the space between ill and well.

Treatment settings are often spaces that remove people from their environments and require time to stop in order for people to pursue recovery (Eli, 2014; Lester, 2007); while this model may work for some and while treatment settings can be spaces that provide help and tools for recovery, it is not always realistic for participants to stop their world and pursue treatment. People in this position are often framed as being unmotivated or not being ready for treatment; however, participants’ accounts made this assumption more complex. Many described their decisions to not re-admit as being *because of their desire to recover “for good.”* The decision
not to return to treatment also reveals that the decision to attend treatment, which asks for a lot of sacrifices (monetary, etc.), is never an uncomplicated one and depends on a person’s space of social belonging. Again, the ways that participants’ accounts challenged dominant discourses on what “wanting recovery” and being “committed” to attending treatment looks like, and complicated the idea of “choosing” recovery.

5.1.6 Liminality.

In-between, or as it will be described here, liminal space (see also Eli, 2014, 2018; Lester, 2007), pervaded participants’ accounts and the way that participants oriented to spaces both surveilled and safe. As Eli (2014) describes, eating disorders treated on clinical units might be characterized by an experience of double liminality in that eating disorders are socially marginalized and hospital wards are spaces out of the normal that generate “alternative sensory worlds that permeate one’s own experience and self-definition as a patient” (p. 6). This liminality featured in participants’ accounts as they moved into the ambiguous space of “recovery,” an uncharted and ill-defined landscape of conflicting flows of information, affect, and time. Participants often described liminality—being caught in between, neither here nor there (Turner, 1967[1964] in Eli, 2014) prior to having their eating disorders recognized (by themselves or others), between diagnosis and treatment, between treatments, and between treatment and recovery. Lester (2007) also explored how treatment may itself be configured as liminal, a place wherein a transition from ill to well is taking place, abstracted at least momentarily from the world. Eli (2018) describes how this liminality may also sometimes be sought or desired—it presents the possibility of embodying “a lived state and a mode of being, an embodied drawing inward and away, at once within and without society” (p. 15) and perhaps a coping mechanism or even live-saving technique.
Building on Eli and Lesters’ observations about liminality on eating disorder treatment wards and in the embodied experience of eating disorders, we might consider how time unfolds—and enfolds—on and off treatment units to generate liminality in relation to recovery time. Complicating the linearity of time and the presumed spaces in which recovery trajectories take place, participants accounts speak to how thoughts and behaviours are not always neatly associated in a way that means thoughts lead to behaviours. Liminal spaces were not always treatment units; jumping off from accounts that describe embodied experiences of eating disorders and treatment as liminal (Eli, 2014, 2018; Lester, 2007), we might consider how liminal spaces beyond treatment might be configured as experimental—spaces in which participants experienced a forward-and-back motion they commonly reflected on as critical to their movement toward a configuration of recovery that worked for them. These spaces were decidedly more playful, creative, and dynamic than recovery-as-prescribed. This experimentation was not always easy or done with the support of helpful professionals. Sometimes liminality was imposed: for instance, liminality imposed by wait lists for treatment.

Here, participants’ experiences of liminality might be configured as polytemporal: a composite of “internal” and “external” ways of being in relation to time (Browne, 2014). Participants interacted with systems of treatment operating on neoliberal time logics that impose waiting—a practice of power that may paradoxically reinforce psychiatric distress (McWade, 2015). Making people wait—making people be patient—might be understood as “symbolic display of degradation” within a system that prioritizes “urgency and immediacy” (Zerubavel, 1987, p. 345). As participants waited to enter treatment or to be considered well, they were often simultaneously living at a different temporal frequency, experiencing time in a way that became quite difficult to articulate “after” the fact, as evidenced by their frequent drawing on the
memories of loved ones to complete their accounts of their recoveries. In a context that encourages constant vigilance and self-monitoring (Novas & Rose, 2000), this temporality might also be lived in relation to risk, in a kind of hyper-vigilance (Kafer, 2013). While we might, on the one hand, problematize a temporality of looking forward and backward to avoid psychologically challenging responses, we might also imagine it, as Kafer (2013) does, as a “strange temporality” that reflects “a different way of being in the world, a creative, flexible, and non-linear way of relating to time” (Morrigan, 2017, p. 56). In other words, for those who looked forward and backward, not necessarily in predictable ways (i.e., those who experienced flashbacks or constructed their realities and timelines in relation to others’ accounts), time might itself take a curved and looping trajectory, rather than a linear one.

Facing barriers to treatment also generated a sense of pre-treatment and pre-recovery liminality through the experience being stuck in time, neither here nor there, engaging but not fully engaging with “the real world” and “the treatment world.” Disjunctures in expected trajectories to recovery and expected timelines pushed participants into confusing relationships with others, with their bodies, and with systems. Participants were often asked or required to put their lives on hold to pursue treatment; this ask is imbued with a deficiency framing within a system that positions “those who cannot perform their state-defined ‘duty’ [as] morally suspect” (Skeggs, 2004, p. 82). Even before being diagnosed or asked—if not demanded—to step off the normalized linear trajectory of time logics, participants experienced loops of time in relation to their eating disorders, or a suspended animation between realizing the problem or the extent of distress in their lives and reaching out for help with it. Unlike the way that decisions to seek help have sometimes been described, for instance as a moment of realizing that one needed to make a change out of one’s own desire to get better, participants’ accounts were much less utopic.
Though sometimes the decision to seek help fits this narrative, some described the decision to seek treatment as being borne of not knowing what else to do. As participants “lived time” (Urry, 1995) in relation to their eating disorder and recovery, they experienced a kind of “dislocated presentism” (Jameson, 1984) or liminality (Eli, 2014, 2018; Lester, 2007) wherein their embodied narratives were flattened into multiple and non-reconcilable temporalities.

Liminality was compounded in the spaces in between treatment and “real life” – treatment settings were most often highly surveilled spaces, which participants sometimes experienced as simultaneously freeing and constraining (Eli, 2014). Lester (2007) describes treatment as liminal; in treatment, “a client moves from a locally construed “sick self” to an imagined future “healthy self,”” (p. 370). The stories of participants explored in this dissertation indicate that this liminality continues into the post-treatment/acute distress phase, and in relation to social discourses on body and health. Rarely did participants have significant support in making the leap from this space to a far less surveilled one in which they were expected to suddenly make all the decisions for themselves. In this way, choice features more strongly in the imagination around those with eating disorders and treatment; eating disorder recovery is more explicitly configured as based in choice in this space, where if patients “choose” not to eat, they are left without this form of support and discharged (Lester, 2016). An epidemiological or contagion discourse (Allison et al., 2014; Crandall, 1988) is commonly employed as justification for this discharge: on the one hand, there is a fear that “refusal to eat” will breed amongst other residents of the unit, and on the other, the spot is seen as being offered to a person who “wants” the treatment more, as is evidenced by their agreement to follow the imposed protocols on the unit. Choice on the typical adolescent unit is largely absent, a practice deemed to be in line with the developmental capacity of the teen with an eating disorder (e.g. Lock et al. 2001). Resistance
is expected, not only because of the aforementioned subsuming of identity into that of the eating disorder but also because of the developmental stage of adolescence’s association with resistance and rebellion. Indeed, others (e.g. Gremillion, 2003) have written about the intersection between developmental discourses and eating disorder treatment in adolescence (Pickhardt, 2013); a degree of resistance is even built into the expected trajectory to recovery (through the individuation process), which maps cleanly onto developmental theories (Gander, Sevecke & Buchheim, 2015).

The transition from adolescent to adult treatment, or adolescent treatment and adult life, felt equally jarring for some participants, and ties into constructions of people with eating disorders in general. Those with eating disorders here also become constructed as sub-functional adults, without a recognition of the ways in which systems have contributed to an “inability” to make choices often taken for granted by those without eating disorders – such as “normal eating” or how to eat in general. Without adequate transitional support, liminality between treatment and “the rest of life” was described as a challenge by participants. Even when not transitioning from adolescent to adult treatment, participants encountered challenges related to a lack of support during transitions: the transition from treatment to home was one of the biggest hurdles in the pursuit of recovery for participants in this study.

The disjunctures between the treatment space and the home space might help to at least partially explain the liminality of the transitional experience. A common way of accounting for difficulty staying well after discharge is to explore the extent to which individuals apply what they learned in treatment, the extent to which they have a support network, and what their goals are, contrasted with feelings of loss of connection, self-defeating beliefs, and the stressors in their environments (Cockell, Zaitsoff & Geller, 2004). While these factors impact the transition
experience and include both individual and environmental factors, they do not fully account for the fluid and dynamic experience of bodies in between illness and wellness.

To explore at the boundary of embodied recovery, we might also look at how people in transition negotiate and experience conflicting discourses on agency and choice in relation to levels of surveillance in different spaces. In the treatment space, the patient is configured as a person unable to make choices, subject to surveillance that, as noted, can function as positive and/or negative influence in their life, often both (Lester, 2007, 2016). In the rest of their lives, particularly when their bodies are not read as eating disordered and/or people do not know about their eating disorders, people are expected to behave in line with neoliberal, postfeminist discourses of choice (e.g., Rabinow & Rose, 2006; Riley et al., 2017). This move from being constructed as incapable to being expected to make all of the choices (in ways that produce the right bodies) goes beyond simply moving from an environment of surveillance to one of freedom; there is surveillance and freedom in both spaces, both self-surveillance and other surveillance. However, the nature of expected agency and choice directives shifts in the balance; there is a movement from an environment of explicit care in which participants’ bodies are disciplined through clinical care (Lester, 2016) to a space in which discipline is expected to emerge from the self (Rose, 1999). While in treatment, the onus for recovery is on the person (Adeponle, Whitley & Kirmayer, 2012; Duff, 2016); still, where eating disorder recovery in particular is concerned, this self-responsibilization is generally juxtaposed with a context of alleviated choice and control.

In a way, the treatment space operates as a space where time and choice are suspended—or dictated from clinical teams (see also Eli, 2014, 2018; Lester, 2007; 2016). Again, participants—and their supporters—were often asked to stop engaging in all activities other than
the pursuit of recovery, with little attention paid to the possible material consequences of doing so. This suspension of time leads to only a certain kind of time occurring in the treatment context: treatment time, highly dictated by treatment professionals. The treatment space is a space out of neoliberal time but also managed by a recovery time that itself embodies discourses of rehabilitation and cure (Duff, 2016) and that is predicated on an individualistic worldview (Adeponle et al., 2012; Harper & Speed, 2013; Topor, Borg, Di Girolamo & Davidson, 2011).

This temporal disjuncture may be particularly challenging in a day-to-day sense in day treatment style approaches, wherein participants spend the day in suspended time only to rejoin time that has not stopped in the meanwhile. Moving from a suspended space to a forward-moving one—one that acts on neoliberal, productive time—might contribute to a problematic encounter for participants, but not one that is processed in the treatment space; not one that is often explicitly acknowledged as liminal by clinicians. This liminality has implications for how the “after” is attended to, as exemplified in participants’ accounts. Perhaps the liminality is unavoidable; any intensely delivered treatment modality necessarily centres around attempts to “solve” the presenting issue. When this is the case, participants’ accounts reveal the disconnects that can occur in terms of time and safety of various spaces. They revealed how these might be reconciled at least partially by an acknowledgment of the multiple trajectories of time in operation. Doing so might allow for a vision of recovery not predicated on discourses of chronicity and/or solution, but one that sees “recovery as an emergent capacity to manipulate the affects, signs, spaces and events of a body’s ‘becoming well’” (Duff, 2016, p. 58); neither simply restoring health nor becoming chronic (Duff, 2014, 2016).
5.1.7 Recovery as Life.

Participants nearly uniformly described discontent with the ways in which recovery is represented and understood by a number of audiences, including healthcare providers, the general public, family members, friends, and others in their lives. They often felt ill-equipped to enter into the recovery space because the articulations of recovery they had encountered did not capture the struggles associated with recovering from an eating disorder (see also Holmes, 2016). Eating disorder recovery was not only about more than weight, as is so often mentioned in the research literature (Bardone-Cone et al., 2010; Noordenbos, 2011a; Noordenbos & Seubring, 2006), but was also not the single most salient part of all participants’ identities, not always “proven” or “performed” through the expected trappings of success, and not always an easy and linear pathway. This contrasts sharply with a framing of recovery that centralizes the importance of recovery to a person’s identity and foregrounds the ways in which recovery means, for instance, “becoming whole” (Jenkins & Ogden, 2012).

Recovery could not be defined as a choice made by weighing alternatives and enacting health as expected under a neoliberal rhetoric. Flows of power and privilege, representation, and temporality informed recovery pathways in a way that complicates a simple choice-to-be-whole narrative so commonly associated with eating disorder recovery. Rather than replicating this narrative of redemption through eating disorder recovery, many participants’ accounts reveal that recovery is ever-changing and shifting in relation to the rest of their lives, co-influential with and “sustained by broad networks of humans and nonhuman entities (Price & Epp, 2015)” (Price-Robertson et al., 2017, p. 6). This perspective on recovery as life and without a specific, linear timeline lies in tension with even narratives of recovery that configure recovery as a forward-and-backward motion toward a finality (Lamoureux & Bottorff, 2005). Participants were
sometimes unsure what they were ultimately aiming for, or what recovery would look like for them; they reported varying degrees of comfort with this idea.

This is not to say that some participants did not take joy in their recoveries, wish to contribute to the eating disorder community by sharing their “success stories” or sometimes find hope in others’ stories. Some participants also *did* articulate a more “traditional” version of recovery, where they were “free” in the expected ways. Those participants often still reflected on how their privileges had afforded them the choices in recovery and resources not made available to all. These perspectives are likely at least in part related to how participants were recruited for this study: participants had something to say about recovery that they felt had not yet been captured in the literature, whether popular or scholarly.

By recruiting for not only participants who had already received a seal of legitimacy for their recoveries, I found participants who were, at times, unsure of what or where they “were.” Some participants were occasionally engaging in symptoms that would be coded as eating disordered; others questioned weight thresholds that had been suggested for them by professionals. Some had not received treatment for their disorders and had recovered with the help of more informal supports. In these cases, participants did not engage “as expected” with the medical-psychiatric complex, and thus had no “proof” for their recovery. Others sought proof for their recoveredness in popular depictions of recovery and found that they did not cleanly fit into the before or after, again speaking to experiences of liminality for those neither “normal” nor “pathological.” Recognizing their “abnormality” around food, but not diagnosed along medical lines, they became liminal in their expression of “abnormal abnormal” (McClintock, 2000) behaviours around food, weight, and shape. Their behaviours were such that they significantly impacted their lives, but were not deemed “medically significant” to the extent that
they might receive a diagnosis, which carries a certain seal of legitimacy (Eli, 2014). In recovery, participants may also become trapped in between normal and abnormal, a state mediated by others’ perspectives on both their corporeal presentations and their behaviours around food in relation to social norms. This liminality is compounded by a significantly lacking consensus on what recovery means (Bardone-Cone et al., 2010) that results not in an opening to different ways of “being recovered” but rather participants’ subordination to the particular perspectives on recovery espoused by individual clinicians, loved ones, and people in the general public—which may or may not conflict (Holmes, 2016; Noordenbos, 2011a,b). On the other hand, the consensus itself may operate as another kind of regulatory ideal. Participants’ self-questioning itself reveals the tenacity of clinical discourses around eating disorders for delineating illness, wellness, and legitimacy.

Participants sometimes measured themselves against popular accounts of recovery and/or clinical ideals for recovery and found themselves wanting. However, some participants chose not to measure themselves against these accounts, instead distancing themselves from anything to do with eating disorders and recovery. This also speaks to the difference between the sample recruited for this study versus samples typically recruited for recovery studies. I did not define the need to have, or not to have, sought professional treatment for the eating disorder, the need to have been diagnosed, or the criteria I was using to define recovery. If I had, I would have found a population that matched my particular vision of recovery, as opposed to allowing the participants’ accounts to construct a vision of what recovery “is.” In a study designed to explore what recovery looks like for diverse people, the need to avoid imposing my perspectives on what recovery looks like certainly did result in speaking with participants who would not have been considered recovered by the medical-psychiatric complex. It is important to note, however, that
the focus of the study is not to establish a set of criteria that will allow us to assess the legitimacy of participants’ recoveries. Establishing such criteria might have practical value, allowing us to better assess, for instance, when people are ready to leave treatment (Bardone-Cone et al. 2010). However, establishing a set of fixed criteria lies in opposition to a point of view that considers recovery to be interpersonal, dynamic, and co-influential with context (Duff, 2016; Price-Robertson et al., 2017).

As articulated in the results section and above in the discussion, people with eating disorders are not assumed to be trustworthy sources (Eli, 2004; Holmes, 2016; Malson et al., 2004; Malson et al., 2011a; Saukko, 2008, 2009); they are not assumed to be capable of making choices in their own best interests—until they are thrust into circumstances in which they are expected to make all choices. Paradoxically, “recovered people” should, using a logic of cure, be restored of their rationality and thus trusted to assess their own recoveries, but given a) lack of agreement around the point at which this occurs and b) whether it does, or people remain “in recovery” forever, the point at which the person’s own account is trusted rarely occurs, particularly for those whose embodiment transcends the normative. This tension orients us to the complexity of looking at recovery, as well. Participants’ accounts are not necessarily representative of some inner truth of their experiences of recovery any more than we should not assume that a clinician or loved one’s perspective is necessarily “more accurate.” This is not to say that participants are not telling the truth; rather, it offers a contextualization of the idea of voice and truth and choice within social milieu that firmly bounds all of these. All voices in defining recovery are a product not of some autonomous expression of reality or truth, but rather an assemblage of experience, expertise, power, and embodiment.
5.1.8 Embodied Recoveries.

In reflecting on their recoveries, participants noted that recovery was only talked about in a very general way in their treatment settings, if they attended treatment. Most commonly participants reported the word recovery, but not its meaning, to have been described to them. This left them with a number of ways to determine when they were or should be (in the clinical imagination) “recovered enough” using a number of proxy measures, including: weight gain, discharge from treatment, or a proposed timeline shared with them by healthcare providers. When participants did report having discussions about the timeline for recovery or an idea of what recovery would entail, they primarily remembered the specific numeric timelines put forward by clinicians. Participants were often uncertain about their recovery timelines; they did not always trust their accounts, despite having embodied or visceral memories of the experience of recovering. Elsewhere, theorists have explored people’s embodied memories of eating disorders that impact their embodied presents (e.g. Eli, 2016). Like in Eli’s (2016) study, participants’ memories “arrived suddenly, flashes of the past made present” (p. 80) and were relational and systemically-embedded. However, while for Eli’s participants the memories helped participants to bridge self-conceptualization in the past and present, for participants in this dissertation study these memories were not always held as trustworthy, as the constructions of people with eating disorders as unable to be believed discussed above worked their way into participants’ interpretations of their own experiences. Here, memories were often disruptive to lived, embodied, present “realities,” disrupting participants’ expectations for linear recovery set forth in the popular imaginary.

Exploring bodies in time allows us to probe normative assumptions about when bodily distortion begins and ends in eating disorders and recovery and poses questions about when, why and how to discuss these issues with patients seeking eating disorder care. It also enables a
probing of the temporal boundaries of recovery itself—whether one is recovered, always-actively-in-recovery, or always-passively-in-recovery, in the sense of remission. Given a) the tenacity of assumptions about body image and body distortion around eating disorders b) the commonness of the questions “when will I be recovered?” and “when will my body image issues resolve?” amongst those with eating disorders in treatment settings, we might look at the ways that participants report their experiences of body in time and the flows of information they have deemed as trustworthy sources to inform their constructions of their own recovered/ing bodies.

Eating disorders might be positioned outside of normative time to explore how memories about eating disorders are constructed intercorporeally; how multiple temporalities might coexist in participants’ recovery accounts (Browne, 2014). Participants constructed their memories in relation to supporters’ perspectives on or memories of their bodies, specialists’ perspectives on their trajectories, and the imagination around what an eating disorder trajectory is and what constitutes recovery. The recovery “event” becomes less about an individual’s striving to wellness and more about an assemblage of factors and people that open and/or constrain the possibilities of recovery (Duff, 2016).

In general, the person with an active eating disorder is the least trusted in the memory construction task; their brain is interpreted as starved and thus unable to be trusted. There is no imposed temporality on this distrust of “the anorexic brain” implied in the literature and/or the popular interpretations of this literature. There is, however, the enduring construction of person-with-eating-disorder as someone not to be trusted or believed (e.g. Eli, 2014; Lester, 2007, 2016; Malson et al., 2004; Saukko, 2008, 2009) that may continue into the recovery space, as participants’ stories showed. Participants are thus faced with options for whose versions of their corporeality and memories to believe – their own, which may be foggy and fuzzy and perhaps
distorted, or those of others in their lives in supportive capacities, whether those people are clinicians or loved ones. Arguably, the more highly surveilled the body, the less their version would be seen as “counting” or trustworthy.

5.1.8 Embodying Wellness.

The refrain of “fat is not a feeling” is a familiar one to those who have eating disorders and/or are attempting to recover from them. This phrase, while well-intended, discounts the materiality of fleshiness and does little to offer alternative orientations to that corporeality. As embodied experiences are not constructed in isolation, we must also consider participants’ changing orientations to the concept of body image and embodiment as they experienced treatment and into recovery. Normative trajectories of treatment entail many encounters with clinical articulations of what body image and distortion “look like” for people with eating disorders. These encounters are also narrowly characterized by a focus on the visual, as opposed to the interoceptive (Emanuelsen, Drew & Koteles, 2015) and emotional (Damasio, 1994, 1999; Herbert & Pollatos, 2012) aspects of felt embodiment. Again, those with eating disorders, framed as they so often are as untrustworthy and dishonest, are assumed to be in distress with what their bodies look like no matter what they report; they are expected to be deeper in thrall to bodily discontent (Bray, 1996; Holmes, 2016; Levitt, 1997). This may or may not feel “true” to participants, as is evident from the varied ways in which participants described their bodily relationships and memories of being embodied as children, into adolescence, and “before/during/after” their recoveries. Regardless of how true this feels, participants are presented with the traditional linear view of what the course of an eating disorder looks like, in relation to body image: feel bad about body, complete exercises that deconstruct the ideal body and challenge distortions, feel at peace with body.
Returning to a consideration of timelines to recovery, this trajectory is complicated by participants’ varied understandings of how their eating disorders began, how body image and sensation featured in their experiences, and whether or not distortions endure into recovery. Those who reported not having body image issues nearly uniformly described feeling as though they did not belong in treatment or were not sick enough to warrant treatment. The degree of tenacity that the discourse of a linear body image/eating disorder trajectory holds forecloses this option for some. When these individuals do seek normative treatments, they often describe feeling unsatisfied by the extent to which treatment explores bodily sensation and body in relation. Further, nearly all of the participants in this study reported feeling discontent around the widespread assumption that eating disorders and body image were deeply entwined, regardless of whether or not they felt this was true for them. This reveals an interesting tension, again, around legitimacy: they had been told by those who hold the positions of power that allow them to define the ill/legitimacy of their disorders that eating disorders are related to body image. Over time, many came to incorporate this into their understanding of their own eating disorder. However, the conflicting experience of not/always feeling that this was their experience and the dissatisfaction with the depth of addressing body in treatment led to a more general articulation of discontent around how eating disorders are treated in the dominant imagery.

The rejection of a picture of eating disorders as solely tied to body image also links to a perception about the seriousness of such concerns in the public imagination. Removing the body image criterion gained importance for participants as they sought legitimization of eating disorders in the public eye—and body image concerns, as feminized discourses, are not “taken seriously” as worthwhile concerns. Distancing oneself from this concept then makes sense from a perspective of the desire to be trusted and believed.
Returning to the lack of overt discussion about what recovery would “look like” in clinical settings, this lack of description may be due to a fear on the part of clinicians to articulate a vision of recovery that is not in line with participants’ realities; of course, it is beyond the scope of this dissertation to comment on clinicians’ reasons for not explicitly discussing recovery and the image of recovery. However, in the lack of discussion, other actions and decisions in the treatment space become read as indicators of when participants are considered to be moving forward in their recoveries. Related to the theme of liminality in eating disorder recovery, some participants described the abrupt rupture of treatment alliance upon the termination of eating disorder treatment, which may be read as the assumption that one should be recovered and able to “function normally” immediately following hospitalization. Often, participants were told that the “real work” of recovery occurs after treatment, but not provided with the resources to do this work. They may have been informed that they were not to expect to be fully recovered upon leaving treatment, but this statement lies in opposition to the stoppage of support in a way that once again leaves patients in a liminal space between ill and well that is not accounted for in the social imagination about how to act on one’s body in accordance to health directives.

5.2 Supporters and Healthcare Providers

5.2.1 Relational Entanglements.

The expectation that all people in eating disorder recovery will have support, particularly from their blood and/or legally related kin, might lead to additional recovery expectancies that limit our imagination around who is recoverable. Families are important to the recovery process insofar as “being a part of a family can profoundly shape the material, social, discursive and affective organization of peoples’ lives, which in turn has implications for the ways in which their mental ill health manifests, is understood and managed” (Price-Robertson et al., 2017, p. 3). However, in speaking to participants about their support experiences, many were unable to
identify a supporter in their immediate family reconfirming the importance of moving beyond
the primacy of the nuclear family as supporters de facto. This is not to say that this kind of
support never exists or that families are pathological, somehow producing eating disorders and
leaving their children to manage them alone. The relational complexity of families, however, has
been undertheorized in imagining support configurations. Throughout the literature, we see the
association of “supporter” with “family,” or, more particularly “parent” — if not “mother” — in a
way that may also elide the experiences of those who do not fit this description. This association
is also imbued with expectations around the gendered division of care and the emotional labour
that women continue to contribute in many relationships. Support from supporters both
immediately related and not has elsewhere been deemed the “family assemblage” (Price & Epp,
2015), a term that makes room for multiple flows of relationality into and out of the support
network in recovery. Family assemblages are not static, but rather dynamically constituted and
constitutive throughout the process of recovery (Price-Robertson et al., 2017); this perspective
also helps to account for the different relational configurations that participants found more or
less helpful throughout their stories.

Contrary to the focus on nuclear family in the eating disorder literature, many participants
identified non-related supporters when asked to choose a supporter to join the study. Of the
supporter participants interviewed, six were partners. All of these partners were young men
between the ages of 20 and 40, who had been with their partners for varied lengths of time,
ranging from less than a year to 10 years. Interviews with these young men revealed
complexities around supporting partners with eating disorders, including the challenge of trying
to empathize with a highly gendered experience, navigating sensitivity and masculinity, and
managing privacy concerns with a closely related set of friendships. The young men’s stories
resonated with broader societal discourses around masculinity and caretaking; the young men were often identified (both by themselves and by their partners) as the sole strong supporter, again contravening expectations around who might be a supportive other or constitute “family” in eating disorder experiences and into recovery.

Age and developmental stage likely play into the choice of partners as primary supporters. The bulk of the literature about caregiving for eating disorders reflects on the experiences of younger people with eating disorders, often adolescents (e.g. Lock & LeGrange, 2015; Lock, 2015). In this study, participants were mostly young adults, often building and living their own lives, rather than being cared for by their parents. At the same time, many participants had struggled with distress around food, weight, body, shape, and exercise for many years, including their adolescent years. They often described their relationships with their parents as significantly impacted by these experiences—to the extent that some had completely stopped discussing their eating disorders with their parents. For many participants, not discussing the eating disorder with parents became a strategy for ensuring the continuation of some kind of relationship with their parents. Even when still living with parents, some participants described the eating disorder as a topic of conversation off limits, even when it came to discussing recovery. Instead, these participants saw their partners as better able to navigate the complexities of their recoveries-in-progress with them. This might in part be due to the partnered relationship in contrast to a parenting relationship—a co-building experience where partners could articulate their needs and desires for the supportive relationship, rather than negotiating long-ingrained patterns of interaction. Partners are also not socially inscribed with responsibility to the same extent; they are coded as witnesses or bystanders more readily than culprits.
Because many of the supporters in this study did not fit the stereotype of who might be supporting someone through an eating disorder, they did not themselves seek support in the expected places. Looking at the landscape of support for caregivers of people in recovery, it is worth noting that there are few examples of partner-specific support, particularly for those in recovery, as opposed to those in active treatment for their disorders. While some examples exist of programs designed to support partners and enlist them in the care of their loved ones—such as Bulik’s work in North Carolina (U-CAN, Uniting Couples in the treatment of Anorexia Nervosa, Bulik et al. 2011)—these programs are rare, often tailored to those undergoing treatment, and sometimes specific to a particular eating disorder. The young men supporting their partners in this study often reported that they did not have any support at all as they tried to help their partners navigate the complexities of the recovery landscape.

A part of this lack of support was tied to the young men’s hesitancy to seek out support for fear of breaching their partner’s privacy. Often, partners in recovery were not “out” or open about their eating disorders with friends and/or family; accordingly, the young men did not want to infringe on their partner’s choices by disclosing the eating disorder to anyone, particularly when they shared friend groups with their loved ones. A particularly interesting relationship configuration relates to partners-in-recovery who had stopped talking to their relations about their eating disorders—or whose families were skeptical or unsupportive around the eating disorder itself. Partners reflected on how they were better able to manage the uncertainty of recovery than were family members, with whom discussions of recovery would lead to upset or fear. In a way, partners in this circumstance were supporting their partner, but also the partner’s family, by avoiding upsetting the family members or unnecessarily worrying them. Perhaps because they were speaking with their partner more regularly or were more comfortable with
recovery as a non-linear process, these supportive partners felt better able to manage—without significant distress—the ups and downs of the recovery process.

Partners were not completely without fear about their partner-in-recovery’s trajectory or progress. On the contrary, partners expressed longing for their partner’s overall wellness, and expressed the frustration they had felt over the course of the disorder and into recovery around sometimes not knowing how best to intervene or support. Often partners sought reassurance that how they were helping was “right”—both reflecting on how they sought this reassurance from their partners and/or their partners’ more formal supporters (e.g. therapists) and also, at times, asking me as interviewer whether it seemed like they were doing enough. A recurring theme for what partners-in-recovery found helpful was their partner simply “being there” with them, not necessarily trying to fix anything. And yet, the partners often doubted that this was truly enough.

This question of “whether their support was enough” is also tied up in dominant constructions of masculinity and protection over their partner. As Nikunen (2016) reflects, the dominant mode of expressing care for those embodying masculinity is that of the “rescuing heroes who are able to solve a range of problems” (p. 173). Interestingly, participants in this study did not seem, by their own report or those of their partners, to provide this kind of pragmatic, solutions-based, masculinized support. Instead, the value they described in their support was their ability to be with their loved ones through struggle *without* trying to “fix” them. More so than others participants had encountered, they were able to deliver a kind of empathetic concern without expecting that it would necessarily lead to a particular version of recovery (Lester, 2016). However, in their interviews with me, partners *did* express a desire to “fix”—more in line with a patriarchal or classically masculine model of care—and a desire to
know more about whether they were doing the “right thing,” a kind of yearning for pragmatic support acknowledged elsewhere in the caregiving literature (Perkins et al., 2004).

While I was surprised to find that participants often nominated chosen kin over their families of origin, there were some who identified supportive parents and siblings. When I spoke with parents, I was struck by the amount of emotion that the discussions yielded. This was not surprising; when reflecting on an experience that put their children in danger of losing their lives, it is not shocking that a parent would feel distressed. The way my methodology worked is important here in interpreting the extreme distress and emotionality of parents’ stories. I was speaking with parents whose support was seen as effective and helpful by the people in recovery with whom I spoke. Often, the parents who were described as less helpful or supportive were deemed explicitly unhelpful by their children, sometimes even harmful. Entering this statement into a canon of eating disorder literature that historically demonized or blamed parents feels risky, but it is not a question of parents being “to blame” for their children’s eating disorders. I wish to nuance this point in a number of ways.

Firstly, the parents I did not speak with were not necessarily implicated, by their children, in the causation of the eating disorder. There may have been other reasons for the participant to not suggest that I speak with the parent, including but not limited to the parent not wishing to be interviewed. I cannot speculate on the reasons for which the participants selected the people they did for interviews as I did not specifically ask. Participants had varied relationships with their parents during their disorders and into recovery, but often noted that their families were not particularly unhelpful with respect to food and/or body image in general, or that there was necessarily significant family trauma in their lives. While several participants did cite trauma as inciting factor in their eating disorder, they did not specifically ascribe this trauma to their
families of origin. The ways in which participants described their families of origin as unhelpful largely centered around their family’s: a) orientation to the concept of mental illness in general or eating disorders in particular and/or b) the person in recovery’s sense that their eating disorder was “too much to handle,” emotionally, for their parents. The reasons that participants distanced themselves from their families of origin often revolved around this idea that they were protecting their family members, who had enough concerns of their own without dealing with the eating disorder and the complexity of recovery.

The way that a misunderstanding of eating disorders plays out in relation to the recovery landscape and participants’ decision to distance themselves from their family of origin is important to unpack. When participants suggested that they did not talk about their eating disorder or their recovery with their family members, they often specified that their family members were skeptical that there had ever really been a problem in the first place or that there were significant events going on in the family that struck the family as more important, for instance demanding economic circumstances. They also hesitated to discuss recovery in particular with parents or to be honest about the non-linear quality of recovery because of the fear that their parents had about the possibility of a relapse. Instead of hiding the fact that recovery is not always rosy and perfect in discussions of eating disorders with their families, these participants chose instead to avoid talking about it altogether. Particularly once they occupied bodies that were socially read as normal, they chose to simply leave the questions unasked and treat the recovery as “accomplished” rather than as a process. The reactions that family members might have to the idea of a symptom happening while in recovery felt more distressing for these participants than just managing the experience alone or with other supports. This has an interesting relationship to splitting subjectivities in recovery; while in some areas of
their lives, participants continued to think through and orient to themselves as recovered, in other settings they downplayed the importance of their recovered status, focusing instead on other aspects of their lives.

The ways in which this splitting contravenes a traditional caregiving dynamic between parents and children is worth noting and putting into conversation with the experiences of supporting a person through recovery that emerged from interviews with parents who participants did perceive as helpful. This dissertation is not about what makes a “good supporter,” but the ways in which those parents deemed as helpful challenge dominant notions of care are worth lengthy comment. For participants in recovery who did not nominate their parents as helpful supporters, there was an emerging discourse of the need to protect parents who they either feared were too fragile to accept the reality of recovery’s complexity and non-perfect nature. Those who did nominate their parents, however, noted the importance of the instrumental support these parents were able to provide – for instance, planning meals, etc. – and their “being there” for the participant in recovery without trying to fix things all the time.

Those who talked about their parents that they had not nominated as supporters were, in contrast, described as becoming overly surveillant upon any suggestion of eating disordered behaviour or trying to immediately intervene when participants might prefer someone simply listening to them. This reaction might be easily justifiable; traditionally, we might think about the parenting reaction of one of trying to make the child’s life easier. As the children in question aged, however, this response felt stifling—often especially so for children who had repeatedly cycled in and out of treatment settings that strictly monitored their every move in the name of fixing. This extreme surveillance felt, for some participants, replicated in their home lives to the extent that they could no longer talk about their disorders. They were also attuned to the
challenges that the eating disorder had brought to the family dynamic, and so, as they became adults themselves, they took on the role of protector themselves.

Participants’ attunement to the family’s upheaval during the eating disorder was not off-base – similar to other accounts of the eating disorder in family life (e.g. De La Rie, Van Furth, De Koning, Noordenbos & Donker, 2005; Hillege, Beale & McMaster, 2006; Whitney, Haigh, Weinman & Treasure, 2007) family members including both parents and siblings interviewed for the study noted the extreme distress that the eating disorder wrought in their family environments. They reflected on the feeling of fearing for their child’s life, trying everything possible to get their child well, and often feeling lost in a complicated system that makes little space for various circumstances. The idea of blame also circulated in interesting ways in the parents’ words: they reflected, for instance, on things they might have done better, while also citing examples of their good parenting.

Importantly, we might explore the potential that good parenting and good ED-caregiving might not necessarily be coterminous. Treasure & Nazar (2016) explore the ways in which a parent might develop skills at being simultaneously surveillant and empathetic. Parents might be engaged in behaviours that might not “under normal circumstances” be considered “good parenting,” but might be necessary for the acute care situation. However, caregiving for eating disorders, particularly when it takes place with adult children, might also be considered a “fraught politics of care” (Martin, Myers & Viseu, 2015, p. 3 cited in Lester, 2016, p. 2) and the practices and discourses deployed within this fraught politics might contain contradictory messages “about which lives are worthy of material investment and care, and which lives are, instead, ungrievable” (Lester, 2016, p. 2). We cannot abstract care (e.g. Lavis, 2015; Lester, 2016; Martin et al., 2015) or parenting (Bonner, 1998) from power, nor, in the context of eating
disorders and recovery, from the biopedagogical messages about health that circulate and impact individuals involved in the caring assemblage. The strategies that supporters in this study employed to navigate and account for their caring exist at the boundary between respecting the person with the eating disorder’s desires and needs for their recoveries and awareness of the broader discourses about care, eating disorders, autonomy, and power with which they came into contact.

5.2.2 Temporalities of Family-Based Treatment (FBT).

While an externalizing framing (i.e., being “against ED”) may be helpful for parents in terms of helping them to engage in different modes of relation with their children than their normal ways of interacting, in times at which they see their child transformed, the implications of the framing for the trust of the person in recovery might also be considered in light of the lack of transitional programming for people in recovery. If we continue to use FBT as an example, there is a focus on offering control back to the person in recovery; more so than in other modalities, there is a transitional process proposed where choices are gradually offered back to the child (Lock et al. 2001). This, however, reflects FBT as prescribed, rather than the lived reality of many people accessing eating disorder care and might be considered in light of: a) the fact that trained FBT practitioners are few and far between given that therapists also face barriers to implementing FBT and treatment centres claiming to offer FBT are not always offering FBT as prescribed (for numerous reasons including lack of funding) (Couturier, Kimber, Jack, Niccols, Van Blyderveen & McVey, 2013) and b) the resource requirements of FBT for parents involved in its delivery (LaMarre, Robson & Dawcyzk, 2015; Rienecke, 2017; Treasure & Nazar, 2016).
The first point is relatively self-explanatory; while in theory FBT involves significant training for parents in offering control back to their children, this does not always materialize in certain programs claiming to offer FBT (Couturier et al., 2013). Further, FBT follows a linear time logic in which those in recovery are expected to follow a path from being subsumed into the eating disorder (which at that point can be fully externalized) to being emancipated from its grips. The expected trajectory of FBT follows an expected trajectory of adolescent development; there is little room made for deviations of course that might interrupt a flow from controlled to intuitive eating; from nurturance to individuation—problematic in itself from a gendered perspective. Complicating the FBT trajectory still further, in Canada at least, there are few practitioners who offer FBT. Even fewer are covered by provincial healthcare. Resultantly, supporters commented on their experiences of needing to quit jobs and/or relocate for treatment. If the family needs to return to work during the transitional phase – or, arguably, even if they do not – supporter-participants described little being offered in terms of practical help for re-envisioning the child’s subjectivity as a whole person beyond the eating disorder. Even when the eating disorder is seen as resolved, there may be a lingering framing of the person in recovery as controlled by their eating disorder or never fully able to be “normal.” Skepticism about recovery status may endure long into recovery; behaviours may continue to be interpreted as tied to the eating disorder even when the person constructs themselves as distant from that aspect of their lived experience.

The watchful and skeptical orientation to eating disorder recovery appeared to be less common amongst those who haven’t sought out or been offered support themselves – specifically partners. The construction of eating disorders as “Ed” is largely tied up in clinical discourses around eating disorders, to the extent that those who prefer to not engage with this
construction and the anticipated surveillance of “Ed” may choose not to engage with clinical help for their eating disorder. Partners may also orient differently to the supporter role, and to the idea of “Ed” as enduring. Partners described challenges in accessing formalized support and/or chose not to engage in formalized support out of a desire to let their partner take on that aspect of their lives on their own and to support them in other ways the parent and partner roles in supporting someone through recovery are differentiated not only by their different access to professional supports but also by the fundamentally different care relationship embodied in a parent-child and partner relationship.

The parent-child relationship carries a different expectation of direction or care than does the partner relationship; parents may feel socially and personally responsible for their child’s life and happiness. Partners may also be deeply invested in their partner’s health and happiness, they may not face the same social dictates around responsibility for their partner. The care relationship is expected to be two-way in a partnered relationship. There may also be a gendered component to the different orientation to providing care in the recovery context; all of the partners interviewed (6) were men. Socially, emotional labour is differently configured for men; women are expected to bear the majority of the emotional labour within relationships (Hochschild, 1989; Morris & Feldman, 1996). As such, men may not be expected to take on their partners’ recoveries in the same way that parents, particularly mothers, might be expected to engage.

This is not to say that partners did not care about their girlfriends’ or wives’ recoveries; socially, they were not made responsible for its achievement. On an individual, personal level, the men I interviewed were deeply invested in their partners’ recoveries and often sought ways of learning about how to provide appropriate support or even asked me for reassurance that they
were doing the “right thing” as they supported their partners. Unlike mothers interviewed, however, the men I interviewed did not inhabit as socially fraught a caring space as mothers did. Their actions might even be praised as exemplary displays of sensitive masculinity for their lack of general representation. This is not meant to problematize their behaviour or care work, but rather to suggest that we might call for more representation of different ways of caring for those in recovery. The partners also cared in ways that might be constructed as open – largely embodying a listening stance and citing love as their main way of – and way to – provide care. These differences in the delivery of care and orientations toward support between partners and parents, and between differently gendered people, might be explored in more depth in future research to draw out the subtleties of the framing and experiences of those involved.

5.2.3 Different Conceptualizations of Recovery.

Supporters of all kinds seemed to orient to recovery slightly differently than did participants-in-recovery. Immediately, this difference seems to be (at least partly) attributable to the fact that supporters do not have access to the inner thoughts and emotions of the participants-in-recovery. Though this seems like an obvious statement, it reflects the complexity of being and knowing other, and how social expectations and locations filter into interpretations of what recovery “is” or “should be.” This does not mean that supporters were necessarily satisfied with the way that recovery was represented in media and social media sources; most supporters noted that they found depictions of recovery lacking in a number of ways, which I will touch on shortly. However, their talk about recovery did to a certain extent replicate an internalization of dominant norms around normal eating and body management that reflects a particular kind of expectation that those in recovery may or may not wish to live up to. This appeared through the supporters’ hopes for their loved ones; this kind of benevolent normalization illustrates the
deeply social character of expectations. Rather than saying they wished their loved ones would be “normal” around food in order to make their lives easier, they wished that loved ones would be normal around food as a way of making their loved ones lives easier—or what they perceived would be easier. Supporters differed markedly in terms of how much they insisted on loved ones demonstrating normalcy around food and body image as proof of recovery, ranging from suggesting that symptoms were not necessarily illustrative of illness or wellness to arguing that full recovery would mean not thinking about food or body image.

This last point lies in relationship with the idea of recovery as possible or impossible. Some supporters who saw full recovery as not having any thoughts about food or body image made the argument that full recovery was not possible. Conceptualizing recovery instead as a process, they suggested that their loved ones would never be “as they were before.” This is not necessarily reflective of their disappointment in their loved one’s “inability” to recover, but rather a different orientation to the concept of recovery – one that may or may not mesh with the person-in-recovery’s perspective. Other supporters saw full recovery as a possible, but described recovery more in terms of quality of life – they would perceive their loved one to have recovered if the loved one was able to do all of the things they wanted to without being constrained by hang-ups around food, weight, shape, body, or exercise.

This tension reveals the difficulty of defining recovery from the outside. The explanations of what recovery is—either a complete reversal to the person one was before the eating disorder is or a good quality of life—conflict with one another, and help to explain statements like “full recovery is possible” or “I don’t believe in full recovery.” The first perspective illustrates a cure orientation more rooted in a biomedical paradigm. From this perspective, it makes sense that full recovery would be “impossible,” because even by the very
nature of their development, people-in-recovery will not be the same as they were before the eating disorder. Indeed, in many cases, it even becomes challenging to identify timelines and so to find the “before” the eating disorder. Many participants had been struggling with eating disorders for upwards of ten years. During these ten years, they would have been growing and changing and developing—especially given that many of them began their symptoms in early adolescence in a way that precludes us suggesting that recovery might entail returning to some state ostensibly before the beginning of the eating disorder. While supporters might not mean to suggest this possibility in their talk, the suggestion of recovery-as-cure carries a confusing legacy of determining what might be “recovered” in being carried out.

The alternative perspective advanced in carers’ accounts reveals a markedly different and arguably more open conceptualization of recovery. Unlike the cure attribution, a conceptualization of recovery they articulated allows for varied states of relationship to food, weight, shape, and body while focusing on quality of life. Some in the medical community—particularly around eating disorders—might argue that this is only an appropriate lens to take with severe and enduring anorexia nervosa; that focusing on quality of life somehow signals failing patients (Robinson, Kukucska, Guidetti & Leavy, 2015). However, this more open stance on recovery is not about settling for less, but rather about allowing the person and their social networks of supportive others to make the decisions about what their goals are. Of course, all decisions are constrained to a certain extent by social location; we do not have freedom of choice to each ensure that our quality of life is exactly what we would wish it to be, given the constraints on our time and our bodies under neoliberal capitalism (and other systems of power and oppression) (Howell & Voronka, 2012). We all face, to a certain extent and to varying degrees, a number of instructions about what to do with our bodies and how to be productive that
are not tailored to our personal circumstances (Rabinow & Rose, 2006). Nonetheless, this perspective on recovery allows for a non-symptom-based definition of recovery. This definition of recovery would meet with a great deal of resistance in some communities, particularly those using provisional symptom remission-like criteria to judge the effectiveness of programs. However, we might begin to question what it is about symptom remission that signals recovery more than a quality of life assessment that more thoroughly integrates the person’s goals and wishes for their life. We might also recognize the social construction of symptoms themselves—particularly those that are unable to be measured—something that feminist writers on eating disorders have long expressed as an issue in defining the boundary between illness and wellness (Hepworth, 1998; Malson, 1998; Malson & Burns, 2009; Rice & Langdon, 1991). This statement and conceptualization of recovery will not be met with open arms; many cling dearly to a perspective that tethers recovery to proving that one is not and will never be again in thrall to problematized relations with food, weight, and body. As participants articulated, however, this orientation does not allow for imperfections in recovery and can itself act as a barrier to feeling well.

Supporters generally described their own relationships with food as “normal,” but commented on how their experiences with their struggling loved ones led to them developing a greater awareness of the strictures around food that operate societally. Seeing a loved one struggle with food made many of the supporters cognizant of the ways in which their friends, doctors, and others talked about food, interacted around food, and ate food in a white Western milieu. Some reflected on their family cultures as generally fairly “normal” around food; it is worth briefly unpacking what is meant by normal in this context. Those who commented on their family food culture in this way largely fit the white Western family structure: a nuclear family,
from a middle/upper-class background. They were able to understand their food experiences as normal as they see representations of the types of foods they eat everywhere. Often, this went unmarked in the interviews. When asked about how they or their family culture was around food, they generally said “normal” and moved on fairly quickly. There was not much discussion of what that “normal” looked like. When asked to expand, they might specify that they ate meals together as a group and/or that they did not think about food very much until their loved one started to struggle. Not thinking very much about food reflects a number of privileges, including class privilege (food is readily available), and cultural privilege (the types of foods a family prefers are available in the supermarkets in their city).

There were families that commented on their family food culture as being tied to their ethnicity; often both the supporter and the person-in-recovery noted this difference. For instance, a participant-in-recovery and her sister both spoke about their Greek family’s culture around food as being one where food was very much a centre of family activity. In this context, the participant-in-recovery also commented on how challenging it was for her family to understand her eating disorder because they ascribed to the “just eat” solution and felt that her withdrawal from food reflected in some way her desire to distance herself from family life. Her sister noted this lack of understanding as well, noting how the presence of an eating disorder in the family changed the dynamic around food from one of joy and happiness to a fraught relationship wherein the entire family was strained. Because food was so central to their family’s culture, the eating disorder operated as a significant barrier to family connection. Both the supporter and the participant-in-recovery reflected on the immediate family’s efforts to not blame the participant-in-recovery for her eating disorder – and yet, both expressed feelings of tension that continued even into recovery around eating and people watching eating.
Other participants noted a family culture around food; sometimes, a food culture that differed extensively from the white Western norms around eating was one among several factors contributing to a participant-in-recovery’s parents not understanding or even believing the eating disorder. In the case of one participant-in-recovery from a Punjabi-Canadian background, her family did not believe that an eating disorder was a major concern, in part because of different views about the role of food in one’s life. The participant felt misunderstood by her family of origin, particularly because her eating disorder involved – more than fears about weight gain and body image – a fear of throwing up that led to significant food restriction. She eventually distanced herself from her family because of the trouble she had being listened to in that context; she instead nominated her partner as her supporter for this study.

Culture was not the only complexity that mitigated family support for and understanding of eating disorders and recovery. One participant who was unable to identify a person who was supportive to her during her recovery – which began in adolescence but continued into her teens and twenties – noted that class struggles impacted her family’s understanding (or lack thereof) around her eating disorder. She was from a low-income family where food was scarce and parents were either working or ill (her mother suffered from psychosis and was in and out of hospital). The first person to notice her eating disorder was a favorite teacher at school, who noted significant weight loss. The participant’s father had not noticed that his daughter was not eating because the family did not eat meals together – the participant was 11 at the time. The participant reported that her father continued to disbelieve her eating disorder even to this day. The eating disorder seemed of less pressing importance in a family where earning money was needed to provide the basics of life. During much of her early recovery, the participant lived with her aunt and uncle, who ate meals as a family, which made it hard for her to skip meals and engage
in eating disorder symptoms. Of course, it would be easy to interpret this account in a way that a) blames the parent for not noticing the eating disorder and for disbelieving his daughter for her eating disorder or b) suggests that a nuclear family structure based on a white Western model of eating where meals that appear “normal” in the cultural imaginary are eaten together at 3 set times per day. I would explicitly like to avoid such a simplistic orientation, however, given that the situation is much more complex than that.

What this vignette reveals more than a particular moral value associated with a way of eating with which those who embody and enforce normate ways of being are comfortable in a white Western milieu is the need to make sure that the ways that eating disorders are treated prepare people for their lived realities once they have left treatment in order to scaffold a sustainable eating disorder recovery. Our treatment systems are built around a model of interaction around food that reflects white Western class privilege. In most publicly-funded treatment in Canada, patients are encouraged to eat according to a schedule that reflects a neoliberal, white, Western family’s eating patterns. The foods provided in treatment are (often hospital versions of) a standard middle-class diet. A great deal of this is attributable to limited funding for treatment, as well as the challenge of being flexible around meal timing due to the need to provide standardized programming, as well as possible ignorance and the unequal distribution of power in terms of whose “professional opinions” are counted (e.g., the prominence of white, middle-class, and normatively embodied knowledges).

However, the ways in which patients in intensive treatment settings are fed do not necessarily mesh with the lived realities of their families. Often, transitional programming is lacking; the assumption is that the family of origin will be the one supporting their loved one through recovery after treatment. Alongside this assumption, there is an assumption that the
family will both be able to afford to do so and that they are able to do so in a way that the
program expects (read: in a white, middle-class way). In the case of the participant just
mentioned, this was not the case—resultantly, she lived with her aunt and uncle during the time
and reflected on the emotional challenge of being away from her father following her mother’s
death. While her father could not provide the financial support required to sustain her recovery
and he struggled to understand her eating disorder as real or serious, the participant reported
wishing that she had more access to her father during a challenging time. This is not to say that
her aunt and uncle were not supportive; she also reflected on their generosity of time, food, and
even emotional support during the time. However, she noted that her reasons for following
treatment rules were largely to “get out of the hospital,” and that once she had, there was not a
strong effort made to understand her family circumstances.

Even for families whose circumstances more closely resemble treatment expectations,
and in which the participant is returning to their family of origin, supporting a loved one around
food after treatment can conflict with the family’s culture around food in terms of their
internalization of social expectations around food. We live in a society in which there are many
messages offered to people about how to manage their bodies: what to eat, what not to eat, how
to exercise, etc. In many cases, these contravene the prescriptions offered to participants in their
treatment programs (LaMarre & Rice, 2016a). Both participants-in-recovery and their supporters
reflected on the challenge this presents, though in slightly different ways. For supporters, many
struggled to move beyond their fears for their loved ones; they reported watching what the
participant-in-recovery was eating and being unsure of when the person was genuinely not
hungry or when they were restricting; alternatively, when the participant was enjoying a food
socially deemed to be indulgent and when they might be preparing to binge and/or purge. For
participants-in-recovery, this surveillance often felt stifling, if not overtly contradictory with the others’ behaviours. It is worth considering, also, the role that other biopedagogies play in determining the extent to which this surveillance is felt. Biopedagogies do not fall equally on people’s bodies; those in larger bodies or otherwise marginalized bodies, for instance, face more intensive scrutiny and othering (LaMarre et al., 2015; LaMarre et al., 2017). Internalized weight stigma may further exacerbate the sense of being watched; in general, weight stigma may also inform others’ perspectives on food behaviours—after all, a person in recovery in a larger body will not be seen in the same way by a person without knowledge of their history while “indulging” (LaMarre & Rice, 2016a).

Some participants and supporters alike reported on how the individual’s post-acute-eating-disorder diet might be seen as some as restrictive but enabled them both to “be healthy” and to feel comfortable around food. Food is far from neutral; certain dietary choices carry with them the sheen of health but have been deemed overly restrictive in the social imaginary—and yet revered for this restrictiveness at the same time (Boepple & Thompson, 2014). In this particular case, the participant-in-recovery self-diagnosed as celiac and found that eating no gluten significantly reduced both her anxiety and physical symptoms. In many studies, this would be coded as “an eating disorder in disguise.” However, the participant discussed her continually improving quality of life. Her supporter also reflected on marked improvement, as well as the pragmatic discussions the two had about the choice and opted to join her efforts as well. For them, eating “Paleo” was a choice that matched their social circumstances (they could afford to do so and committed to doing so) in a way that did not restrict other aspects of their lives. This example complicates simplistic attempts to diagnose eating disorders amongst those who ‘eat clean,’ for instance, as media sources tend to do. It illustrates how it is not enough to
simply look at what someone is eating; eating is not an activity devoid of social and personal meaning and must be understood in relation. Of course, there will be some who argue that there is objectively a way that people in recovery must eat to prove their recovery; I would argue, however, that this re-imposes the very surveillance that some with eating disorders have found so problematic and contributory to their disorders (Long, Wallis, Leung, Arcelus & Meyer, 2012).

Both participants-in-recovery and their supporters noted the challenge of navigating the dominant cultural notions about healthy eating. Often, supporters became much more aware of what kinds of messages we receive about how to be healthy after they saw their loved ones struggle. Prior to that time, many of them reported sometimes dieting or not noticing if friends or co-workers mentioned dieting or even eating-disorder-like behaviours. After their loved ones began struggling, however, they felt differently about the dominant messages we receive about health. The ways in which supporters managed this discomfort with disagreeing with dominant messages about health and diet culture varied, largely depending on the extent to which others in their social worlds knew about their loved one’s eating disorder. For many partners in particular, a concern for their loved one’s privacy was important. Particularly because of closeness in age and shared friend groups, many supporters who were partners reported that they often noticed other friends saying things about food that they felt were unhealthy and wanted to speak out about the existence of eating disorders and engage in education but did not know how to do this without disclosing their partner’s eating disorder – which they did not wish to do because it would constitute a disclosure their partner had not yet made.

5.2.4 Recovery Model and Healthcare Providers.

Perhaps surprisingly, screening digital stories to healthcare providers (HCPs) revealed relatively open attitudes around what constitutes recovery amongst HCPs. The similar views on
recovery espoused by HCPs and people in recovery mirror studies revealing only minor differences between the perspectives of therapists and former patients demonstrated in earlier studies (Noordenbos & Seubring, 2006; Noordenbos, 2011; Vanderlinden, Buis, Pieters & Probst, 2007). Uniquely, however, the HCPs included in this study were not eating disorder specialists—in fact, the majority of HCPs involved had not interacted with people with eating disorders in a clinical capacity at all. Echoes of the recovery model, focused on the idea of individual recoveries (Price-Robertson et al., 2017), were present in HCP data, reflecting broader shifts in the healthcare environment in Canada and elsewhere toward more patient-centered care.

Viewing the films reinscribed the importance of viewing people with eating disorders as individuals, rather than fitting them into proscribed treatment approaches and definitions of recovery for the HCPs who viewed them. Screening the stories revealed the possibility of making micro-shifts in HCP understandings of eating disorders, even when some HCPs desired longer and more in-depth, specific stories.

While these data are encouraging, it is worth engaging in a brief critique of the recovery model in light of some of the other findings—particularly, the neoliberal focus on autonomy and choice. We are entangled in complex and intersecting relationships, power structures, and flows at the same time that we imagine ourselves to be agentive (Lambek, 2004, Lavis, 2011, Musolino et al. 2015). It is, therefore, important, to question whether recovery model practice may inadvertently collude with dominant discourses on what it means to be an individual making autonomous choices. This is a particularly salient critique given the extent to which participants in recovery often felt thrust from overly-surveillant contexts in which they had no choices to a world based around an apparent freedom of choice. Recovery model rhetoric has promise but has not necessarily infiltrated practice (Price-Robertson et al., 2017). At present, literature on the
recovery model “fails to account for the diversity of recovery experiences and the diversity of bodies, spaces, and objects that facilitate, or otherwise participate in, each recovery event” (Duff, 2014, p. 59). In fact, some of the practices of self-spoused by participants in recovery might not fit into a clean version of recovery consistent with the recovery model, with its focus on quality of life. HCP responses to the post-screening questionnaire did indicate movement from solely seeing recovery as individual, which might inadvertently signal a focus on rugged individualism, toward seeing recovery as at least contextual. This step is an important one in devising an approach to recovery that treats recovery, and the hope for recovery, not “as a function of a given individual’s effort or will to recover” (Duff, 2016, p. 62) but as “a collective, relational achievement” (Duff, 2016, p. 70, drawing on Bird et al., 2014) facilitated in certain times and places.

This orientation to the recovery model as grounded in contexts and interpersonal relations is essential to avoiding a simplistic argument for a self-structured recovery that justifies further withdrawal of the state in terms of providing resources for recovery (Braslow, 2013). After all, participants in this study emphasized the need for greater resources in recovery and experienced those times in between treatment and illness—and treatment and wellness—as liminal and challenging. Thus, we might focus on how to provide support that is more open to diversity, but that nonetheless provides needed and desired help for those who seek it, regardless of their embodiment.
Chapter 6: Conclusion

6.1 Providing Support to Those in Recovery

Supporters’ perspectives on recovery, and experiences in assisting their loved ones in the attainment of recovery, reveal the gaps that exist in the treatment continuum for eating disorders, as well as insights into the “recovery assemblage” that is inherently interpersonal (Duff, 2016; Price-Robertson et al., 2017). Supporters were often placed in the support position with little prior knowledge or experience of eating disorders, and with their own body histories, and expected to provide a caring and compassionate response. Participants who supported people in their recoveries who participated in this study certainly rose to this seemingly impossible challenge, often putting their lives on hold in order to support their loved ones. And yet, this placing-lives-on-hold reveals some major problems with the way we structure care for people with eating disorders and their loved ones.

As a result of their often sudden involvement in the care of their loved ones, supporters tended to conceptualize recovery outside of the cure optic foregrounded in biomedicalized accounts of eating disorders. They tended to align more easily with perspectives on recovery advanced within recovery model approaches that assert that people are always in a dynamic state of being, thus making the binarizing before and after impossible (McWade, 2015). This perspective is not easily welcomed in eating disorder literature and practice, which often resists a recovery model frame other than in cases of “severe and enduring” eating disorders (e.g., Robinson, Kukucska & Leavy, 2015; for notable exceptions, see Dawson et al., 2014; Musolino et al., 2016). Interestingly, these perspectives are also deeply rooted in embodied and affective relationships (i.e., those that transcend a simple accounting of symptoms or lack thereof and implicate understandings of loved ones’ particular needs and desires). Recovery is commonly framed in popular discourse, including that articulated by supporters, in a biomedical way,
presenting hope for recovery in relation to “scientific cure” (Blackman, 2007). Eating disorders become reduced to largely biological illnesses, a construction foregrounded for its promise of stigma reduction, which is contested (Easter, 2012; 2014). Here, however, supporters transcended reliance on biomedical markers of illness and wellness and provided loved ones with affective attunement, wherein they offered their loved ones space to be more than medical objects but rather embodied beings engaged in relationships (Lester, 2016). Being attuned to their loved ones, in turn, offered participants the space to feel heard that they often lacked in other spaces in their recovery experiences.

Integrating the findings from this dissertation into practical implications for caregivers is inherently challenging due to the individuality and somewhat esoteric nature of “affective attunement.” What they reveal as necessary are a) more space and time to engage with a wider variety of supporters beyond the nuclear family; b) talking to supporters about recovery in complex ways that move beyond a push for easily-measurable, biomedical markers of success or failure and toward a contextualized and trustful perspective. Rather than being encouraged to doubt their loved ones’ recoveries, for instance, supporters might be encouraged to trust and engage with them, even when their enactments of recovery do not fit the taken-for-granted assumptions held about recovery. It means acknowledging the counter-cultural nature of recovery (LaMarre & Rice, 2015) and exploring the borderland that supporters often occupy between normative prescriptions for health and those offered to people in recovery.

Healthcare providers’ responses contextualize these issues, revealing as they do the ways in which they are ill-prepared to understand and manage the complexity of eating disorders and their social surrounds. Participants’ digital stories exemplify artful imaginings of the embodied, relational, and dynamic quality of recovery assemblages. While these stories did not fully satisfy
healthcare providers’ desires for training in how to understand eating disorders and recovery, they did begin to open to the diversity of eating disorders and recovery that providers may encounter in practice. Healthcare providers themselves reported vastly different perspectives on recovery and its possibilities, as well as on eating disorders themselves. The films sparked interest and curiosity into the context of each story, revealing a need to build dialogue between healthcare providers, people in recovery, and supporters to break down the long-entrenched “us versus them” perspectives set up by the adversarial assumptions embedded in treatment contexts described herein (Boughtwood & Halse, 2010). Rather than resisting the artful or lengthy nature of participant-generated films on recovery created by people in recovery and supporters, the healthcare provider audiences reflected on a desire for more complexity and diversity in the versions of recovery they saw. By engaging with this complexity and diversity, we might begin to story recoveries differently in healthcare contexts.

6.2 Not All Sunshine and Rainbows.

Participants were adamant that recovery was not a perfect place; these results echoed my Masters’ findings (LaMarre et al., 2015; LaMarre & Rice, 2016a, 2016b) and revealed problems in the dominant framings of recovery observed in clinical, research, and popular discourses on eating disorders. The idea of recovery not being all sunshine and rainbows—and, concordantly, the need for diversity and uncertainty in representations of recovery—was not only articulated in terms of the call for body love, but also the types of foods one is expected to eat in recovery and the surveillance that accompanies eating once one is known to have recovered from an eating disorder. Participants in recovery negotiated the food they ate in different ways, revealing the variety of ways in which one could “be recovered” and what this meant in relation to “normal eating” and “healthy eating” discourses. The normal eating taught in treatment worked for some;
some participants preferred a more rigid approach to eat that allowed them to make sure that they were adequately nourishing their bodies even when they were anxious, busy, or preoccupied. For others, dietary preferences and intolerances coloured the extent to which they could eat the types of food available in treatment, and the ways they ate in their recoveries. Either of these options might be coloured as “not recovered enough” if I were to follow a classical definition of recovery as articulated in popular culture which might presume, for instance, that following normatively defined “clean eating” is a gateway to a relapse in recovery (Rollin, 2017; Eating Disorder Hope, 2017; Marsh & Campbell, 2016). For some participants, this rigidity in eating was simply a prerequisite for living their lives in the way they desired.

Even when friends and family members had the best interests of their loved one at heart, participants sometimes felt that any admission of struggle would result in their supporters panicking, provoking social panic in their supporter network. Returning again to the relationality of recovery, recovery perfection was more performed than felt, perhaps because of the relationships that participants were in with loved ones, who had seen them acutely struggle and understandably did not want them to be struggling. Putting aside judgements about “who recovery is for,” this raises the question of seeing and feeling recovered, and when these are at odds and when they align. It also raises the possibility of supporters acting in ways that might be received as less pressure-filled. Several participants, reflecting on their recoveries, described themselves as most supported in doing their recovery when they felt that they could be truly open and honest with their supporters without feeling pressured to recover perfectly or in line with an external vision of what recovery “is.”
6.3 Fear of Return.

Avoiding blaming those who might react more intensely to admissions of struggle is imperative here, of course. The relational character of eating disorders and recovery means that all of those entangled in the experience may have visceral reactions—including fear—to the possibility of “returning” to the state of eating disorder; supporters may also feel the pressure to speak about recovery as perfect, for fear of being blamed for not holding their loved ones to a higher standard of recovery. This pressure might take the form of being labelled not strict enough and lacking the authority deemed to be required to support someone in recovery (Ryan et al., 2006). Further, it may be framed as a “settling” for a life of less than ideal relationships with food and body for their loved one. These messages about the need to perform recovery perfectly as a supporter network may be delivered from various sources, including but not limited to treatment settings, mainstream media, and others in recovery.

Beyond seeing recovery as more complex than dominant narratives would assert (Holmes, 2017), participants’ recoveries were not always described as the single most important part of their lives, as described above. This may be tied to the population recruited for this study, versus populations recruited for prior studies on recovery. In this study, several participants described how they did not orient their identities around recovery. For them, recovery was one among many experiences that happened to them. Often, these people are not heard from, because they have largely distanced themselves from eating disorder recovery communities. This might also reflect a distancing from the recovery identity itself, which may become another regulatory ideal. The assumption that everyone in recovery is interested in telling their story broadly (James, 2016; NEDA, n.d.; Eat, Breathe, Thrive, n.d.) or that they engage with communities of support around recovery is not a universal reality for those who have experienced recoveries. Participants explored shades of this phenomenon, ranging from seeing their eating disorder as a
phase in their past that was not a huge part of their identity, to seeing their recovery as an important aspect of who they had become, but deciding not to engage with others’ articulations of their recoveries.

For those participants who held to the perspective that recovery was one among many experiences, there was a necessary distance-building between themselves and their disorders—including the story of the disorder. Again, the importance of this perspective is not that eating disorder recovery has been made out to be more than it is in the academic and popular literature around it. The importance of acknowledging the stories of those who do not keep eating disorder recovery as a core part of their identity; or, indeed, feel they need to distance themselves from this storied aspect of their subjectivity to move on is to highlight the differences between recruiting for a version of recovery the study designer has chosen and leaving this open to interpretation; recruiting without the word recovery, and calling out for those whose experiences have not been told not only yields a more diverse set of participants from a socioeconomic, racial, gender, sexuality, and ability perspective, but also from the perspective of the salience of the concept of recovery to participants.

6.4 The Power of the “Recovery” Language.

Recognizing the power of and associations with the term recovery helps us to understand which versions of recovery are commonly represented and what this means for both social and research imagination around the concept. Many participants noted that the word recovery did not resonate for them, not because they did not think that they were doing better in their lives and had moved beyond acute distress around their bodies, food, and weight. On the contrary, many simply did not find that the word captured their experience, and identified that it, at times, carried its own stigma and pressures (LaMarre & Rice, 2016a). In these cases, participants
sometimes adopted alternative terminology, for instance adopting the “always in recovery”
perspectives common to an alcoholics anonymous frame (A.A. Grapevine, 1984). Others chose
to distance themselves entirely from the discussion where eating disorders are concerned,
moving away from the associations between eating disorders and choice, recovery and choice,
delayed developmental trajectories, and feminized assumptions that have material impacts on
how they are understood by those around them.

People who choose this path are not often heard, because they are not often asked. If
eating disorder recovery is no longer a salient aspect of one’s subjectivity, how is this framed in
medical, research, and popular literatures? Does a person need to tell their story and/or consider
their eating disorder and recovery to have been the single most challenging hurdle they have
experienced for it to be interpreted as “true” or legitimate? What happens to those who have
experienced other challenges in their lives and/or who consider their eating disorder to be one
among many aspects of struggle they have been through? The push to move beyond the eating
disorder and do other things with one’s life and yet to acknowledge the formational and central
importance of the eating disorder and recovery experiences lie in tension.

On the one hand, there are some who suggest that those who have recovered should not
have any relationship to the eating disorder world in a clinical capacity, arguing against this out
of a concern for countertransference and over-preoccupation with eating disorders when people
are supposed to be “moving on with their lives.” Others advocate for the importance of recovered
professionals’ insider points of view (de Vos, Netten & Noordenbos, 2016). Beyond this debate,
there is a clamorous call for the stories of those who have recovered, and a near insistence, in
action and/or in words, that the eating disorder must have been the hardest thing one has done
and that recovery must be a part of the identity the person has built. “Making meaning” out of
the experience is a common feature of the eating disorder recovery literature (e.g. Lamoureux & Botorff, 2005; Jenkins & Odgen, 2010), but the ways of making this meaning are circumscribed as opposed to left open. Once again, choices about the “how” of this meaning-making are foreclosed and assumed to be through active processing of eating-disorder-specific experiences. This resonates with some, but not all, participants’ responses. Some participants did engage in that path, noting that they wanted to give back to those who had helped them, and sometimes noting how going through the eating disorder had made them who they are today.

At the same time, others wanted nothing to do with the eating disorders community or never sought out relationships and engagement with clinicians, researchers, and people in the recovery community for the reasons cited above. For these people, this study was the first time they had talked about their eating disorder since it had happened; they lived their lives largely without thinking about the eating disorder. Here, it is important to frame neither of these pathways—and the divergences within them—as more ideal than the other. Either pathway could be appropriate, but participants’ accounts reveal the need for room for either pathway, as well as the importance of at once untethering recovery from the notion of “choice” (as it is currently constructed under neoliberal rationality optics) and re-tethering the concept to openness. Arguably, the “what” and “how” of recovery cannot be untethered from context, and the power of the language itself to select whose stories are told must be taken into account.

Despite the fact that, as discussed above, what recovery will look like or even how to get there after one has left treatment is not always a feature of treatment systems and prescriptions, participants do not recover without a knowledge of what recovery is “supposed” to be (Holmes, 2017; LaMarre & Rice, 2017). They are also aware of how being associated with their eating disorder and/or recovery has been interpreted by clinicians. Along these lines, participants often
mused about whether their own preferred identifications match with the ways in which they have been constructed by clinicians, who have various experiences with people with eating disorders—and representations of eating disorders. They were cognizant of stereotypes around eating disorders, and to family and friends’ reactions to their “imperfect” recoveries. These facets all inform participants’ orientations to “recovery” as concept, and to the degree to which this will feature in their lives. Importantly, it is not that one always “chooses” to either become involved in eating disorder recovery communities and share one’s story everywhere, research or treat eating disorders or completely distance themselves from the disorder. Even amongst those who distanced themselves from the concept and did not see it as central to who they were occasionally chose to disclose to very close others in selected moments; this disclosure was less an “admission” of a major part of their background and more a part of their interaction with the other person, who they were willing to let into their version of recovery.

6.5 Recoveries: As Diverse as Life Itself.

Participants’ recoveries, though they were linked by the themes and stories described above, were as diverse as life itself. Differences and similarities were tethered to participants’ cultures, experiences of family and support, varied embodiments, orientations to the dominant social status quo and living in similar geographic locations. In a way, attempts to establish consistent themes of what recovery “looks” like for participants feels futile, as recovery might be regarded as life itself. There is not necessarily as much in common between those who have experienced eating disorders as there are differences, which also impacts the differences that surface in relation to recovery. This is not to say that there are not common threads amongst participants’ stories, but these commonalities must also be understood in relation to the lenses researchers, healthcare providers, and the general public are looking through as we classify their
experiences. Participants’ stories stand alone as they reflect their personalized experiences; and yet, they stand in relation to years of work on eating disorder recovery and in relation to clinical and popular discourses and representations around what it means to be recovered. Participants do not recover into cultural vacuums that hold specifically raced, classed, sexed, gendered, abled, etc. discourses about bodies; equally, they do not recover into a void in which they know nothing about what eating disorder recovery “is” and “how to get there.” Regardless of their treatment or lack thereof, participants’ responses speak in relation to these varied and multiple discourses that work in, through, and around their bodies and interact with other discourses in their lives—dominant cultural discourses, specific familial discourses, and flows of time and space that shape their experiences and relations to those experiences.

It may seem like a caveat emptor to describe recovery as life itself: as an experience shaped by time and space and relationships. And yet, participants’ accounts consistently reveal the constant negotiations between inner experience and external discourses in a way that reveals ongoing attempts to define, redefine, and refine subjectivities in relation to the worlds around them. Rather than claiming that participants’ accounts can be collapsed to form a coherent representation of a singular pathway to or articulation of recovery, it might be more fruitful to explore how the individual—and yet socioculturally linked and intercorporeal—experience of recovery requires listening to participants as authors of their own stories, while also acknowledging their “sources” and “audiences” that impact their story construction. Participants acknowledged the presence of the researcher, discussed their stories-in-relation, acknowledged that others’ stories are different from their own, and spoke to the need to be listened to and heard deeply by those around them—including the researcher.
Throughout the study, the issue of the need to pre-define criteria for recovery surfaced in relation to the need to answer the research question and determine themes without collapsing diverse experiences. Participants were also reflexively and lucidly involved in research in ways that challenge our traditional hierarchizing of research encounters while simultaneously reinforcing the researcher as the “knower” in the relationship, who might determine whether or not the participant fits research criteria. The research relationship itself became another relationship participants navigated and negotiated in constructing their recovered subjectivities. This, amongst the relationships participants configured as important to their self-elaborations demonstrates the ways in which recoveries are always embodied in a broader assemblage—including the research assemblage itself (Fullagar, 2018). Recovery might be best imagined as an “atmosphere”; more than a subject or object, but something assembled and affected (Duff, 2016); a coherence of contextual embodied experiences and affects (Bissell, 2010).

The idea of recovery as life is intricately tied to the intercorporeal relationships participants described as important to their ability to live their lives as they wished and to move beyond acute distress. Participants’ narratives were entangled not only in the discourses of recovery that circulate in and beyond medicalized contexts, but also with their relational experiences, desires, and affects. Recovery took place not only in time and space but in relation to those who had not listened to them, and to those who had heard them and honoured their ways of being. In selecting supporters for the study, participants selected those who they described as hearing them and walking with them on their life paths, as opposed to those who were trying to “fix” them or who had strict policies around what recovery might look like. This is not to say that providing support never looked like challenging the person to move beyond distress; sometimes participants’ relationships with their supporters did entail moments of conflict about
what recovery would look like. However, participants articulated a difference between caring and supportive structures and contingent ones. Supporters that were chosen by participants in recovery were those who were able to nimbly balance concern and freedom—much like the preferred systems of care participants desired (and often could not access). They chose not to communicate with or at least discuss recovery with would-be supporters whose responses did not encourage them to live the recoveries they preferred.

This is not a matter of providing the “wrong” response or somehow blaming these would-be supporters for the eating disorder and/or struggle in recovery. It does, however, help to explain why participants might not share their recovery stories or frame the eating disorder recovery as the most important part of themselves, at least not in all spheres of their lives. While some participants were uniformly open about their prior and/or continuing struggles, most were taciturn about their stories at least in some contexts, again revealing the interactional nature of storytelling, an awareness of audiences’ affective responses, and managing ways of avoiding being framed as solely eating disordered. Again, this was particularly important for those with intersecting spaces of marginalization.

To say that recovery is as complex as life itself is not to dismiss the specificity of the recovery experience or to say that there are no commonalities between participants’ experiences. It is, however, to reflect on the ways in which it is challenging, if not impossible, to isolate people’s experiences of recovery from the contextual features of their lives, as well as the time and place in which recovery is taking place (Price-Robertson et al., 2017; Duff, 2014, 2016). Recovery for a participant with a rich network of open, empathetic support is not the same as recovery for another whose family of origin dismisses and misunderstands their eating disorder as borne of vanity and as overblown, who avoids the topic of mental health, or who struggles
with their own issues around mental health. Trajectories toward wellness are also contingent on the systemic supports available in a person’s geographical area and their ability to suspend time in order to seek the treatment they are told they require, and the recognition that doing so did not always mean participants were met with the kind of treatment they desired. The need to listen to lived experience and participant-articulated desires surfaced again and again within their accounts, regardless of the individual trajectories toward or definition of recovery, however, emerging as a central feature of the recovery process.

There may be resistance to listening to participants’ lived experiences because of the aforementioned disbelief and distrust of those with eating disorders. In a rush to externalize the eating disorder, participants are often seen, when actively ill, as simply vessels of their disorders’ voices (Malson et al. 2004; Saukko, 2008). And yet, participants articulated coherent accounts of how the silencing of their voices and desires early in treatment and the stoppage of life and time in intensive treatment was either such an oppressive choice as to make them unwilling to engage with it, or made it much more challenging for them to re-enter a world in which their choices were again their own, resulting in self-surveillance in accordance with treatment norms or continual re-entering of the treatment space. Somehow, participants did reach a state of wellness, following vastly different routes and orienting to the concept of recovery in very different ways. Participants did not articulate a shared version of recovery, but rather a shared discontent for the dominant framings of this concept. Even when people did find the word resonant, they occasionally saw the term as something that “wasn’t for them,” for reasons ranging from self-doubt around how sick they had really been (borne of responses from doctors delegitimizing their eating disorders or reading their bodies as other-than-ill) to not seeing the eating disorder as a core feature of their overall life story.
Participants’ accounts gesture toward a definition of recovery that is not foreclosed or externally defined. Their recoveries speak back to a call for a definition of recovery that collapses difference and opens to a definition of recovery that welcomes in divergence. Difference is configured, in this definition, not as hierarchical levels on a linear scale of recovery or illness, but as variations on a theme, much as difference might be reconfigured in life itself. There were elements of forward motion in recovery in participants’ accounts and the idea that recovering entails a kind of overcoming. The nature of this overcoming varied in accordance with a) the significance the participant placed on the eating disorder in relation to other aspects of their life and b) the part(s) of the eating disorder that they perceived as most interfering in their lives. Using this broadened definition of recovery would mean looking less at what are clinically defined as the most harmful elements of the eating disorder and considering instead which elements of the eating disorder participants conceive of as most closely tied to their experiences of distress. For some, this might resemble a clinical definition, including the stoppage of symptoms and resolving of body image. For others, however, recovery might mean the ability to identify one’s needs and ask for help. For still others, it might mean moving beyond fears, whether those fears are related to food, weight, and shape or other things in their life. Recovery might mean resolving bodily distortions or alternatively reframing bodily distortions as less important to who one is.

Given these conflicting and dynamic articulations of recovery, we might once again raise the question of the desirability of developing a consensus definition of recovery. While such a definition might carry pragmatic implications (e.g. being able to determine when to alter level of care, etc.), it bears the possible weight of inscribing still more regulatory ideals. Further, the application of such a definition likely depends on being inscribed with the pathology of eating
disorder from a clinical perspective, which is not something that all participants had experienced or were interested in. A consensus definition of recovery will itself necessarily miss certain bodies, no matter how collaboratively and comprehensively it is developed. In order to avoid its existence as yet another regulatory surveillance device, it may be worth considering how and whether it is possible to establish a moving definition, more attuned to the lived, embodied, and varied recoveries people experience. To avoid the kind of lip-service paid to, for instance, recovery-model oriented care (Tait & Lester, 2005) that is surfacing in Western contexts, too, it is worth considering whether the solution for uncertainty is fixing or inscription. Perhaps a more open and generous consensus on recovery might depend more holistically on the individual—and their supporters’—experiences of their recovery.

Participants’ multifaceted and varied accounts of recovery, their degree of engagement with dominant discourses on recovery, and their varied trajectories to recovery illustrate the dynamic, interactional, and intercorporeal nature of recovery. They also illustrate the intertwined nature of recovery discourses with dominant conceptualizations of time, developmental trajectories, and normative performances of selfhood. Saying that recovery is life is more than a catchy way of framing this multifaceted construct, but rather a way of acknowledging that we may never alight on a commonly-shared definition of recovery, but this does not need to be problematic. If our treatment systems were more nimble and resourced to respond to individual needs, individual definitions of recovery that honour voice would be more readily welcomed. Such a system would be undergirded by a fundamental respect for difference and a more consistent commitment to avoiding the pitfall of subsuming the identities of those with eating disorders and in eating disorder recovery into the eating disorder itself, which plays a different role in the lives of different individuals. It would provide better access not only to any kind of
care, but to the kind of care that might allow those in distress to determine ways of moving through distress as it relates to their own experience as opposed to presuming that all people with distress around food, weight, and shape require the same approach in order to recover.

6.6 Honouring Lived Experience.

This approach to recovery may sound utopic, and in a sense it is, but the ask emerging from participants’ accounts is not outrageous or beyond the scope of reasonable (and meaningful) practice. Fundamentally, it is an ask for honouring of lived experience. At the heart of enacting such an approach, however, is a reconsidering of power dynamics as they operate in dictating which performances of eating disorders and recovery will be honoured as “legitimate” and whose pathways to recovery will be respected. Given that participants often responded to the question of whether definitions of recovery they had heard resonated with them tended to be that such a definition might be for “someone else” but they were not “at that point,” we might start to ask: who is the definition for? Is it to “prove the effectiveness” of treatment modalities, or is it to generate models of recovery for those who are seeking to resolve their distress.

Opening up the possibilities for recovery does not mean completely doing away with criteria to diagnose eating disorders or determine when someone might be ready to move on from eating disorder treatment. These criteria can act as proxy measures and are necessary within the current system of healthcare provision to allow for any kind of treatment to take place. In an environment that calls for evidence-based treatment and requires diagnosis for treatment, the use of such measures are more often than not a systemic requirement. There is pragmatic value, too, in establishing a consensus definition of recovery in order to more effectively compare treatment models that might be helpful to those in recovery. Participants were interested in there being a definition of recovery, if only to help those in the future who might experience eating disorders
know what kinds of treatment might be more effective for them. Pragmatic measures for
determining eating disorders and recovery are not without value, but they reflect only one source
of power in determining the what and how of the processes and outcomes of recovery. The
centrality of being listened to in recovery that surfaced in participants’ accounts highlights how
in addition to these measures, we need to consider the what and how of recovery as it actually
operates in people’s lives; diversely situated and embodied people will necessarily express and
experience recovery differently. While quality of life may be an important consideration in
recovery (de Vos et al., 2017), it is not enough, alone, to gauge the extent of recovery given the
complexities of people’s lives in/outside of their eating disorder recovery. Rather than framing
divergent experiences as aberrant or problematic, we might make room within the pragmatic
clinical and research definitions for the lived experiences of diversely embodied folks in
recovery to return to the ostensible focus of all recovery-oriented work: the well-being of those
who have been suffering.

6.7 Limitations

This analysis is, of course, not without limitations. Despite my best efforts to engage with
a diverse group of participants, the participants in the study still to a certain extent embodied
some of the “told story” about eating disorder recovery. Further, and as noted, some social
scientists and eating disorder scholars in particular may disagree with the loose exclusion criteria
and the lack of definition of recovery. There may be concerns about whether participants are
“truly” recovered, and thus trustworthy storytellers. However, this limitation itself relates to one
of the key findings in this dissertation: that people with eating disorders are not commonly seen
as trustworthy. Though this logic may seem somewhat circular, it draws our attention to the ways
in which our research is always limited and always contextual. How we relate to and understand
participants and their stories depends deeply on our own theoretical and methodological orientations, about which I have attempted to be clear throughout this work. Digital story analysis is limited by our lack of knowledge about why some participants chose not to participate, and whether the stories of those who did participate are significantly different than those that didn’t. Similarly, we cannot say that supporters’ stories are generalizable to the experiences of all supporters of those with eating disorders. Because of the difficulty in recruiting supporters through participants—due to the fact that many could not identify a helpful supporter—this is of course itself a finding; that support for people in recovery is often fleeting and limited. In terms of healthcare provider participation, the sample of healthcare providers was limited to those who have some kind of interest in eating disorders and/or recovery. Further, many healthcare providers included were students. This could be seen as a strength, in that this catches these individuals at the beginning of their careers. It does not, however, account for how the stories might be received by those at later stages of their careers or those who are completely disinterested in eating disorders and recovery. Finally, while I have been inspired by and attempted to take up post-qualitative framings in this work, it remains tethered to some of the workings of qualitative research in that it collapses participants’ experiences into themes about which I write, rather than integrating artful or embodied representations into the text itself, which might have helped to engage the materiality of experiences at the same level as the discursive (Fullagar, 2018). Nonetheless, as an experimental first step, I did “think through theory and method together” (Fullagar, 2018, p. 10) and “think with [my] data” (Jackson & Mazzei, 2013, p. 261) entangling, as well, the practices of this research in its representation by making them visible (Fullagar, 2017). I sought to avoid the disembodiment that some argue can make research harmful in its reproduction of “patriarchal traditions of knowledge and authority” (Inckle, 2010,
p. 31). In future research, I hope to continue to explore ways of bringing this re-thinking of research into the way research is presented.

6.8 Implications and Contribution

This dissertation represents a first step toward imagining the multiplicity of recoveries that might become open once we begin imagining recovery to be as complex, multifaceted, dynamic, and contextual as life itself. Though the research did not begin with the lofty goal of defining life itself, conversations with participants and an exploration of these conversations in light of the ongoing debates in the field sparked a desire to generate an account of recoveries of lives, rather than the establishment of another set of criteria against which people might be judged and found wanting. If recovery is, indeed, counter-cultural (LaMarre & Rice, 2016a) and unimaginable while in the process of treatment (Malson et al., 2011a), it becomes important to understand the specific embodied experiences people with eating disorders have had that have generated this resistance to the concept—more so than the experience—of recovery. Many of the accounts highlighted the importance of being listened to and of affective attunement to their experiences and desires; existing in relation to open spaces and nuanced practices of care made recovery possible.

It may not be easy to imagine a model for treatment that endorses a wide variety of perspectives on and enactments of recovery. While we might look to the recovery model as a source of inspiration, we are inevitably faced with the material, structural constraints that call for evidence-based approaches built on linear time logics that push people through manualized treatments in short order. Temporalities of recovery—systemic pushes for efficiency versus looping and unfinished embodiments of illness and wellness—compete for a role in the fashioning of subjectivities here and elsewhere (McWade, 2015). At present, providing
“resources for recovery” often means engaging with systems that may or may not be open to not only different versions of recovery, but to different bodies, full stop (Duff, 2016). Truly imagining recoveries that are open and uncertain, relational, collective, affective, and assembled (e.g. in Duff, 2014, 2016) means moving beyond elaborations of recovery that envision it as a linear process of getting back to work and productivity. It means placing trust in people who may not be engaging “as expected” in neoliberal society, wherein “all time must be consumed, marketed, put to use; it is offensive for the labour force merely to ‘pass the time’” (Thompson, 1967, p. 90-91)

Engaging with recoveries also means trusting those who have been traditionally rendered untrustworthy, and unduly vulnerable: people with eating disorders (Holmes, 2017). While we cannot ignore the life-saving capacity of treatment innovations, neither can we look away from how the normative subjectivities prized in emergence from such contexts may be left unagentic, rendered chronic by a medical-psychiatric complex that limits, rather than opening, the possibilities for their lives (McWade, 2015). As participants’ accounts illustrated, choices in recovery were often made more challenging because of the ways in which choice was removed during active treatment. Advocating for increased choice and voice in treatment does not, and did not to participants, mean simply “giving in” to the person’s desires. Participants often articulated a keen awareness of the moments in which their “choices” were not in their best interest. However, there is a difference between imposing surveillance and truly listening to someone’s voice and preference and engaging in a dialogue about how different options might yield different results.

Supporters’ affective attunement participants in recovery offers a hopeful perspective on the role that loved ones might play in supporting recoveries. Supporter participants emphasized
the struggles they experienced not only in the attempts to emotionally and materially provide support for their loved ones, but also in negotiating the dictates around health imposed from society in general and from eating disorder recovery programs. Navigating various perspectives on health and its embodiment made many supporters more sensitive to the ways in which biopedagogies operate in society, uniquely positioning them as advocates for their loved ones in the counter-cultural process of recovery (LaMarre & Rice, 2016a). Providing meaningful ways for supporters to become engaged with recoveries as more than enforcers or surveilling agents might help to mitigate the significant personal strain that helping someone through recovery can entail.

The different perspectives on recovery espoused by different actors in this study—and in society in general—need not necessarily lie in uneasy relationship. While reconciling multiple temporalities of recovery in particular may yield uncertainty and disagreement, we might consider the possibility of not trying to reconcile, but rather to experiment with these temporal disjunctures and what they tell us about contexts of recovery. Engaging with these temporalities may also help to resolve some of the issues of legitimacy and memory that surfaced in this data. Rather than seeking a singular narrative of even a single eating disorder and recovery, we might seek instead “a cross-fertilization of a ‘mutual contamination of nows’” (Browne, 2014, p. 44). This also allows for multiple forms of expertise to coexist and to create possibility, rather than foreclosing certainty and finality on recovery trajectories.

In configuring recovery as multiple, intercorporeal, multilinear, and dynamic, this dissertation offers us the possibility of engaging with uncertainty. Engaging with uncertainty may appear to lie in direct tension with the desire to provide hope to those who are struggling and their supporters. It becomes necessary, given the power dynamics explored herein and the
dictates and contingencies (without accompanying openness and person-centered support) that sometimes accompany hope in recovery (Blackman, 2007; Duff, 2014) to think about both hope and recovery differently. We might practice a kind of hope that is less about enunciating oughts and shoulds and more about imagining possibilities (Duggan & Muñoz, 2009); possibilities for systems becoming less exclusionary; possibilities for more embodiments to be welcome; possibilities for recoveries.
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NIED (nd) Need for NIED. http://nied.ca/need-for-nied/


Appendix A: Script for Screening with Healthcare Providers

Eating disorders are complex and multi-faceted; there is no one way of having and recovering from an eating disorder. Medical professionals are not often taught about eating disorders, how to treat them, and how to speak to people in eating disorder recovery about their experiences. While medical professionals might learn about anorexia, bulimia, binge eating disorder and otherwise specified feeding and eating disorders in broad terms or on the basis of their symptoms, the broader picture of eating disorders and their personal, social and contextual impacts is rarely present. In my dissertation work, I spoke with 20 people in eating disorder recovery and 14 supporters about their experiences. Some of these people also participated in a digital storytelling workshop, where we worked together to create short 3-5 minute films about their experiences. In their films, they tell their stories of having and recovering from eating disorders.

In the stories, you’ll see a diverse range of experiences that may at times contradict each other. Participants’ versions of recovery often differed, and this became one of the most important themes to emerge from my dissertation work. It lives in an interesting relationship with the way recovery is described in the literature, as well. Despite years of study, there is not a common, shared definition of recovery amongst those who treat or research eating disorders. Usually, eating disorder recovery is measured using a number of proxies, including weight gain and scores away from one standard deviation from “normal” on scales used to diagnose eating disorders, like the Eating Disorder Examination Questionnaire (EDE-Q). Those who administer these scales are usually aware that these metrics are not enough on their own to assess eating disorder recovery, and note that eating disorder recovery is about more than simply gaining weight and restoring nutrition. And yet, there’s never enough time or space for those in recovery to tell their stories.

What we see in the media tend to be fairly stereotypical stories of eating disorder recovery. They often depict thin, young, thin, white, able-bodied, cis-gender women with anorexia nervosa who seek and obtain treatment and, subsequently, recovery. We rarely hear from others in their lives, like supporters. When we do, we usually only hear from parents, as opposed to those who the people in recovery found most helpful to them as they sought to recover. In my study, I had participants nominate supporters to participate in the work, and you’ll hear from the sister of a young woman with an eating disorder.

The goal of the stories is to start to open up perspectives on what recovery from eating disorders looks like and how to support people on their way. They are a first step toward this goal – there are many more stories to be shared. Some of the participants in this project were diagnosed, while others faced barriers to diagnosis and treatment. They all identify differently in terms of their orientation to recovery – not all are comfortable with that terminology, particularly in a society that makes “health” out to be something one can achieve by following a strict diet and exercise routine. It’s important to note that there’s work to be done in making storytelling more accessible to people with different stories of recovery; because of the surfeit of stereotypical eating disorder stories, and because of structural and cultural barriers, it can be hard, if not unsafe, for some to share their stories.
In the first story I will share, Meghan tells her story through a poem and a letter to her younger self. She explores what recovery means to her by looking at a non-linear pathway to wellness. She makes a call for living in the present, as opposed to always resorting to ingrained habits. Meghan found emotion-focused therapy to be particularly helpful in her recovery, and uses the language and practices she was taught in this type of therapy to construct her story; she speaks to her younger self, reassuring her that there is no need to remain tied to the past or live in the uncertain future. You’ll notice that Meghan does not use the words eating disorder in her story – while she was diagnosed with an eating disorder and experienced several types of treatment, her recovery story is about the broader context of her life beyond the eating disorder symptoms.

In this second story, Kay tells her story of coming into a recovery that works for her. For Kay, an early encounter with a holistic practitioner made her averse to food. This is one of the moments in which society’s obsession with the “clean” was internalized as a struggle – for Kay, this message led her to fixate on keeping her body clean and pure by rejecting food. Recovery entailed working on finding a combination of methods that worked for her, as opposed to those that were prescribed to the masses – for Kay, this involved psychiatric medications, as well as a specific meal plan.

Unlike Kay, Gina found that medication numbed her pain in a problematic way that made her feel separated from the world and unable to engage. Describing her experiences of searching for love throughout her childhood, Gina was met by bullying both from her peers and, later, from the medical profession. Her experiences of having an eating disorder were complicated by the social praise she received for shrinking her body from a larger body to a small one. She describes how, upon re-gaining weight, she “disappeared completely.” For Gina, recovery meant reflecting on the value of finding love within herself, as opposed to seeking it outside of herself.

In this next story, you will hear from Catharine, who supported her sister during her eating disorder recovery. In Catharine’s story, we can see how intertwined eating disorders and recovery can become with people’s relationships. Catharine describes her family “team’s fight against the eating disorder, and the looming spectre of “Ed,” who she describes as an unwelcome guest. In exploring her family’s coming together to fight Ed, she does not gesture at a perfect resolution, but rather an openness to continuing to support her sister as life challenges all of them. Catharine’s story highlights the interrelational nature of eating disorders and recovery, neither of which happen in isolation.

Finally, Amy’s story depicts an artistic rendering of recovery. Amy uses artwork she drew as she recovered to explore the “trauma of being normal.” As an immigrant from Singapore to Canada, Amy found herself living with family members who tried to place her into a specific box and found herself crushed by expectation. In her eating disorder, Amy found a place to put her energy and self-expectation, separate from the idealized self she felt her family expected. She found art helped her to “find her power,” in a way that was true to herself, to accept and welcome in those parts of herself she had cast off in an effort to be “normal.”

So, as you can see, recovery is different for each of the participants involved in this work. Participants’ stories demonstrate how no one size fits all for eating disorder treatment – for instance, while medication might help one person, it may make life feel unlivable to another.
While one family might band together to fight against the illness, another might create expectations of perfection – in the eating disorder and/or in recovery – that are perceived as too stringent. The thread that weaves through the stories is one of the search for understanding and presence; moving beyond a singular definition of recovery or a standard to live up to and toward an embrace of different and diverse recoveries.
Appendix B: Interview Guide for Participants in Recovery

Demographics (all self-identified)

1. Age
2. Gender
3. Sexual orientation/identity
4. Ethnicity/race
5. Highest level of education
6. Currently a student?
7. Current paid work? (How many jobs? Unemployed/underemployed?)
8. Current unpaid work?
9. Province or territory

Eating Disorder Experience

1. What made you respond to the call for interview participants?

2. Have you experienced significant distress around food, exercise, weight, shape, body, etc.?

3. Can you tell me a bit about what that experience was like for you?
   a. When did it begin?
   b. Did you seek any kind of support, formal or informal, for the distress?
   c. If yes, what kind(s) of support? (e.g. medical care, inpatient, outpatient, community-level support, individual or group therapy – and kind – CBT, DBT, EFT, MMFT, FBT, feminist, narrative etc.)
   d. Did you face any barriers to seeking or receiving this care?
   e. Were you ever diagnosed with an eating disorder (or more than one?)
   f. What were your interactions with healthcare providers like when you were experiencing distress? (Did you feel heard, validated, understood, marginalized, etc.?)

4. Were there any people in your life who were particularly helpful during your distress?
   a. If so, who was/were these people?

5. How would you describe your relationship with these supporters during your distress?
   a. Was there anything they did that was particularly helpful?
   b. What were some challenges you faced with respect to this support?

Recovery Experiences

6. Do you consider your eating distress [or term participant has chosen to refer to their distress/disorder] to have significantly resolved?

7. What does the word recovery mean to you?
8. Is this a word that resonates with your experiences?
   a. If so, what is it about the word that you feel captures your experience?
   b. If not, is there another word you prefer to use to refer to your experience?

9. Have you encountered many representations of eating disorder recovery?
   a. If so, how do you feel about these representations?
   b. Is there anything missing from the picture of eating disorder recovery you have seen?
   c. What would you add to this narrative?

10. Has your relationship with your supporters, who we talked about earlier changed as your distress has resolved?

11. Do you ever talk about “recovery” with your supporters?

12. What are the top things you wish healthcare providers knew about eating disorder recovery?

13. Is there anything you wish you knew about life after eating distress is no longer a major part of your experience while you were experiencing distress?
   a. Is there anything you wish your supporters had known during this time?

14. If you could have had/could have any type of support/therapy you wanted what would it be?

15. Those are all of the formal questions I had for us today; is there anything that I didn’t ask you that you were hoping to share today?

16. How are you feeling? [If distressed, refer participant to resources relevant to area and in consent form]
Appendix C: Interview Guide for Supporters

Demographics (all self-identified)

10. Age
11. Gender
12. Sexual orientation
13. Ethnicity
14. Highest level of education
15. Currently a student?
16. Currently employed? (How many jobs? Unemployed/underemployed?)
17. Province or territory
18. Relationship to person with direct lived experience of distress

Supporter Eating Disorder Experience

17. When was the first time that you knew your [child/friend/significant other/etc.] was in distress around food, exercise, weight, shape, body, etc.?
   a. Have you ever struggled with these things yourself?
      i. If so, do you think this helped you know how to respond?

18. Can you tell me a bit about what that experience was like for you?
   a. Did your [child/friend/significant other/etc.] seek any kind of support, formal or informal, for the distress?
   b. If yes, what kind(s) of support? (e.g. medical care, inpatient, outpatient, community-level support, individual or group therapy – and kind – CBT, DBT, EFT, MMFT, FBT, feminist, narrative etc.)

19. Were you involved in the process of navigating the systems involved in providing this care?
   a. Did you face any barriers as you helped your [child/friend/significant other/etc.] seek support?
   b. What were your interactions with healthcare providers like when you were experiencing distress? (Did you feel heard, validated, understood, marginalized, etc.?)
   c. How did you know where to look for support?
   d. Was there support for you as a supporter?

20. How would you describe your relationship with your [child/friend/significant other/etc.] when they were experiencing significant distress?
   a. How did you feel during this time?
   b. Did anything go particularly well?
   c. Were there any significant challenges you faced together?

Recovery Experiences

21. What does the word recovery mean to you?
22. When you think about your [child/friend/significant other/etc.] during their experiences of acute distress versus who they are now, are there any significant differences that stand out for you?
   a. If so, what are they?

23. Have you encountered many representations of eating disorder recovery?
   a. If so, how do you feel about these representations?
   b. Is there anything missing from the picture of eating disorder recovery you have seen?
   c. What would you add to this narrative?

24. Has your relationship with your [child/friend/significant other/etc.] changed as your distress has resolved?

25. Do you ever talk about “recovery” with your [child/friend/significant other/etc.]?

26. What are the top things you wish healthcare providers knew about eating disorder recovery?

27. Is there anything you wish you knew about life after eating distress is no longer a major part of your experience while your [child/friend/significant other/etc.] was experiencing distress?

28. If you could imagine the best possible form of support or therapy for people with eating disorders, what would it look like?

29. Those are all of the formal questions I had for us today; is there anything that I didn’t ask you that you were hoping to share today?

30. How are you feeling? [If distressed, refer participant to resources relevant to area and in consent form]
Appendix D: Summary of Research Results: Eating Disorder Recovery in Context (People in Recovery)

I interviewed a total of 20 people doing significantly better than during the time of their distress around food for this research project. Recognizing the fluidity of “recovery,” this status reflects how participants felt at the time of the interview. The average age of participants was 28. 14 participants identified as heterosexual; 6 identified as bisexual, pansexual or sexually fluid. 19 identified as women and one as gender non-binary. 15 identified as White (with a variety of cultural backgrounds, and 4 as Asian (East Asian, Singaporean, Japanese, Punjabi). 9 had graduate degrees, 8 had BAs/college degrees, 2 had high school diplomas, and 1 had part of high school. Not all participants had been diagnosed with eating disorders, nor had all experienced formal eating disorders treatment.

To analyze the interviews, I used an approach called thematic analysis, which means identifying similar parts of the various interviews and recognizing patterns across the data set (your interviews). The following themes reflect my interpretation of the main patterns that characterize the experience of “recovery,” recognizing that this is not a word that everyone chooses to define their experiences. Similarly, not all participants chose to refer to their distress around food, weight, bodies, shape, and/or exercise as an “eating disorder.” I use these terms in my dissertation, but talk about ways in which they do not always resonate.

Main theme: Misunderstanding Matrix

This theme relates to the ways in which eating disorders and recovery are misunderstood and/or misrepresented in society in general and amongst medical professionals in particular.

- Subtheme: Untrustworthy illness
  o Many participants described feeling like others did not trust them, including doctors and family members, even after they were doing better with their eating disorders
  o This made participants feel like they were not being heard
  o Sometimes it was actually easier for participants to speak with people who knew very little about eating disorders, because these people did not make assumptions about what eating disorders or recovery should look like
  o Not “looking like” (i.e. fitting the thin, young, white, cis-gender, able-bodied woman stereotype) one had an eating disorder made it hard for some participants to feel like their eating disorders and/or recovery was taken seriously

- Example quote: “When I go to the doctor, I feel like they don't take me seriously. And I don't know if it's… I think it's also a societal thing, because in my culture, like women are just seen as not as intelligent, and you know, they're like "unless you're married, you're pretty much seen as a little girl." Like I'm 24 and my doctor still sort of treats me like a little girl sometimes. And other health professionals have done that too, and sometimes I think that they do discriminate me based on my race and my gender, and it makes me feel like my voice isn't being heard, and then, you know, add an eating disorder to that and people just sort of don't take me seriously.”
- **Subtheme: Choices**
  - Another prominent stereotype about eating disorders is the false idea that eating disorders are a choice.
  - This was often an area of misunderstanding between participants and their families.
  - Participants spoke about how presenting recovery as an easy choice could also be problematic because it makes it seem as though recovery is easy.
  - Example quote: “my parents, they were sort of aware of the situation, but I don't think that they really understood exactly what to do or how to help? I think for them, they just don't have a lot of understanding about eating disorders, and you know, what they are. I don't think they really understand that it's really an illness and that it's not something that you can kind of decide all of a sudden to stop doing.”

- **Subtheme: Non-equivalence of weight & health**
  - Finally, participants generally wished that eating disorders, and recovery, could be separated out from weight.
  - Participants spoke about how eating disorders are often missed by healthcare providers because of the widespread panic about “obesity.”
  - Especially if participants began to engage in restriction and/or over-exercise and/or bingeing and/or purging when in a larger body, this was often praised.
  - Participants referenced a desire to have other measures to gauge recovery other than weight gain, because weight is not necessarily related to health.
  - Focusing on weight also makes other aspects of recovery less of a focus, when focusing on these other aspects of recovery might help participants to feel better.
  - Example quote: “I was also thinking a lot about ensuring eating disorder is where it is to me, you know people post before-and-after photos, which is not helpful at all. I mean, yeah, they talk about "oh, like you know, I'm so much better", which is great, but I don't know, I just, I wish they talked more about how hard it is instead of like fixating on the physical aspects, like weight gain, for example, or like the before-and-after photos, but the person at their lowest state and now.”

**Main theme: Surveilled Spaces to Safe Spaces**

This theme is related to how participants often felt watched, both during their eating disorders and into recovery. It also relates to how some spaces felt “in between” rather than “before” or “after.”

- **Subtheme: Being watched**
  - Participants talked about how being watched on treatment units often made the kind of self-surveillance they were engaging in (through eating and exercise behaviours) more intense.
  - Overly-rigid treatment environments sometimes created new rules for participants; some participants described not knowing how to eat once they left this environment.
  - Some participants remarked upon how being in treatment was challenging because they felt that others in the environment did not want to get better.
Participants sometimes felt watched in recovery too, which sometimes made it hard to talk about struggling or about anything other than the eating disorder with would-be supporters, even when they just wanted to move on.

This sensation of being watched once someone knew you’d had an eating disorder made some participants wish to not disclose their eating disorder or recovery to anyone.

Example quote: “And then there's the layer of... people stigmatize you. They make assumptions, and they expect certain things, and then they watch you. They watch you, what you're eating, and they judge. And I don't like that. So for me the decision to tell someone is always a really big deal and based on: is this gonna change the way that we interact? Are you suddenly going to start interacting with me weirdly, and is food, if we go out for a meal, is that gonna become weird?”

- **Subtheme: Being heard**
  
  - Contrastingly, sometimes participants felt heard, which helped them to feel better in their lives and could enable recovery.
  
  - Participants sought out spaces where they could be themselves, and distanced themselves from places, things, and people that made them feel like they had to “perform” a certain way.
  
  - Being heard and listened to was one of the most important things that helped participants feel supported and well.

- Example quote: “I also did like a social media purge at that time too, so that was also so helpful [...] It was hard at first, ’cause I felt bad because I knew some of my friends are nutritionists and so I'd want to support them, and especially on things like Instagram. I stopped going on Facebook completely and that was difficult, too, ’cause I felt—I realized, wow, that's how we get all of our information, people just assume that you know what's going on because they posted it on their Facebook.”

- **Subtheme: Being liminal**
  
  - Being liminal, or “in between,” relates to the experience of time during recovery.
  
  - Sometimes it was hard to wait for treatment; participants tried many other things before going to treatment, particularly if they were on a wait list.
  
  - These things often felt like a stop gap, and not particularly helpful.
  
  - It was not always realistic for participants to put their lives on hold to pursue treatment, and treatment did not always prescribe ways of living that worked with the context of participants’ lives.
  
  - At the same time, the feeling of being trapped in a cycle of behaviours that was causing distress was a reason some participants cited for seeking out treatment.
  
  - Participants remarked on the lack of transitional support from treatment to home, or, if they did not do intensive treatment, the lack of community-based support.

- Example quote: “I went away for university without giving my eating disorder a second thought and thinking I didn't need any care there, because I was re-fed to a certain amount and so I think like it just, it never got really dealt with underlying issues, and, and then just unraveled from there.”
Main theme: Recovery is Life

This theme relates to the experience of feeling like in many ways, eating disorder recovery is really just living life, including highs and lows, and both mundane and interesting aspects of life.

- **Subtheme: Unguided pathways**
  - Participants spoke about how it was often unclear how they were supposed to achieve recovery; healthcare providers and others did not often provide a lot of information about what it meant to get to a place of recovery or how to get there, beyond basic treatment plans.
  - Many participants could not put an exact timeline to their experience; often memories were vague or there was some uncertainty around when “recovery” existed or did not exist.
  - Sometimes participants talked to supporters to help establish a timeline or to think about their recovery.
  - There was not necessarily a before and after to the eating disorder story.
- Example quote: “He remembers things very vividly and I don't have as strong of a memory from that time about things I did, or what I looked like, or how I acted. So he'll bring it up from time to time about how, how far we've come and what the experience was like for him and us—and then, I think I tend to bury it a lot because like, and I don't know if this is common, but I almost have like flashback-style memories of things that'll happen just randomly […] and I barely remember being there but I can remember it like very vividly, certain things.”

- **Subtheme: Not only recovered**
  - Participants lives were about more than their recoveries.
  - Some participants spoke about how in order to be recovered, they needed to distance themselves from the identity of “someone recovered from an eating disorder”.
  - There was value in sharing the recovery story for some, but not all, participants.
  - Some participants did not see the eating disorder as having been the single most important life event they dealt with.
- Example quote: “I'm tired of letting things get in the way of what I want to do. And I'm just not willing to let them anymore, so if someone has a problem, like whatever. I have goals that are bigger than you, so I'm gonna pursue those.”

- **Subtheme: Not all sunshine and rainbows**
  - Almost all participants spoke about how recovery is often painted as a perfect place of sunshine and rainbows in mainstream representations.
  - This was an unsatisfying picture, and it did not resonate for most.
  - Most participants preferred a more “realistic” version of recovery that made room for imperfection or living life differently.
  - The idea that one needs to love their body all the time in recovery was particularly simplistic; participants spoke about how this also makes it seem like the aesthetic aspects of recovery or body-related aspects of recovery (like weight gain) are the most important, which they disagreed with.
- Some participants spoke about how they felt like people in recovery are held to a higher standard than people in general when it comes to loving their bodies.
- “Normal eating” looked different for different participants → there is no one single version of normal eating in recovery
- Example quote: “I think for me right now my biggest thing that I'm working on is just being compassionate towards myself, and for me that means not—letting myself not be perfect and not, everything doesn't have to be done in a certain way.”

- **Subtheme: Life of recovery**
  - Participants had their own definitions of recovery which sometimes did not mesh with clinical or popular definitions
  - There was no single way to “be recovered”
  - Importantly, many participants did not like the term recovery to define their experiences or did not consider themselves to be “100% recovered,” partly because of the way recovery is defined
  - Recovery was either facilitated or inhibited by contexts, including places and people that made it harder or easier to live a life participants enjoyed; for example, being a part of a community helped some participants live their recoveries
- Example quote: “The thing that really pushed me forward, too, was being this community girl, and seeing people who had been really ill who are doing great and live fantastic lives and making their decisions and just feeling that sense of connectedness”
Appendix E: Summary of Research Results: Eating Disorder Recovery in Context – (Supporters)

I interviewed a total of 14 supporters of people who had experienced eating distress/eating disorders.

To analyze the interviews, I used an approach called thematic analysis, which means identifying similar parts of the various interviews and recognizing patterns across the data set (your interviews). The following themes reflect my interpretation of the main patterns that characterize the experience of “recovery,” recognizing that this is not a word that everyone chooses to define the experiences. Similarly, not all participants chose to refer to their distress around food, weight, bodies, shape, and/or exercise as an “eating disorder.” I use these terms in my dissertation, but talk about ways in which they do not always resonate.

Main Theme: The Im/Possibility of Recovery

- Supporters spoke about recovery differently depending on their relationship with the person, how they related to their own health and wellness, how much time had passed between the period of acute distress and when we spoke, and how they felt their loved one was doing at the time we spoke.
- Most supporters thought that recovery was possible, though some thought of recovery as something that would always be “in process.”
- Supporters acknowledged that recovery means different things to different people.
- The longer time that had elapsed between the period of acute distress and the interview, the more participants generally felt that their loved one was on the “recovered” side.
- Some supporters felt frustrated with how recovery had been described by clinicians, who were described as either not presenting much information about what recovery was and how to get there or presenting only very standard benchmarks for recovery that did not necessarily reflect their realities.
- Example quote: “I would say it's multi-leveled, you can look at it from a physical standpoint and say, okay, we're re-fed, the scale is say that there's enough weight on this person, so in terms of a physical recovery; but there's ongoing recovery, ongoing acceptance […] recovery is like an ongoing thing, there's that level of, these things are stable, and then there's that area where it's an ongoing development, it's never, you're never really recovered, I don't think.”

Main Theme: Surveillance and Normalcy

Supporters’ accounts revealed how it is complicated to help someone recover in a world that has very specific directions for “how to be healthy,” that do not necessarily work for a person in recovery.

- Subtheme: Watching/Being Watched
  - Supporters sometimes felt responsible for and uncomfortable with watching what their loved one was or was not eating; particularly when they described
themselves as people who were not normally dictating others’ behaviour, they did not always wish to tell their loved one what to do.

- Many supporters tried to be a “good role model” for their loved one, rather than being explicitly directive on “how to eat.”
- Being involved in supporting their loved one through recovery often made supporters re-evaluate their own relationship with food and their bodies, often for the better.
- Example quote: “I definitely try to be as good of a role model as I can when it comes to food—I try and be normal, I try not to be overly cautious and, cause she’s not stupid, she’ll know if I’m acting. So I just try and be normal and I would say that she — before I met her, when I was younger there was a time period when I was more of a healthy eater — I don’t know if healthy is the right word — just, I didn’t eat as much you know ice creams and snacks as I do now and when I met her I just felt like, I didn’t want to do that in front of her so, and actually it made me a better person too in a sense because I think my relationship with food is better now, just trying to be a good example for her. But yeah like I just try and be normal.”

**Main Theme: Recovery Time/Family Time**

This theme relates to how supporters experienced the time between illness and recovery, and things they thought would have helped along the way.

- **Subtheme: Timely and Appropriate Support**
  - Even when supporters’ loved ones had “good outcomes,” they reflected on what might have been helpful along the way.
  - Supporters were grateful for the support they had received, but noted how support was often not available without a wait, cost money and other resources, did not involve supporters to the extent they wished, and was especially lacking after the intensive phase (if there was an intensive phase).
  - Supporters often felt powerless while waiting for treatment or other support for their loved ones.
  - Example quote: “That was… there's not really words to describe it, I don't think, that can clearly describe the pain involved. Because — knowing how painful it is for them that are suffering. To feel like that unworthy of being able to do the right thing for yourself, that was the pain that, that I, I did through, because you know that they're suffering so much, right? And, yeah, so there's not really, like a good adjective to describe other than just painful, incredibly sad, concerned, I was really determined that this — you just don't leave any log unturned, they're gonna get the right help here.”

- **Subtheme: Relational Loops**
  - Lack of support rippled through relationships, especially for supporters who were partners of those in recovery.
  - For partners in particular, it was often a challenge to be supporting someone who was also their primary supporter: if the partner-in-recovery was not doing well,
they were not available to help their partner if something was challenging in their life.

- Supporters often had to put their own needs aside, at least momentarily, to support their loved ones.
- When support was not available from systems, supporters felt that they had to step up to fill these gaps.

- Example quote: I would really try and obliterate my own self and say – shut up she needs you right now, she really needs to see you eat and not care, not care about what you’re doing

- **Subtheme: Thresholds of Care**
  
  - Supporters expressed a great deal of empathy toward their loved one’s struggles.
  - Sometimes relapses and repeated strain made it harder for supporters to maintain this degree of empathy constantly over the years.
  - This sometimes provoked feelings of guilt and wishing that there were more support available for supporters themselves, in addition to more support available for the loved one.
  - Many supporters remarked on how putting their own needs to the side during the period of acute distress was necessary due to the lack of systemic support, but in hindsight made them wish they had sought or had access to more support along the way

- Example quote: “I care about her. I mean, that's number one, I love her, she's my wife. And, you never want to see somebody that you love suffer. So, I mean, there's that to deal with. But, we also live in very close proximity to each other. I don't necessarily have a short fuse, but if you keep hitting me with the same thing over and over again, I start to get frustrated, or irritated, and I feel guilty about that every time it happens. Because I know why she's doing what she's doing, but it's a fight. It really is. I'm not complaining, I refuse to complain about it, because I care about her and I want her to be happy. In the back of my mind, I still know, all she needs is someone in her corner and she's gonna go light years under her own power. I've never forgotten that.”

- **Subtheme: Finding Connections**
  
  - Given the limited amount of support available for supporters, supporters often sought out a great deal of information about eating disorders to try to learn more about what their loved one was dealing with.
  - Some were able to find others sharing the experience of supporting someone through an eating disorder, though this was more often the case for supporters who were parents.
  - Supporters knew that they were never going to be able to fully know what it is like to have an eating disorder (when they had not experienced one themselves) but tried to learn as much as they could from their loved ones to better support them.
• Example quote: “I was kind of like, “okay, I really have to figure out what I should do or not do or whatever, so I went, I went Googling looking for like ‘what should you do when you're dating someone with an eating disorder’”

**Overall**: Supporting someone in recovery was described as challenging and often under-supported from a systemic perspective. It involved empathizing with the loved one and often going to bat for them in various venues; supporters did not always share the person in recovery’s definition of and orientation to recovery but they were able to engage with the person in a way that enabled at least a positive relationship. This was not without struggle, and often came at the expense of their own personal wellbeing. In order to minimize this strain, systems should provide more and more varied types of support for those supporting loved ones through this time, if they desire it.
Appendix F: Ethics Board Approval

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human participants in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that researchers:

- Adhere to the protocol as last reviewed and approved by the REB.
- Receive approval from the REB for any modifications before they can be implemented.
- Report any change in the source of funding.
- Report unexpected events or incidental findings to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants, and the continuation of the protocol.
- Are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants in the jurisdiction of the research project.

The Principal Investigator must:

- Ensure that the ethical guidelines and approvals of facilities or institutions involved in the research are obtained and filed with the REB prior to the initiation of any research protocols.
- Submit a Annual Renewal to the REB upon completion of the project. If the research is a multi-year project, an Annual Renewal must be submitted annually prior to the expiry date. Failure to submit an Annual Renewal will lead to your research being suspended and potentially terminated.

The approval for this protocol terminates on the EXPIRY DATE, or the end of your appointment or employment at the University of Guelph, whichever comes first.