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**Australian Women's Accounts of Eating Disorder Treatment and Recovery: Qualitative
Analysis of an Online Focus Group and Interviews**

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Abstract

The aim of the research reported in this thesis was to use a phenomenology and a recovery approach to understand the experiences of participants in eating disorder (ED) recovery. Eating disorders are chronic disorders with low prevalence but high relapse and mortality rates. Treatment is provided in multiple settings and often requires specialisation, both of the setting and of the providers. While mental health treatment in Australia has shifted to a recovery centred approach focused on assisting people with mental illnesses to live their life to the fullest, there is insufficient evidence to demonstrate whether this approach is being applied effectively to ED treatment, although this is a necessary area of research. There has been a significant amount of research into the experiences of people with EDs but this research has seldom linked the experiences during treatment with those during recovery. To this end, the current research sought to examine the experiences of people with EDs by asking what their personal experiences of treatment and recovery were like and what helped or hindered them. This research was conducted across two studies comprised of an online focus group (OFG) with seven participants, and thirteen individual interviews. The analysis of these results of both studies indicated that the elements of the recovery model were applicable to ED treatment, that treatment experiences impacted recovery outcome overall, and that interpersonal relationships had an effect on recovery. These findings suggested that it is necessary to examine how EDs are treated, both because the recovery model may be a viable alternative treatment model and because people with EDs reported that their experiences with both treatment and allied professionals impacted their willingness to engage in treatment overall. The findings have implications for treatment and policy decisions in the future.

Student Declaration of Originality

This thesis is an original work of my research and contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signature:

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Date: 9/11/20

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Introduction

Eating disorders (EDs) are characterised by extreme eating behaviours and distorted beliefs or concerns around food, weight, and body shape. They are complex disorders to treat with high relapse and mortality rates. The complexity of treating EDs derive from their mixed physical and psychological presentations, which means they often require specialised treatment settings and professionals. Modern mental health care in Australia has shifted to a recovery centred model. Care based on this model is holistic, client focused, and aimed at expanding the definition of recovery beyond symptom cessation to include overall satisfaction with life and having hope for the future (Anthony, 1993; Resnick, Fontana, Lehman, & Rosenheck, 2005). This thesis aimed to understand how people with EDs experience their treatment and recovery. The experiences of Australian adults in ED recovery were examined to determine what helped and hindered them during recovery and treatment. Results indicated that the recovery model (Daswson, 2014) was applicable to ED recovery, that treatment experiences did impact overall recovery outcomes, and that interpersonal relationships affected recovery. This research is important because it examined the applicability of the recovery model to ED treatment and also examined the effectiveness of treatment as it was experienced by people with EDs. This has implications for how care can be improved and for further research and policy development.

The overarching aim of this thesis was to the understand people's experiences of treatment and recovery. This aim was contextualised within EDs relatively low prevalence in the general population (Bulik et al., 2006; Keski-Rahkonen & Mustelin, 2016; Nagl et al., 2016) compared to their mortality (Arcelus, Mitchell, Wales, & Nielsen, 2011; Franko et al., 2013; Papadopoulos, Ekbom, Brandt, & Ekselius, 2018). Additionally, EDs are chronic disorders (Steinhausen & Weber, 2009) with high relapse rates (Fichter, Quadflieg, & Hedlund, 2006). This suggests that EDs are an at-risk population with poor treatment

outcomes. Treatment for individuals with an ED is often provided in a number of settings including inpatient (IP), partial hospitalisation programs (PHP), and outpatient programs with movement through the levels of care following a stepped model of care (Willenge, Thornton, & Touyz, 2012). In this model, people receiving care are monitored by a treatment team so that they receive the most effective treatment at the appropriate time, moving up and down levels of care according to the severity of their illness. There are a variety of allied health professionals who provide care across these levels of treatment and the number of professionals involved in a person's care team varies during their recovery journey. ED treatment in Australia recommends a multi-disciplinary model with a stepped-care approach (Hay, Chinn, Forbes, Madden, Newton, Sugenor, Touyz, & Ward, 2014a).

Mental health care in Australia uses a recovery approach. This model has its origins in radical psychiatry and consumerist movements. These movements were predicated on the belief that psychiatry was damaging to those it was meant to help because of unequal power dynamics that in turn lead to situations of coercive oppression (Wall, 2018). Among their many goals, these movements sought to shift power within the treating relationship so that it was balanced in favour of the client (Wall, 2018). The recovery model is a model of care that is consumer focused. From this perspective, the focus is on a holistic definition of recovery where the individual's experience of mental illness and recovery is made central to treatment (Deegan, 1988). Recovery is seen as the development of meaning beyond mental illness and disability to include a person's quality of life, welfare, and wellness (Anthony, 1993; Noordsy et al., 2002; Resnick et al., 2005). There have been some applications of the recovery model to EDs (Dawson, Rhodes, & Touyz, 2014) but ED care is often delivered under a biomedical model due to the combined physical and psychological nature of the disorders.

Though mental health care in Australia overall has shifted to a recovery centred model (Dawson, River, McCloughen, & Buus, 2019a; 2019b), there is not enough evidence to suggest how effectively this model is being applied to ED treatment. In order to examine the recovery model's efficacy in ED treatment, it is important to examine if people receiving ED treatment notice elements of the recovery model in existing models of care and also to examine their understanding of ED recovery to determine if it fits within the recovery model. This type of exploratory research sets the basis for future recovery model oriented ED research. The ED recovery experience has been examined in numerous qualitative studies, which have investigated treatment and recovery experiences using multiple methods and samples (Bowlby, Anderson, Hall, & Willingham, 2012; Conti, 2017; Keski-Rahkonen & Tozzi, 2005a; McNamara & Parsons, 2016). While many studies exist, few studies link how these experiences effect overall treatment outcomes.

This research used phenomenology and recovery approaches. In phenomenology, the objective is to analyse experiences in order to understand the human experience. This is necessary because individuals process and understand their experience within the context of the world as a whole (Langdridge, 2007). As such, phenomenology has a specific interest in how an individual's consciousness can be analysed in order to identify the fundamental concepts of a phenomenon. Similar to phenomenology, a recovery approach is focused on the individual experience. Here, however, the focus is on how recovery is defined and understood (Davidson & Roe, 2007). Recovery-based research emphasises that individual experience of recovery is best understood through the accounts of those who have experienced mental illness and who are in recovery. This approach is in opposition to the prevailing biomedical model, under which recovery and mental health research has often been carried out (McCranie, 2015). Phenomenology and a recovery approach can be paired with ease due to their focus on individual experiences and the particular concern both

approaches have with how the person is engaging with the world during their recovery journey.

To better understand ED recovery from a phenomenological perspective within the context of the recovery model, two research questions were explored. First, what is the personal experience of ED recovery and what helps or hinders it? Second, what is the personal experience of ED treatment through the recovery journey and what helps or hinders it?

A number of key concepts relating to recovery and ED treatment were used throughout this thesis and whose definition is important from the outset. Recovery as it is used in psychology has been defined in a variety of ways. Because this research uses the recovery model, Anthony's (1993) definition was selected as a guide because his research relied on the first hand experiences of people with mental illnesses in developing a clear definition. According to Anthony (1993) recovery is

... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and life purpose in one's life as one grows beyond the catastrophic effects of mental illness. (pg 19)

This research focused on the experiences of people in ED recovery, which meant someone who had been diagnosed with any ED and who was in self-assessed recovery at the time of participation. The author was careful to avoid unintentionally stigmatising participants, so language was carefully considered. Those with mental health diagnoses were not referred to in a way that would personalise the diagnosis (e.g. anorexic, bulimic, etc). Other language was also used intentionally to diffuse any stigma associated with mental illness or receiving treatment for it, such as the use of "people receiving treatment for an ED" instead of client or patient. Treatment was understood to be any kind of formal therapeutic process a person with an ED undertook to manage their ED symptoms and had to involve an allied health

professional. It could involve any of the range of treatment options available in an inpatient or outpatient program. An allied health professional is a person who received formal training to assist in caring for people's health; they did not have to be specialised in mental health or EDs. Allied health professionals were also referred to as treating professionals or, simply, professionals. Examples of allied health professionals included but were not limited to general practitioners (GPs), dieticians, psychologists, and psychiatrists.

This research consisted of two qualitative studies. The first study was an online focus group (OFG) comprised of seven Australian participants in ED recovery. During the three hours OFG participants discussed experiences of treatment and recovery. The data was analysed using thematic analysis and the results were used to inform the development of the interview schedule used for the second study, a series of individual interviews. The individual interviews, which were between 60 and 90 minutes long, were conducted with thirteen participants in ED recovery. They were also focused on experiences of treatment and recovery but were able to go into more depth. The data was analysed using interpretive phenomenological analysis (IPA). Studies were analysed individually, and their results were compared looking for similarities and differences across the datasets.

Elements of the recovery model were supported by findings from both studies, namely that recovery is ongoing and an identity re-organisation process. For people with EDs this suggested a more holistic conceptualisation of recovery and indicated a need to re-evaluate the biomedical model's role in treatment. Treatment experiences were found to impact recovery. This applied to the participants' experiences with treatment overall and to their experiences with allied health professionals. Positive interactions with allied health professionals, especially psychologists, impacted motivation to recover. Negative experiences with multiple allied health professionals were also noted and these impacted participants' willingness to engage with treatment, contributing to relapse. Interpersonal relationships

effected recovery, especially interfamilial ones. Supportive and empathic relationships both encouraged participants in their recovery. Experiences of being misjudged and stigmatized were also described and these were managed by creating emotional distance from family members.

1.1.Thesis Outline

Chapter 1- Introduction: This chapter introduces the research, briefly contextualises it within the existing literature, and explains the significance of it by explaining the experimental design and results. It also includes the outline of the chapters.

Chapter 2- Eating Disorder Treatment: This literature review chapter provides the broad context for why research into ED recovery is necessary based on the epidemiology and current treatment of EDs.

Chapter 3- Recovery Model and Eating Disorders: This literature review chapter examines the recovery model based first on the radical psychiatry movement. It then examines the various ways recovery has been defined in the literature and how it has been studied and applied to EDs.

Chapter 4- Methodology: This chapter explains the theoretical stance and research design used in both studies. It also discusses how the study was carried out, who the participants were, and the style of analysis.

Chapter 5- Results of Online Focus Group: In this chapter the results of the thematic analysis of the OFG are explained. The themes are detailed as are the changes made to the research schedule based on the results of this study.

Chapter 6- Results of Individual Interviews: Here, themes and subthemes which were the results of the individual interviews were described.

Chapter 7- Discussion: In this chapter the results of the OFG and individual interviews are explained and contextualised. Their significance is discussed. Overall significance of both studies is also discussed.

Chapter 8- Conclusions: The summary of the findings and their significance is provided in this chapter. Strengths and limitations are explored.

Chapter 9- References: Here, the complete references for the study are collated.

1.2. Chapter Summary

This chapter introduced the purpose of this thesis, which was to increase the understanding of ED treatment and recovery experiences. The background and rationale for undertaking this thesis were explained, as were the theoretical influences that influenced it. The general methodology and results were described.

Chapter 2

Eating Disorder Treatment

There is a growing body of data on the epidemiology of eating disorders (EDs) that seeks to develop an accurate picture of the incidence, prevalence, and mortality of these disorders (Keski-Rahkonen & Mustelin, 2016; Kolar, Rodriguez, Chams, & Hoek, 2016; Nagl et al., 2016; Thomas, Vartanian, & Brownell, 2009). However, epidemiological research has also contributed to the debate around the accuracy of diagnostic criteria, due to the wide variation in criteria used across studies (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; Keski-Rahkonen & Mustelin, 2016; Wade, Bergin, & Tiggemann, 2006). This has implications for ongoing discourse around how to improve diagnosis and treatment so that more people are diagnosed and treated earlier (Machado, Gonçalves, & Hoek, 2012; Mancuso et al., 2018).

2.1. Eating Disorder Epidemiology

2.1.1. Prevalence and incidence

Prevalence studies are used to measure the distribution of EDs within the population. Overall, they demonstrated that, EDs are relatively rare within the population, with the lifetime prevalence ranging between .3% and .6% for anorexia nervosa (AN), .51% and 1.0% for bulimia nervosa (BN), 1.12% and 2.15% for binge eating disorder (BED) (Hudson, Hiripi, Pope, & Kessler, 2007; Preti, Rocchi, Sisti, Camboni, & Miotto, 2011; Swanson et al., 2011). Additionally, prevalence studies also showed that EDs are most common among young women (Compte, Sepulveda, & Torrente, 2015; Keski-Rahkonen & Mustelin, 2016; Nagl et al., 2016; Smink, van Hoeken, & Hoek, 2012). Recent research attempted to establish global prevalence trends and found that, generally, prevalence was stable and low in most countries (Bulik et al., 2006; Keski-Rahkonen & Mustelin, 2016; Nagl et al., 2016), though there were regional variations, such as higher levels of BED in Latin America when

compared to European samples (Kolar et al., 2016). There were some areas of the world that remain understudied, such as swathes of Africa, Asia, and the Pacific, for which there were few studies (Thomas, Lee, & Becker, 2016; van Hoeken, Burns, & Hoek, 2016). By improving the understanding of the local prevalence trends, research will be able to more clearly tailor treatment-based research.

Notable twin studies have been carried out in Finland, Sweden, and Australia and helped to paint a more nuanced picture of ED prevalence. Together these studies found much higher lifetime prevalence rates than those using community data. Keski-Rahkonen and colleagues examined the prevalence of AN and BN in two separate studies using a Finnish female twin population, finding a lifetime prevalence of 2.2% and 2.3% respectively (Keski-Rahkonen et al., 2008; 2007). A twin study in Sweden of AN found a lower lifetime prevalence of 1.20% (Bulik et al., 2007). An Australian twin study found lifetime prevalence rates for AN, BN, and BED of 1.9%, 2.9%, and 2.9% respectively (Wade et al., 2006). While these prevalence rates from twin data are slightly higher than those found in community samples, demonstrating the strength of twin studies, the overall low prevalence of EDs is still maintained throughout.

The higher lifetime prevalence found in the twin studies does, however, call to question the actual prevalence of eating disorders in the community. All of the twin studies reviewed here except for Bulik et al (2006) utilised broader diagnostic categories in their studies as a means of capturing people with subclinical presentations who would not normally be represented in prevalence studies (Keski-Rahkonen et al., 2007; 2008; Wade et al., 2006). In the broader categorisation, AN also included people who did not have amenorrhea or those who did not have weight loss of more than 15% of their total body weight. People who had subthreshold bingeing and instances of purging with no other history with an ED were included under an eating disorder not otherwise specified category

(EDNOS). The broadened diagnostic criteria used in the twin studies also touched on the importance of measuring prevalence rates of people whose ED diagnosis does not fit into the AN, BN, or BED diagnostic criteria. Wade et al (2006) found that the lifetime prevalence of DSM-IV formulation EDNOS was 5.3%, even with the broadening of the diagnostic criteria used in their study. Contemporary researchers noted that EDNOS is the most commonly diagnosed eating disorder but, to date, does not have an operationalised or validated treatment system, leaving psychologists to adapt treatment from existing ones (Fairburn & Bohn, 2005; Thomas et al., 2009). The DSM-V attempted to address this diagnostic difficulty by broadening diagnostic criteria and creating the ‘other specified feeding and eating disorders’ (OSFED) criteria to replace EDNOS. Since this change, research demonstrated changes to the proportion of people with EDNOS/OSFED diagnoses, suggesting more people are being accurately diagnosed and possibly treated (Machado et al., 2012; Stice, Marti, & Rohde, 2013). Clear diagnosis will ultimately allow clinicians to not only provide effective treatment but will also allow researchers to develop a clearer understanding of EDs affect the wider community over an extended period of time. Because EDs are chronic and because existing studies have demonstrated that their prevalence is relatively stable within a population, the accuracy of this information is important to detect shifts within it.

Incidence studies have been used to measure the new cases of eating disorders in a population and have been of particular interest to researchers as a means of tracking changes within the population. A series of large-scale studies in the UK demonstrated that incidence of AN remained stable through the mid-1990s and into the first decade of 2000. BN, however, showed a spike in new cases diagnosed between 1988 and 1993 but then showed a decline and stabilization (Currin, Schmidt, Treasure, & Jick, 2005; Micali, Hagberg, Petersen, & Treasure, 2013; Turnbull, Ward, Treasure, Jick, & Derby, 1996). This spike was attributed to increased attention paid to BN following its introduction as a diagnosis and the

subsequent media attention this inspired (Currin et al., 2005; Turnbull et al., 1996). A similar spike in incidence was found for EDNOS between 2000 and 2009, which was attributed to increased clinical attention on EDs generally and EDNOS specifically (Micali et al., 2013). Taken together, these studies demonstrate that the overall detection rate of EDs in Western countries like the UK remains generally stable and low.

The ‘Finn-Twin’ studies carried out by Keski-Rahkonen and colleagues (2007) found the incidence for both AN and BN using broad diagnostic criteria, as described above. They found that the incidence of AN was 270 per 100,000 (CI 95%= 180-360) and that for the broader definition of AN was 490 per 100,000 person-years (CI 95%=370-61) (Keski-Rahkonen et al., 2007). For BN, they found that the peak age group at risk was women aged between 16 and 20 years and that the incidence of 200 per 100,000 person-years (CI 95%= 130-290) was twice that of the 10 to 24 year age group of 100 per 100,000 person years (CI 95%= 75-140) (Keski-Rahkonen et al., 2008). This pattern was repeated with the incidence of the broader definition of BN used in this sample.

In isolation, incidence rates provide little context or explanation for the change in rates of eating disorders. Unfortunately, there are limited studies examining the incidence of EDs and also using as broad a community sample as the Finn Twin studies, so comparison is difficult. There were a number of incidence studies carried out in the 1980s and 1990s, which are reviewed by Hoek (2006) along with the UK studies discussed above. These studies all drew from health care records or health care settings, so they, on average, found a lower incidence rate than those found in the Finn Twin studies, 8 per 100,000 person years for AN and 13 per 100,000 person years for BN; no incidence was recorded for BED or EDNOS (Hoek, 2006). Comparison between these incidence rates should be done with caution. The studies reviewed by Hoek (2006) used a variety of sampling methods and populations and were carried out under DSM-III and DSM-IV diagnostic criteria. Hoek

(2006) did note that the incidence rates found in the literature review were most likely under reported because the samples were drawn from health care settings, which contrasted with the Finn Twin study's more representative community sample that used a broader diagnostic category drawn from the DSM-IV TR.

What the studies reviewed by Hoek (2006) did demonstrate was that the incidence rate of EDs increased during the latter half of the last century until the 1970s, particularly, AN in females aged 15-24 years. After this, the incidence rate appears to have plateaued. This plateau is confirmed by the British studies discussed above, which found that incidence rates for AN and BN remained relatively stable, with some spikes from the late 1990s through 2009 (Currin et al., 2005; Micali et al., 2013; Turnbull et al., 1996). However, the Finn Twin studies call this conclusion into question. First, whether the initial incidence rates were accurate to start with is a matter of contention, as they were measured from health records and in health settings. These records may not have yielded accurate representations of the population with EDs, as a proportion of this population does not seek treatment in these settings (Hepworth & Paxton, 2007; Mond, Hay, Rodgers, & Owen, 2006; Turnbull et al., 1996). Second, none of the studies, aside from the Finn Twin studies, examined the modern community incidence of EDs, so there are few studies to compare these rates against and to develop a picture of the worldwide incidence. A study of the point prevalence of eating disorders in South Australia in a community sample found that there has been an increase in diagnosed eating disorders over a 10 year period, particularly EDNOS (Hay, Mond, Buttner, & Darby, 2008). Of course, point prevalence and incidence cannot be compared directly, as the former shows a snapshot of the number of people with an ED and the latter is a statistic of how many people developed an ED disorder in a period of time. However, the increase in ED diagnoses found by Hay and colleagues (2008) and the higher incidence found in the Finn Twin study suggested that there may be a shift in ED behaviours. This further suggested the

necessity of further rigorous epidemiological studies. Understanding how EDs shift and change across time is necessary and would have resounding implications for allocation of resources to treatment and ongoing research into the development and course of eating disorders.

Incidence and prevalence studies raised some interesting points about ED diagnosis. In particular, these studies have consistently found that both incidence and prevalence were higher in younger women than in men (Compte et al., 2015; Javaras et al., 2015; Micali et al., 2013; Smink et al., 2012). However, while EDs are frequently characterized as a women's disorder, recent research found that a high proportion of young men's diagnoses fell within the EDNOS category, suggesting that traditional diagnostic categories may not be accurate for this population (Compte et al., 2015; Micali et al., 2013). Therefore, while the women, particularly young women, remain at distinct risk for an ED, so too are young men and interventions should be tailored to these unique at-risk groups. Changes to the DSM-V broadened AN and BN diagnostic criteria, formalized BED as a diagnosis, and created the OSFED criteria to replace EDNOS (APA, 2013). This in turn had implications for the high-risk groups mentioned above, who were diagnosed and treated at a higher rate under new DSM-V guidelines (Machado et al., 2012; Mancuso et al., 2018). As such, some changes to incidence may reflect these changes and improvements in diagnosis.

2.1.2. Mortality

While EDs are present in a small proportion of the general population, their impact is severe and long lasting. Multiple studies found that the mortality risk was higher for people with EDs (Arcelus et al., 2011; Fichter, Quadflieg, & Lindner, 2013; Franko et al., 2013; Papadopoulos et al., 2018). In particular, the mortality rate for people diagnosed with AN is especially high. Recent studies found that there is between a 3% and 6% increased risk of death for people diagnosed with AN when compared to the general population (Fichter &

Quadflieg, 2016; Papadopoulos et al., 2018; Winkler et al., 2017). The wide range in these mortality rates can be attributed to differences in study method, with some using a clinical sample and others using a population register design. The differences in method make for more restricted or more diverse samples, respectively, both of which are useful in epidemiological research, but also mean that it is difficult to develop a clear picture of mortality rates among this population.

People diagnosed with BN, BED, and EDNOS/OSFED all tended to have lower mortality rates than those with AN, though their rates were still elevated when compared to the general population. Of note were people diagnosed with BN, who were found to have a roughly 3% increased risk of death compared to the general population (Crow, Peterson, et al., 2009c; Suokas et al., 2013). So, while the mortality rate for people with BN was lower than the rate for people with AN, there was still a pronounced risk when compared to the rest of the population. A limitation of mortality research has been its tendency to focus on AN and, to a lesser extent, BN. There is a scarcity of research on BED and EDNOS/OSFED related mortality. The research that is available on EDNOS as diagnosed in the DSM-IV showed a wide range of standardized mortality rates (SMR), ranging from 1.3 (95% CI= 1.1-1.5) (Hoang, Goldacre, & James, 2014) to 2.39 (95% CI = 1.83-3.06) (Fichter & Quadflieg, 2016). The SMR is the ratio of observed deaths in a study sample to the expected deaths in the general population. Crow, Peterson and colleagues (2009) found that people diagnosed with EDNOS according to the DSM-IV, with an SMR of 1.81 (95% CI= 1.31-2.45), showed a fivefold increased mortality risk compared to the general population. To date, no studies have been carried out with the new OSFED criteria found in the DSM-V. Additionally, there were relatively few studies examining BN specifically. The most recent study on mortality in BN was conducted in 2012 and found that mortality risk was significantly higher than previous studies, at 6% increased risk compared to the general population (Huas et al., 2012).

Mortality research needs to be replicated and conducted with all ED diagnoses in order to create a clear picture of the risk associated with these disorders.

As it stands, the current research demonstrates that some EDs present a significant risk of death for those diagnosed with them. While current research has shown AN to have the highest risk, both BN and EDNOS carry significant risk as well, although further research is necessary to clarify the nature of that risk. Existing research demonstrated that the mortality risk for people with some EDs was comparable to that of people with severe psychiatric diagnoses. In particular, the SMR of people diagnosed with AN was found to be comparable or higher to that of people diagnosed with schizophrenia, bipolar disorder, or major depressive disorder (Arcelus et al., 2011; Hoang et al., 2014). So, AN presents a comparable risk of death to major psychiatric disorders, even though the prevalence and incidence are low.

Current research also demonstrated that people with EDs were at increased risk for early death when they had a comorbid diagnosis and that they were at increased risk for suicide. People diagnosed with AN and a comorbid diagnosis, such as bipolar, major depressive disorder, or schizophrenia had between a two and five percent increased mortality risk compared to controls, who did not have psychiatric comorbidities (Kask et al., 2016). Similarly, substance use increased mortality risk for people diagnosed with AN (Kask et al., 2016; Papadopoulos et al., 2018). This research confirmed findings that substance use can become a secondary coping mechanism for people with EDs and that this use is especially risky in the ED population due to the complex medical issues related to the disorders (Papadopoulos et al., 2018; Sullivan, Bulik, Fear, & Pickering, 1998). Researchers suggested that an increased mortality risk was also due in part to treatment complications, which may include the lack of appropriate treatment available for multiple comorbid disorders. Instead, treatment may be provided for one disorder at a time and this may in turn contribute to

treatment non-adherence as patients may feel that their needs were not being met (Kask et al., 2016).

Suicide risk was also pronounced among people diagnosed with EDs and was markedly high among people diagnosed with AN (Pisetsky, Thornton, Lichtenstein, Pedersen, & Bulik, 2013; Smith, Zuromski, & Dodd, 2018; Yao et al., 2016). This risk was especially high when there was a comorbid diagnosis with the ED, most especially a substance use disorder, which have been conceptually linked to suicide due to an increase in impulsive behaviour (Kask et al., 2016; Papadopoulos et al., 2018; Pisetsky et al., 2013). However, while suicide risk was higher among people with both EDs and a comorbid diagnosis, the presence of psychiatric disorders alone did not explain the increased risk for suicidality and mortality. Recent research conducted with a clinical population controlled for comorbid diagnoses found some of the risk for suicidality and mortality came from the EDs themselves, though the researchers noted that not all of this risk was attributable to the EDs (Yao et al., 2016). Consequently, EDs are a risk factor for both suicidality and mortality, regardless of the presence of comorbid diagnoses.

Epidemiology studies demonstrate that, while people with EDs are proportionally a small percentage of the population, they were none the less an at-risk population. Most striking was their mortality risk, which was comparable to most major psychiatric disorders. Given that there are a number of at-risk subgroups, including young women, and, increasingly, young men, in the ED population, the need for ongoing research is particularly pressing. Taken together, these studies illustrate the necessity of understanding the mechanisms that underlie recovery and relapse, so that more effective treatment options can be developed.

2.1.3. Burden of illness

2.1.3.1. Quality of Life. In ED research it is not sufficient to understand the physical and psychological morbidity associated with the disorders; increased research has been directed at understanding the impact of symptoms on people's lives. This research examines people's quality of life (QoL), which is best understood as being the subjective experience of health and functioning on a range of domains including and not limited to physical and psychological health, social relationships, and cognitive functioning (World Health Organization Quality of Life Group, 1995). This metric can be further specified to health related quality of life (HRQoL), which measures a person's subjective experiences in the areas of health and wellbeing (Cook et al., 2013). Since EDs present with such wide-ranging symptomology, the interest in measuring QoL and HRoL introduces a novel way of understanding the ED experience, both during the acute phase of the disorder and into recovery. These findings have implications for the treatment of EDs and the ultimate definition of recovery.

While ED related QoL research is relatively new, a consensus about the effect that EDs have on QoL is already being tentatively established. Recent research demonstrated that people with EDs consistently had low QoL and HRQoL (Ágh et al., 2016; Jenkins, Hoste, Meyer, & Blissett, 2011; Winkler et al., 2014). Weigel, König, Gumz, Löwe, and Brettschneider, (2016), found that lower BMI was correlated with higher scores on depression scales of a HRQoL measure. This study also found that more somatic complaints, which were particularly common at lower weights, were also correlated with lower HRQoL (Weigel et al, 2016). Other research found that people with EDs scored low on mental components of HRQoL measures (Baiano et al., 2014) and people with AN were noted to have lower QoL in mood, mental, and social domains (Sy, Ponton, De Marco, Pi, & IsHak, 2013). These findings together suggested that the effects of EDs extended far beyond physical symptoms and into other areas of people's lives. This has implications for treatment.

While there is a demonstrated need for weight restoration and symptom reduction treatment, there is evidence suggesting that treatment should also be aware of the damaging mental repercussions of the ED.

The effect on QoL was not isolated to the acute phase of the disorder. Recent research demonstrated that HRQoL remained poor among a small sample of patients with AN and BN up to eight years after treatment (Pohjolainen et al., 2016). The small sample and necessity of replication aside, Pohjolainen and colleagues' (2016) research supported the notion that EDs have far-reaching effects, such that the toll on HRQoL can still be experienced well into recovery. This suggested that ED recovery may not be defined by symptom cessation alone and may instead be a broader construct. The reach of EDs was also felt on the family of people with EDs, whose QoL also decreased during the illness period (Anastasiadou et al., 2016). In particular, mothers were more likely than fathers to report negative QoL as it related to caring for their child. The authors attributed this negative QoL to mothers tending to be primary caregivers, therefore having more contact with their sick child and the stress inherent to this situation (Anastasiadou et al., 2016; Gilbert, Shaw, & Notar, 2007; Hillege, Beale, & McMaster, 2006). Further research is needed to demonstrate how this stress feeds back into ED recovery. Studies have also been carried out to compare the relative impairment of EDs against other psychiatric conditions. They demonstrated that the QoL and HRQoL was comparable to other disorders, such as depression, schizophrenia, alcohol addiction, and panic disorder (Jenkins et al., 2011; Pohjolainen et al., 2009; Weigel et al., 2016).

This is not to say that treatment has no effect on QoL and HRQoL. Multiple studies showed that specialized inpatient treatment does improve HRQoL (Baiano et al., 2014; Pohjolainen et al., 2009; Weltzin, Bean, Kloserterman, Lee, & Welk-Richards, 2015). Due to the lack of specificity in this research, however, Baiano and colleagues (2014) questioned whether this change was due the treatment itself or whether it was due to general caring

found in treatment. Further research is necessary to determine the method by which treatment acts on HRQoL. While treatment is seen to improve HRQoL, people with EDs were still found to have poor HRQoL well into clinical recovery, suggesting that there are improvements to be made in how treatment effects the areas measured in QoL literature (Baiano et al., 2014; Pohjolainen et al., 2009; Weltzin, Bean, Kloserterman, Lee, & Welk-Richards, 2015). While the field is still new and research is developing, it is worth noting that existing research has already suggested that treatment should address a full spectrum of recovery, encompassing psychological, social, and physical recovery (Ackard, Richter, Egan, & Cronemeyer, 2014; Ackard, Richter, Egan, Engel, & Cronemeyer, 2013). Continued research into these areas will determine how treatment can specifically act on various aspects of QoL.

2.1.3.2. Cost of Illness. The impact of EDs has also been measured in terms of the monetary cost of the disorder. Analysis of this kind extends the understanding of the wider implications of the disorder beyond psychological concerns and to the cost at both an individual and societal level. On the individual level, various studies have been carried out in a number of countries examining the cost of ED related treatment. This research found that treatment costs for AN, BN, BED, and EDNOS, as it was classified at the time of study, were extremely high (Bellows et al., 2015; Samnaliev, Noh, Sonnevile, & Austin, 2015; Striegel-Moore, Leslie, Petrill, Garvin, & Rosenheck, 2000). In some cases, the cost of treatment was found to be comparable to other serious psychiatric disorders, including schizophrenia (Striegel-Moore et al., 2000). While the differences in countries and currencies used as a metric do complicate comparisons and no formal literature review or similar analysis has been conducted to date, the consensus in the existing literature of the high cost of treatment is significant and demonstrated the burden that recovery can place on an individual and/or family. It is also worth noting that, to date, few studies have examined whether the treatment

has caused financial hardship. A single Australian study indicated that treatment for EDs does create significant economic hardship (Gatt et al., 2014), suggesting that not only is Australian ED treatment expensive, but it also creates conditions that are aversive for long term recovery. This is notable because of Australia's hybrid public-private health care system, which is meant to provide some protection against financial hardship due to healthcare costs. In the Australian system, access to basic healthcare services for low or no cost is available to citizens, permanent, residents and refugees through the government subsidised health system, Medicare (Dixit & Murali, 2018). Private insurance can be purchased, providing access to more treatment options with specialists and private hospitals. The necessity of buying private insurance to access treatment with specialists and private hospitals creates inequalities when the cost outweighs the means available (Murali & Dixit, 2018). This creates a barrier and a burden to some people accessing care (Gatt et al. 2014; Dixit & Murali, 2018). While further research is necessary to more definitively state the economic burden of ED treatment on Australian families, research by Gatt et al (2014) suggests that such a burden exists despite protections built into the Australian healthcare system.

Individual ED costs were also found to extend beyond the treatment. For example, Crow and colleagues (2009) examined the cost of BN to the individual and found that, in 2006, the cost of binges was measured to be 32.7% of an individual's yearly food costs. Another notable area of financial burden to the individual was the impact of the disorder on employment, though research in this area is still developing. Both people with BN and those with subclinical symptoms of the disorder were found to lose a significant number of days of work due to their ED; the annual number of days lost was found to be comparable to days lost to moderate depression (Lynch et al., 2010). This study and that by Crow, Frisch, et al (2009) attested to the particular costs associated with binge eating and the necessity of

measuring burden outside of treatment costs. Other research has found that having an ED may impact employment rates and that there is an associated loss of earnings in having an ED (Samnaliev et al., 2015). This again demonstrated that the implications of EDs extend beyond the psychological and that even individual economic burdens can extend far beyond clinical recovery.

While a number of studies have been carried out into the cost of EDs to society, this literature is currently limited. Some of this literature was outdated or did not cover all elements of treatment (e.g. outpatient therapy, pharmaceuticals, psychotherapy, etc). Also, as with studies carried out on individual costs, it was difficult to make accurate comparisons between studies carried out across several years, countries, and currencies. Finally, there were few studies that actually cover this information, so, the existing studies will be reviewed and discussed, despite their age and taking into consideration the differences in study location and associated currency. The first known study of the cost of EDs to a society's health care system was carried out by the Office of Home Economics (OHE; 1992) in the UK. This study found that the total cost to the healthcare system in the year that study was conducted in 1990 was £4.2 million. Mathers, Vos, and Stevens (1999) conducted the first Australian study of healthcare costs for the Australian Institute of Health and Welfare as a part of the first Burden of Disease and Illness in Australia. This study found that the total health system expenditure on EDs to be AUS \$22 million for the surveyed time period of 1993-94. While subsequent Burden of Disease and Illness studies have been carried out, none of these have included EDs in this this specific statistic. A more recent study was conducted by the Butterfly Foundation (2012), Australia's largest ED charity. It found that healthcare costs to the federal government were AUS \$42.6 million during the surveyed years. Finally, an update to the healthcare costs in the UK was provided by BEAT (2015), the UK's leading ED charity. In this study, the total healthcare cost was between £3.9 and £4.6 billion during the surveyed

years. This study also reported lost income to the economy, that is income lost due to illness that would have otherwise contributed to the growth of the economy, as being between £6.8 and £8 in the years surveyed.

Taken together with the aforementioned limitations to the research, these studies demonstrated that there is significant expense to the health care system from ED treatment. Without comparative data it is impossible to say whether EDs are more or less expensive than any other disorder. It is also noteworthy that there has been an increase in the healthcare cost and that this increase has been marked in both Australia and the UK. How much of this increase was due to currency inflation and the general rising cost of health care is not clear. Finally, it is of interest that the authorship of this particular research shifted from governmental offices to disorder specific charity organisations, though the reason for this shift is not commented on and could be due to the availability of these organisations for such research, shifting of governmental resources, or any number of factors beyond the scope of this review. Suffice to say, ongoing research is required in this particular area, as the cost of EDs to a healthcare system helps researchers and policy makers to gauge the burden of these illnesses on individuals and society.

Examining the cost of EDs to society as a whole also raised questions about whether ED treatment was cost effective. Again, this area of research is relatively novel, so there was little conclusive evidence and there exist the same constraints as discussed above (e.g. comparing across years, countries, and currencies) with the added difficulty of comparing across treatment modalities and facilities. Despite these limitations, the literature does demonstrate potential relationships between the cost of treatment, access to it, and the cost effectiveness of various modalities. This opens new avenues for improving treatment for people with EDs.

Existing research demonstrated that a portion of people with EDs either do not stay in treatment for the recommended number of days (Striegel-Moore et al., 2000) or do not seek treatment at all (Ali et al., 2016; Cachelin & Striegel-Moore, 2006). While the scope of a study by Striegel-Moore and colleagues (2000) did not cover reasons for treatment non-completion, the justification for not seeking treatment was covered in depth in other studies. Multiple barriers were discussed but of particular interest was the real and/or perceived financial burdens of treatment (Ali et al., 2016; Cachelin & Striegel-Moore, 2006). It has already been established above that the cost of treatment was comparable to other serious psychiatric conditions (Byford et al., 2018), validating the concerns of people with EDs that treatment could be a significant burden.

Some research has turned to improving the cost effectiveness of treatment. To date various treatment models have been assessed but no single model has demonstrated outstanding success. For example, both family-based therapy (compared to adolescent focused therapy) and specialist outpatient treatment (compared to several other treatment settings) have been found to be cost effective for treating AN in adolescents (Byford et al., 2018; Le et al., 2017a). A specialised form of cognitive behavioural therapy (CBT) was found to be cost effective for BN (Le, Hay, Wade, Touyz, & Mihalopoulos, 2017b) while guided self-help was found to be cost effective for BED (Lynch et al., 2010). The mode of delivery was also examined, with telepsychiatry being investigated as a means of delivering CBT to people with BN in a cost-effective manner (Crow, Mitchell, et al, 2009). While the study by Crow, Mitchell, and colleagues (2009) was conducted prior to the wide availability of computers and phones with built in phones, and so used the phone for therapy, further applications could be extended to the use of the internet. It is worth noting that prevailing literature consists of comparative research, with no systematic literature reviews. Such systematic reviews would reveal trends in the literature allowing for more conclusive

findings and direction. Lacking this, it is only possible to say that a number of cost-effective approaches have been studied and some have been found to be more cost effective in their individual studies. Beyond this, further research is necessary.

The reviewed literature demonstrated that epidemiologically, EDs pose a clear and persistent risk to the people diagnosed with them. While their prevalence is low and the incidence remains relatively steady, mortality is high. Examination of HRQoL and QoL use quantitative measures to demonstrate that the ED extended far beyond the outward symptom expression and the eventual cessation of these symptoms. Of added interest was the burden of illness, which was felt significantly both by individuals and families in terms of cost of treatment and time lost at work, and by the society, in terms of healthcare costs and lost income to the economy. Together, this data illustrated that there is a clear and present need to both understand EDs and to improve treatment outcomes.

2.2. Eating Disorder Treatment

There is a demonstrated need for treatment in this population, given the high mortality rate discussed above. However, to date, the empirically sound treatment options for EDs remain sparse, despite there being a long history of treatment for the disorders. It is beyond the scope of this literature review to discuss the history of ED treatment (for historical analysis see Brumberg, 2000). Instead, attention will be focused on current treatment interventions, with a particular consideration being given to the continuum of care model as it relates to the direction of treatment from inpatient to day patient and finally to outpatient treatment. This is the model that directs mental health practice in Australia and so, directs the treatment of EDs.

2.2.1. *Continuum of Care Model*

Current ED treatment is based on a multifactorial aetiology of the disorders. From this perspective, EDs are complex disorders and the “multiple factors predisposing to illness,

precipitating the illness, promulgating the illness, and ameliorating the illness may be different” (Andersen, Bowers, & Evans, 1997, pg 329). Multiple factors need to be addressed at different stages of treatment, which necessitates a multi-disciplinary team whose members can bring their experience and expertise (Fox, Woodrow, & Leonard, 2012). The members of this treatment team vary considerably based on treatment setting and on individual patient needs but some general trends emerged from the literature. Inpatient teams tend to involve more members, including physicians or paediatricians, psychiatrists, nursing staff, psychologists, dieticians, occupational therapists (OT), family therapists, art therapists, and/or social workers (Andersen et al, 1997, Fox et al, 2012). Day hospital teams involve a number of allied health professionals, because treatment is still quite intensive though patients are allowed to remain at home and to attend school. As such, treatment teams are often made up of similar allied health professionals to those on inpatient treatment teams (Kaplan & Olmstead, 1997, Simic et al., 2018). Outpatient teams had still fewer members, usually being made up of a general practitioner, a psychologist, and/or a dietician, with some teams including a psychiatrist (Gordon, 2010). Thus, while treatment teams decreased in size as treatment severity decreased, they still maintained support across multiple disciplines.

In the continuum of care model, people with EDs move through the various levels of care according to need. They are assessed and enter at the level that is appropriate for the severity of the particular presentation of the disorder and then move up or down levels of care according to their individual progress (Willinge, Thornton, & Touyz, 2012). At the different levels of treatment, different aspects of the ED are treated, so the continuum of care model ideally ensures that the multi-faceted nature of the ED is managed in a logical and sequential nature, especially when continuity of care is maintained across transitions (Anzai, Lindsey-Dudley, & Bidwell, 2002). The continuum of care model can be contrasted with a stepped care model, where treatment is provided to patients in a stepwise progression. Patients begin

with the least invasive and most clinically appropriate treatment; they then follow the same hierarchy of treatment until a positive treatment response is established (Gardner & Needleman, 1997). It had been noted that a drawback of stepped care is the demoralizing effect that successive perceived failures of treatment may have on the individuals receiving them (Wilson, Vitousek, & Loeb, 2000). The clinically informed decision making inherent to a continuum of care reduces some of this effect, though people with EDs may still move through the levels of treatment a number of times during their recovery journey.

2.2.1.1. Inpatient Treatment for Eating Disorders. Inpatient treatment (IP) is the highest level of care available to people with EDs. IP is usually reserved for people who require more intensive support in their recovery journey, as there may be risk associated with suicide, self-harm, or low-BMI (Fox et al, 2012). People with AN and BN can be treated on the same IP unit (Guarda & Henberg, 2004), though BN can be treated in less intensive levels of care, while AN often requires ongoing support, especially in the early stages of recovery to manage the physical and psychological effects of starvation (La Puma, Touyz, Williams, & Thornton, 2009). Given the unique needs of AN treatment, it is not unusual for IP treatment to predominantly focus on the needs of this population in particular.

Overall, the goal of IP treatment is to restore the mental, physical, and social functioning to a point that people are able to discharge to lower level of treatment (Bowers, Andersen, & Evans 2004). For people with AN, this usually involves weight restoration and early work on normalization of eating and exercise and resolution of body and weight distortions (Andersen et al, 1997). By contrast, for people with BN, this involves breaking severe bring/purge cycles and establishing healthy eating habits (Wintson & Weber, 2003; Richard, 2005). As weight restoration can prompt complex emotions that were previously avoided through ED behaviour, IP treatment is often recommended to help people learn new coping strategies in a structured environment (Fox et al, 2012). However, IP treatment for

AN can become overly focused on weight restoration to the detriment other elements of the ED. As such, IP treatment needs to balance weight restoration with developing nascent coping strategies (Andersen et al, 1997). IP treatment for AN that emphasises weight restoration is not considered sufficient for recovery, particularly in light of high relapse rates among this population (Thornton, Touyz, Willinge, & La Puma, 2009).

By its very nature IP treatment involves extensive contact between the people receiving treatment, as well as allied health professionals. Treatment is usually delivered in a group modality, though individual sessions are offered in some IP facilities. The content of groups is largely dictated by the therapeutic approach of the facility but also by clinical realities of providing treatment to a population that may be experiencing significant impairment due to starvation and/or refeeding. Additionally, from a continuum of care perspective, IP groups need to focus on preparing people for less clinically supportive treatment. So, groups tend to focus on providing psychoeducation and often use CBT in groups emphasizing coping or body perception (Bowers et al, 2004). Family therapy may also be provided, especially for adolescents, for whom family-based therapy has been found to be particularly effective (Andersen et al, 1997). Individual therapy can similarly be used according to the cognitive functioning of those being treated and may be used begin to address cognitive distortions, improve motivation to change, and to smooth treatment transitions (Andersen et al, 1997).

From a clinical perspective, the main benefit of IP treatment is the level of consistent care it provides to people with severe ED presentations. IP treatment provides consistent boundaries so that weight and/or eating stabilization and the ensuing emotional reactions can be managed safely (La Puma et al, 2009). The structure provide by IP treatment is considered necessary to scaffold people with EDs out of the disorder, as the disorder itself is maintained by control. However, the constraining nature of it can create a stressful environment for both

the people undergoing treatment and staff. Patients may at times struggle to manage their emotions and staff require a high level of training to most effectively support patients on a ward where high staff to patient ratio is expected but not always achieved (Kaplan & Olmstead, 1997). Additionally, while there is therapeutic benefit in patients living alongside one another during IP, there are concerns that such a milieu can be psychologically toxic, with patients competing with one another or learning new ED behaviours during their stay (La Puma et al, 2009). This raises the importance of carefully considered boundaries, well trained staff, and regular assessments of treatment effectiveness.

Research on the efficacy of IP treatment is sparse despite a long history of hospitalisation as a means of ED treatment. Of the studies that do exist, few are randomised control trials (RCTs), due to the ethical difficulty creating trials with participants who are severely ill, both psychiatrically and physically (Friedman et al., 2016). The existing evidence shows that shorter IP stays are effective for reducing ED symptomology (La Puma et al, 2009) and that longer IP stays are not necessarily more effective for weight restoration (Madden et al., 2014). This signals a shift in IP use for chronic admissions to use for acute, short-term admissions. A caveat to this is that with the decrease in chronic, long-term admissions, there has also been an increase in readmission rates at some hospitals (Wiseman, Sundday, Klapper, Harris, & Halmi, 2001). While this does not present a complete picture of relapse, it does lend credence to the argument that weight restoration alone is not sufficient for AN recovery and demonstrates that ED treatment is complex. It also suggests that the transition to lower levels of care needs to be well managed.

2.2.1.2. Partial Hospital Treatment for Eating Disorders. The next step down in treatment is day treatment, also known as a partial hospitalisation program (PHP). Compared to IP, there is considerably less clinical observation and oversight, as people receiving treatment spend part of the day, usually the evening, overnight, and/or weekends, outside of

treatment (Bowers et al, 2004). Amount of time spent away from the hospital varies and can increase as treatment progresses. This means people are able to practice skills learned in treatment while still having access to regular structure and support (Willinge, et al, 2012). While IP tends to concentrate on nutritional rehabilitation and normalizing eating patterns, PHP is directed at the cognitions and behaviours that sustain a person's ED (Thornton et al, 2009).

The overall goals of PHP follow the same trajectory as the goals of IP treatment. For people with AN, the goals of PHP are to continue weight restoration and to focus more intensively on psychological and social rehabilitation (Willinge et al, 2012). This may involve cultivating new coping and leisure skills, as well identifying and treating underlying psychological and interpersonal processes (Kaplan & Olmstead, 1997). As noted above, BN is often treated in a PHP. The goals here are slightly different, in that they focus less on weight restoration and more on normalization of eating, through breaking the binge/purge cycle (Kaplan & Olmstead, 1997). Aside from this, goals for BN and other iterations of EDs remain the same as with AN. The focus for all EDs in PHP is on psychosocial rehabilitation and treating elements of eating pathology that would impact long term engagement with outpatient treatment (Piran et al., 2005).

PHP treatment is delivered predominantly in a group format, as it is done with IP. Groups are considered appropriate because they provide structure and emotional containment while maximizing therapeutic contact (Piran et al., 2005). PHP group topics vary but can be similar to IP topics, including groups on body image, cognitive therapy, nutrition, and psychoeducation (Bowers et al, 2004). There is also the opportunity for more group variety in PHP, as people receiving treatment tend to have improved functioning overall compared to those in IP. Additionally, the psychological needs of patients increase as they move through their recovery into PHP. Examples of group topics include nutrition, eating, cooking, leisure,

art, family, exercise, and interpersonal skills (Kerr & Piran, 1990). Individual sessions with psychologists are incorporated into PHP treatment as further means of psychological support and to assist in preparation for transition to outpatient treatment (Willinge et al, 2012).

The most significant benefit of PHPs is in the mixed nature of treatment. As mentioned above, due to the semi-autonomous nature of the treatment, people in PHP are able to confront difficult and complex areas of their lives, such as interpersonal relationships or developing coping skills, while they simultaneously manage eating and weight gain (Kaplan & Olmstead, 1997). Periods away from hospital allow people receiving treatment to practice skills learned, to make therapeutic gains through this practice, and to bring any difficulties back to their treating team (Thornton et al, 2009; Willinge et al 2012). People receiving treatment also benefit from maintaining contact with peers, family, work, and school (Thornton et al, 2009). As a form of intensive treatment, PHP is considered cost-effective compared to IP because it eliminates the need for hospital beds, food, and intensive nursing staff (Kaplan & Olmstead 1997, (Piran et al., 2005). This does not, however, completely eliminate the need for IP treatment, especially for people with severe AN, for whom PHP would be contraindicated due to the need of ongoing medical support. While the semi-autonomous nature of PHP does encourage therapeutic gains, there is also an increased risk for a return of ED behaviours, self-harm, or suicidal behaviours (Piran et al., 2005). To mediate this, clinicians must closely monitor patients while in treatment and set up detailed care plans to manage risky behaviour, inclusive of changes to level of care.

As with IP treatment, the research on the overall effectiveness of PHPs is still developing and there are few studies comparing PHPs to other levels of treatment. Again, the same ethical risks exist here, especially as it relates to developing RCTs for a clinically risky population. An early review of the effectiveness of PHP (Zipfel et al., 2002) was only able to compare three programs and therefore suggested that, despite the similarities between

programs, further research was necessary in order to comment on efficacy of PHP treatment. A number of studies examining the efficacy of PHP treatment (Anzai et al., 2002; Brown et al., 2018; Kong, 2005; McFarlane, MacDonald, Trottier, & Olmsted, 2015; Thaler et al., 2016) have been carried out since then and their results generally suggest that PHP is effective for the treatment of EDs. Literature reviews on the topic further support these findings. Willenge and colleagues (2012) found that cognitive and behavioural changes were common outcomes of PHP, as were improvements in ED related attitudes. The authors noted that these improvements were maintained for up to two years. A review conducted by Hepburn and Wilson (2014) examined the effectiveness of PHP in greater depth than previous literature reviews, which tended to be descriptive in nature. Hepburn and Wilson (2014) confirmed that attendance to PHP is related to improvement in BMI, binge/purge symptoms, anxiety and depression, and other ED symptoms. Binge/purge frequencies generally remained within clinical DSM-V parameters, though this effect varied with the number of days attending PHP. This review suggested that the effectiveness of PHP is perhaps dependent on the number of days a patient attends treatment, an area that requires further research. So, while the existing reviews demonstrated that PHP is effective, further research is necessary to demonstrate how sustainable improvements are in the long term and to examine how to improve relapse and drop-out rates.

2.2.1.3. Outpatient Treatment for Eating Disorders. The final step down in the continuum of care model is outpatient (OP) treatment. Here, treatment has transitioned away from managing the high-risk medical issues that were at the fore of IP and PHP treatment and focus has moved to addressing the issues underlying the ED, while also maintaining recovery. This is usually managed with a small multidisciplinary team made up of a psychologist, GP, and dietician, with the possibility of other allied health professionals being involved in care as needed. While weight and eating are no longer the focus in OP treatment,

as in IP and PHP, they still remain a central issue to treatment (Gordon, 2010). The goals in OP treatment tend to be focused on the interpersonal and dynamic issues as they relate to the ED, along with the normalisation of body image, weight concerns, and exercise. There is also consistent assessment of comorbid disorders and relapse risk.

As the continuum of care model is flexible, OP treatment does not necessarily have to flow from PHP, so a person with an ED may begin (and end) their treatment in OP. This ability to move through levels of care as clinically necessary is one of the clear benefits of the continuum of care model and of OP treatment. People with EDs may be wary of treatment, so having the option to try treatment, especially with trusted GPs can be a method of providing care to people with low motivation to change. However, it is worth noting that GPs and other allied health professionals require specialized training to diagnose and treat EDs effectively (Boyd, Aisbett, Howard, & Filiades, 2014), so further community education may be necessary to increase OP efficacy. While OP treatment does also offer less clinical support than either IP or PHP, this may increase the risk for relapse in some people (Gordon, 2010). This risk can be managed with safety agreements that address restriction, bingeing, and purging.

There is some limited research on the efficacy of OP treatment as a specific treatment model, though it appears that such research is complicated by terminology differences. That said, research has tentatively found that OP is neither more or less effective than IP (Meads, Gold, & Burls, 2001) and that PHP may be more effective than OP (Kong, 2005). Another method of determining the effectiveness of OP treatment is to examine the impact of individual psychotherapy, as this is one of the main components of OP treatment. Research of this nature has examined the efficacy of the wide variety of the therapeutic approaches used to treat EDs.

The major psychology governing bodies, namely the American Psychological Society (APA), the National Institute for Health and Care Excellence (NICE), and the Australian Psychological Society (APS) recommend CBT or enhanced CBT (CBT-E), which was developed specifically for EDs, for the treatment of AN (Hay, Chinn, Forbes, Madden, Newton, Sugenor, Touyz, & Ward, 2014; NICE, 2017; Yager et al., 2006). Research found that CBT and CBT-E were effective in reducing ED symptoms (Byrne, Fursland, Allen, & Watson, 2011; Chen et al., 2003; Poulsen et al., 2009; Serfaty, Turkington, Heap, Ledsham, & Jolley, 1999). Despite this effectiveness at reducing symptoms, research shows that people with EDs struggle to complete the full course of therapy, with dropout rates from CBT-E ranging from a 33%-24% of people (Fairburn et al. 2013; Garte et al., 2014). While these dropout rates have been closely associated with people who start treatment at a low BMI (Fairburn et al., 2013), qualitative research suggested that having a history of low weight was more relevant than starting treatment with low weight because this may be associated with lowered expectations of treatment and increased scepticism (Cater et al., 2012). As such, having a variety of treatment options available is necessary for this population.

Family therapy is also recommended for both AN and BN. In particular, family based treatment (FBT), also known as the Maudsely method, is recommended as a first line treatment for adolescents with AN (Hay, et al 2014; NICE, 2017; Yager et al., 2006) due to consistent evidence of its efficacy with this population (Couturier, Kimber, & Szatmari, 2013; Keel & Haedt, 2008). While further research is necessary to determine how effective family therapy is for BN and BED, it is still recommended by the major psychology governing bodies for the treatment of these disorders (Hay, et al, 2014; NICE, 2017; Yager et al., 2006). Motivation based therapies such as motivational interviewing (MI) and motivational enhancement therapy have been modified for use in conjunction with other eating disorder therapies and have shown some effectiveness (Casasnovas et al., 2007;

Nordbø et al., 2008). Interpersonal therapy (IPT) has also been adjusted for ED treatment, particularly for treatment of BN (McIntosh et al., 2005; Miniati, Callari, Maglio, & Calugi, 2018; Rieger et al., 2010). IPT is currently suggested as a possible alternative treatment for BN by Australian and American psychology governing bodies (Hay, 2014; Yager et al., 2006). Due to the amount of research supporting these therapeutic approaches, they are the ones most often recommended and used for ED treatment.

Third wave therapies like acceptance and commitment therapy (ACT) and dialectical behavioural therapy (DBT) have only recently been applied to ED treatment. Preliminary findings show that both ACT (Berman, Boutelle, & Crow, 2009; Juarascio et al., 2017; 2013; Manlick, Cochran, & Koon, 2012) and DBT (Ben-Porath et al., 2020; Federici & Wisniewski, 2013; Wisniewski & Kelly, 2003) can be modified to treat various ED diagnoses and that ED symptoms improved in study samples treated with these approaches. Linardon, Fairburn, Fitzsimmons-Craft, Wilfley, and Brennan, (2017) found in their meta-analysis that third wave therapies like DBT and ACT produced statistically significant changes in ED symptoms, but could not be considered clinically effective due to the low number of studies conducted using randomised methods. Similarly, narrative therapy (NT) and emotion focused therapy (EFT) have been adapted to treat EDs (Dolhanty & Greenberg, 2007; Glisenti, Strodl, & King, 2017; Golan, 2013; Weber, 2007; Weber, Davis, & McPhie, 2007). While research has demonstrated that these approaches are effective, further examination is necessary to confirm how they can be applied to ED treatment. The extensive research being conducted on multiple approaches demonstrates the ongoing development of the field and the willingness for experimentation in treatment. This is especially important given the complexity of ED treatment and the necessity for flexibility and therapeutic range.

2.2.2. Eating Disorder Treatment in Australia

Treatment of EDs in Australia follows guidelines set out by the Royal Australian College of Psychiatrists. These guidelines are extensive and cover all aspects of treatment for all major ED diagnoses (Hay et al, 2014). Overall, they suggest a stepped care approach, having seamless transitions between levels of care, and opting for the least restrictive level of care possible. It is suggested that care be provided through specialised IP, PHP, and OP services, as available, as well as through general psychiatric wards and the community mental health sector. It is suggested that care be provided as appropriate for level of psychiatric severity and availability of care (Hay, 2014). The stepped model of care closely mirrors the fundamental features described by Bower and Gilbody (2005), who also explain that in order for a stepped care system to be effective, it must also be self-correcting in its monitoring of decisions about treatment and treatment results. This information is used to understand how to improve treatment outcomes. There are some particular difficulties to ED treatment in Australia, most notably the availability of specialised care. There is a tendency for specialised treatment to only be available in metropolitan cities, meaning people who live regionally are not able to access care easily. Increased training of allied health professionals at regional hospitals would improve access to care in these areas. The divide between public and private healthcare presents a significant issue as well. Some programs may not be readily available to people without private health insurance, meaning access to care is unequal (Thornton, Beumont, & Touyz, 2002). In 2019, Medicare reform led to the addition of new Medicare Benefit Scheme items that would cover people with EDs for up to 40 sessions with a psychologist and 20 with a dietician, where previously psychologist sessions had been capped at ten and five with a dietician (Australian Department Government Department of Health, 2019). This reform recognised that ED treatment was complex and that people with EDs required ongoing support and theoretically improved people's ability to access care. This

change is relatively new, so whether it has been effective in improving people's access to care, reducing treatment burden, or impacting treatment outcome will need to be examined.

2.3. Relapse, Remission, and Recovery

Any discussion of treatment must ultimately lead to the outcomes of treatment. In the context of the current research, three outcomes will be briefly discussed: relapse, remission, and recovery. There is some intersection between these terms so clear definitions are critical. Relapse is understood to be the return of clinically significant ED symptoms after a period of abstinence. It is important to note that definitions of relapse may vary individually and may change across time. Remission is taken to mean the cessation of symptoms for a defined period of time (Couturier & Lock, 2006; Kordy et al., 2002). It tends to be used in medical settings, especially compared to the term recovery. While recovery has a similar meaning to remission (e.g. the cessation of ED symptoms), the term has been taken up by a community health movement, which sees recovery as individually defined. This movement, which will be discussed in depth in the next chapter, envisions recovery as extending beyond the simple cessation of symptoms and into multifaceted and individually defined areas of people's lives (Dawson, Rhodes, & Touyz, 2014c; Jacobson, 2001).

It is well established that, despite having a relatively low prevalence, as mentioned above, EDs tend to follow a chronic trajectory (Steinhausen, Jakobsen, Helenius, Munk-Jørgensen, & Strober, 2014). Much research has been devoted to ED treatment and it has been found that in multiple treatment settings, this chronicity presents as high relapse rates (Carter, Blackmore, Sutandar-Pinnock, & Woodside, 1999; Fichter et al., 2006; Keel, Dorer, Franko, Jackson, & Herzog, 2005). Recovery from an ED has been documented to be long process (Herzog et al., 1999; Nagl et al., 2016). This group is also unique because they are a population at distinct risk due to its high mortality rates, high relapse rates, and low recovery rates. Given the unique nature of this population, it is worth considering why relapse remains

high even after treatment has been available for a significant number of years, and how treatment can be improved.

2.4. Chapter Summary

This chapter discussed the wider context for the need to examine ED recovery. First various metrics of ED epidemiology were explained in order to demonstrate the severity of EDs in relation to the general population. Next the various modalities of ED treatment were examined. This was in preparation for the following chapter's discussion on the broader concept of recovery and ED recovery specifically.

Chapter 3

Recovery Model and Eating Disorders

One of the many unique features of EDs are their chronicity. Existing research has demonstrated that recovery rates across this diagnostic category are low despite ongoing efforts to improve this with novel treatment. There is an existing body of literature examining people's experiences of ED recovery (Lindgren, Enmark, Bohman, & Lundström, 2014) and experiences with treatment and allied health professionals (Musolino, Warin, Wade, & Gilchrist, 2015; Smith et al., 2014; Wright & Hacking, 2011). This literature has been vital in expanding conceptualizations of ED recovery to incorporate the subtleties of individual experiences. The recovery model is an approach to mental health care that defines recovery from a psychiatric illness as an ongoing process through which a person uses their individual experiences to develop new insight and purpose for their lives (Stylianidis, Lavdas, Markou, & Belekou, 2016). It also draws a distinction between personal recovery and clinical recovery. By understanding the recovery model and its application to severe psychiatric illnesses, a new and perhaps more effective way of conceptualising ED recovery can be explored.

3.1. Contextualising Recovery

The early vision for the recovery model can be found in the aftermath of the policy of deinstitutionalisation in the 1960s and 1970s. With the needs of former patients no longer being met by state run hospitals, mental health professionals were suddenly faced with the reality that people with severe psychiatric disorders had needs beyond simple symptom relief (Anthony, 1993). The mental patient's liberation movement, also known as the consumer survivor movement, was a prefigurative political movement made up of people who had experienced psychiatric interventions and who sought independence in their care (Beckwith, Bliuc, & Best, 2016; Chamberlin, 1990). Activists within the mental patient's liberation

movement questioned the utility of treatment where diagnosis was dehumanizing and created an unfair power imbalance with mental health professionals (Chamberlin, 1978). It sought to give those with mental illnesses an opportunity to participate more fully in their treatment and in defining their recovery. In encouraging these changes, it strove for lasting social change in the treatment of people with mental illnesses (Beckwith et al., 2016). The mental patient's liberation movement also favoured individual definitions of recovery (e.g. those defined by the person in recovery) instead of depending on clinically based ones (e.g. those coming from both treating professionals and medical literature), which often centred around symptom cessation. This was a notable switch from a pathology focused approach to a strengths-based one. Early first-person accounts of psychiatric treatment and recovery formed the basis for early definitions used in the recovery movement. Themes in these early accounts centred around hope, acceptance, engaging in a social life, developing new coping skills, and self-development (Deegan, 1988; Leete, 1989; Lovejoy, 1982; Unzicker, 1989). These themes were equally important to the mental patient's liberation movement, which placed particular emphasis on people having control over the definition of their experience and their treatment (Chamberlin, 1978).

3.1.1. The Radical Psychiatry Movement

The discussion of the consumer-survivor movement needs to be contextualized within an overview of the radical psychiatry movement. This movement, which was most active through the 1960s to 1980s, was a re-examination of psychiatry and the harm it caused with an intention to provide more effective and humane care. Theorists examined the role psychiatry played in enforcing social identities on people with mental illnesses. In Michel Foucault's (1971) historical account of psychiatry's development, mental illness (here, termed Madness), was seen as a leprosy of the mind in the 16th century. Foucault (1971) suggested that during this time, Madness was seen as akin to death, "The head that will

become the skull is already empty...Madness is the *déjà là* [already there] of death” (pg 16). As with leprosy, Madness was considered contagious and as such required separation and confinement to preserve society. In confinement, the Mad were marked for brutal and torturous treatment by being more visible because of their confinement (Parker, Georgaca, Harper, McLaughlin, & Stowell-Smith, 1995). Morality became a central aspect in the treatment of the Mad when religious reformers of the 17th century advocated treatment involve more human kindness with the belief that such treatment would not only relieve Madness but would also be of spiritual and moral benefit. According to Foucault (1971), such treatment was equally confining because its rejection was seen as an amoral act that tied refusal of treatment to defects in spirituality and conscience. The link between Foucault and the radical psychiatrists lies in the ability to make choices. Foucault’s (1971) historical examination of Madness illuminates how psychiatry is built on a foundation of those receiving treatment not being able to make choices about their care. Parker, Georgaca, Harper, McLaughlin, and Stowell-Smith (1995) note that it is necessary to examine psychiatry’s past in order to understand how it came into being, especially given the tendency of psychiatry to promote a story of progress. Foucault’s work challenges this narrative, as does the work of the radical psychiatrists, whose movement was predicated on choice and re-examining the patient-psychiatrist power dynamic.

Other theorists within the radical psychiatry movement looked at psychiatry’s impact on the people it treated from a phenomenological perspective. In this instance, phenomenology is understood to be the study of the subjective human experience, which was of particular interest to the radical psychiatrists because they sought to understand mental illness from the perspective of the person with the illness. Thomas Szasz (1961, 1970), worked in the US and theorized that mental illnesses were inherently different from physical ones because they did not have endogenous origins. In the case of physical ailments, doctors

based their diagnoses on the deviations from functional or structural norms in the body. Szasz believed that this system could not be applied to mental illnesses because norms of behaviour could not be universally defined and because science at the time lacked the ability to diagnose structural and chemical difference in the brain (Kelly et al., 2013; Szasz 1970). In determining what constituted normal or acceptable behaviour, Szasz believed that a comparison was made between the observer's (e.g. psychiatrist's) and individual's beliefs, with the observer's beliefs usually taking precedence (Kelly et al., 2013; Szasz, 1970). By positioning mental illness as a myth that was constructed from the assertion of the psychiatrist's beliefs over that of the patient's, he framed contemporary institutional psychiatry as dangerous and in need of reform.

Two other prominent radical psychiatrists, R.D. Laing and David Cooper, worked in the UK and also saw psychiatry as needing reform, though their approach varied considerably from Szasz's and indeed, he was often at odds with them. Laing (1970), who had trained as a psychoanalyst, approached the study of mental illness through understanding the experience of madness. He sought to understand what was being communicated by people with psychotic symptoms (Oakley, 2017) because he saw behaviour as a true expression of experiences that had been ignored by the wider medical community (Rissmiller & Rissmiller, 2006). Laing's approach emphasised compassion, not only of the experience of madness but also in the experience of treatment. He often invoked the Golden Rule, reminding those who delivered treatment that they should consider how they themselves would want to be treated should they ever be in the position of patient (Thompson, 2015). Cooper, a colleague of Laing's, formed theories about the effect of the origins of mental illness diagnosis on individuals. Cooper (1967) postulated that madness was a clash between a person's true identity and the identity being imposed upon them by society in the form of medical professionals and family. From his perspective, diagnosis, labelling, and confinement had a

corrosive effect on a person because they took away personal liberty and exerted one person's will (e.g. the psychiatrist's) over another's. In this way, his theories were similar to Szasz's, though Cooper's work focused on the effects of family in more detail.

As a group, the theories and approaches developed by the radical psychiatrists were ground-breaking. Their phenomenological approach to the experience of Madness challenged the prevailing biomedical model for the treatment of severe psychiatric illnesses in academic and practical ways. While Foucault (1954, 1965), used a socio-historical lens to expose the inhumane conditions experienced by people in the course of psychiatric treatment, Laing and Cooper used a more practical approach in establishing anti-hospitals and novel therapeutic communities with the intention of deconstructing institutional roles and facilitating more genuine human interaction (Wall, 2018). In these communities, residents' treatment was not predicated in curing mental illness or addiction, but was instead focused on teaching residents to live well (De Leon, 1997). This style of treatment was in direct opposition to the biomedical approach of the time. The approach used in these therapeutic communities was a response to the belief that institutionalized, non-consensual treatment had a corrosive effect, not only on individuals but also on society. The radical psychiatrists also gave voice, in varying degrees, to the experience of being mad, which until that point had been largely defined by medical professionals.

Modern advances in psychology and medicine opened new avenues of critique that were not available when the radical psychiatrists were developing their theories. In particular, advances like the discovery of the role of neurotransmitters in the development of schizophrenia and the use of schizophrenia twin registries added support to the argument that some mental illnesses had endogenous origins (Rissmiller & Rissmiller, 2006). Despite these credible critiques of his theories, Szasz continued to assert that mental illness was defined by deviations from socio-cultural norms (Kelly et al., 2013). There have been claims that the

radical psychiatry movement was a forebear to the mental patient's liberation movement and consumer-survivor movement (Rissmiller & Rissmiller, 2006). While these movements are similar in their aims to change modern psychiatric practice, it is more accurate to say that they were contemporaries of 1960s and 1970s counterculture. While the radical psychiatrists may have influenced the consumer-survivor movement, this movement was more influenced by the Civil Rights struggle and the Gay Rights Movement in the United States (Oaks, 2006). For people within the consumer-survivor movement, radical psychiatrists were seen as members of the academic elite who wrote about Madness theoretically, whereas the consumer-survivor movement was a people's struggle for equitable rights. However, their academic and practical examination of mental illness provided important contemporaneous material for the consumer-survivor movement to use in their exploration of recovery.

3.2. The Development of a Recovery Definition

The consumer-survivor movement was defined by the desire to keep treatment decisions firmly in the hands of the people who were receiving treatment, that is, the consumers. While Laing and Cooper sought to dissolve the institutional demarcations between patient and psychiatrist and questioned the legitimacy of psychiatric diagnoses, the consumer-survivor movement was focused on securing rights for the people in psychiatric treatment (Irwin, Mitchell, Durkin, & Douieb, 1972). Early consumer-survivor literature acknowledged the socially oppressive role psychiatry could have on people with mental illnesses. These commentators also suggested that trusted psychiatrists have acted as members of their movement but noted that people receiving treatment have felt side-lined by the anti-psychiatric movement overall (del Vecchio, 2006). Radical psychiatrists did not necessarily seek to end psychiatry but instead wanted the profession to change so that it could not exert undue social control. Whether this change took the form of Szasz's (1961, 1970) contractual relationships between psychiatrist and patient or Laing and Cooper's softening of

boundaries between staff and patient to near non-existence, these changes were meant to ultimately reduce the corrosive effect psychiatry had on a person's identity and free-will. The consumer-survivor movement, conversely, recognized the utility in relationships with psychiatrists but sought expression for their rights within these relationships (Irwin et al., 1972). While psychiatry had the potential to be abusive, this was not always the case and people receiving treatment had the right to make choices about how it would be employed in their care. It was within this context of self-directed psychiatric care that the recovery approach developed.

3.2.1. Outcome Definitions of Recovery

The recovery approach was one answer to the failures of the policy of de-institutionalization. As the consumer-survivor movement asserted the need for consumers of mental health services to have increased rights relating to how their care was delivered, the recovery movement took this autonomy a step further to include how recovery itself was defined. From this perspective, recovery was a personal journey that went beyond the simple cessation of symptoms and was instead an ongoing journey for improved quality of life and meaning and purpose. Current research lacks uniformity in the definitions used for recovery, which creates a degree of ambiguity and difficulty in research and policy (Stylianidis et al., 2016). Given this, it is instructive to discuss a selection of definitions used by the recovery approach. In research, recovery is discussed in terms of outcome and process models, with outcome models being ones that discuss the overall end result or definition of recovery, and process models being ones that cover what takes place during it. Since research has used both models, sometimes at the same time and sometimes interchangeably (Resnick et al., 2005), there has been some understandable confusion about the definition of recovery.

Like the consumer-survivor movement, the recovery approach depended on early first-person accounts of mental illness and recovery to develop its theoretical construction of

the definition of recovery. These early accounts of being a mental patient both acknowledged the despair the authors felt when treatment did not acknowledge their rights and needs but also recounted the hopeful and individualized process of recovery (Deegan, 1988; Leete, 1989; Lovejoy, 1982; Unzicker, 1989). It was through these early accounts that experiential conceptualizations of recovery developed. As Deegan (1988) understood recovery, it went beyond the services a person used during their treatment. Instead, it “relate[d] to the actual life experience of the individuals who accept and move beyond the challenge” posed by their mental illness (pg 11). Anthony’s (1993) conceptualisation also acknowledged the necessity of building new meaning and purpose in life, noting that this was necessary as psychiatric disability was destructive. Experiential accounts and definitions recognised radical psychiatric theory when they emphasized the destructive impact, not only of mental illness, but of treatment. They differed greatly, however, in their resolution to this tension, where they conceptualised recovery as residing in the hands of those with mental illnesses. From this perspective it was the people with the mental illnesses who defined when they were ready to begin their recovery journey and who to include in the journey.

3.2.2. Process Definitions of Recovery

Increased interest in the recovery approach spurred research into uniform definitions of recovery and its defining features. Researchers in the field noted that without developing a more precise understanding of recovery, ongoing replicable research was not possible, nor could symptoms be quantified accurately (Lieberman & Kopelowicz, 2009). There were specific concerns around whether recovery was a process or an outcome, as early definitions did not make this distinction clear (Resnick et al., 2005). When in use on an individual level, the lack of distinction created few difficulties, but with empiricism and the development of recovery-based instruments, Resnick and colleagues (2005) noted that recovery was “often described and defined as a process but then used as an outcome” (pg 120). Noordsy and

colleagues (2002) noted that contemporary definitions of recovery were vague but that using exhaustive lists encompassing its multiple facets was not feasible in empirical research. In some ways the desire for standardization conflicted with the recovery approach's original intentions to move away from the standardization common in the biomedical approach. The individualized nature of recovery was a defining feature of the movement and something that could not perhaps be captured in empirical research.

Nonetheless, empirically based definitions did present comprehensive conceptualisations of recovery. By defining recovery in terms of its key components, experiential accounts were operationalized so that they could be measured in ongoing research. A literature review that covers the multiple operationalized definitions of recovery has yet to be written, though a review of the experiential accounts of recovery does exist (Onken, Craig, Ridgway, Ralph, & Cook, 2007). Existing literature showed some cross-over between empirically derived definitions. This was evident in the case of recovery being an act of personal empowerment and responsibility and the necessity of hope to the recovery process (Noordsy et al., 2002; Resnick et al., 2005). While Noordsy and colleagues (2002) included a person's ability to live their life beyond the illness, Resnick and colleagues (2005) emphasized the importance of satisfaction with one's quality of life. Process definitions can be further broken down into dimension and stage models of recovery.

3.2.2.1. Dimension Models of Recovery. Dimension models are an attempt to further classify recovery into different dimensions or stages. While research on process models is still developing, a number of dimension and stage models do exist. Dimension models examine the components of recovery, building models from the components that could then be used as guides for the subjective experience of recovery (Jacobson, 2001). According to Jacobson and Greenley, (2001) dimensional models conceptualise recovery as being made up of internal (such as hope and healing) and external conditions (such as human rights and

recovery-oriented services) that, when taken together contribute to and have a reciprocal effect on the overall recovery experience. Jacobson and Greenley's (2001) model contrasts with models that attempt to categorise the components of recovery. These components, which can include examples such as the self, others, systems, and the overall problem (Jacobson, 2001) or the clinical, functional, existential, physical, and social components of recovery (Whitley & Drake, 2010), are used as a framework to understand individual experiences. Another example of a process model was devised by Andresen, Oades, and Caputi, (2003), who used more subjective categories, including hope, self-identity, meaning in life, and responsibility. Similar, Leamy, Bird, Le Boutillier, Williams, and Slade (2011) proposed that recovery support from services could be broken down into connectedness, hope and optimism about the future, identity, meaning in life, and empowerment (CHIME). Regardless of their specificity, dimensional models provide a tool for researchers and professionals to understand the composite elements of recovery as they are experienced on an individual level. They allow a degree of flexibility, making them ideal as conceptual models to be used in therapy. However, due to recovery being a relatively new field and dimensional models being new within the field itself, ongoing research of their effectiveness is necessary (Andresen et al., 2003; Leamy et al., 2011). It is worth noting that while the dimensional models mentioned above were developed from stringent qualitative research and systematic review of qualitative studies (Leamy et al., 2011), this research was by no means exhaustive and does not encompass an overall recovery experience. It can be argued that because recovery, as a concept, is subjective, it may not be possible to accurately cover it in a dimensional model.

3.2.2.2. Stage Models of Recovery. Stage models categorise the recovery process more stringently so that it can be measured within each category (Leamy et al., 2011). An early model developed by Davidson and Stauss (1992) covered people's sense of self during recovery and broke the process down into four stages: (1) discovering a more active self, (2)

taking stock of the self, (3) putting the self into action, (4) and appealing to the self. Davidson and Stauss (1992) acknowledged the role that identity played in motivation and in maintaining recovery. Another early model illustrated the emotional stages of recovery (Baxter & Diehl, 1998). The emotional stages of recovery model conceived recovery as involving three critical psychological events, each followed by a stage: (1) psychological crisis, followed by necessary recuperation, (2) decision to put life back on track, followed by rebuilding of independence, (3) awakening to a new sense of self, followed by effective recovery. Within each psychological crisis and stage Baxter and Diehl (1998) described the emotions and needs that are expected, making this model a useful tool for therapeutic practice.

Andresen et al. (2003) approached recovery differently, dividing it into five stages (moratorium, awareness, preparation, rebuilding, and growth), through which a person can progress any direction and which can be used to both conceptualise recovery and plan a treatment approach. Based on this model, Andresen, Caputi, & Oades (2006) developed the Stages of Recovery Instrument (STORI), which measured a person's position in their model. While the model has been empirically validated with a population diagnosed with schizophrenia, the authors note that it requires further refinement and further testing among populations with other psychiatric conditions (Andresen, Caputi, & Oades, 2006). Similar to Andresen and et al.'s (2003) model is the Recovery Advisory Group model (Ralph, 2005). Here, recovery is broken down into six stages: (1) anguish, (2) awakening, (3) insight, (4) action plan, (5) commitment, (6) empowerment. These stages include internal and external dimensions, comparable to those described by Jacobson and Greenley (2001). Ralph (2005) described recovery in this model as being non-linear because it involved movement backwards and forward through the stages, again, similar to Andresen et al. (2003). One final model was developed by Spaniol, Wewiorski, Gagne, and Anthony (2009) and divided

recovery into four phases: (1) being overwhelmed by the disability, (2), struggling with the disability, (3) living with the disability, (4) living beyond the disability. This model is notable because it encapsulates the process a person goes through as they learn to first accept having a life changing psychological diagnosis and then, learning to live a rich, meaningful life.

The stage models described here can be loosely grouped chronologically, with earlier research being focused on describing the stages specific elements of recovery such as sense of self (Davidson & Staruss, 1992) or emotion (Baxter & Diehl, 1998). While useful, these models only addressed one element of recovery and so, were not as comprehensive as later models, which examined the overall recovery process (Andresen et al, 2003; Ralph, 2005; Spaniol et al., 2009). Overall, there are several similarities between the models, such as the non-linear nature of recovery and recovery being a learning process. All stage models are relatively new and require further research to examine their applicability to a variety of psychiatric diagnoses.

3.2.3. Accepted Definition of Recovery

Through this discussion of the varied and complex conceptualisations of recovery, an overarching definition is not immediately clear. This is partially because within the recovery movement, ensuring the individual's ability to define their recovery journey remains a central feature. While ongoing research has taken this into account by using first-hand accounts in the synthesis of definitions and models, these require further refining and testing (Andresen et al., 2006; Leamy et al., 2011). Anthony (1993) defined recovery as,

... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and life purpose in one's life as one grows beyond the catastrophic effects of mental illness. (pg 19)

This definition encompasses many of the major elements of recovery discussed in empirical models, including accepting responsibility for one's own recovery journey, hope, and

empowerment (Leamy et al., 2011; Noordsy et al., 2002; Resnick et al., 2005). This will be the definition used for this research.

3.3. The Recovery Model and Eating Disorders

Recovery from EDs has consistently been a difficult concept to define. As discussed in the previous chapter, outcome studies of relapse and recovery have not been able to determine a stable relapse and recovery rate for any of the ED diagnoses (Grilo et al., 2011; Halmi et al., 2002; Herzog et al., 1999; Keel et al., 2005; Le Grange et al., 2014). This is partially due to differences in relapse and recovery criteria and the lack of uniformity indicates the necessity of re-evaluating the existing definition of ED recovery. There has been a call by some authors to re-assess ED recovery, not based on the clinical outcomes, but instead based on the content of the recovery experiences (Noordenbos, 2011a; Nordbø et al., 2008). They propose that research cannot be conducted on a construct that cannot be clearly defined. They also suggest that attempting to understand this area from the perspective of those living through it may yield a clearer understanding of the motivation behind recovery and how it can be sustained (Nordbø et al., 2008).

There are few examples of the recovery model in its entirety being applied to ED treatment. An area of increased interest for researchers has been the basic criteria that comprise successful recovery. Researchers thought that if the key ingredients could be understood, then inquiry could be conducted to determine how to increase their presence in people with EDs. Two existing literature reviews on the topic found that important characteristics and mechanisms of recovery included having positive relationships, hope, autonomy (Dawson, Rhodes, & Touyz, 2014), self-acceptance, personal growth, and a decrease in ED behaviours (de Vos et al., 2017). Many of these align with the recovery model's key criteria, including having hope, autonomy, personal growth, self-acceptance, and positive relationships (Davidson & Roe, 2007; Noordsy et al., 2002; Resnick et al., 2005;

Whitley & Drake, 2010). This suggests that the recovery model has existing theoretical links to ED treatment but that further research is necessary to determine how exactly it can be applied (Dawson, Rhodes, & Touyz, 2014). Particular attention needs to be paid to the unique physical symptomology of EDs. The recovery model suggests that each person's definition of recovery is unique and may involve lingering symptomology, similar to how minor hallucinations may remain for someone with a psychotic disorder (Davidson & Roe, 2007). For someone with an ED, whether restriction and/or binge/purge symptoms will remain through some or all of recovery is a question that necessitates further examination, both by people with EDs and with researchers. Nonetheless, the possibility that the recovery model can be applied to ED research and treatment opens new possibilities for improving treatment outcomes.

3.3.1. ED Recovery in Context of Qualitative Literature to Date

Any review of the qualitative conceptualisations of ED recovery would be well informed by the role that the ED voice, identity, and ambivalence play in the ED experience. Existing qualitative research has demonstrated that some people with AN experience an anorexic voice that is felt as separate from their authentic self (Williams, King, & Fox, 2015; Williams & Reid, 2012). The ED is seen to serve a number of vital purposes, including being a guardian, providing control, power, and conferring a sense of individuality or uniqueness (Espíndola & Blay, 2009). Pride has also been found to contribute to positive feelings toward the ED, as people with AN feel a sense of accomplishment for their self-control and their weight loss achievements (Faija, Tierney, Gooding, Peters, & Fox, 2017; Lavis, 2015). In this way, the person shares both a sense of self with the ED and also becomes defined by it. The conflict between this sense of self and threats to it, such as desire for recovery or treatment attempts can create ambivalence (Lavis, 2015).

The anorexic voice is a phenomena where people with anorexia felt that the ED was taking on a persona separate to their authentic self (Williams et al., 2015; Williams & Reid, 2012). Tierney and Fox (2010) found that the anorexic voice asserted itself during periods of vulnerability. For the people with AN, the anorexic voice was initially a companion, providing positive qualities such as security and comfort during distressing times (Tierney & Fox, 2010; Williams & Reid, 2012). However, as the ED progressed, the anorexic voice became more bullying and demanding, such that people with AN went to extremes to appease it. This appeasing relationship was found to be similarly toxic to abusive relationships between two separate people, particularly in that people with AN felt imprisoned by the anorexic voice (Tierney & Fox, 2011). The confining nature and bullying quality to the voice go some way to explaining the behavioural extremes found in EDs. The desire to purge and restrict was described as being a means to appease the anorexic voice's overwhelming demands (Tierney & Fox, 2010; Williams & Reid, 2012). As the ED progressed, the anorexic voice became a vital part of the self, as it became the predominant method of coping (Williams et al., 2015). The conflicting nature of the anorexic voice was understood by people with AN to be both functional and harmful but they were still unable to easily extract themselves from its influence (Higbed & Fox, 2010). Williams and Reid (2012) described the experience as being an ongoing battle between two opposing forces even before recovery becomes an option, as the authentic self attempted to exert itself and was pushed back by the anorexic voice.

While the current discussion covered anorexia exclusively, this was due only to the availability of literature on the anorexic voice. The phenomena of the ED voice has been explored in BN by Broussard (2005). Although there were some similarities about feeling trapped by the ED, it is worth noting differences may have arisen due to the presentations of the disorders. In the anorexic voice, pride about the ability to control weight contributed to

the development of the ED voice as a means of controlling the self, whereas in Broussard's (2005) research, the out of control nature of the binge-purge cycle was reflected in the participants' desire to pacify their anxious and demanding minds by surrendering to the desire to eat and then, purging to alleviate the subsequent physical discomfort of having eaten too much. Aya, Ulusoy, and Cardi's (2019) systematic literature review covered the quantitative and qualitative literature on ED voice to date. Their research affirmed the omnipotence and power of the ED voice and summarised the positive relationship between strength of ED voice and severity of the ED (Aya et al., 2019). They also found that the relationship to the ED voice changed over time, with it being a source of comfort, guidance, and solace in the early stages of the ED and then progressing to a dominant, bullying, toxic relationship. Further research, both quantitative and qualitative, should be conducted to establish the role that the ED voice plays for people with a variety of ED diagnoses and across stages of recovery. The extant literature has demonstrated that the ED voice plays a significant role in the development and maintenance of the ED, so understanding the role it plays through the stages of recovery and how long it remains into recovery would assist in directing therapeutic interventions.

Ambivalence towards treatment and recovery has been related to conflict with the anorexic voice and identity. The conflicting dynamics with the ED were such that the ED was both hated and cherished because it provides succour for the person while also causing significant physical and mental distress (Fox & Diab, 2014). For people with AN, desire for the ED and recovery was not static but fluid (Lavis, 2015). They could want to maintain the ED and to recover at the same time, creating a state of ambivalence. This was felt very poignantly when recovery was predominantly an experience of trying to fend off the anorexic voice whenever attempts were made to stop the ED (Williams & Reid, 2010; 2012). Some people described living within the strict rules dictated by the ED as being like living in a

prison with no escape (Tierney & Fox, 2011). With the ED serving a significant function in the person's life, both as a means of managing emotions and as an established facet of the identity, it was difficult for people with AN to imagine a future without it, however much that was desired (Malson, Finn, Treasure, Clarke, & Anderson, 2004). Recovery was not a simple task, therefore, and did not involve the simple cessation of symptoms, which instead "represent[ed] a break in their *modus vivendi*, that is taking away what keeps the subject alive" (Espíndola & Blay, 2009, pg 78). By understanding the relationship between the ED voice, identity, and ambivalence, recovery is more firmly rooted in the individual's subjective experience.

A consistent theme in ED recovery literature was that recovery was an ongoing internal process, as opposed to something with an end goal. With recovery conceptualised as a non-linear process both by people with EDs (Matusek & Knudson, 2009) and their parents (Sharkey-Orgero, 1999), dominant medical narratives of illness, where recovery is complete with symptom cessation, were challenged. The literature also frequently discussed how the experiences of the person going through recovery gave meaning and depth to individual definitions of recovery. Recovery was often found to extend to all areas of peoples' lives, with definitions of recovery being felt as most accurate when they encompassed the whole self, rather than symptom remission alone (Matusek & Knudson, 2009). Interestingly, in studies comparing the views of people with EDs and therapists on what elements were important to recovery, both groups tended to agree on the same elements being important, though there was some minor disagreement about the degree of importance of specific elements (Emanuelli, Waller, Jones-Chester, & Ostuzzi, 2012; Noordenbos & Seubring, 2006). For example, both parties tended to agree on holistic definitions that included all areas of the person's life and that placed less emphasis on symptom remission alone. The importance of identity as it related to an individual's experience of their ED and recovery was

also highlighted in the literature. The ED recovery experience was considered to be a self-initiated process of identity change where a person regained access to and then rebuilt their healthy, authentic self, separate from the ED (Conti, 2017; Patching & Lawler, 2009). As such, studies showed that people felt that their experiences were highly personal and were not easily encompassed by the biomedical approach.

Qualitative inquiry also conceptualised recovery as a process of empowerment and building responsibility. Given that EDs had an identity serving function, the recovery process involved gaining control over the ED (Patching & Lawler, 2009) by way of accessing the authentic self (Lindgren, Enmark, Bohman, & Lundström, 2014; Williams & Reid, 2012). The self-development process in ED recovery was likened to Erikson's developmental model (Lamoureux & Bottorff, 2005). In Erikson's model, healthy human development was characterized by accomplishing psychosocial tasks at age appropriate stages (McInnery & Putwain, 2016). The utility in the comparison between the two arose from Erikson's model being specifically focused on identity related tasks, which seemed to be side-tracked or delayed in people with EDs. A notable difference between the two was that ED recovery was largely a conscious effort, where a choice has to be made about the ED being too difficult in order for recovery to begin effectively. Movement through Erikson's model, by contrast, was an unconscious developmental process.

ED recovery, by its very nature required an internal locus of control, with multiple studies finding that individual motivation was necessary for recovery to be successful (Arthur-Cameselle & Quatromoni, 2014; Federici & Kaplan, 2008; Hay & Cho, 2013; Keski-Rahkonen & Tozzi, 2005b). Recovery required personal insight and, therefore, could not be forced onto people. ED recovery also involved connecting with elements of a person's life that empowered and encouraged self-development and growth, such as religion, spirituality, and social activism (Matusek & Knudson, 2009). These elements inspired people with EDs to

connect with aspects of their identity that were significant prior to the ED developing or that could add meaning to life during and after recovery. Recovery was, therefore, a conscious effort of both connecting with a sense of self and with broader parts of the sociocultural sphere that supported that identity. In this way, recovery was a comprehensive life change.

Though recovery literature in general addressed at length the role of hope in the recovery journey, this element had a different relationship to ED recovery. For people with EDs recovery could seem, at times, unattainable or unimaginable when the ED was a stable aspect of the self (Malson et al, 2011). It was difficult to maintain hope in the face of a future that was murky, at best, and at worst, was unimaginable. Additionally, the ED recovery journey could include repeated attempts at treatment, which contributed to feelings of hopelessness (Dawson, Rhodes, & Touyz, 2014). This was where peers with lived experience could play a crucial role in maintaining hope and facilitating the development of a recovery identity (Arthur-Cameselle & Quatromoni, 2014; Dawson, Mullan, Touyz, & Rhodes, 2018; McNamara & Parsons, 2016). Instead of addressing hope directly, qualitative studies examined the importance of self-esteem and self-efficacy in recovery. Both Hay and Cho (2013) and Arthur-Cameselle and Quatromoni (2014) noted that as self-esteem improved, so did mood and motivation for change. Hannon, Eunson, and Munro (2017) suggested that recovery was a two-phase process, with phase one establishing readiness to change through cognitive and behavioural work and phase two encompassing commitment to change through self-esteem and identity work. This demonstrated that hope was not necessarily a spontaneous phenomenon but instead developed as an identity beyond the ED seemed more feasible. The identity and self-esteem work that was intrinsic to ED recovery allowed people on the recovery journey to let go of their ED and imagine a future self that had previously been completely unimaginable (Conti, 2017).

Multiple studies reported suggestions of changes to ED treatment that expanded definitions of recovery. The notion that recovery extended beyond simple symptom remission has been supported repeatedly in qualitative literature (de Vos et al., 2017; Emanuelli et al., 2012; LaMarre & Rice, 2016). A strength of these studies, compared to long term outcome studies, was that they gave voice to the subjective experiences of people who would often be considered in recovery because they no longer fit the DSM-V criteria for an ED. These findings need to be replicated in larger studies and more detailed models of ED recovery need to be developed that take these voices into consideration. These models could then be used in policy and treatment development. Such research would also be beneficial because it would bring ED treatment in line with the American Substance Abuse and Mental Health Services Administration's (SAMHSA) guidelines about the definition of recovery. At the time of their development, these guidelines represented the first national, broad based attempt to define recovery and has since become instructional for researchers globally. Specifically, these guidelines note that, recovery oriented systems of care provide treatment that acknowledges that recovery is person-centred and that includes the perspectives and experiences of the people receiving treatment and their families (Sheedy & Whitter, 2009).

Taken together, current qualitative literature suggests that treatment providers need to be aware of the complexities of the ED and how it interacts with identity, as well as how this contributes to recovery overall. There is evidence to suggest that a biomedical approach could make people receiving inpatient treatment for EDs feel pathologized when their symptoms and emotions were attributed solely to the ED (Malson et al., 2004). Further, dominant therapeutic approaches, such as dialectical behavioural therapy (DBT) and cognitive behavioural therapy (CBT), that created a power imbalance with the therapist as the person with all the knowledge or power to explain the disorder, devalued the resilient experience and knowledge of the person with the ED (Botha, 2015). As EDs are frequently

considered to be egosyntonic (Westwood & Kendal, 2011) and complex to treat, there is a risk of over-pathologizing ED behaviours. The dominant biomedical approach that is often used to treat EDs prioritizes the knowledge of allied health professionals over that of the person with the disorder (LaMarre & Rice 2015). In this fashion, allied health professionals misunderstand the sources of emotions and behaviours as being solely related to the ED, when in reality they often have varied and complex origins (Pemberton & Fox, 2011). This over-pathologizing ignores the realities of ED experiences and reduces trust in treatment.

While more training and more diverse approaches such as narrative therapy (Botha, 2015), emotion focused therapy, and motivational interviewing (Espíndola & Blay, 2009) have been suggested, it is worth noting that further research is necessary. Much of the above discussion is based on research carried out on small samples of people with AN. Further research with participants across the ED diagnostic spectrum is necessary, as the ED recovery experience is not categorically the same. Some of the findings need to be translated to quantitative studies, particularly those that examine the long-term outcomes of treatment and the beliefs of people providing treatment. There may be sufficient qualitative evidence to broadly define AN recovery (Conti, 2017; Dawson, Rhodes, & Touyz, 2014c; 2015; Noordenbos, 2011b), but this evidence needs further translation to larger populations in order to determine how the definition applies to a broader population and how it can be effectively worked into treatment. This is especially important because much of the qualitative literature has been conducted with specific samples that have left out broad swathes of the ED population, such as men with EDs, people with a wide variety of ED diagnoses, including BN and BED, and also people from varied racial, cultural, and gender minority groups. A variety of ED recovery models need to be developed. So far, ED recovery has only been explored on a definitional level and even here, there is still disagreement in the literature on an empirical definition based on the experiential accounts of people with EDs (de Vos et al., 2017;

Emanuelli et al., 2012; Noordenbos, 2011a). No dimension or stage models have been explored. Dimension models would illuminate the process of ED recovery, which is quite different from the recovery in other disorders, thus allowing for more targeted treatment. Stage models would further categorize ED recovery, as much as is possible, given that it is a highly subjective experience and would potentially involve the development of psychometric tests to measure ED recovery. Such tests, if they are found to be effective, may assist in targeting treatment and measuring progress.

3.4. Chapter Summary

This chapter first gave a broader context for recovery by examining the radical psychiatry movement, in which the recovery movement has its origins. Definitions of recovery were examined by first discussing the definitions used by early recovery movement activists and then moving through outcome definitions, process definitions, dimension models, and stage models. The agreed upon definition of recovery was stated. ED recovery was examined to demonstrate that, while there has been a history of examining ED recovery, there is also a lack of research applying the recovery model to ED treatment.

Chapter 4

Methodology

4.1. Theoretical Stance

This research adopted the basic tenets of critical realism as a guide for the study method. Critical realism is a philosophy of science that an objective reality exists, however it also recognizes that part of the world constitutes subjective interpretations, which influence the ways it is experienced by people (O'Mahoney & Vincent, 2014). Critical realism is considered to strike a balance between the two dichotomies of objectivism and constructionism. In objectivism, theories about the world are developed based on empirical observation and correlational science, which are used to develop universal statements and laws (Mitchell, 2003). Objectivism has been criticised for being too reductionist and dependent on numerical data to explain the complex processes of the human experience (Mitchell, 2003). Comparatively, constructionism claim that there is not external reality because it is relative and based on people's experiences and social interactions; thus, no single world view is privileged, as truth is in a constant state of being rewritten (O'Mahoney & Vincent, 2014). Constructionism has also been subjected to robust critique, particularly for the potential of strict adherence to its tenets to contribute to the myth of mental illness (Pilgrim, 2014). When mental illness is perceived as an entirely subjective experience, the possibility of its biological determinants are neglected, as their examination requires objectivist approaches. Critical realism provides an alternative to these two dichotomies by acknowledging that reduction can provide theoretical illumination while also accepting that there are sociocultural and political influences on reality (Gorski, 2013).

The qualitative methodology used in this research was the phenomenology. The recovery model was also used in developing the method of this research. Based in the philosophical work of Husserl, Heidegger, Sartre, and Merleau-Ponty, the phenomenological

perspective, at its core, is the study of the human experience that seeks to understand the way events are perceived in the individual's consciousness (Langdridge, 2007). The philosophical basis of research phenomenology relates closely to why and how the methodology is carried out. Therefore, it is important to clarify some of the fundamental concepts that are at the roots of this theoretical stance before explaining how it is related to the recovery model. The recovery model, as explained in the previous chapter, takes the stance that mental health recovery is a highly individualised experience that may not involve complete cessation of symptoms and is instead based on the individual's value system, goals, and preferences (Davidson & Roe, 2007). Both the phenomenological perspective and the recovery model are focused on the individual's experience and perceptions, which make them well suited to research about the experience of recovery.

Phenomenology seeks to understand the building blocks of a given phenomenon. Philosophical phenomenology seeks the building blocks through a personal, experiential method that uses the inquirer's own understanding and interpretations of an experience to come to conclusions about it. Psychological phenomenology uses a similar method of analysing experiences, but the analysis is intrapersonal in order to reduce the potential bias of an inquirer analysing their own experience (Langdridge, 2007). However, the objective remains the same in both instances, that is, to use the analysis of experiences to understand the human experience. This focus on individual experience demonstrates Husserl's concept of intentionality, which is central to his understanding of consciousness and to phenomenology. From Husserl's perspective, a person's experience is always individually understood and processed as being a part of the wider world, despite the cognitive and neurological processes that support perception. This is in direct opposition to the Cartesian conception of consciousness, which holds that in being aware of one's own thoughts, attention and consciousness is directed inwards instead of outwards (Langdridge, 2007).

Phenomenology is therefore focused on the individual's consciousness to draw conclusions about the human experience. Critical realism and phenomenology align with each other conceptually and methodologically. Critical realism has a specific interest in developing new interpretations of data in order to explain and evaluate social conditions and mechanisms of power (Oliver, 2012; Fletcher, 2016). Critical realism also methodologically inclusive, allowing for a range of scientific questions to be asked and the most appropriate methodological approach to be applied (Maxwell & Mittapalli, 2015).

The recovery perspective is similarly focused on the individual experience. Here, the focus is specifically focused on how individuals define and understand recovery, as opposed to how recovery is clinically defined (Davidson & Roe, 2007). Research done using this perspective takes the stance that the individual experience of recovery is best understood through the accounts of those who have experienced mental illness and who are in recovery. This is in direct opposition to the prevailing biomedical model of recovery, which rarely uses individual accounts of recovery, instead depending on quantitative measures to determine recovery rates (McCranie, 2015). The recovery perspective and phenomenology pair well together as they both focus on individual experiences and on the intentionality of those experiences, which is to say, they de-emphasized the cognitive processes involved. Instead, they are concerned with what goes on between the person and the world they are engaging with during their recovery journey. Phenomenological techniques have been used successfully in recovery based research in the past (Armour, Bradshaw, & Roseborough, 2009; Bradshaw, Armour, & Roseborough, 2007; Dawson, Rhodes, & Touyz, 2014a; Federici & Kaplan, 2008; Song & Shih, 2009). Using a phenomenological perspective for the current research ensures that the individual experience of recovery is given primacy in the design and analysis.

Phenomenology was chosen for this research because the research attempted to understand the experience of experiences of ED treatment and recovery and to determine if there was a link between the two. As such, it was necessary to use an approach that allowed for the close examination of individual, subjective experiences. This research was also informed by the recovery model, which prioritized the individual's understanding of recovery. This too fit with phenomenology and helped provided structure for the methodology.

4.2. Design

To investigate the lived experience of maintenance of recovery and how this interacts with participants' experience of treatment, this thesis was comprised of two qualitative studies. The two studies consisted of an online focus group (OFG) and a series of individual interviews, both carried out with people who were in ED recovery. Both studies covered similar topics relating to recovery, identity, and relapse prevention, but the difference in setting and number of participants ensured a diversity of responses. Both studies were carried out in Australia. The initial study, an online focus group (OFG), was advertised to Australia-wide participants. The second study, comprised of interviews, was advertised to people within the Melbourne metropolitan region with the option for Skype interviews available to regional participants. The two studies ran consecutively, beginning with the OFG on February 25, 2017; the interviews were completed from March to September of 2018. The results from the OFG informed the development of the questionnaire used in the individual interviews. Participants could only contribute to one study or the other; this was confirmed using the e-mail address they provided to contact the author of this thesis. In this research, participant, the questions from the interview were developed using the OFG data. This meant that there would be some repetition in the areas covered by the two studies. It was necessary for participants to attend without preconceived notions of the research or the researcher that may

have formed from previously engaging in the OFG. Participants were asked to meet recovery-based eligibility criteria, which were verified using a series of questionnaires (see section 4.5).

The design for this study was chosen for a number of reasons. First, this area of research is relatively new, so an exploratory method was deemed necessary. A number of alternative options to an OFG were possible, such as using short answer questionnaires or a series of short focus groups. Alternatively focus groups could have been carried out in person. Ultimately, an online method was selected because it allowed for the mingling of variety of participants in a virtual space where there was the possibility that they would feel more comfortable to talk than in person. The data from the OFG was used to inform the development of the interview research schedule so that themes and areas of particular interest could be explored at greater depth during the interviews. An alternative to this design included using the research schedule from the OFG with the interview participants in order to maintain consistency across studies. The exploratory nature of this research was prioritized, so the interview schedule was changed in order to investigate data from the OFG at greater depth.

4.2.1. Online Focus Group Design

As a research method, focus groups can be used to examine new areas of research because they bring together people to express ideas about a topic that have not previously been explored (Morgan, 1997). They can be used to clarify preliminary information in conjunction with other research methods, either qualitative or quantitative. In qualitative research, researchers are interested in specific topics relating to thoughts, opinions, and emotions, many of which cannot be explained by numbers and figures. Instead, the use of focus groups and similar qualitative methods can assist in illuminating these issues in ways that is not possible with quantitative methodology alone. The area of research for this thesis,

namely, how people's experiences with ED treatment and recovery impact their overall recovery outcome, is still unexamined in the literature and so, is well suited to a focus group design. Focus groups bring participants together so that they can express their similarities and differences on a chosen subject. This style of relating in a research setting is unique to focus groups because the interaction of participants encourages the sharing of experiences with others, which is unlikely to occur in individual interviews (Madritz, 2000; Morgan, 1997). By accessing the group dynamic, this research seeks to understand the shared experiences of people with EDs, as increased insight into treatment experiences may be gleaned through discussion of shared experiences.

Focus group methodology has also been described as ideal for amplifying the voices of people who have been marginalised, particularly women and people who have been impacted by mental health issues (Madritz, 2000). Bringing marginalised people together to share their experiences with others in a way that can increase a shared sense of experience and decrease isolation. In this way, they can be empowering and a means of coping with oppression (Braun & Clarke, 2013). The data from this study is important because the participants represent two marginalised communities- women and people with a mental illness, in this case, eating disorders. It is worth noting again that the population of people with eating disorders is proportionally small in terms of prevalence, which means research attention has not traditionally been focused on them. However, the mortality rate for this population is comparable to several major psychiatric conditions, including schizophrenia (Hoang et al., 2014). This population does warrant further research attention because they are at significant risk. The use of a focus group assisted in exploring the experiences of a marginalised population and was the basis for the second phase of the research, the individual interviews.

The group was held online for two reasons: (1) to secure access to a wider participant pool and (2) to build a rich source of data. Online mediums are useful for bringing together participants from varied geographic locations without issues of transportation (Evans, Elford, & Wiggins 2009). Given that a relatively small proportion of the Australian population has EDs (Hay, 1998; Hay et al., 2008; Wade et al., 2006), the ability to bring together participants in a virtual space was considered appropriate. An online medium allowed for the possibility of participants from interstate and/or rural locations to be involved in this research, meaning there was the possibility for a diversity of treatment experiences. This range was particularly important because research has shown that people with EDs are not likely to seek out treatment for the disorder and that, among those who do seek out treatment, people are more likely to receive medical treatment for weight loss than they were to receive treatment for the psychological complications that underlie the disorder (Hart, Granillo, Jorm, & Paxton, 2011). Using an OFG increased the probability of participants with a variety of treatment experiences because it increased access.

Computer mediated communication was also chosen because of the impact it has on self-disclosure (Bargh, McKenna, & Fitzsimons, 2002; Joinson, 2001). Early research using e-mail to form focus groups found that this style of research was successful in reaching participants who would have found traditional face-to-face focus groups inconvenient (Adler & Zarchin, 2002). This early research also found that the qualitative data generated using computer mediated communication was rich and informative, a finding that has been supported by Woodyatt, Finneran, and Stephenson (2016) who compared the quality of data between online and face-to face focus groups. They reported that the data from OFGs was comparable to that of face-to-face groups and that OFG discussion led to more candid sharing of sensitive topics. An OFG design was also used to address a potential limitation of a focus group design. Focus groups have been criticised because the findings can be influenced by

particularly opinionated or vocal participants or groups of participants (Morgan, 1997). In using an OFG, this research was designed to reduce some of the social pressure exerted on group members by placing them in an online anonymous environments that allowed for a sense of confidentiality (Woodyatt et al. 2016). This effect was explained by Suler (2004), who suggested that the online environment was disinhibiting for participants because it allowed them to make shifts in affect and cognition with greater ease than they may do in face-to-face interactions. This research sought to create a secure and confidential environment in which people could comfortably make these shifts because people with eating disorders also have a complex sense of identity. Williams and Reid (2012) documented the phenomena of the anorexic voice, that critical and perfectionistic part of the self that dominates the thought processes of people with EDs; this part of the self has been shown to significantly impact on identity and the recovery process. While this aspect of the self may change through the recovery process, the assumption that it and the person will return to pre-morbid functioning are part of the medical model that this research hoped to avoid (Conti, Rhodes, & Adams, 2016). The confidential and peer supported environment provided participants with the opportunity to discuss topics surrounding their recovery and identity that may have previously been psychologically or socially inhibited. The OFG created a context where these experiences were more accessible and could be shared in a more equitable fashion.

OFGs have been used successfully in a number of studies to collect rich qualitative data from a variety of populations. The most obvious strength of OFGs lies in their ability to bring participants separated by distance into a research environment (Boshoff, Alant, & May, 2005; Kenny, 2005). Participants who would not normally be able to interact with each other are brought into a digital and anonymous space where they can share ideas and experiences. This makes OFGs particularly useful for engaging vulnerable or difficult to engage

populations, such people with physical disabilities or mobility issues (Adler & Zarchin, 2002; Caron & Light, 2015; Morris, Dudgeon, & Yorkston, 2013), people with cancer (Campbell et al., 2001; Sullivan, 2003; Thomas, Wootten, & Robinson, 2013), and people who self-harm (Adams, Rodham, & Gavin, 2005). All studies with vulnerable populations discussed the benefit of the OFG in engaging these populations on topics that face-to-face interviews were sometimes unable to address due to their sensitivity. Similar endorsements were made in studies that used the OFG format with sexually and gender diverse populations, for whom discussion of sensitive topics such as coming out, sexual experiences, and intimate partner violence is often fraught with difficulty and risk due to the stigma associated with these identities. (DuBois et al., 2015; Jervaeus et al., 2016; McKenna & Bargh, 1998; Woodyatt et al., 2016).

The ability to bring participants together who are separated by distance and the strength in engaging participants in discussions on sensitive topics makes OFGs useful for research with people with eating disorders. Despite these strengths, their use is sparse in the ED literature. Instead, when online methods have been used with people with eating disorders, they have either focused on qualitative analyses of existing digital pro-eating disorder content, such as blog posts or discussion groups (Gavin, Rodham, & Poyer, 2008; Tong, Heinemann-LaFave, Jeon, Kolodziej-Smith, & Warshay, 2013; Wooldridge, Mok, & Chiu, 2013) or on analysis of the online provision of treatment for eating disorders, most often through the CBT model (Gollings & Paxton, 2006; Ljotsson et al., 2007). Keski-Rahkonen and Tozzi, (2005) downloaded and analysed existing recovery-oriented content from an online ED discussion group. This study demonstrated early use of computer mediated communication in ED recovery research and concluded that the internet can be powerful tool for reaching individuals with eating disorders.

With the possibility of a larger participant pool than traditional focus groups, an OFG can be a rich source of qualitative data. It allows conversation to develop between participants due to the relative anonymity of the online space; in this way, topics are raised that may not have otherwise been touched upon (Kenny, 2005). Focus groups also dilute the influence of the researcher, as the group dynamics mean participants act as co-facilitators, so content is more nuanced than in one-on-one interviews (James & Busher, 2009). This dilution was considered beneficial to this research for two reasons- first, the primary researcher is not a member of the research population, not having had an eating disorder and so, does not share many of their experiences. Second, the primary researcher is a provisional psychologist and is therefore part of the mental health sector that participants may have had negative experiences with; putting space between the primary researcher and some of the participants allowed for a rich conversation about treatment.

Two studies by Williams and Reid (2010; 2012) demonstrated the use of an OFG with people with EDs. These two studies examined how EDs related to identity formation, specifically for people diagnosed with AN. They used both an OFG and email interviewing to develop a body of qualitative data that supported the theory of the anorexic voice, eating disorder identity, and discussed how these can impact recovery. Both studies noted the benefit of using an online method, particularly because it provided anonymity. The participants in both studies reflected that this anonymity allowed them to be more candid in their discussion. The current research is modelled on these two studies and aimed to demonstrate that OFGs can be an effective tool for qualitative research with people with EDs.

People with eating disorders are a technology and internet proficient population- there is a documented online 'pro-anorexia' and 'pro-bulimia' (pro-ana and pro-mia) movement that encompasses blogs, message boards, and social media sites dedicated to pursuing and promoting their eating disorder (Lyons, Mehl, & Pennebaker, 2006; Mulveen, 2006; S.

Williams & Reid, 2010). This ability has been harnessed into treatment and prevention modalities successfully, showing that the internet medium is accessible to this population across the course of the disorder (Aardoom, Dingemans, Boogaard, & Van Furth, 2014; Sánchez-Ortiz, Munro, Startup, Treasure, & Schmidt, 2011; Skårderud, 2003). The OFG method was considered to be accessible and familiar to population in recovery whilst allowing for a degree of anonymity to discuss potentially confronting topics.

This current research opted for an OFG that was synchronous in its message delivery in order to ensure the safety of group members and maintain continuity of the group. Asynchronous groups, which are usually conducted over an online message board, further dilute the researcher's influence but this can come at the expense of participant safety and engagement. Asynchronous groups require the participants to log online regularly to answer questions, placing an increased burden on them and increasing the risk of attrition (Leetaru, 2008; Bloor, Frankland, Thomas, & Robson, 2011). In the event of immediate concerns for participant wellbeing, reaching a participant from an asynchronous group can be more difficult as clear guidelines around safety planning have to be established and without them firmly in place, making contact when concerns for wellbeing have been raised can become chaotic and pressured. Comparatively, synchronous groups only require participants to log in once for a set period of time, during which their wellbeing can be monitored in real time (James & Busher, 2009, Bloor et al, 2011). While clear guidelines need to be in place around participant wellbeing and correct emergency contact information needs to be available, the immediacy of the OFG allows for a clearer picture of wellbeing than with an asynchronous group. The population in this study self-defined as being in recovery and while this was confirmed using questionnaires, the participants were not clinically interviewed nor was their treatment managed by a program affiliated with author's university. This meant that the research had to balance a degree of risk against the adherence to a recovery-oriented

perspective. As such, the OFG was synchronous to allow the researcher to maintain contact with participants for the duration of the group while also being able to provide appropriate follow-up if participant wellbeing came into question (please see section 5.8 for a discussion on risk and ethical issues).

4.2.2. Individual Interview Design

Qualitative interviewing with people diagnosed with eating disorders has been used to develop a nuanced understanding of their experiences and to inform the development of treatment options. This nuanced perspective has been pertinent for formulating an understanding of recovery, as historically, the biomedical model has prevailed and has reduced individuals to patients within a case study. This was the case with Sir William Gull, who conducted the first case studies of women with AN in 1874. In his work, the mental status of the women in question was barely mentioned nor were psychological interventions included in the treatment regime (Gull, 1894). Roughly 100 years later, Dr Hilde Bruch's seminal books on AN used quotes from people with EDs to give insight into the experience of living with an ED. These perspectives informed Bruch's development of treatment for the disorders and provides an interesting counterexample to the heavily medical accounts that preceded her work (Bruch, 1973, 1978). While these are not examples of formal qualitative interviewing and analysis, they demonstrate the importance of that individual voice has in ED research. The most notable difference between Sir Gull's studies and Dr Bruch's (1973, 1978) writing, is that in Dr Bruch's the people with the disorders had a voice to explain what they experienced and how they wanted to be treated. Sir Gull takes authority for treatment upon himself, so that the women in his case studies remain voiceless and powerless.

Eating disorders treatment is heavily dependent on medical interventions due to the medical nature of the disorder. This may partially explain the pre-eminence of evidence based practice (EBP), that is, interventions that are based on research evidence derived from

randomised controlled studies where statistical relationships can be drawn between interventions and outcomes. Tanenbaum (2006) suggested that the difference between EBP and the recovery movement lies in where they place authoritativeness for “describing the world and making decisions about how to live in it” (pg 197). The EBP movement provides systematic approach for managing treatment of a disorder. Authority is placed with the evidence and the people who administer the treatment, so participation from people with the disorders is minimal. The recovery movement, by contrast, conceives recovery as being a self-defined and directed process, so research from this perspective privileges personal experiences. As such, authority is placed with the people who have the disorders. The recovery perspective takes the stance that people with mental disorders have had their care dictated to them and therefore benefit, both from being active in contributing to ongoing research and from making their own decisions about treatment (Tanenbaum, 2006).

Tanenbaum’s (2006) analysis of the recovery perspective highlights the importance of qualitative research on EDs from a recovery perspective. The medicalisation of eating disorders means that there is an over-reliance on EBP as the sole means of delivering treatment (Dawson, Rhodes, & Touyz, 2014a). This favouring of authoritativeness of treating professionals marginalises the voice of the people with EDs, with the understanding that the best treatment is that with the strongest empirical data. However, the use of qualitative studies relating to the experience of having an ED demonstrate that EBP research paradigms are not sufficient to understand the experience of EDs and how to treat them (Cohn, 2006; Matoff & Matoff, 2001; Pemberton & Fox, 2011; Weaver, Wuest, & Ciliska, 2005). These qualitative studies illuminated diverse aspects of the ED and recovery experience and provided new research pathways for treatment research (D’Abundo & Chally, 2004; Pettersen, Thune-Larsen, Wynn, & Rosenvinge, 2012; Reid, Williams, & Burr, 2010; Wasson, 2003).

Recent qualitative literature on ED recovery covered a wide range of topics and examined the experiences of multiple stakeholders within the recovery journey. A significant portion of the recent studies dealt with the actual process of recovery and can be divided broadly into two categories: those that develop a model for the recovery process and those that report on themes relating to the recovery process. The studies that develop a model for the recovery process from participant accounts tended to come from a grounded approach, as this allowed the researchers to develop theories inductively (D'Abundo & Chally, 2004; Krentz, Chew, & Arthur, 2005; Weaver et al., 2005). The qualitative studies that developed themes relating to the recovery process illuminated areas for treatment to explore based specifically on what participants' experienced. (Björk, Wallin, & Pettersen, 2012; Lindgren et al., 2014). Recent qualitative studies also gave participants the opportunity to discuss their experience of treatment, examining both specific therapeutic approaches and treatment settings. Such qualitative studies demonstrated the factors that helped and hindered recovery and what participants' perspectives were of the therapeutic modalities used in treatment (Pemberton & Fox, 2011; Poulsen, Lunn, & Sandros, 2010; Tierney, 2008b; Vanderlinden, Buis, Pieters, & Probst, 2007). ED recovery research has used phenomenology to examine how the ED experience informs recovery (Sternheim, Konstantellou, Startup, & Schmidt, 2010; Williams et al., 2012), to examine treatment experiences (Colston & Pistrang, 2004; Offord, 2006; Pemberton & Fox, 2011) and to understand ED recovery itself (Björk & Ahlstrom; Nordbø et al., 2008; Williams et al., 2010). A gap exists in the qualitative and phenomenological research of eating disorders. Existing qualitative research has examined the experience of eating disorder treatment and eating disorder recovery separately, but they have not been examined together. The aim of the current research was to investigate how recovery overall might be influenced by experiences in treatment and in their day-to-day life.

An OFG was used to first explore the topic and to determine what would need to be examined in greater depth during individual interviews. These interviews were considered necessary because, although the OFG provided a wealth of information drawn from the responses and interactions between participants, there were inherent limitations to the internet medium, including loss of visual and auditory cues, accessibility, and the loss of rapport built during a one-on-one interview (Evans, Elford, & Wiggins, 2008). Conducting one-on-one interviews mediated these limitations while also providing an opportunity to use the information gained in the OFG to inform the line of questions used during subsequent interviews. The use of a focus group allowed for the development of ideas that may not have been established without the input of people in eating disorders recovery (James & Busher, 2009). Being able to incorporate these ideas into the interview schedule allowed for more personalised questioning on themes and topics in the context of the one-on-one interviews. This ultimately resulted in a richer source of data for analysis.

4.3. Participants

The participants in this study were limited to people who were in ED recovery and were not experiencing active suicidal ideation. Participants were asked to self-identify as being in recovery and not actively suicidal. This was verified using the STORI (Andresen et al., 2006) and the SBQ-R (Osman et al., 2001). Any participants scoring outside of the acceptable range were contacted and told that they did not meet the inclusion criteria. They were also provided with the contact information for appropriate crisis services, as such scores could have indicated psychological distress.

4.3.1. Sample

The use of multiple recruitment streams across the two studies was designed to use convenience sampling to develop a diverse participant group. Because this population is made up of people with a variety of diagnoses, the author hoped that using this method would

result in a sample with participants representing all ED diagnostic criteria, and so, a wider range of treatment experiences. This method of sampling was successful, as the sample comprised a wide range of both ED and psychiatric diagnoses as well as a diverse array of treatment experiences that spanned not only Australia but also the world.

4.3.1.1. OFG Sample. This research used a synchronous OFG, meaning the sample would be limited in size so that the primary researcher could adequately oversee the flow of conversation during the group. . As such, this group's sample size was capped at 12 participants, keeping in line with previous research (Adams et al., 2005; Williams & Reid, 2010; 2012). This cap allowed for attrition, as participants expressed interest but either were not able to attend on the day of the study or did not show up. Due to attrition, the sample on the day of the OFG was seven participants, which is also in line within an appropriate range, as judged against existing research (Adams et al., 2005; Adler & Zarchin, 2002; Caron & Light, 2015).

4.3.1.2. Individual Interview Sample. Through the use of an OFG, preliminary data and general themes were gathered that informed the second phase of the research. Similar qualitative studies with individuals with eating disorders have used samples ranging between 10 and 24 participants (Colton & Pistrang, 2004; Tierney, 2008b). As this thesis included an OFG with seven participants, the use of a moderate sample size for the one-on-one interviews was considered appropriate. The individual interviews would complement and enrich the data gathered during the OFG and as such, recruitment was originally capped at six participants. When there was a significant expression of interest in the study, this sample size was revisited, and the cap was increased to thirteen participants.

4.3.1.3. Recovery Requirements. A review of similar qualitative studies found that they used one of two recovery criteria. The first was comprised of the self-assessed cessation of DSM-IV criteria for a set period of time, usually between three and six months; some used

clinical measures or interviews to test confirm this assessment, others did not (Arthur-Cameselle & Quatromoni, 2014; Krentz et al., 2005; Sharkey-Orgnero, 1999). The second depended on the participants to self-identify as recovered based on their own definition and understanding of this term and to opt into the study based on this identification (D'Abundo & Chally, 2004; Lindgren et al., 2014; Pettersen et al., 2012; Weaver et al., 2005). As discussed in the previous chapters, recovery takes on a personalised definition for each individual, which moves beyond the boundaries of biomedical diagnostic criteria. In keeping with the recovery model, DSM-V criteria were not included in the definition of recovery used in this study and its recruitment material, beyond the requirement that participants self-identify as not engaging in major ED behaviours (restricting, bingeing, purging). This was confirmed by the use of a psychometric measure, the STORI, which was developed specifically to measure people's stage of recovery (Andresen et al., 2006). Participants were also asked to self-exclude based on the presence of active suicidal ideation, which was confirmed with the SBQ-R (Osman et al., 2001).

4.4. Measures

The measures used in this study were part of the intake procedure and were not used to gather data on the participants. They were used to ensure that the participants were in eating disorder recovery and to test for suicidal ideation, as these were the two exclusion criteria for both studies.

4.4.1. Stages of Recovery Instrument (STORI)

The STORI was developed in order to assist in delivering recovery oriented services to people with mental illnesses (Andresen et al., 2006). It is conceptually supported by a recovery model that was developed based on the accounts of people with schizophrenia and that is comprised of five stages with four underlying processes (Andresen et al., 2003). The STORI is composed of 50 items divided into ten groups of five questions each. Each group of

questions are thematically related to one of the four underlying processes in Andresen and colleague's (2003) recovery model: hope, identity, meaning, and responsibility. Within each thematic group, the progression through the five stages of the model is represented by a statement. Participants are instructed to indicate how true the statements are of them at the present time based on a 5-point Likert scale, anchored by *0=Not at all true* and *5=completely true now* (Appendix F). Items for each sub-scale are totalled. There is no total recovery score as there are with other recovery measures, instead, each sub-scale receives a total and the stage with the highest sub-score is taken to be the stage of recovery (Andresen et al., 2006). The process components are not scored individually and instead provide structure to the measure.

The STORI was only recently developed but has been empirically validated (Andresen et al., 2006). Each subscale of the STORI showed good internal consistency, returning high alpha scores (from $\alpha = 0.88$ [Stage 4] to $\alpha = 0.94$ [Stage 3]), demonstrating reliability of each subscale (Andresen et al., 2006). The STORI also showed moderate to good concurrent validity through its correlation of subscale scores to other similar measures (Andresen et al., 2006). Both Andresen et al, (2006) and Weeks, Slade & Hayward (2011) noted that, though the STORI was designed with five subscales, a three-stage model could be derived using cluster analysis. These particular results require further research, perhaps with different statistical analysis, as cluster analysis may not be appropriate for determining the validity of this scale and factor analysis may yield different results.

The STORI was chosen for this research over other measures of recovery because it was developed using the narratives of people with mental illnesses, unlike existing recovery measures like the Recovery Assessment Scale (Hanock, Scanlan, Honey, Bundy, & O'Shea, 2015). This research required a recovery measure that allowed the flexibility of a stage model allowing the author to determine more discrete exclusion criteria, which a single recovery

score did not. Because the model and measure were both informed by individual experiences of mental illnesses, the STORI was suited to recovery-oriented research and it warranted investigation with the ED population.

4.4.2 Suicidal Behaviours Questionnaire-Revised (SBQ-R)

The SBQ-R was developed using the 34-item self-report survey, the Suicide Behaviours Questionnaire (Linehan & Addis, 1983). It was developed to assess the frequency and severity of suicidal behaviours and to document a history of suicide attempts. Linehan (1996) developed a 14-item version of this instrument and a number of 4-item versions were also developed, both by Linehan and her colleagues and by others (Linehan, Goldstein, Nielsen & Chiles, 1983; Cole 1989; Cotton, Peters, & Range, 1995). The current version of the SBQ-R was developed and validated in response to the number of modified versions of 4-item of the questionnaire; it displayed appropriate internal consistency reliability for both adult clinical ($\alpha = 0.75$) and non-clinical ($\alpha = 0.8$; $n = 80$) populations, as well as high test-retest reliability, ($t(30) = .95, p < .001$) (Cotton et al. 1995). It also showed good convergent validity with moderate significant correlations to a measure of reason for living (Reasons for Living Inventory; $r = .34, p < .01$) and a measure of suicidal ideation (self-report version of the Scale for Suicidal Ideation; $r = .69, p < .001$). The SBQ-R was selected because it is a straightforward measure of suicidal ideation that was judged to be easy for participants to complete. The four items are worded broadly, which allows for a wide range of information to be accessed in one administration. Osman and colleagues (2001) noted that this version of the SBQ-R can be used to identify both at risk individuals and risky behaviours, so it directly assesses suicidality. As such, the SBQ-R was considered appropriate for this research because participants needed to be screened based on active suicidal ideation.

The SBQ-R is a 4-item self-report questionnaire. Each item assesses a different dimension of suicidality. Item 1 refers to lifetime suicide ideation and suicide attempts. Item

2 appraises the frequency of suicidal ideation in the past twelve months. Item 3 checks threat of suicidal behaviour and, finally, item 4 judges self-reported likelihood of suicidal behaviour. All questions used either 5-, 6-, or 7- point Likert scales and all except question four are anchored by *I = never or no*; question four was anchored *0=no* (Appendix G).

4.4.3. Inclusion Criteria

Scores from both the STORI and the SBQ-R were considered together to determine whether a participant was appropriate for this research. For the STORI, participants were judged appropriate if they were in the rebuilding and growth stages of the model described by Andresen et al (2003). According to this particular model, the rebuilding and growth stages are both associated with the work of recovery, namely regaining control of one's life, reassessing goals to determine if they align with values, and building resilience. The earlier stages- moratorium, awareness, and preparation- are focused on developing an understanding of the necessity for recovery and building resources for it (Andresen et al., 2003). For the SBQ-R, participants were divided into one of three categories based on their final score on the questionnaire: (1) those whose scores fell well under the stated cut-off for both adult and adult psychiatric patients who could be at risk for suicidality (scores equal to or less than seven and eight respectively) (2) those whose scores were moderately elevated (between nine and twelve), and (3) those whose scores were extremely elevated (scores over twelve). Participants in group one were included in the study as long as their STORI scores matched appropriately. Participants in group two with moderately elevated scores were forwarded pre-determined follow-up questions based on which element of the scale was elevated (Appendix E). Their inclusion in the research depended on their responses to these questions, which covered their current safety and risk, and on their scores on the STORI. The participants in group three with extremely elevated SBQ-R scores were not included in the research and were instead sent an e-mail with appropriate referral information and that thanked them for

their interest in the research. This three-tiered approach was used for the SBQ-R because it was found that a high percentage of the returned screening questionnaires initially had SBQ-R scores above the clinical cut-off, whilst the STORI scores simultaneously demonstrated established recovery. This presented a unique facet of EDs recovery, demonstrating that it is possible to live in recovery whilst still having clinical symptoms and that the definition of recovery has not been firmly established (Couturier & Lock, 2006; Noordenbos, 2011b). It was determined that strictly ruling out all participants who presented with suicidal ideation would risk reducing the variety of the sample, so a three-tier system with additional follow-up was implemented.

4.5. Recruitment

The initial recruitment for the first study began in November of 2016 and ran until February of 2017, with a target of up to 12 participants for the OFG. During this recruitment period, nineteen total participants were recruited for the focus group, eight were ruled out because they did not meet the selection criteria of being in ED recovery without active suicidal ideation or because they did not live in Australia. Of the remaining eleven potential participants, seven participated in the online focus group.

Recruitment for the second study began in February of 2018 and was designed to recruit a sample of six participants. During this period fifteen participants were recruited; two were ruled out because they did not meet the selection criteria. This left a sample of thirteen participants, which was well above the expected sample. The study interviews were conducted with all thirteen participants and the study was carried out with a larger interview sample than expected.

4.5.1. OFG Recruitment

Participants were recruited from the general population using targeted strategies, including (a) Internet media (b) radio and newsletter interviews. All recruitment information

provided an e-mail address and a work phone number for potential participants to express their interest in joining in the study (Appendix A). Information about incentives were included with the recruitment material. Potential participants e-mailed the primary researcher or a supervisor and were provided, by return e-mail, with a PDF of the explanatory statement (Appendix B) and a link to the online registration site. This registration site, which was set up using Qualtrics, contained a digital version of the explanatory statement (Appendix C), which was signed using a digital captcha. Using a digital consent form with a captcha allowed the researcher to receive informed consent without placing undue burden on the participants, by avoiding the necessity of printing, signing, and scanning the form or using a digital signature. In the online registration participants were also asked for demographic information (Appendix D) to provide a pseudonym for use during the OFG and a phone number at which they could be reached if their safety became a concern during the group. Two psychometric measures were included in the registration for screening purposes, the Stages of Recovery Instrument (STORI) (Andresen et al., 2006) and the Suicide Behaviours Questionnaire, Revised (SBQ-R) (Osman et al., 2001). In some instances, individual participants required follow-up after completing the online registration due to borderline or inconclusive scores on either the STORI or SBQ-R. Participants were contacted by e-mail and asked pre-determined questions (Appendix E) based on their scores on the STORI and SBQ-R (Appendix F & G).

4.5.1.1 Internet Media Used in OFG Recruitment. Eating disorder and eating disorder recovery specific organisations were searched for, as they provided a targeted audience of people in ED recovery. These organisations (Appendix H) were all contacted to list the study's flyer. Some, such as Victorian Centre for Excellence in Eating Disorder (CEED) or Australian, New Zealand Academy for Eating Disorders had existing sections of the websites for research listings. Others, like the Recovery Warriors website and the Science of Eating Disorder blog did not have a designated listing for research recruitment, so the flyer

was included in their social media accounts. Some organisations, like the Butterfly Foundation, composed an additional social media listing that directed viewers to the research. This was part of their ongoing social media campaign. Participants were also enlisted through the Monash University Post Graduate Association monthly digital newsletter, which also contained a designated section for research recruitment.

4.5.1.2 Radio and Newsletter Interviews Used in OFG Recruitment. Wider dispersal of information about this study was sought through radio interviews with local radio stations. Community radio stations with programs relating to mental health and psychology were contacted. The Brainwaves show on 3CR (855AM) arranged an interview for January 25, 2017. The interview was conducted with the author, lasted half an hour, and was made available online.

An interview was arranged by the National Eating Disorder Collaboration (NEDC) for their e-bulletin issue on qualitative research. The interview was conducted via e-mail and was issued by e-mail newsletter in February 2017.

4.5.1.3. Incentives for OFG Participation. Two \$30 Coles/Myer gift vouchers were offered to participants in the OFG for the participation in the group. Participants expressed their interest in entering a drawing to receive a gift card during registration for the group. The names of interested participants were assigned a number and the winning numbers were picked using a random number generator. The two participants were contacted by e-mail, asked for their postal address, and the gift cards were sent by Australia post.

4.5.2. Individual Interviews Recruitment

Participants for the interviews were also recruited from the general population. However, as the interviews were conducted on an individual basis, the sample was drawn from the wider Melbourne area, with some interviews conducted digitally over Zoom. As such, all recruitment information was dispersed through similar internet media to the OFG.

Some participants contacted the researcher seeking information about the OFG after the recruitment period for the first study had ended. These participants agreed to take part in the interviews and were contacted once recruitment for the interviews opened. As with the OFG, all recruitment information included an e-mail address and work phone numbers for the primary researcher and supervisors for ease of contact (Appendix H).

Participants made initial contact with the primary research by e-mail, at which point they were sent a PDF of the explanatory statement (Appendix J) and a link to the online registration site. This registration site was similar to the one used in the OFG except that there were no questions asking the participants about emergency contacts or pseudonyms. These were not considered necessary for the individual interviews because the author would be in face-to-face or voice contact with the participants for the duration of the interview and so, would be able to respond appropriately to any distress caused by the interviews. The registration site asked participants to complete a digital informed consent form (Appendix K) with a captcha code to signify their signature, demographic information, the STORI, and the SBQ-R. The online registration was used for the interviews because it reduced the burden of completing and returning screening paperwork to the researcher by e-mail, which could be inhibiting to potential participants. It ensured that preliminary screening of participants was completed quickly and easily. As a precautionary measure for any participants who were not able to complete the online registration, PDF and paper versions of the screening paperwork were available; however, participants were not able to be interviewed unless they had been screened first. As with the OFG, any participants whose scores on the STORI or SBQ-R required follow-up were contacted by e-mail and sent predetermined questions. Once participants had been screened, they were contacted by e-mail to schedule an interview time and location.

4.5.2.1. Internet Media Used in Individual Interview Recruitment. The same organisations that were used to advertise for the OFG were used to advertise for the interviews. These organisations had an existing relationship with the author and their advertisement was demonstrated to be effective with the OFG. Additionally, because the sample for the interviews was drawn specifically from Melbourne, it was judged that using Australian and Melbourne specific organisations would yield a more targeted sample. Advertisements were placed with the organisations listed in appendix H in January of 2018.

4.5.2.2. Incentives for Individual Interview Participation. Participants were provided with \$20 Coles/Myer gift vouchers. These vouchers served the dual purpose of providing a small incentive for participants and also providing some participants with compensation for fuel, if they had to travel to interview. The voucher's low amount ensured that they did not act as a pay-off for participants, meaning data validity was not likely to be impacted by ulterior motives.

4.6. Procedure

4.6.1 OFG Procedure

4.6.1.1. Online Platform. The study used a focus group platform provided by the software company itracks. itracks develops software for online market research and their online focus group software, itracks Chat, was considered appropriate because it allowed the researcher to register users under pseudonyms, to interact with participants in a private side chat, if necessary, and because it provided mobile functionality. Other platforms considered included Group Quality, Focus Group IT, and Visions Live. In other qualitative studies with an OFG, similar online platforms have been used, including GoPost and WebCT (Campbell et al., 2001; Kenny, 2005; Morris et al., 2013; Williams & Reid, 2012). These platforms were ruled out either because of accessibility or because they were no longer available for use.

4.6.1.2. Group Process. Recruitment for the OFG ran for 12 weeks. During this time, regular contact was made with participants, both individually, and as a group to notify them of the OFG that was run on Saturday 25 February 2017. Two reminder emails were sent in the lead up to the OFG. In the first reminder e-mail, participants were sent the modified research schedule and the posting etiquette for OFG (Appendices L and M). On the day of the OFG, they were sent a link giving them access to the itracks Chat platform. This link provided access to a digital waiting room for 20 minutes prior to the group's commencement. During these 20 minutes, the author was able to ensure that all the participants were present and to troubleshoot any technical difficulties. At 14:00 the participants were invited to begin the OFG by leaving the waiting room to join the formal chat room.

The group was opened with a brief review of the posting etiquette, which allowed the participants opportunity to ask questions and provide feedback. Following the example set by Williams and Reid (2012) in their OFG study of individuals with AN, an introduction question was utilised to allow the author to formally introduce herself and to allow the participants to do the same. During this time, the author ensured that there were no questions about the research or the OFG. Following this, the author introduced the first question on the research schedule, opening the group to discussion. The author used probes, as appropriate, to encourage further participation and to encourage discussion on themes that developed during the course of the interactions. As discussion on one question wound down or allotted time ran out, the author introduced subsequent questions from the research schedule.

The primary sections of the research schedule were allotted 30 minutes of discussion each, with each of the three questions comprising that section allotted 10 minutes of discussion. The remaining 30 minutes of the group was divided evenly between the introduction, the additional section, where participants were invited to provide any further feedback, and the closing, where the group reviewed the overall experience of talking about

recovery experiences. This final closing question was a means to encourage participants to review their emotional state and to provide closure at the end of the group. Though the group was scheduled to last two hours, the participants were eager and gave engaging feedback, so an extra hour was allocated with the participants' consent in order to attend to questions that were not answered in the initial two hours. There was moderate attrition during the group process, as more than half the participants left the group by the end to attend to other commitments; however, a core of four participants remained for the final hour.

A drawing was held after the completion of the group for a \$30 Coles/Myer voucher; this was completed using a random number generator. The winner was contacted by the e-mail address provided at registration and asked to furnish the investigator with a postal address, to which the voucher was sent by Australia Post.

The OFG was a text-based chat group. This meant that, unlike usual focus groups or interviews, transcription was unnecessary, because the chat log could be downloaded from iTracks. However, for readability purposes, it was necessary to make changes to the original quotes from the transcript, such as correcting spelling and grammatical mistakes made in the original transcript. For example, lowercase i's were frequently used in the OFG and were corrected to upper case and there were errors in spelling that were corrected. These changes were judged to not impact the veracity of the original transcript.

4.6.2. Individual Interview Procedure

Recruitment for the interviews ran for sixteen weeks. The interviews were run over a span of eight weeks between July and August 2018. Potential participants were asked to make contact with the primary researcher by e-mail. Upon making contact, they were sent a similar e-mail to the one used for the OFG; it contained the explanatory statement for the second phase of the study (Appendix J) and a link to the digital registration site. Through this site they completed the digital consent form for the second phase of the study (Appendix K),

the STORI, the SBQ-R, and the demographic survey. Participants who were chosen for this research were contacted by e-mail to arrange an interview time and location. The location was chosen based on public access, so many interviews were conducted in meeting rooms at public libraries or using rooms available at Monash university. In cases where participants were interstate or in regional Victoria, interviews were arranged for Zoom.

A week prior to the interview, the modified research schedule was sent to the participant (Appendix N). Two days before the interview, the primary researcher made contact with the participants to confirm the time and location of the interview. On the day of the interview, the primary investigator arrived early at the interview location to set up the room. The room was set up with two digital recorders, one primary and one back-up. The purpose of two recorders was explained to the participants prior to every interview. Wherever possible, the author and the participant sat across from each other at a table with a minimum of one meter separating them; in instances where this was not possible, the nearest approximation of this arrangement was made.

As with the OFG, the interviews opened with a question orienting the participant to the author. Generally, this question asked about the participant's day or a similar pleasantry; this was not included in the data analysis. Following this, questions from the research schedule were asked in order. Probes were used to encourage further discussion on appropriate themes or direct the flow of discussion. At the end of the interview, a final closing question was asked to provide the participants with the opportunity for reflection on the experience of discussing their recovery. This final question was not used for analysis. Following the interview, the participants were given the Coles/Myer voucher and thanked for their time.

As the interviews had the potential to cover stressful or distressing information, procedures were in place to protect the participants and the researcher. For example, the

researcher is a trained psychologist with experience in suicide risk assessment and so, was comfortable asking participants if they were distressed after talking about emotionally uncomfortable topics and was prepared with the appropriate referral information so that participants would not leave the interviews without support. Alternatively, there was the potential for participants to discuss trauma and abuse from their past, so the researcher was prepared to complete a mental risk assessment to determine if the abuse was ongoing and therefore required referral or reporting or if it was in the past and therefore was not part of the researcher's duty of care. In either case, the participant's immediate welfare was monitored and referrals for support were available if disclosure increased distress. In any interview where a participant presented as distressed or raised complex content, the researcher debriefed with supervisors.

Transcription of all the interviews was carried out by a transcription service. The service was one of Monash University's preferred transcription services, SmartDocs, and was paid for with a grant from the University.

4.6.3. Interview Topics

The research schedules were designed for the OFG and the individual interviews, however they differed in their content. The data obtained from the OFG was used to inform the development of the research schedule for the individual interviews, so that the questions asked there could be more targeted and specific. This allowed for the development of a comprehensive and individualised understanding of the recovery experience.

4.6.3.1 OFG Topics. In order for participants to describe experiences that were most relevant to them, a number of open and close ended questions were asked (Appendix L). The content of these questions was created using guidance from Braun and Clarke (2013), who explained that questions needed to prompt discussion between group members. The questions were informed by existing qualitative research and revolved around three main themes that

were informed by the recovery model: the personal understanding of recovery, the internal conditions for recovery, and external conditions for recovery. The questions concerning the external conditions for recovery (C1, C2, C3) were drawn from previous qualitative research on the topic (Williams & Reid, 2010, 2012). Introductory questions were used at the beginning of the OFG to orient the participants to each other and the researcher.

The research schedule opened with questions that built an individual understanding of recovery (A1 and A2) as it related to the participant's personal journey. These questions formed the theoretical basis from which the interview progressed, because, according to the recovery model every person has a slightly different understanding of recovery. The recovery model encourages researchers and practitioners to understand this personal understanding from the outset and not to impose outside assumptions. At the same time, the recovery model espouses commonality of experience to build connection within mental health communities (Slade, 2012). Developing this understanding at the outset of the group facilitated group cohesion and built rapport, both between group members and with the facilitator. Questions A1 and A2 in particular accessed personal interpretations of recovery while also encouraging discussion on the commonality of experience with probes relating to the influences on the definition of recovery. Question A3 addressed the influence of treatment teams on the recovery definition. Le Boutillier (2011) and colleagues suggested therapeutic relationships should encourage individuality and autonomy. Question A3 assessed whether this kind of relationship developed with participants' treatment providers and determined how this relationship impacted their recovery.

From here the line of questioning built on elements of the personal experience of recovery to explore how social connections impacted recovery (B1) and what influences attitudes and values had on it (B3). These questions acknowledged family and social relationships and the connection these relationships have to the development of identity

through the recovery process. They also accessed the interpretative process that individuals with eating disorders have to go through in order to establish an identity as a person with an eating disorder, which must be reassessed in order to begin the process of recovery (Tan, Hope, & Stewart, 2003). In keeping with previous research that identified the importance of identity development as a part of recovery (Björk & Ahlström, 2008; Federici & Kaplan, 2008), particular attention was paid to how participants used their identity to maintain recovery (B2). Probes explored the possibility of threats to that identity and also revealed the elements that make it up, including spirituality and role models.

The research schedule ultimately led to queries about how treatment experiences impacted recovery. This segment began with experientially close questions about the participants' memories of treatment and experiences with allied health professionals, either positive or negative (C1, C2). Probing encouraged the participants to relate these experiences back to their recovery if they had not made the connection already. The segment finished with a general question about how treatment could be improved in the future, as a means of bringing closure to the interview (C3). This question also grounded the research squarely in the recovery model, which promotes the citizenship and community engagement of people with mental illnesses (Rissmiller et al., 2011). In this way, the narratives and opinions of people with mental illnesses were taken into consideration, especially when assessing treatment options. Participants were no longer passive recipients of treatment but were active in their assessment of its impact on their lives and its perceived effectiveness. Their engagement in the process of contributing to the improvement of treatment through feedback changed their role from passive recipients of treatment to active assessors of it.

Capacity for participants to give further feedback was provided in the form of an open-ended question prior to the closure of the OFG (D1). The OFG was closed with a question asking the participants about the experience of discussing their recovery and

treatment experiences. The responses to this question were not retained for analysis because the questions were a means of closure to the interview and to allow the participants the opportunity to raise any uncomfortable feelings that may have developed.

4.6.3.2 Individual Interview Topics. The research schedule for the individual interviews was informed by the analysis of the data from the OFG and previous research on the experience of recovery. Based on this information, the research schedule was modified to more closely examine the ED treatment and recovery experiences (Appendix N). The number of questions asked was reduced to accommodate the shortened interview period of an hour and to also allow the participants more space to discuss their experiences in depth. The structure of the interview was designed using information from Smith, Flowers, and Larkin (2009), who advised that interviews move from begin with descriptive questions and move to analytical ones. After orienting questions that were not used for analysis, the research schedule opened with an open-ended question asking the participants to explain their experience of recovery. This allowed participants to explain, from their perspective, how they came to recovery, what their definition of it was, and how this definition had evolved and situated the research firmly in the recovery perspective (Slade, 2012). Following from this, was a question asking about any stand-out positive or negative experiences that the participants had during their recovery and treatment. This question allowed participants to explore in greater depth the experiences they had during their recovery journey and to relate how these impacted their overall recovery. Previous research has examined the treatment experiences of people with EDs by asking similar questions (Halvorsen & Heyerdahl, 2007; Musolino et al., 2016; Rance et al., 2017). The final question asked how life had changed or remained the same since they had begun their recovery journey. This question opened discussion to the participants' life at present and to explore people, behaviours, and emotions that may have impacted their recovery through their current presence or absence in the

participants' lives. This question was based conceptually on research that examined the elements of a person's life that helped and hindered recovery (Arthur-Camselle & Quatromoni, 2014; Björk & Ahlstrom, 2008). As with the OFG, the interviews were closed with a question asking about the treatment and recovery. This question was not used for analysis and provided a means for feedback and closure.

4.7. Qualitative Analysis

4.7.1. OFG Analysis

Thematic analysis was chosen for the analysis of the OFG because the initial stage of the research was exploratory in nature and sought to establish new patterns within the data (Braun, Clarke, & Terry, 2015). These new patterns were considered important because they would be used to inform the research schedule for the individual interviews, so using a method that accurately developed the most relevant themes within the data was necessary (Joffe, 2012). Thematic analysis was also chosen because of its theoretical flexibility. It is not attached to a specific theoretical framework and so can be used within this phenomenologically based research (Braun & Clarke, 2006). Because the methodology was informed by the recovery model, the thematic demarcation combined inductive and deductive processes. Inductive processes were used when early stages of analysing the raw data, whereby the researcher used qualitative processes to search for patterns in data with coding. Deductive processes were applied at the interpretive stages of analysis. In these stages, existing theories informed the categorization of themes and the development of relationships between themes. This research used latent thematic analysis to not only identify salient patterns within the data, but to give them context and meaning (Braun et al., 2015).

Thematic analysis has been used in a number of recovery-oriented studies. These studies covered a range of topics including the recovery experience of various populations (Castillo, Ramon, & Morant, 2013; Larivière et al., 2015; Tooth, Kalyanasundaram, Glover,

& Momenzadah, 2003), specific factors that support recovery (Boucher, Groleau, & Whitley, 2016; Carpenter-Song, Hipolito, & Whitley, 2012; Firmin, Luther, Lysaker, & Salyers, 2015), and the use of thematic analysis to develop a recovery model (Bird et al., 2014). Thematic analysis has also been used specifically with focus group data, showing it can adjust to working with multiple accounts within one data set (Bird et al., 2014; Böhm et al., 2014). Additionally, thematic analysis was utilised effectively in the analysis of an OFG by Morris, Daluiski, and Dy (2016), further demonstrating its flexibility as a form of analysis. ED research has also widely employed thematic analysis. In this context it has been used to develop research on the experience of having an eating disorder (LaMarre & Rice, 2015; Reid, Burr, Williams, & Hammersley, 2008), the process of recovery (Hay & Cho, 2013; Mitchison & Mond, 2015; Tierney, 2008a), and how this process is experienced by people related to the person with the disorder (Areemit et al., 2010; Bakker et al., 2011).

Analysis was conducted by first thoroughly reading the OFG transcript in order to create familiarity with and immersion in the data (Braun & Clarke, 2006). Following this, the transcript was read through again and initial codes were developed inductively. Initial codes were developed during the transcript. The transcript was then read and re-read and codes were refined, combined, and sometimes removed completely. This iterative process ensured that the entirety of the data was covered. Once the codes were developed, emergent themes were identified and collated based on the relationships between codes (Braun et al., 2015). This resulted in a series of preliminary themes, which were finalised into the eventual review theme list. The list was analysed to determine that the themes fit the original extracts from which they were drawn, as well as the data set overall (Braun & Clarke, 2006). Finally, each theme was clearly defined and named to facilitate the explanation of these themes in an analytical write up.

4.7.2. Individual Interview Analysis

Interpretative phenomenological analysis (IPA) was selected for the analysis of the interview transcripts because it is an experiential approach that focuses on the lifeworld of the participants (Langdridge, 2007). At its core, IPA is focused on understanding how participants make sense of salient experiences in their lives (Smith, Flowers, & Larkin, 2009). The use of a hermeneutic approach is significant to this phase of the research, because the participants were asked to identify the positive and negative influences on their recovery based on their personal experiences of treatment. IPA was also chosen because the topic is experientially close to the participants and was meaningful to them, as demonstrated in the OFG (Larkin & Thompson, 2012). Additionally, IPA was chosen because it is an idiographic methodology and this phase of the research in particular was concerned more specifically with how individual participants understood their recovery (Smith et al, 2009).

IPA is a well-established research methodology that has been used in a wide range of topics. It has been used within the medical field to understand people's experience of their illnesses (Arroll & Senior, 2008; Marriott & Thompson, 2008; Senior, Smith, Michie, & Marteu, 2002). IPA is a useful approach for recovery-oriented research because of its idiographic and hermeneutic features, which are aligned with the recovery model's emphasis on individual experiences. IPA research has been conducted in the recovery field on topics relating experiences with schizophrenia (Connell, Schweitzer, & King, 2015; Davidson, Bellamy, Guy, & Miller, 2012) and the factors that contribute to maintaining sobriety in alcoholism (Flaherty, Kurtz, White, & Larson, 2014; Weegmann & Piwowoz-Hjort, 2014). IPA has also been used extensively in ED research as a means of expanding the understanding of experience of living with an eating disorder. IPA research in the ED field has examined the experience of living with an ED (Williams & Reid, 2010; 2012), undergoing treatment (Colton & Pistrang, 2004; Offord, Turner, & Cooper, 2006; Pemberton & Fox, 2011a), and living in recovery (Björk et al., 2012; Federici & Kaplan, 2008; Mulveen,

2006). It has also been used to examine some features that are specific to EDs, such as pro-eating disorder websites (Mulveen, 2006) and the experience of the anorexic voice (Williams & Reid, 2012).

In the current study, interview transcripts were analysed sequentially. Each transcript was read and re-read to ensure that the participant became the focus of the analysis and develop immersion in the data (Smith et al, 2009). Following this, data was assigned initial codes. These codes made descriptive, linguistic, and conceptual comments on the data. After the initial codes had been established, emergent themes were developed based on the body of commentary developed in the previous stage of analysis (Larkin & Thompson, 2012). These themes represented the essence of repeated or groups of codes and, once developed, were ordered chronologically so that they could be examined for relationships and connections in the next phase of analysis. In this phase themes were mapped to expand the understanding of the connection between them and to aid in the creation of subordinate themes (Smith et al, 2009). Once themes for each participant were established and checked against the data to ensure that they represented the data accurately, a short analysis was written. These short analyses were used to inform the larger description of results included with this thesis, which was drawn from a comparison of themes across the participants and with the OFG.

4.8. Qualitative Rigour

In order to establish the rigor of this research, Lincoln & Guba's (1982, 1986) Four Dimension Criteria of trustworthiness were applied (Forero et al., 2018). In qualitative research, trustworthiness is understood to be the degree of confidence that readers can have in the research. The first criteria, credibility, refers to the confidence that the results are true and believable from the perspective of the participants (Lincoln & Guba, 1986). To meet this criteria, there was prolonged contact with the participants in two studies, with an OFG lasting three hours and thirteen interviews, lasting a minimum of an hour. The total contact time with

participants totalled over seventeen hours. In the second requirement of trustworthiness, dependability, it should be possible to find the same results under the same context, with the same participants, and the same coders (Lincoln and Guba, 1986). To meet this requirement, a detailed description of the study method was maintained with drafts of the study protocols prepared as the research progressed so that any changes to the methodology could be tracked. This ensured that the final methodology reflected any minor changes made during the experimental process.

Lincoln and Guba's (1986) is confirmability, which they explain means the results could be corroborated and confirmed by other researchers. They list reflexive journaling as one of the methods that a researcher can meet this requirement. As discussed below, a detailed reflexive journal was kept as a part of this research. The final criteria discussed by Lincoln and Guba (1986) is transferability, by which they mean how well the research can be generalized to other contexts. In this research, purposeful sampling was used to meet this criteria but was not used to the extent that a homogenous sample was created because the age of the sample varied significantly.

4.9. Ethical Considerations

The research being conducted was targeted at a population that, while in recovery from their EDs, was still at considerable risk for relapse and ongoing mental health issues (Carter et al., 1999; Castro, Gila, Puig, Rodriguez, & Toro, 2004; Fichter et al., 2006; Herzog et al., 1999; Keel et al., 2005). As such, they were considered a vulnerable population and steps were taken to ensure that the issues discussed during the OFG and interviews were dealt with professionally and ethically. The author is a provisional psychologist with previous experience working with individuals with eating disorders. She was under the direct supervision of two supervisors who have considerable experience as counselling psychologists. To ensure the psychological safety of the participants during the interviews,

the author allowed space for the expression of emotions and acknowledged these emotions as they arose. The author was aware of the possibility of terminating the OFG or the interviews and was at all times, aware of the participants' needs (McCosker, Barnard, & Gerber, 2001).

Opportunities for reflection were available in both portions of the study. In the OFG, a topic was posted after the last question to allow the participants to reflect on their reactions to any issues raised and if necessary, participants were directed to the support services outlined on the explanatory statement. After the individual interviews, the author asked the participants about their reactions to the issues raised and again, directed participants to support services outlined on the explanatory statement.

The use of an anonymous online sample presented some ethical difficulties, most notably verifying participant age and maintaining the anonymity of the participants. The participants signed a virtual informed consent form as a part of their registration process. This form included a portion asking the participant to register their birthday; if they were younger than 18 years, they would not be included in the study. While there was the possibility that they could lie about their age, this risk was considered relatively low, as the pay-off for doing so was not high for the participants.

Anonymity in the OFG was considered necessary for the protection of the participants, as they were in a virtual space where they were asked to discuss issues that had the potential to be confronting or could reflect negatively on the mental health industry, of which the primary researcher and the supervisors of this study are all members. For this reason and the need to protect the participants' confidential contact information from one another an anonymous group format was chosen. Participants were asked to choose a pseudonym and this was used for the entirety of the group. Some participants chose to use their first names during the group, but this was not prohibited, as it was an individual choice and did not present an immediate risk to confidentiality.

These issues were taken into consideration during the early stages of the research. A research proposal was submitted to the Monash University Human Research Ethics Committee under a high-risk category because it was being conducted with a vulnerable population. The project was approved on 5th October 2016 (Appendix O).

4.10. Reflexive Statement

A combination of previous professional work in the field of ED treatment and the observation of the ongoing recovery journey of personal acquaintances has informed the development of this research. The primary researcher is an acknowledged outsider to the participant population, neither having had an ED and being a provisional psychologist. As such, the primary researcher kept a reflective journal to maintain neutrality throughout the interviewing and analysis process (Smith et al, 2009). This journal was in a number of ways. After the OFG and after each interview, the primary researcher recorded her impressions and thoughts about both the process of the interview (e.g. flow, technical difficulties, performance as interviewer) and content of the interview. Initial impressions of the participant were also included as well as any important details, such as the revelation of abuse, emotional distress, etc. Journaling was also used during the analysis process to reflect on the overall analysis process. Keeping a journal during this stage in particular was a means of maintaining the rigour of the research because in it was a log of the qualitative procedures undertaken on a day-to-day basis, methodological decisions made, as well as a record of introspection on the data, as suggested by Guba & Lincoln (1982). The overall purpose of the reflexive journal was to assist in maintaining neutrality, however, there may have been points where this was not possible. For example, when a participant revealed an instance of graphic abuse in her past, it was difficult to maintain complete neutrality as this was emotionally confronting and, from a researcher's perspective, represented a point of significant interest. As a researcher, it was important to meet the ethical requirements of the research by checking for safety and

ensuring that the participant had the appropriate referral information. On a personal level it meant bracketing any emotional response off and managing it privately.

4.11. Chapter Summary

This chapter covered the process of this thesis. First, the overall theoretical stance and design were discussed in order to provide wider context for the research. Then, the practicalities of both the OFG and the individual interviews were explained in detail. This comprised recruiting sample for studies, the measures to create the samples, and the procedure used in both studies. The topics discussed during both interviews were explained. The rationale for the styles of analysis used for the results of both studies were justified. Ethical concerns were given consideration.

Chapter 5

Results of Online Focus Group

5.1. Overall Results

5.1.1. Demographics

The online focus group was conducted with seven participants. The participants ranged in age from 19 to 48 years of age. Their self-reported age at diagnosis ranged from 15 to 26 years. The age of diagnosis was in line with the existing literature, which has consistently shown that EDs are most common among young women (Dray & Wade, 2012; Hoek, 2006; Keski-Rahkonen et al., 2007; 2008; Preti et al., 2011). Participants reported a broad span of time in recovery, from twelve months to five years. The primary and secondary diagnoses represented in the sample were typical for this population, including BN (4), AN (3), and EDNOS (3). Other psychiatric diagnoses were represented, including: anxiety disorders (4), depressive disorders (3), post-traumatic stress disorder (PTSD; 1), obsessive-compulsive disorder (OCD; 1), and prosopagnosia (1). While these participants did not constitute a representative sample, together they did present an accurate snapshot of the ED population (Bühren et al., 2013; Jaite, Hoffmann, Glaeske, & Bachmann, 2013; Preti et al., 2009; Swanson et al., 2011).

The participants reported seeking treatment from a variety of allied health professionals and services and in a number of settings. All seven participants reported having appointments with a psychologist at some point during their recovery. The next most frequently endorsed allied health professionals were dietitians, psychiatrists, and GPs, who six participants reported seeing at some point during their recovery. These four professionals—psychologists, dietitians, psychiatrists, and GPs—are often the core components to an ED treatment team (Gordon, 2010). Four participants reported receiving treatment from other, unspecified sources, while two listed online support groups. Finally, one participant endorsed

support from a social worker. In regard to treatment setting, six participants reported having attended treatment at private psychologist clinics. A number of participants had experience with the variety of specialist ED services available in Australia, including outpatient (5), inpatient (4), day patient (3), and outreach (1) specialist services. One participant reported having received treatment at a general inpatient psychiatric ward.

Of the seven participants who commenced the OFG, four remained for the duration of the group. Attrition during the group was due to prior commitments that conflicted with the group's timing. The OFG ran over time by an hour due to the participants' overwhelming feedback on the questions discussed. Those who remained for the duration of the extended three hours did so willingly, while those who had to depart early noted their regret at having to do so.

5.1.2. Effectiveness of OFG

Overall, the OFG was considered a successful means of engaging participants in discussion about their experience of ED treatment and recovery. This was judged based on the ease of engagement with the online platform and the development of rapport during the group, both with the researcher and between the participants. As OFGs have previously been used with this population (Williams & Reid, 2007; 2010), precedence was established, though the effectiveness of the particular software used in this study, itracks, has not. This research found that itracks was very user-friendly and effective for engaging participants ahead of and during the OFG. There appeared to be little difficulty with the use of the software and with the format of the OFG, indeed, many participants expressed positive sentiments of the experience spontaneously during the group.

The author was able to develop rapport with the participants quickly. This was judged by both their willingness to collaborate with the author to direct the flow of discussion and to feel comfortable confronting the researcher when they felt misunderstood. The participants

actively collaborated with the researcher when they sought clarification on questions. They also actively directed the discussion by asking questions that positively contributed to the overall discourse, as demonstrated in the following excerpts:

Nikki 2:21 PM *Capella, is it ok if I ask a question to the group about recovery or do you need to stick to your questions due to time constraints?*

Gee 3:07 PM *I'm interested to hear if anyone has done FBT [family-based therapy]*

As expected, the online setting diluted the author's influence as a leader of the group and encouraged democratic engagement (Bargh et al., 2002; Joinson, 2001). Indeed, this effect may have empowered participants to confront the researcher over a misunderstanding about the relevance of a topic being discussed. The comfort that the participants felt within the group was notable, given that the author was an outsider in many respects, having no ED diagnosis and being an allied health professional, as well as a researcher. Their willingness to explain concerns during the group is ascribed partially to the dynamics of the OFG, though individual personality traits should not be discounted.

Hope 3:45 PM *I think it's still on topic....it seems off topic but it's hard to encapsulate everything that it is*

Capella 3:46 PM *It is in a way. It's just....roundabout, hey?*

Ruby 3:46 PM *This, this connecting with those who 'get it', Capella, that sustains recovery*

Capella 3:46 PM *Why is that?*

Gee 3:46 PM *This is why eating disorders are so complex and difficult to treat. I have actively been in recovery for 8 years and am still learning new things about myself and anorexia every day*

Tiffany 3:46 PM *Knowing that others get how we think is helpful*

Ruby 3:47 PM *For me, when others understand what I've been through - like Hope mentioning the feeling of a purge - I don't feel 'crazy' so then I am more self-compassionate*

Hope 3:47 PM *Yeah. I don't mean to be rude, but you have to have walked the journey to get it and get the significance of recovery. Talking to those who speak about recovery from a genuine place is validating*

Gee 3:47 PM *You can see why most of us think that being truly recoverED [sic] is impossible due the sheer complexity of it all.*

The participants developed quick and warm rapport between each other. Again, this was an expected effect of the OFG format, as it allowed for an increased sense of

confidentiality and the lowering of inhibitions when discussing difficult topics (Joinson, 2001; Woodyatt et al., 2016). Crosstalk in the group was characterised by warm, effusive affirmations and empathetic agreement regarding the experiences discussed. The tone of the discussion quickly became informal, with participants adopting familiarised nicknames for each other (e.g. Tiff for Tiffany and waves for waves 88) and developing inside jokes, both related to the discussion and their shared experiences. For example, participants joked about the similarities their mothers shared in being critical about physical appearance, with Nikki and Gee saying that their mothers should “*hang out together*” (Nikki 3:06) because of how similar they were in not recognizing their daughters’ recovery needs. This kind of dark humour bonded participants over the difficult experiences they shared. The ease with which this rapport was developed was explained in part during a discussion about how the participants felt when they were able to talk to other people with ED lived experience. They described feelings of clear understanding and validation that demonstrated the strong shared connection between people on the ED recovery journey. For participants, the strength of this shared experience facilitated interaction in the OFG, as they felt they were among peers with whom they could freely share their lives without risk of being judged. In this way, the use of the OFG format with marginalised populations is also validated (Madritz, 2000).

5.1.3. Introduction of Themes

Analysis of the OFG data resulted in the development of four major themes (Appendix P).

- The first theme, *recovery is a journey* encapsulated the active, ongoing, and nonlinear nature of recovery. It was made up of three sub-themes: *recovery is purposeful*, *recovery is skilful*, and *recovery is a goal*.
- The second theme, *recovery requires the resolution of inner struggles*, addressed the necessity of addressing emotional and psychological issues as well as weight

restoration during the course of treatment. This theme raised the inherent tension in ED treatment- namely, that EDs are a psychological disorder with very physical repercussions.

- The third theme, *individuals develop a keen understanding of their interpersonal needs*, addressed the opposite poles of independence and isolation that developed during both treatment and recovery.
- The final theme, *treatment impacts recovery*, described the deceptively direct effect of treatment on recovery; however, this effect was complex with both positive and negative poles and significant grey area between. There were two sub-themes associated with this final theme: the *importance of therapeutic relationships* and *treatment specificity makes for more (or less) successful outcomes*.

5.2. Recovery is a Journey

Participants constructed recovery as a journey, both outright and subtly, through their discussion. They understood recovery to be an ongoing and non-linear process, which, like many journeys, had detours. The nature of journeys is also to be confusing and to include periods of being or feeling lost, confused, or overwhelmed. This meant that while participants often desired a specific timeline for their recovery, they felt they had to accept that it could not be planned. This understanding of recovery was best described by Hope,

Hope 2:16 PM *Recovery is like a coil...you feel like you are going around in circles, but each time you come around you reach a new level of coping. Eating disorder recovery is about making a choice to lean into life courageously, despite feeling yucky in your skin and a whole range of other difficult emotions. About using the meal plan as the anchor and holding on tight so that your brain is nourished and fit to process the underlying issues.*

Hope's metaphor of a coil for the recovery journey is apt, because it described both the circuitous nature of recovery but also illustrated its upward movement, as the person passes through levels of coping. Here, recovery was an active process that involved the application

of skills and strategies learned in treatment, such as regularly using a meal plan or positive affirmations. The recovery process was described by Hope as regularly involving choices. The coding around the choice was subtle though the distinction is less subtle in the rest of the OFG. Here, Hope described choosing to “*lean into life courageously, despite feeling yucky in your skin and a whole range of other difficult emotions.*” The choice, for her was between living her life courageously and returning to the means she previously used to cope with uncomfortable bodily sensations and emotions, namely, the ED. With this understanding, the choice becomes quite stark because is framed as a choice between life and death.

Hope’s quote also clearly demonstrated the three sub-themes related to this theme. Hope’s descriptions of actively choosing recovery by using skills and techniques as “*anchors*” demonstrated the active nature of recovery. The use of these skills and techniques also showed the practiced nature of recovery. Finally, the goal of living life courageously was one that Hope had chosen for herself, this not being a universal tenet of ED treatment. Hope’s stated desire to live her life as such demonstrated that the goals sought during the recovery journey need not be tangible but could also be self-actualising goals.

5.2.1. Recovery is Purposeful

This sub-theme developed from discussion about the definition of recovery and how it changed during the course the treatment and recovery journey. Participants repeatedly framed recovery as an action that they engaged in, as opposed to something that happened to them. In the discussion, recovery was spoken about as something that was worked towards and gained through purposeful effort. This effort could extend to choices made regarding the active applications of skills or the mental processes used to remain recovery focused.

waves 88 2:19 PM I think eating disorder recovery means you trying your best every single time you hit that Y-Choice point. It's you, every single day, having to choose recovery. Sure, there will be ups and downs. Many lapses, but that's all part of recovery. You learn from those times, reflect, and you can try to better use the skills learnt in therapy to help you get pass [sic] a similar situation in the future. It's not a

linear path or process...It's about having to keep telling yourself, literally every single day, 'I can do this. People love me for who I am, not how I look.' It's about trying to remind yourself all the reasons why you chose recovery in the first place. Why you should keep going, what your future goals are.

Here, waves 88 demonstrated how choice making was not just life or death, as described by Hope. It was also constantly purposeful and thoughtful. For some participants, this purposeful effort was felt as if it was supported by a treatment team, who were described as being “*integral*” to recovery (waves 88, 3:05). For others, friends and family were able to provide some support, however, there was a prevailing sense that the recovery choice had to be made alone. Some participants described this as a choice they had to make, in the sense that they had to be the ones who chose treatment and recovery for themselves instead of being forced into it. For others, making the choice of recovery was isolating, such that one participant described recovery as, being “*largely on my own and something I work for every single day*” (Tiffany, 3:03). The perspective that the active work of recovery would be a facet of everyday life was repeated by many participants, whose experiences ranged from physical and mental exhaustion (waves 88, 2:34) to acceptance and peace (Zoe, 2:29).

Another notable aspect of this sub-theme was the characterisation of the daily recovery choice that participants made. Participants often framed the recovery choice as being an either/or, black and white decision. They used different terminology for this decision, including “*participating in life rather than opting out*” (Hope, 3:34) or “*me versus eating disorder*” (Nikki, 2:45). The subtle coding of this choice pitted the participant and the life they wanted to live against the ED and the consequences of it, death included. This black and white coding did not extend to lapses, which were an expected part of the recovery journey. Indeed, lapses were seen as a learning opportunity as long as one eventually turned back to the “*right path*” (waves 88, 2:39).

5.2.2. Recovery is Skilful

This sub-theme was also most relevant during discussion about the definition of recovery and how it had changed. Participants characterised recovery as a skilful endeavour, which required therapy and self-reflection for the development of abilities that were actively used against the ED. The skills discussed fell into two categories: those unique to ED treatment and those related to emotional development.

Participants referred to a number of ED specific skills developed during their recovery journey. Given the tendency of EDs to impact people's relationship with food and eating, participants referred to the skills that changed this relationship in positive terms:

Nikki 4:07 At 28 I was learning how to cook, how to grocery shop, how to manage leftovers, how to eat out, how to plan for meals. All life skills stuff I had zero idea how to do. It was epically helpful and one of the main reasons I am where I am today because I came home and knew how to take care of myself.

For other participants, this skill extended to the more granular levels, including learning to “[eat] intuitively” (Hope, 2:24) and to “enjoy food again” (Tiffany, 2:18). For these participants, the development of these specific skills also came with emotional consequences, as they to learned to accept and cope with the previously uncomfortable or intolerable emotions and the bodily sensations that came with eating and enjoying food. So, while eating and food skills assisted recovery in the long run, their use involved further psychological and emotional development.

Participants described the psychological and emotional skills developed during recovery as being a means of handling emotions that had previously been difficult or intolerable. Participants saw these skills as allowing them “to feel the feelings and work through them rather than avoid or squash or stuff them down” (Ruby, 3:44). When incorporated with the theoretical construct of EDs as a means of avoiding complex emotions, this is an especially powerful tool. Participants also discussed being more emotionally present and engaged. This contrasted with their life with an ED, which was characterised by

emotional disengagement and using food-based coping mechanisms to manage difficult emotions. Gee (3:38) described feeling happiness and other emotions more fully in recovery than when she had AN; in this way, recovery served as a means of discovering new depths of emotion, which may have previously felt dangerous. Other ways were becoming “*less judgemental, kinder and empathetic*” (Gee, 3:32) and being “*strong, resilient, and loving of myself*” (waves 88, 3:33). Participants described needing to learn these skills during their recovery journey so that they could then use them to maintain recovery.

5.2.3. Recovery is a Goal

While participants characterised recovery as continuous and ongoing, they also used goal posts to segment the process and to make it attainable. Considering the overwhelming nature of the ED, which was at times described in terms such as being “*in the depths of your eating disorder*” (Gee, 3:35) or as being “*in a very dark place*” (waves 88, 2:39), this technique was an effective way to gradually progress through the recovery journey. For some these goal posts were practical in nature, for example, to “*no longer engage in LOTS of negative behaviours and [be] medically stable*” (Gee, 2:27). However, in Gee’s case, the overwhelming nature of the ED meant that these were the only goals that seemed achievable and that, she did not feel that “*being fully 'recovered' is possible for me*” (Gee, 2:27). Gee’s sense of recovery remained at symptom management with the possibility of change following further treatment and growth, illustrating the self-defining and ongoing nature of recovery.

For other participants, practical goals were focused around careers and extracurricular activities. As Nikki explained, it was important for her “*have a life outside my eating disorder. I worked towards getting a job I really wanted, was fortunate enough to get it so had a focus in my life that was more than just recovery*” (Nikki, 3:14). Waves 88 also used a future career as a goal post, explaining that her desire to become a clinical psychologist was underpinned by a desire to “*be recovered so I can use my experience to help others*” (waves

88, 3:34). She also noted elsewhere that she began to draw on extracurricular activities for purpose, where previously they had been a means of acting on her ED (waves 88, 2:19). The use of career and extracurricular goals provided participants with a renewed focus and purpose in their recovery. This focus was a positive outcome because it allowed them to channel some of their energy into previously neglected aspects of their lives and to develop a flourishing identity without an ED.

Participants also spoke of more abstract goals relating to psychological wellbeing and development. Participants often referenced freedom goals, which, taking into consideration the overpowering nature of the ED discussed above, are particularly poignant. These goals sought freedom from the restraints the ED imposed on the participants' lives. There was a sense of frustration and exhaustion with the ongoing nature of recovery, which was frequently characterised as a struggle or battle. Ruby (2:20) explained this desire clearly, *“I define eating disorder recovery as a process to become free from the hold of eating disordered thoughts, behaviours, habits, rituals and activities. It’s like freedom from shackles of isolation, self-harm, body loathing and shame.”*

Alternatively, recovery was also seen as an identity that was both desirable and attainable with work. Compared with the previous goal of freedom, which was framed in terms of exhaustion and struggle, this goal was coded in hopeful, aspirational terminology. For example, Ruby described the recovery journey as having *“an 'end'...to the real active aspect of having an eating disorder. I often say I'm 'recoverED' [sic]”* (Ruby, 2:28). In this way she claimed both the recovery identity and puts a definite end to her time with an ED and in recovery. Nikki used similar language to identify herself with the culmination of her recovery journey when she said the motivation for her recovery was *“[t]he idea that 'recovered' could be something I could one day call myself”* (Nikki, 3:14). The use of aspirational language by both participants demonstrated that the ‘recovered’ identity was

simultaneously incredibly desirable and achievable. This was taken in comparison to the all-encompassing ED identity that participants were in the process of deconstructing and shedding; an identity of ‘recovered,’ which was the polar opposite of an ED diagnosis, was an incredibly coveted goal.

5.3. Recovery Requires Resolution of Inner Struggles

This theme developed during discussion on the definition of recovery. The participants understood recovery to be an internal process that involved the resolution of underlying psychological and emotional difficulties. The internal nature of this process felt self-explanatory to participants but was, at times, misunderstood by peers, family, and allied health professionals. Tiffany explained this misunderstanding and also highlighted the important difference between physical and psychological recovery in the following quotes:

***Tiffany 2:56 PM** Despite looking healthy on the outside, this doesn’t mean that your mind is and this is what so many people are not aware of*

***Tiffany 2:57 PM** I got told by doctors that I was a healthy weight so I didn’t have disordered eating or an eating disorder – even when trying to explain how my mind worked and how painful it was.*

The difference between physical and psychological/emotional recovery was touched on by a number of participants. Some participants’ early definitions of recovery were heavily influenced by physical indicators of recovery, such as “*putting on weight to be physically healthy*” (waves 88, 2:49). However, while this understanding was in line with the goals of treatment teams, it also created a sense of “*hopelessness because I couldn’t imagine myself tolerating the meal plan, the sensation of food in my stomach, the weight gain and then what it was masking*” (Hope, 2:38).

Participants described experiences of being misunderstood by allied health professionals, peers, and family members as it related to their understanding of recovery. These experiences were often centred around physical appearance and weight, with participants repeating the sentiment that weight restoration did not equate with overall

recovery. They emphasised the danger of focusing on physical symptoms over psychological and emotional ones:

Hope 4:16 *It's about how desperately sad, alone, scared, frightened, angry, you feel and how you can't let it out any other way. About how difficult it is to feel all these things, how you will burst if you don't use the ED.*

Emotions, and loneliness in particular, were described in strong, moving language, giving clarity to the deep pain the participants felt. When they felt misunderstood in this fashion, participants found themselves at a difficult point in their recovery. Faced with professionals who focused on physical symptoms at the cost of psychological and emotional ones, participants were forced to choose between professionals who invalidated their experience and the ED, which provided the means of avoiding the uncomfortable emotions. Given this, “[going] right back into negative behaviours because the main issue hasn’t been dealt with” (Gee, 4:16) was understandable and may provide some context for high relapse rates among this population.

The nature of this internal struggle varied among participants and across the recovery journey. Most participants spoke of needing to resolve the difficult and confronting emotions that they felt was at the core of the ED. Participants described “[using] food, or more specifically, the control over food as a coping strategy for anxiety and childhood trauma” (Gee, 4:16) and explained how behaviours like “the violent action of vomiting neutralised the emotion in the short term” (Hope 3:44). Recovery was a means of addressing these emotions, and, as Ruby (3:29) explained, learning to feel feelings, despite the discomfort of that learning process.

Participants also described the silencing nature of the ED and, in turn, what they gained in recovery. Hope (3:29) explained that “the ED silences you,” upon which Gee (4:16) expanded, saying specifically that “[food] became my voice when I didn't know how to express my emotions and feelings of being overwhelmed.” The participants’ voices, which

they used to advocate for themselves and to story their own experience, were tied closely to their identity. They described their recovery journey as being “*a process of finding my voice and sense of self*” (Hope, 3:02) and a process of “[*finding*] my voice and [*writing*] my own life story without trying to meet others' expectations” (Ruby, 3:38).

Recovery, as described by the participants, also involved realignment of this new identity and self with chosen values and faith. Participants described acting out of line with their values and faith during their ED and feeling cognitive dissonance as a result of this. Hope (3:19) discussed the role her Christian faith played in her recovery a number of times during the OFG and explained that “*when I started living in a way that reflected my values and faith, I felt like the me I wanted to be*” (Hope 3:19). While other participants did not endorse strong religious convictions, they did discuss the impact that spiritual practices, such as a regular yoga practice had on their recovery. Waves 88 (3:23) explained that the meditative quality of yoga encouraged her to begin facing her own thoughts, which she felt was a difficult process to undertake.

5.3.1. Individuals Develop a Keen Understanding of Their Interpersonal Needs

This theme was raised during discussion on the impact that family and friends had on recovery as well as during the discussion around the definition of recovery. This theme was characterised by the constant tension between independence and isolation in relationships that developed during and after ED recovery. Participants discussed negotiating the desire to assert their own voice and identity in their close relationships with the possibility of being isolated from family and friends. Participants saw this isolation as being a result of both the ED and recovery. Participants discussed developing a new sense of their personal boundaries during the course of their recovery. The use of boundaries was also demonstrative of the purposeful nature of recovery.

The independence pole of recovery was often framed by participants in a manner that signified the purposeful nature of recovery and a desire “*to take charge of my own recovery*” because family support was “*making everything worse*” (Gee, 3:02). This process was also described in self-discovery terms, as exemplified by Hope (3:02), “*I had to find 'me' as cliché as that sounds, because I put too much emphasis on what family and friends thought about me, did to me, or whether I felt loved.*” These participants spoke of making a concerted effort to develop their independence, demonstrating the purposeful nature of recovery. Of particular note, was the clear insight participants had into their family and interpersonal dynamics and how these influenced their recovery. They spoke knowledgeably about the complex dynamics within their families and the interactions that they encountered with their friends and whilst in treatment. This was best illustrated in a comment from Nikki:

I think my mother is hurt and doesn't fully understand why I don't communicate with her - but I think she is in denial about the fact she has her own food and body image issues. She believes the way she is, is 'normal' and 'the right way to be'. Unfortunately, I can be my best self when I'm not around her, so I had to choose between my full expression or my relationship with her...I chose me. That looks a bit harsh written down, but it's the truth. (3:05)

Their insight into the impact that these dynamics and interactions had on their recovery was carefully considered, in that they were aware of the need to maintain their identity and sense of self but also demonstrated compassion and empathy towards others.

However, some participants were, at times, isolated by their recovery. Several participants spoke of recovery as being carried out alone by their own choice and spoke about how this decision to isolate themselves whilst in recovery was made to protect their recovery. Participants described needing to make decisions between their family and their recovery, and, with their new-found senses of self, described a willingness “*to lose relationships to remain recovered*” (Ruby, 3:02). By making this choice to protect their recovery by imposing boundaries with family members, participants created communities of choice. One participant

felt she could be described “*as independent when in reality I’m extremely dependent. Just not on my family. I use my friends and treatment team as supports*” (Gee, 3:05). While some participants’ families were described as “*largely unhelpful*” (Ruby, 3:01) or “*not conducive to healthy eating*” (Zoe, 3:02), the overall consensus seemed to be that when family and friends provided unconditional love and “*didn’t need to have the answers*” (Gee, 3:09), they could assist recovery significantly.

The isolation was also felt in a negative context. For some, the loss of important relationships with family or friends was a reason to mourn and, eventually, to accept changes in the family dynamic. As Gee (3:05) explained, “*[i]t’s sad, but it’s what I needed to do in order to recover. I’ve had to grieve in therapy that my family will never be what I wanted them to be.*” Comparatively, other participants had friends who misunderstood recovery and who attempted to impose their notions of recovery caused rifts in friendships, driving participants into isolation. Waves 88 recounted how a friend’s threats to report her recovery-focused exercise isolated her and ultimately also contributed to relapse,

...in a way that held me back... Because I was finally enjoying myself and exercising for the right reasons, but it just seemed that my efforts weren’t recognised. And it made me angry, and as a result, many a time I fell back into old habit. (3:08)

This was illustrative of the harmful effects that isolation in particular had for people with EDs because the symptomatology of the disorder often included isolation and obsessive features, so the aspects of people’s relational lives that influenced these features would be expected to be detrimental. That these participants spoke of managing isolation was notable, as was their awareness of the reciprocal impact that their ED has on their friendships. Gee noted, with some regret, that she had kept her friends at a distance initially and that their support had been unwavering both during her recovery and relapses. While the distance had initially protected her recovery, she also noted how isolating herself impacted her recovery and her friendships, “*[i]t’s hard because my eating disorder thrives on isolation so when I am unwell*

I often push everyone away which I can see is difficult on my friends” (Gee, 3:03). In this way, isolation, which was seen as a protection mechanism, also served the purposes of the ED and could lead to relapse, while also causing ruptures in supportive friendships.

In the context of balancing independence with isolation, participants spoke of needing to develop clear boundaries in their relationships. Again, this was an example of the purposeful nature of recovery, whereby these boundaries were consciously considered to maximise their chance at recovery. Notable examples of this were when waves 88 (4:16) pointed out that it was necessary to be aware of when friendships developed during inpatient stays as they might “*[start] slowing you down and triggering you....because your EDs get so competitive.*” For the friends met during inpatient treatment, participants expressed both compassion and an acute awareness of the impact these relationships could have on their own recovery. As Ruby explained, people’s reaction to her ED influenced how strict her boundaries were with them,

I know that might seem a contradiction to what I said that some close people don't get to know when I'm struggling yet I will write or speak about my recovery journey publicly...I find strangers or those who are more 'distant' friends and co-workers are more empathetic than close family or friends. (3:15)

Again, this was demonstrative of the communities of choice that participants spoke about throughout this theme. The decision around boundaries and communities of choice were developed using personal experience. Previous negative interpersonal experiences, either with family or friends, influenced the desire for stricter boundaries and more distant communities of choice.

Where participants felt they were able to relieve the tension between independence and isolation was in meaningful contact with people who had lived experience of ED recovery. In all cases, participants endorsed this sort of contact as being both crucial and, for some, life changing, to their recovery. Participants spoke of feeling like they were not “*alone*

and crazy” (waves 88, 3:48) when they spoke to people with lived experience of ED recovery because they understood very specific details, such as “*the feeling of a purge*” (Ruby, 3:47). Participants described the benefits of speaking to others with lived experience of recovery in overwhelmingly positive terms and as including feeling validated, affirmed, hopeful, and more self-compassionate. For participants, the isolation they felt was relieved when they were able to talk freely with others with whom they felt a strong connection. This was evident in the group’s overall dynamic and the quick rapport built between participants, who were all unknown to one another prior to the OFG. The need for independence was relieved, likewise, by the community being one of choice and one made up of like-minded individuals, all with similar goals. This community was different from friendships and family groups, where participants felt they had to maintain boundaries or risk being misunderstood. Among a community of peers, participants spoke of feeling extremely positive about their recovery and the future but were also able to frankly express worries and concerns.

5.4. Treatment Impacts Recovery

This theme covered the seemingly straightforward relationship of treatment impacting recovery. However, this effect was complex and was understood as having positive and negative poles with grey area between. In questions related to this theme, participants were incredibly reflective on their experience with treatment. They demonstrated repeatedly that choices around treatment were purposeful and made considering all the options available to them. Their reflections were indicative, again, of the purposeful nature of recovery. They also indicated that participants actively engaged in recovery and reflected on the effectiveness of elements of their treatment. These were not passive recipients who were healed or cured by medical professionals.

5.4.1. Importance of Therapeutic Relationships

It is important to first acknowledge that when this research references therapeutic relationships, it is referring to all interactions with allied health professionals, from psychologists to GPs to nurses. This is pertinent because the care for EDs is multi-modal, so participants saw numerous professionals during their recovery journey, all with varying knowledge and skill levels. For participants in this study, it was the knowledge and skills that were particularly important in the development of a sustainable therapeutic relationship.

A number of participants shared the experience of attending multiple allied health professionals and not being understood or validated because the professionals lacked ED experience. Tiffany (4:12) explained that she saw *“multiple psychologists and didn't get anywhere, it was only when I started seeing a dietitian trained specifically in EDs that he helped to start seeing things differently.”* The change in attitude and perceptions that was described by Tiffany was echoed by other participants, who described finding allied health professionals who understood their disorder and experience as *“so liberating because I could finally be free and just be completely HONEST with her”* (wave 4:33). For Gee (4:02), receiving validating support from an allied health professional, *“made me realise that I was deserving of recovery,”* which was a turning point in her journey. For these participants, the repeated lack of knowledgeable therapeutic relationships created a sense of isolation and uneasiness around treatment that was alleviated when they engaged with professionals who understood EDs and validated the participants' individual experience.

During conversation about what constituted a supportive professional, participants revealed that they had a keen sense of when a professional was genuine and skilled. This sense was developed during their recovery journey and was again indicative of the purposeful nature of recovery because it allowed the participants to enact agency in their treatment. They were not passive recipients because they held very well-informed opinions about their practitioners that shaped how they interacted with treatment. Participants explained that it

was important to see professionals who had actively pursued specialist ED training and that they “*can tell who is and who isn’t*” (Hope, 4:12) experienced because “*[the] real ones know it’s not about the food*” (Hope, 4:13). This implied that professionals who focused solely on weight gain and food routines risked alienating their clients. Hope (4:25) further noted that if a practitioner “*isn’t genuine, you can’t connect*” and Gee (4:25) explained that she “*won’t engage at all with someone who is not validating.*” For these participants, a key requirement of treatment was being validated and when this was not present, they felt less emotionally connected to those providing treatment and so, less engaged. This finding offers some context for studies that show high relapse rates and poor engagement in treatment. Perhaps those delivering the treatment itself lacked the validation necessary to engage participants adequately.

Participants spoke highly of professionals who were genuine and validating. They explained that in doing so these professionals were helping to keep “*hope alive that recovery [was] possible, it [made] a difference*” (Ruby, 4:15) to the clients. Through the act of listening, professionals kept hope alive for their clients. This allowed them to move forward into recovery on their own instead of being propelled by others. Tiffany (4:25) explained the importance of validating professionals clearly, saying “*you feel listened to and that there is hope and you can slowly make steps into being you again.*” Validating professionals were seen as people who provided support to their clients through the therapeutic relationship. In this way they were a means of motivation and encouragement so that the client was always empowered to direct their own recovery. Waves 88 (4:27) described the role her psychologist played in her recovery as being someone who “*constantly reminds me of my own purpose and why I chose recovery in the first place.*” Waves 88 was empowered to do the therapeutic work with the support of her psychologist, who validated her experiences in recovery and illness.

The need for professionals to recognise issues that were specific to EDs was of particular importance to the members of the OFG. They noted that the therapeutic relationship was improved when the professionals understood that the ED was “*not just about losing weight or not eating*” and that “*it [was] way deeper than that*” (Tiffany, 4:15). In particular, they noted that they experienced intense emotions that they managed with ED behaviours; they felt that these intense emotions needed to be a central part of treatment, rather than the behaviours alone. The emotions were clearly described by Hope (4:16) who said, “*it’s about how desperately sad, alone, scared, frightened, angry, you feel and how you can’t let it out any other way.*” The loss of identity and voice was also raised as a central issue here and was mentioned in previous themes. For these participants, the ED behaviours were their voice when they “*didn’t know how to express my emotions*” (Gee, 4:16). They felt that if addressing this loss of identity and voice were a central aspect of treatment their overall recovery would be improved. As a point of comparison, other participants mentioned the shame associated with their ED, especially as it related to lapses and relapses. For participants, it was beneficial to have professionals like Ruby’s (4:25) health coach, who “*didn’t flinch*” when told of binge/purge episodes and helped understand the precipitating factors of the lapse. Again, the focus was not on the behaviours themselves but instead on the underlying issues and on how to relieve them. This approach empowered clients on their recovery journey.

The lack of a therapeutic relationship with professionals was related to isolation, invalidation, and misunderstanding. In particular, this was often spoken about in the context of the biomedical model of treatment, which prioritised physical symptoms over psychological ones. Participants spoke of their symptoms being minimised or misunderstood by medical professionals, especially when participants were being treated for BN. Zoe found this be problematic because was trying to be pro-active in her recovery but was limited by the

responses from professionals, “[like] until you were either over or underweight it wasn't a problem even though I wanted to prevent it becoming worse” (4:05). Treatment experiences of this kind were discouraging because they undermined the individual's understanding of the disorder. As Tiffany explained, being misunderstood by a treating professional was an incredibly disheartening experience and provided little motivation for re-engagement:

It takes so much inner strength to even admit you have a problem in the first place and then to speak to someone (who works in the area of health and wellbeing) tell you that you're not sick, and you don't have a problem??? (4:08)

The medical model was understood by participants to create a situation where they had to be “sick enough” (Nikki, 4:08) to be noticed for treatment. The prioritisation of physical symptoms at the expense of psychological symptoms as it was discussed by the participants in this OFG is notable in the context of poor treatment engagement and high relapse rates among people with EDs. Hope (2:55) spoke of feeling that professionals “*couldn't see how badly I was hurting*” when treatment was based on physical symptoms. Other participants described feeling less motivated to actively engage in treatment when they worked with professionals whose treatment focused on physical symptoms and invalidated the rest of the participants' ED experience. As aptly noted by Gee (4:27), “*Why would I tell someone about my behaviours if they act like they don't give a shit? I'll just pretend I'm doing the work in order to get discharged. Which is obviously super disordered and unhelpful.*”

The prevailing literature described treatment engagement and relapse as being largely related to changes in the client's weight and behaviours (Bodell & Mayer, 2010; Carter et al., 2012; Olmsted, MacDonald, McFarlane, Trottier, & Colton, 2015; Vall & Wade, 2015) but based on the data from this OFG, treatment needs to encompass the wider ED experience. The participants explained clearly that, while they were actively engaged in their treatment, they were also keen observers and consumers. When they felt that treatment was not

validating or respecting their experience, they were aware of their choices, namely, to return to the ED or to continue to engage in treatment that was invalidating.

5.4.2. Treatment Specificity Makes for More (or Less) Successful Outcomes

This sub-theme covered a unique conundrum for the participants in this OFG, that specialist services were perceived to be helpful and necessary for treatment, they were also found to be lacking in their availability and in their service provision. Participants found specialist psychological support to be particularly helpful for their recovery, especially when it incorporated lived experience.

The particular strength of psychological support was spoken of highly by participants. Specialist psychological support was characterised in extremely positive terms, with participants saying that working with a specialist felt like *“a light switch was turned on”* in their recovery (Ruby, 2:57), indicating that it was a turning point. Specialist psychologists were also described as being the *“only one who understands me”* (waves 88, 4:22) and, when paired with a GP, *“the most important people in maintaining my recovery”* (Gee 3:16). The participants’ trust of their specialist psychologists was understood in terms of the validation, clarification, and encouragement that they provided, as explained in previous themes. Where participants were clear that they had been let down by professionals in the past, they were equally clear on instances where their psychologists had provided them with the validation necessary for a strong therapeutic relationship. For participants in this OFG, it was evident that this manner of validation was often grounded in a strong theoretical and practical understanding of EDs. Hope (4:12) explained, when asked whether the specialists were knowledgeable enough to meet treatment needs, that professionals could only do so *“if they [allied health professionals] have experience treating it, and actively pursue professional development. You can tell who is and who isn’t.”* The keen acuity with which these

participants observed the skilfulness of their treating professionals was displayed here, as was the sense that professionals were held to a high standard by the participants.

Participants also spoke of the special importance of incorporating lived experience into their treatment. As discussed above, lived experience was an avenue for participants to connect with others along the recovery journey, during which they often felt misunderstood. As this related to treatment specifically, participants explained that lived experience could be incorporated into individual or group settings. In individual settings, participants spoke of their specialist psychologists and health coaches sharing their lived experience with EDs, if applicable, and this in turn “*gave me courage to embrace my body*” (Hope, 4:53) and to “*know there were other over 40 years olds who were also 'professionals' who struggled*” (Ruby, 4:29). The incorporation of lived experience into treatment was a means of building individual motivation to continue recovery, which was often difficult to maintain throughout the journey. In a group setting, participants spoke of wanting speakers brought to treatment facilities, because “*we don’t know how it [recovery] looks like, but those who can speak to us can tell us, motivate us, and tell us to not give up because it is so incredibly worth it at the end*” (waves, 4:45). The strength of connection with the shared lived experience is palpable. Harnessing it into treatment was considered extremely helpful by all participants.

Discussions contained within this sub-theme also highlighted the participants’ feelings about the failings of the health care system at the institutional and societal level. They spoke at length about the lack of specialist services available and how this influenced their recovery. They explained that it was “*extremely hard to find specialists who have specialised in ED*” (Tiffany 2:54) treatment. Waves 88 passionately noted that in less populous states, treatment options were limited,

Here in Western Australia, there is only ONE hospital that treats both the psychological and medical side of an eating disorder. AND IT’S PRIVATE. Which

means many can't afford it. There are also only 10 MISERABLE BEDS. The rest of the public system has no specialist ED beds available in the entire state. (4:07)

This sentiment was shared by Tiffany and Hope, who both recounted their experiences of the limited treatment options in Queensland and New South Wales, respectively. Even when the participants saw specialist services, some noted that not all these were equal in their knowledge of ED treatment. Gee (4:11) recounted an experience with a psychologist, which illustrated the importance of professionals seeking specialised training and supervision, “*I saw a psychologist for 2 years who had 'eating disorder experience' and just got worse and worse. I had to seriously hunt for my current one.*” Tiffany also noted that there were “*lots of psychologists say that they work with eating disorders, but it is very hard to find someone with specialised experience*” (4:11). To these participants, with their lived experience of treatment and recovery, ED specialists fell onto a spectrum ranging from those who had actively sought out specialised training and supervision to those who said they had but had not and finally to those who had no experience at all. Interactions with specialists varied in their effectiveness based on how much specialised training and experience with EDs the professional had.

Another failing at the institutional level, was when participants received treatment that did not meet their individual needs. In such cases, participants spoke of feeling alienated and invalidated, which decreased their willingness to engage in treatment. Examples included Hope's (4:02) experience while inpatient, during which she struggled to separate PTSD symptoms from ED symptoms and “*felt that many decisions around my care as an inpatient were about convenience for the treatment team.*” While a degree of individualisation is often lost while inpatient, Hope's experience illustrated that this could alienate those receiving treatment and contributed to a sense of betrayal, which could in turn contribute to treatment disengagement. Waves 88 (4:48) spoke of how repeated and overlapping re-admissions were

discouraging, explaining that it would be beneficial for “*psychiatrists to not just jump to ‘inpatient’ sometimes*” because “*sometimes we need that break to let us fall on our own, and use the skills we’ve learnt to pick ourselves up ON OUR OWN.*” For participants in the OFG it was important for treatment teams to understand their individual needs and to encourage and welcome individual participation in treatment decisions.

The final institutional failing that participants noted was the expense of treatment. As Hope (4:47) succinctly explained, “*You gotta have a person in your corner...those people are very expensive.*” This sentiment was echoed by Tiffany (4:06), who noted, “*If my parents hadn’t financially supported me I never would have explored therapy for my issues.*” The participants were clear about the particular difficulty that Medicare and private health funds played in treatment. According to guidelines imposed by the Australian government at the time of the study, only ten sessions with a psychologist were rebated under the Medicare Better Access to Mental Health Plan unless the person was eligible for a Chronic Disease Management Plan. In this case, the person was eligible for five Medicare rebated services with other allied health professionals like a dietician. However, many ED specialist services were in private hospitals that were not accessible to people without private insurance. The participants explained further that it was confusing to use private health funds due to variance in both the hospital and health fund guidelines. Hope (4:07) described how in New South Wales, a private hospital received maximum benefit from the health fund a certain number of weeks and then “*the benefit diminishes and you are not worth as much to the hospital. It’s better for them to turn over the bed and get someone in fresh so they can get more money.*” Participants felt this was disenfranchising and invalidating because their care was determined, not by their symptoms or recovery progress, but by the availability of their Medicare funding. Nikki (4:11) noted that this gave the impression that their “*recovery is ‘time limited’ and we all know that recovery doesn’t take weeks or months, it takes years of*

consistent support.” Years of recovery are expensive and these participants noted they could not always be sure of having financial support for their whole recovery.

At this societal level, participants spoke passionately about the difficulties presented in defining EDs. As discussed previously, many had experiences of physical symptoms being prioritised over psychological ones. Participants questioned “*why is help only determined on your physical state when eating disorders are a mental disorder*” (Gee, 4:48). They felt the over dependence on physical symptoms with intake criteria in treatment settings meant that patients who were suffering psychologically were excluded and made to wait until their condition deteriorated before they were able to access support. They noted that the over-dependence on physical criteria at the expense of psychological ones also affected their relapse, because overarching treatment and societal norms reflected the prevailing image of the emaciated patient with AN. As Gee (4:49) explained, she “*relapsed multiple times because I believed that I was only deserving of help when I reached a certain weight.*” Invalidating experiences reinforced the false idea that only the most ill were deserving of help, which supported existing ED thoughts around weight equating worth. Waves 88 provided a very clear explanation of how overarching treatment and societal norms played into her relapses,

For me, when I relapse, part of it is because I think to myself, I’m still struggling internally although I’m weight restored. Well then, might as well lose weight to match my mindset, so people won’t think I’m a phony because everyone just thinks EDs are about being thin!!!! WHICH IS COMPLETELY FALSE. (4:52)

These participants felt that more inclusive definitions were necessary in delineating who required treatment. From their perspective, the definition needed to include elements of the person’s overall psychological and emotional functioning as well as their physical symptoms.

5.5. Key Findings

This study found that recovery was purposeful in nature and that it was a daily effort, as opposed to a process that happened passively to a person. Recovery was also found to be an internal process, not simply the relief of symptoms. Boundaries and relationship management were also found to contribute to successful recovery, as the relationships themselves were found to impact recovery. Finally, experiences in treatment were found to impact recovery, the development of validating and supportive therapeutic relationships in the context being strongly endorsed as a means of supporting recovery. Overall, this is indicative of a more nuanced understanding of recovery, one which incorporates the individual experience while also acknowledging that individuals are not passive recipients of treatment.

5.5.1. Changes to Interview Schedule

Based on the themes developed in this study, a more concise research schedule (Appendix N) was developed for the second stage of the research. The schedule for the second study focused on the experience of recovery, first asking the participants to explain their recovery journey as a means of both orienting the researcher to their personal understanding of recovery and to gain access to information about their particular recovery experience. The second question asked for stand-out positive or negative experiences during recovery or treatment. This question focused more closely on specific experiences and how they impacted recovery. Finally, participants were asked how their life had changed since they had begun their recovery journey. This question accessed further experiential accounts but also gave the opportunity for participants to discuss interpersonal, behavioural, or value changes.

5.6. Chapter Summary

This chapter explained the results of the first study conducted as a part of this thesis. It discussed the overall demographics of the sample as well as the overall effectiveness as the

OFG as a tool for research with an ED population. The four main themes were introduced and explicated in depth.

Chapter 6

Results of Individual Interviews

6.1. Overall Results

6.1.1. Demographics

The interviews were conducted with thirteen female identifying participants whose ages ranged from 19 to 67 years at the time of interview. Their self-reported age at time of diagnosis ranged from 13 to 27 years ($M=20$, $SD=4.21$). As EDs tend to be diagnosed in younger women, this was in line with existing literature, where age of onset was reported to be between 10 and 20 years of age (Keski-Rahkonen et al., 2007; 2008; Preti et al., 2009) and with the online focus group (OFG) sample. As with the OFG sample, the length of time in recovery varied from six months to four years. The primary and secondary diagnoses identified by the interview sample were, as with the OFG sample, typical of the overall ED population, AN (8), BN (4), EDNOS (1), binge eating disorder (1). Other ED related diagnoses included body dysmorphia disorder (BDD; 1) and exercise addiction (1). A number of other psychiatric disorders were also represented, including anxiety disorders (9), depressive disorders (9), obsessive compulsive disorder (OCD; 2), and bipolar affective disorder (1). As with the OFG, these interview participants did not constitute a representative sample in terms of diagnostic distribution, but did nonetheless show key features of the ED population (Bühren et al., 2013; Jaite et al., 2013; Preti et al., 2009; Swanson et al., 2011).

The interview participants sought treatment from a variety of allied health professionals across different settings. As with the OFG sample, all thirteen participants reported having seen a psychologist at some point during their recovery. Following this, the most frequently endorsed allied health professionals were dietitians (10), GPs (10), psychiatrists (7), social workers (3) and non-professional sources such as online support groups (3) and spiritual leaders (1). Five participants reported receiving support from other

unspecified sources. In relation to treatment setting, ten interview participants reported receiving treatment in a private psychologist clinic. Many participants had experience with ED specialist services, including outpatient (8), inpatient (6), and day patient (1). Six of the interview participants reported receiving treatment at a general inpatient psychiatric ward.

6.1.2. Introduction of Themes.

Analysis of the interview data resulted in the development of three overarching themes, two of which had related subthemes (Appendix Q).

- The first theme, *that the eating disorder was a means of connecting with the self*, encapsulated the function and purpose of the eating disorder. It included two subthemes, *the eating disorder filled individualized needs in a way that ultimately had a resounding impact on identity* and *recovery was an identity reorganization process*.
- The second theme, *that the need for interpersonal connection or the lack thereof was experienced across the ED and recovery journey*, covered how social relationships influenced recovery.
- The final theme, *that perceptions of eating disorder treatment were focused on how needs beyond symptom remission were met by treating professionals encompassed perception and experiences of treatment*. Three subthemes were included, first *that in interactions with health professionals, definitions of the eating disorder and recovery relied heavily on a biomedical model*, second, *effective treatment addressed the whole person*, and third *ineffective treatment only addressed part of the person*.

6.2. The Eating Disorder was a Means of Connecting with the Self

This theme addressed the function of the eating disorder. While it was acknowledged that EDs could serve a myriad of functions, within this small data set it was found that overall

the ED contributed to a strong need for connection with the self. This connection with the self ultimately translated to the ED having an overall identity serving function. The ED was found to be intrinsically related to how the participants understood themselves and their body. This in turn impacted how identity was understood through recovery, with the recovery journey being one of identity discovery and re-discovery.

6.2.1. The Eating Disorder Filled Individualized Needs in a Way that Ultimately Had a Resounding Impact on Identity.

The ED was found to fill needs that initially may have seemed quite localised but that changed how participants thought about themselves. Participants constructed their experience of the ED as being both isolating and special to themselves. For some, the ED was carried out in secret, either away from family and friends (April 54:07; Alba 35:07) or for others, there were very few people who knew about their symptoms, so the sense of secrecy was intensified, as was the sense of isolation (Lilianna 35:35). April noted that hiding the ED had a negative effect, as *“eating disorders feed on secrecy and shame”* (54:07), while Alba explained that not being able to express the emotional turmoil related to ED meant that she *“started in a shame cycle that then it [sic] got to an unbearable kind of distressing level”* (8:49). Lilianna remarked that being isolated, both in terms of her friendships and by the ED itself meant that *“it was easy for [her] to keep continuing [her] disorder because [she] didn’t have anyone to think about, in a way, and none really kept [her] accountable”* (35:35). Alba also felt the negative effects of isolation, explaining that lack of contact with friends meant that there was no one to provide a *“reality check”* on her because the ED magnified fears that *“every tiny physical change is huge, so then there’s your fear of perception, of people seeing you”* (35:07). While Serena noted that she felt her ED as an experience unique to herself, she also felt this experience helped to define her identity because of that very fact. She explained,

I have an issue that no one knows about and this is who I am. It helped me to form...I know this wasn't a healthy way of thinking by any means, but it helped me find my place in the world (50:36).

Social isolation was a means of hiding symptoms and, in this social vacuum, it was possible for the ED to assert itself as a surrogate identity where this process would usually be facilitated by a person's social milieu.

For participants, the ED served a number of purposes. Understanding the purpose of their ED facilitated the participants' recovery journey because it helped them to detach from the ED and to find new ways of living without it. Broadly speaking, many participants found that their ED was a means of coping with complex and overwhelming emotions. Participants described these as being "*stressful situations or stressful emotions*" (April, 17:14), "*pent up emotions*" (Lilianna, 27:38), and "*tension and anxiety that was in my stomach*" (Serena, 29:12). The language around emotions being trapped inside was particularly notable, given that the ED overall was experienced as a private matter by this sample, it seemed that the emotions prompting the ED itself were also hidden away. For these participants, the ED was sometimes the only tool they had available for managing such emotions (April, 17:14; Lilianna, 27:38). Serena spoke at length about how BN helped her to manage her feelings, explaining that the act of purging was "*cleansing in a way*" (10:18) and that "*[it] softened the edges. It was this one thing that I could do to kind of just help me get rid of the way I was feeling*" (48:48). Other participants similarly felt that the ED provided comfort, with April saying that the dissociative qualities of the binge-purge cycle helped her to cope with an abusive relationship, because she could instead be "*consumed by thinking about food and my body all day instead of all the other things*" (24:45). The ED also provided comfort through the time-consuming nature of its symptoms, which took the place of hobbies, friendships, and extracurricular activities in both the time dedicated to them and the pleasure derived from

engaging in them. Primrose Lou described her relationship with her ED as being a constant companionship

At times, on days where I just, you know, day off school or work or whatever it was, some people want to go out with friends. Some people want to go take their dog for a walk, or a movie. I literally just got pleasure in body checking for hours, going to the supermarket and reading food labels, cooking for others, obsessing about food, measuring myself, watching documentaries and stuff on eating disorders, just every behaviour under the sun. (7:30)

The strength of the language in this excerpt and the ones above conveyed the necessity of the ED to these participants. It was a constant companion; it was all consuming. The emotional turmoil that was the alternative to these ED behaviours was distressing to the point of being unbearable. Based on the descriptions of these participants, the ED was one of the few means of coping available to them at the time.

The ED was also seen as a means of control as participants sought to manage their bodies and weight (April, 16:02; Primrose Lou, 20:09; Anya, 22:08). Because weight and body were closely tied to identity, by controlling these, identity and self were also tightly controlled. For April (16:02), this meant avoiding being like her mother, who April witnessed being teased by family members because of her weight. For Anya (22:08) it was a determination not to return to a previously undesirable weight that led to a backslide into eating disordered behaviours. For others, this control extended further. Lina described the need she felt for control as, “*Can I be at home for the next six months so that I can control everything? It’s so, yeah, you’re just anxious and living in the future and planning for it*” (15:16). In comparison to this anxiety driven control, Primrose Lou experienced the control of AN having a thrill-seeking element because “*I’m going against human nature. You’re not powerful [sic] to do that. I’m more powerful*” (6:32). By exerting control over their bodies and weight, participants were able to control elements of their lives that felt out of control and to feel a sense of mastery.

6.2.1.1. The Eating Disorder Influenced Identity Development. At times, the ED was felt to be very closely related to identity, such that it was an integral part of the self. At other times the ED was separate from the self. The contradictory nature of the ED identity is notable and suggested that the purpose of the ED varied between people and across time. The participants also noted that it was possible for the ED to influence identity development throughout the recovery journey.

6.2.1.1.1. Eating Disorder is Self. It was common for the ED to be identified as being an intrinsic part of the identity. Participants used emotive language to convey the image of being trapped by the ED. Clarissa's description of her internal experience demonstrated this most effectively:

I was like a shell. I didn't even feel like ... it was like I was still in there somewhere but it like was rather than me being in control of my mind it was like I was in the little locked off corner, and the eating disorder was just everywhere. (5:54)

Other participants used similar language to explain how they felt trapped or cornered by the ED thoughts, which limited their freedom (Ebony 2:43). Evangeline explained how any move to treat the ED was felt negatively because, "*I thought those thoughts were me and it was an attack on the eating disorder, aka me*" (22:48). In this way, the ED was experienced as a dominant part of the self. Indeed, Sophie noted that initially she wanted to try to have "*the image, I suppose to other people that I had it all together even though I obviously didn't, but internally I was still suffering enough to want to keep on punishing myself and pushing on with the eating disorder*" (1:45). As she explained, the ED infiltrated her sense of self and trapped her in a cycle of self-punishment and suffering. Though she was trying to present the positive image of herself to others, her internal experience was still dominated by the ED identity.

The ED was also used as a way to define the self. Some participants saw themselves as being born with the ED (Primrose Lou 5:21) and it was there their predominant and

sometimes sole defining feature, that of the skinny girl (Clarissa, 4:35; Serena, 49:52). This identity was contentious. Despite feeling driven to attempt to decrease weight significantly, participants also felt that they were simply not skinny enough to have an ED and either had to push themselves to be slimmer or denied the existence of the ED (Evangeline, 12:04). Again, the strength of the relationship between the ED and identity can be felt keenly in the language used to describe it. Primrose Lou spoke of the ED in terms that suggested predestination, explaining how she had vivid memories of hating the size of her body from a very young age, such that the ED itself felt innate (5:05). Serena explained that the ED helped her develop an identity in high school,

***Serena (49:48)** ...I was kind of an outlier in that I wasn't like a popular kid and I didn't have a real kind of strong group of friends, and also a place, I didn't feel like I had a place in high school, but within this eating disorder, I found a genre of music, you know that kind of helped ... Gave me comfort as well. And it helped me ... it was like a huge part of my identity*

***Capella (50:26)** Oh I see.*

***Serena (50:28)** It became who I was as a person.*

***Capella (50:30)** You're likening the eating disorder to a genre of music. It was a way of ... Like it was your thing.*

***Serena (50:36)** It was my thing. Yeah, and even though a lot of people didn't know about it. I didn't announce it or print it on a T-shirt or anything like that, but it gave me comfort. It gave me like an 'I am unique. I am an individual. I have this issue that no one knows about me and this is who I am.' It helped me form ... I know this wasn't a healthy way of thinking by any means, but it helped me find my place in the world.*

For these participants, ED identity, while conflicted, was also experienced as something that helped them understand their place in the world.

6.2.1.1.2. Persistent Self-identification as Being Outside the Norm. Participants in this study spoke about being different, unusual, and/or extraordinary. This feeling arose both before and during the ED and was linked to their experience of the ED itself. Anya spoke of herself as not being a “proper person” because she “*didn't feel ordinary touch and feelings like hunger*” (1:58). She also described herself as being like “*some alien from outer space*” (Anya, 1:58). Primrose Lou also had a depersonalizing experience of her ED, though she

described herself as being “*literally a black hole. Like I’m Satan. I would walk around being like I’m literally Satan’s little devil child*” (1:01:04). While Anya’s experience was of alienation, Primrose Lou’s related to the sense of invincibility that she drew from her ED. For her the ED created an identity where she was able to ignore the human need for food and to feel as if she could defy death. Anya’s experience, meanwhile, created a numbing effect and could be an example of the alexithymia that is a symptom of AN (Amianto, Bertorello, Migliore, Abbate-Daga, & Fassino, 2016; Nowakowski, McFarlane, & Cassin, 2013).

Primrose Lou spoke frequently about how she identified as being special or different, both in general and because of the ED. She explained that, even in comparison to others with EDs, she was different because she felt that she “*was destined to suffer this disorder*” (46:01) and that among those with ED symptoms, her expression of these symptoms was more extreme (2:20). For Primrose Lou, the ED alone did not set her apart, instead she saw herself as quite uniquely different, and that extended to how she experienced her ED, to the point of extremity. As noted above, she described herself as a “*black hole*” and “*Satan’s little devil child*” (1:01:04). Primrose Lou noted how her symptoms were more extreme when describing herself in relation to others with EDs. When describing her belief that people with EDs tended to be “*intelligent, manipulative, [and] extremely sneaky,*” Primrose Lou described herself as a “*freak of nature*” who had “*always been known to bargain, to negotiate, to manipulate in that sense to the highest of degrees*” (2:20). During her story of her first admission, Primrose Lou highlighted how she began her ED journey as overweight at age 13 and within a year had “*I lost 50% of my body weight. And the day after my 15th birthday, I was admitted to the ICU [intensive care unit] under cardiac arrest*” (21:02). For Primrose Lou, the ED was a means of feeling powerful and invincible, which was clearly expressed in how her ED experience was set above and apart from that of ED peers. Other participants explained that they felt their difference in how their non- ED peers experienced

them. Both Sophie and Serena discussed how peers without EDs might experience them as scary if they knew too much about the ED (Sophie, 29:04; Serena, 32:48). Here, the self was experienced through other's perception of the self as being scary because the ED could be confusing or overwhelming. For Sophie and Serena, this perpetuated a consistent sense of unease with others around emotional intimacy.

6.2.1.1.3. Eating Disorder is Other. Participants also identified the ED as being inherently separate from their identity. Evidence here was primarily linguistic in nature, with the ED being spoken about in metaphors and more subtly. Nathalie separated herself from the ED by explaining that it was like an exploitive and unwanted guest that *"I shouldn't host, needn't host"* (6:00). By comparison, Wendy used the metaphor of falling down a rabbit hole to repeatedly describe the experience of being *"sucked in by the ED,"* which created a sensation of losing her true self (4:19; 13:02). For both Nathalie and Wendy, the ED was something that overwhelmed them and while they were, in a sense, overtaken by it, they remained separate from it. Wendy explained that though she was deep in the ED rabbit hole, *"there was a little part of me that knew I needed help. I knew I needed help, but I didn't know how to begin, because I was so far down that rabbit hole"* (5:30). Much like Alice falling down the rabbit hole into Wonderland, she retained her central sense of self, while the confusing events of the ED unfolded around her.

Participants used language in subtle ways to maintain a separate identity from the ED. Sophie frequently spoke of the ED both as an entity that was acting on her by dictating her self-impression as a selfish person (11:46) and also as something that she acted in concert with when she was particularly ill (26:58). In this latter instance, Sophie referred to herself and the ED together, saying *"It can get bad enough that we're really, really bad, and we need to get in [inpatient], but let's not get so bad that they're going to admit us involuntarily"* (26:58), highlighting how the ED became so separate that it almost took on the role of co-

conspirator. Here the conflictual nature of the ED selves is evident. While Sophie felt negatively about her self-concept being defined by the ED as selfish she also acknowledged that at times her needs had corresponded with the EDs. This created a sense of ambivalence and confusion about the role the ED played in identity development.

6.2.1.1.4. Identity was Intrinsically Linked to Experiences of the Body. The physical nature of EDs meant that the sense of self was also experienced through body and weight. For some participants, there was a sense that the body was in some way wrong and that this wrongness extended to the self. Participants felt that their bodies needed to fit specific criteria in order to qualify for an ED diagnosis. Nathalie noted that this impression came from the material for treatment services, where the images were of *“pretty thin blonde girls with worried mothers with polo necks. It’s all terribly middle class”* (16:12). At the time that she was seeking treatment, Nathalie was an early middle-aged woman with BN, and so did not feel that the treatment was suitable for her because her body was quite literally not represented (Nathalie, 1:05:26). Primrose Lou also spoke about the myth of not being sick enough for treatment, noting that *“just me personally, no matter what I did, I never had the disease. I was never sick enough”* (29:47). For Primrose Lou, this myth took on a different meaning because at times, she was extremely physically sick but due to the severity of the body dysmorphia and trauma she had experienced during the course of her treatment, she struggled to recognize herself as being sick enough. These participants defined their illness and their willingness to access treatment by their bodily experience. Their bodies were their means of understanding their place in the world, where they were welcome, where they belonged, where they fit in.

6.2.2. Recovery was an Identity Re-Organisation Process

Recovery was also understood to be active, identity driven work. Participants spoke of developing a new conceptualisation of themselves through the recovery process. Clarissa

spoke of the process in revelatory terms, explaining that she thought she “*was so sure that [she] was just going to have it [the ED] forever*” (30:47) and that because of the physical presentation of her disorder (e.g. very thin, amenorrhea) she “*didn’t feel womanly*” (46:23).

As she moved through recovery and was validated by professionals, she explained that recovery “*gave me myself back*” (Clarissa, 5:38). Ebony spoke of reclaiming elements of her bubbly personality that were suppressed during her ED (29:52). In reclaiming these elements of herself, Ebony was surprised at how much she had missed laughing and was happy to explore new hobbies and friendships that she would not have explored previously.

Meanwhile, Lilianna’s experiences while in IP treatment were also revelatory. She noted, after spending some days with other patients,

...I remembered sitting there thinking, like, ‘I don’t want to live the rest of my life like that.’ And seeing other girls either pick apart their food or look at their sandwich like it’s the most horrendous thing ... I know they’re not doing it on purpose but for the first time, I could see what it looked like. I never did before because I didn’t see myself. It was like I ... yeah. And I looked at that and I was like, ‘Wow. Is that what it really looks like to other people who saw me?’ And when conversations were nothing but talking about food, I was like, ‘Wow, this is really boring.’ (51:04)

Lilianna’s experience changed her perception of herself enough so that she felt compelled to leave her ED identity behind. Her revelation suggested a degree of amazement and embarrassment, as if she had not previously considered how she might appear to the outside world. The egosyntonic nature of EDs, which makes the goals of the ED feel acceptable to the ego, also make it difficult for people with the ED to consider alternative points of view to those related to the ED. This may explain why some participants perceived parts of their recovery as revelatory. Perhaps, as treatment acted on the egosyntonic elements of the ED, participants were able to consider outside perspectives more effectively.

The identity re-organising nature of recovery involved the literal reclamation of a self that had previously been subsumed by the ED. Participants spoke of this process using heavily metaphorical language. Clarissa, for example, explained that she slowly came to

understand that she could hold a variety of different identities, saying *“I’m going to be an osteopath and I am really smart and I’ve got all these other things going for me and I don’t have to be just a skinny person”* (4:35). Ebony and Wendy both used metaphors that personified the ED in some way, with Ebony (1:07) making the ED into a voice that was in control and Wendy (14:08) making the ED into a force that shielded her from experiencing all aspects of life and pushed people away. Nathalie (6:00) personified the ED into an unwanted houseguest that she had no way of asking to leave. The strong images these personifications present suggested how difficult it would have been to extricate the self from the ED, so all-encompassing and unwanted was the experience of it. Even so, participants spoke of feeling like the ED would always be a part of their personality (Sophie, 27:44) and that their ability to cope with it had improved (Clarissa, 54:32; Serena, 17:50). Thus, while major ED symptomology was no longer present, the matter of how participants incorporated the ED into their identity in the long term still remains to be explored.

6.2.2.1. Recovery was a Personal Journey. Just as the ED ultimately had an identity serving function, it was found that participants considered recovery to be profound process of reclaiming and/or rebuilding their identity. Participants spoke of recovery in terms of a journey that involved a concerted choice and a personal timeline with perseverance through adversity. The choice to commit to recovery was made for personal reasons. Participants spoke of reaching a crossroads, where they began to realize the negative effects of the ED on their life and then made the choice to explore recovery. For Wendy (00:48), this point came when she was in a destructive relationship and was trying to manage her ED as well. For Clarissa (3:11) it came when she was overseas and realized that she was not able to enjoy her travels because she was so focused on the ED. Lina recalled using a logical argument when she reached her crossroad,

Because I remember thinking, 'Oh, yeah, I can be happy, and be at this weight,' or whatever, and that was a huge lie, because being at that weight meant doing all of these other unhealthy things. So, inherently, it was unsustainable, just because it was too far along the negative unhealthy spectrum, is how I think of it. Yeah, so just saying that to myself, that it will never lead to well-being, and you'll always be unhappy and miserable. It was like a way to logically convince myself that, I may as well try something else, kind of thing. (6:05)

Ebony was similarly methodical in her choice to commit to recovery, explaining that her recovery hinged on her transition from high school to university at age eighteen, because she “*wanted to be fully functioning in the next chapter of [her] life, going into young adulthood*” (00:14). It was interesting to note that both Lina and Ebony felt that they could not live full or complete lives with the ED. For these participants, at least, the ED was not so closely tied to the sense of self as to make the future wholly unimaginable without the ED. Alternatively, they wanted a more integrated sense of self and felt that the ED was no longer able to help them manage this. Nathalie felt emphatically that her recovery was “*entirely self-motivated [her] whole life*” (4:45). Alba, meanwhile, began recovery to appease her worried family but later found that she “*some part of me wanted it too, 'cause I was fed up with where I was at*” (00:12). For these participants, the ultimate success of recovery depended on their motivation to achieve it, which had to come from their own realizations that their ED was harmful and unsustainable.

The timeline for the recovery journey was variable and subject to constant changes. April (6:33) and Serena (17:50) spoke of the recovery journey being a nonlinear, everyday practice rather than a process with an endpoint. Sophie spoke of the nonlinear nature of recovery in ardent terms saying, “*It's a constant battle and a constant weighing up of decisions every day*” (5:57). In this way, recovery did not have an endpoint, rather, some participants described feeling like they would always have to manage aspects of the ED in their life (April, 6:56; Clarissa, 54:32; Serena, 11:30; Sophie, 5:57). These participants spoke of hoping to one day be free of their ED symptoms but also accepted that the reality of

recovery meant that this may not be the case. For these participants, recovery was seen as being a lifelong learning process, making it into an ongoing journey.

The recovery journey was described richly and in terms that demonstrated the difficulty and adversity that was experienced along it. Lina (27:48) and Sophie (5:57) both noted that there were repeated attempts at recovery. Participants observed that they continued with their recovery through acute periods of adversity (Serena, 6:18) and despite negative experiences along the way (Clarissa, 39:23). Primrose Lou clearly conveyed, both the chaos she felt during parts of her recovery (30:26-31:29) and the ways that she continuously and ferociously fought for her recovery (36:09). Primrose Lou understood recovery, not just as an ongoing journey, but a significant feat that she had yet to achieve (37:20). Though she readily acknowledged her own progress in terms of a reduction in AN symptoms, this progress was overshadowed by lingering body dysmorphia, which contributed to an overarching sense that she had never been sick in the first place (51:52). In this way, though Primrose Lou's life was unimaginable without elements of the ED, recovery was a continuous process of developing and working towards goals that would eventually disentangle the self from the ED (52:10). Recovery as a process was thus understood to be ongoing and to consist self-defined goals, whose overall timeline and outcome were subject to change.

6.3. The Need for Interpersonal Connection or the Lack Thereof was Experienced Across the ED and Recovery Journey

This theme related to how participants addressed the vital need for interpersonal connection during the ED and recovery from ED. It was found that, while participants often had significant supportive relationships, they also had reason to find this area of their lives lacking. In both cases, the nature of these relationships influenced overall recovery.

6.3.1. Relationships Could Hold a Person Back in the Eating Disorder

The experiences that participants had with interpersonal relationships influenced the person's progress through the ED and into recovery. Interpersonal relationships that lacked empathy, encouragement, or support had a restrictive effect on recovery. April explained that being in an abusive relationship limited her ability to "*process and deal with [her] eating disorder, which [she] was using as a coping mechanism*" (00:54). She noted that the relationship encouraged ED behaviours because her ex-partner made comments about her weight to the extent that she hid her symptoms and the abuse in her relationship from her therapist (April 19:40). In this way, non-supportive relationships could have a collusive effect with the ED. Lilianna observed a similar effect with her mother, who felt she was always trying to please with her achievements, including her weight loss, and when this did not yield the desired result, she found herself thinking "*'Oh that's not getting enough of attention.'* So, *I just kept going [with the weight loss]*" (38:37). For Alba, the lack of understanding from her family was felt so acutely that she was not comfortable addressing her recovery around them. She noted that she was "*so conscious of hurting them, but then wasn't able to just keep myself neatly together*" (Alba, 24:06). The lack of support from her immediate family added a layer of complexity to her recovery as she found herself needing to seek out supportive individuals outside of her family to assist with her recovery. Lack of connection in significant relationships could maintain the EDs hold on a person, as the lack of support or the desire for approval was acted out through ED behaviours.

Participants in this study explained that they went to great lengths in order to manage the difficulty presented by unsupportive family members. They spoke at length about the emotional boundaries they imposed between themselves and their family members, which were seen as necessary because they allowed the participants to navigate complex family dynamics while also coping with the emotional distress of an ED. For Alba, this presented significant difficulty because her family did not understand her ED. As a result of this lack of

understanding Alba felt she had to manage their discomfort with her distress and, as a result, *“would feel guilty and I would feel like, well that's even more the need that I just need to suck it up or, you know, let's not spill out everywhere here”* (28:48). While there was also a lack of understanding of her ED by her immediate family, Lina also identified her family's complicated dietary requirements as triggering her disorder because she would have preferred to *“have people who eat healthily around [her]”* (51:28). Lina felt that family meals were stressful because everyone's serving was different and there was no way for the family to emulate the healthy eating patterns that was meant to be learning during her recovery. As Lina was not able to depend on her family to assist during one of the more complex phases of treatment, she felt that establishing boundaries between herself and her family was logical as it allowed her to pursue recovery in her own way. Such boundaries allowed people like Lina to balance family relationships with recovery.

Boundaries were strictly managed and in a variety of creative ways because of the complexities in family relationships. A number of participants explained that they maintained distance from family members as an act of self-preservation and because they felt that they could not depend on their family members to understand them (Ebony, 21:11; Evangeline 41:02; Nathalie, 50:16). Participants also spoke of only allowing access to certain parts of themselves. For example, when she asked for assistance with paying for psychologist appointments, April told her mum she was seeing a psychologist but did not tell her it was for an ED because she did not want her mum to feel any responsibility for the diagnosis (53:91). April revealed that her mum had struggled with her own weight concerns but that she did not feel these were related to her own ED diagnosis; instead, she felt protective of her mum and wanted to manage her recovery without her mum's concern or guilt. Clarissa realized that she could depend on her mum to pay for psychologist appointments and to teach her to cook but that she could not depend on her for emotional support during her recovery (16:01). In

contrast, Alba was able to accept practical support from her family in the form of a place to live and transportation to appointments but noted that, “*I think with family it never felt good. I think I always felt indebted to them*” (33:03). Allowing practical support was a means of giving family some access to the recovery journey, and thus, to the self, but it still created tension in complex family relationships. Lina noted that even though her family was eventually included in her recovery, she felt a degree of ambivalence about this, saying, “*I feel like I could have not told them, and I would have been fine with it*” (56:27). For her, this boundary management was a means of control over a complex family dynamic, a means of asserting control over her recovery, and a means of managing the vulnerability she was willing to show to her family. It was considered necessary because Lina’s family was brought into her treatment against her stated will by her inpatient treatment team and because her family’s complex eating habits meant she was not able to have a support at home for her recovery. For participants in this study, boundary management with their family was both a means of asserting control over their recovery and of self-preservation. In engaging in this kind of boundary management, participants protected themselves during the ED and into their recovery while also maintaining a semblance of a relationship with their family.

6.3.2. Relationships Could Keep a Person from Going Back into the Eating Disorder

Significant relationships that provided supportive encouragement and empathy kept participants from returning to ED behaviours. Many participants spoke of people in their lives being helpmates, whose encouragement and empathy went beyond practical support (e.g. driving to appointments, providing monetary assistance, etc). Instead, relationships with such people encouraged positive recovery behaviours during times of stress or helped sustain new behaviours (April, 50:18; Wendy, 40:05). Wendy placed particular emphasis on the importance of open communication between herself and her family and friends. She attributed her feelings of emotional closeness to a willingness to share her emotional

experiences with her family and friends (47:10). For her, the emotional intimacy provided increased support because she knew that her emotions would be validated in respectful conversations (Wendy, 44:05). For Lilianna, her husband's narratives of how he experienced her as being beautiful, too skinny when she was unwell, and needing to put on weight were in direct opposition to the narrative made by her ED (37:44). She used his encouragement as a reminder to counter disordered narratives about her body, which had previously compelled her to lose weight obsessively. Participants who had experiences with supportive, validating relationships felt encouraged in their recovery. These relationships emphasised open communication about emotions, encouragement and support through adversity, and validation of ED experiences.

Participants spoke of the differences they noticed in their relationships when they began to share their experiences with those to them. This was sometimes done in a creative manner, as Anya did when she gave a copy of a memoir she wrote about her ED experience to her children (16:32). She noted that between this and a case management meeting that was attended by her whole family, there was a marked positive change in her relationship with her children (18:36). Nathalie also noted a change in her relationship with a long-term partner after she revealed her ED to him. She described the support he provided and the simple fact that someone knew her lifelong secret as a *“luxury of somebody that knew that I trusted”* (40:34). The idea of trusted relationships being a luxury was echoed in other participants' explanations of such relationships. Lina valued a friendship where the ED was not made into a primary issue in every interaction because she felt *“more normal having him around and more like I was a person- real person- not just a mentally ill person”* (1:02:13). Similarly, Sophie valued the opportunity to redefine herself at university because she was able to form friendships that were not based on her having an ED, as they had been in her hometown; instead she *“was able to develop more, or deeper, relationships with them that were more*

intellectual, and actually provided me more hope, I suppose, that I was able to actually develop these meaningful relationships with other people” (29:04). Supportive relationships like this were a luxury because of their emotional and intellectual intimacy, which, for these participants, had been inaccessible previously. Relationships that allowed this kind of intimacy by providing hope and a sense of self beyond the ED.

The bounds of supportive relationships also encouraged a degree of responsibility that kept participants focused on recovery. For participants who were mothers, there was a strong sense of responsibility to their children, both in the sense of needing to remain alive for them and to not pass on the ED behaviours. Both Lilianna and Serena described a protective instinct that began once they found out they were pregnant. Lilianna noted that she was overjoyed because she questioned her ability to have children and that *“I was so excited, so happy, that I was like ‘Fuck, I’ll eat ten donuts a day. I don’t care’”* (31:25). Serena also felt an overwhelming urge to protect her unborn child from the effects of her ED, saying, *“I didn’t want to take away nutrients, and food, at that point, I guess I was valuable and I didn’t want to take that away from my baby”* (3:43). Both women similarly remarked that they did not want their children to struggle after they were born. Lilianna talked about how she did not want to be sick because she had a wider net of responsibility. She used the example of feeling the impulsive decision to drive her car into a tree. When imagining this, her thoughts turned to her children and she would find herself thinking, *“‘That’s horrendous, imagine the kids in an orphanage.’ I don’t know whether that’s healthy or not, but it keeps me kind of not doing anything silly or making choices that aren’t going to really affect me”* (32:19). Serena explained that she felt responsible for shaping her daughter’s relationship with her own body and with food, saying,

I want to be this really strong, healthy role model for her, so I try and eat as well as I can and I do CrossFit and I try to exercise as much as I can. You know, of course, without going the other way. (16:56)

For both women there were self-sacrificial elements to this decision. Serena explained that she felt that she “*had more respect for the baby than [she] did for [herself]*” (36:10).

Lilianna observed that making the choice between the time-consuming ED behaviours and the equally time-consuming needs of a newborn was difficult and that, in the end, making this decision, while right for her child, resulted in a period of depression (24:25). The connection between mother and child was such that it gave these participants purpose outside of their ED but this purpose, having children, came with complications that needed to be managed without the help of the ED. It was also noteworthy that the motherhood identity had such an influence on the progress of recovery. The data from this study suggested that the motherhood identity was helpful in the identity reorganisation process and, as such, may be a point for therapeutic intervention.

Participants also felt responsible to people who had provided support during the recovery process. For Evangeline this was friendships that she did not want to lose by becoming isolated in the ED again (12:42). For Primrose Lou, a similar sense of responsibility was felt to the network of family, friends, and treating professionals who had showed her that they cared about her by not abandoning her through a tumultuous recovery. She explained that “*I want to do the right thing for these people who have shown me such respect*” (Primrose Lou, 14:28). Supportive relationships that demonstrated caring empathy seemed to breed this sense of respectful responsibility that in turn encouraged further recovery.

6.4. Perceptions of ED Treatment Were Focused on How Needs Beyond Symptom Remission Were Met by Treating Professionals

This theme related to experiences with allied health professionals and treatment. Overall, it was found that the participants wanted allied health professionals and treatment to

shift its focus from a biomedical model. They were keenly aware of how being treated in this model made them feel and how it influenced their ability to recovery.

6.4.1. In Interactions with Allied Health professionals, Definitions of the Eating Disorder and Recovery Relied Heavily on a Biomedical Model

When the ED was diagnosed and treated by allied health professionals, participants felt that the outward presentation was given more attention than the underlying causes. There was a sense of confusion about why they were experiencing their symptoms and why they were not improving despite receiving ED diagnoses. Participants spoke about feeling as if they were going to have the ED forever, saying *“This is just my life, this is what I’m gonna be like forever”* (Clarissa, 30:47). Serena explained,

It makes me feel like maybe things would be different if someone had understood what I was going through, and that I wasn’t making myself sick because I didn’t want to be fat. Even though I didn’t recognize that at the time either. ‘Cause that’s what I thought it was. I didn’t understand it. (27:31)

This sense that the ED was entrenched in the self was echoed by April who said that it felt like her ED was in *“my core, like right down inside and it was really tough to confront it”* (28:29). Nathalie also felt that there were deep underlying issues that were *“an expression of some other stuff in [her] life”* and noted that she was *“very aware that until the underlying issues were looked at and dealt with, it [the ED] was still going to recur”* (11:30). These underlying issues as they were experienced by the participants to extended far beyond the presenting symptoms and required to extensive treatment and recognition from treating professionals so that recovery could progress.

Unfortunately, participants found that the diagnostic criteria used in both categorising their disorder and in triaging them into care, did not encompass their ED experience. Clarissa felt that she was met with explanations of her condition but was not given options for how to actually handle it herself, leaving her feeling helpless (30:26). Other participants noted a

consistent feeling of needing to meet certain weight requirements in order to qualify for treatment programs (Alba, 12:28). When they were told they did not meet the requirements, there was a perception of needing to be a certain kind of sick in order to qualify for treatment developed (Alba, 16:37; Serena, 8:17). This kind of sick was equated with a low body weight, which participants felt was not an accurate representation of their overall ED experience and which also related closely to the sense that their core self was not acceptable. These ideas further maintained the ED because they were consistent with the ED voice and identity. As noted above, the participants' ED experience extended to their sense of self and encompassed their relationships.

Participants felt that they did not encounter experientially accurate definitions of recovery. This disparity was focused on the use of definitions that were physically bound as opposed to ones that incorporated the whole recovery experience. Alba noted that she felt she had internalized misconceptions about what an ED looked like to such an extreme, “[t]hat it was shameful to ... If I was gonna talk about stuff related to eating, and body, and mental health, then I had to be in this thin, anorexic category, otherwise, I had to just shut up” (16:06). This contrasted with Sophie’s experience of loss of control during treatment, during which she described herself as being “just part of this group of people who needed to be fixed, and the only way to do that was to eat these meals and gain this amount of weight, and then everything will be okay again” (52:17). For both Alba and Sophie, the physical aspects of recovery were emphasized to the extent that recovery was synonymous with symptom reduction. However, the focus on physical symptoms in treatment meant, that the only way to speak about recovery was in these terms, making it very limited. Serena similarly focused on the physical aspects of recovery from BN but found that,

My anxiety, my depression, my bulimia, it's all one big thing, it's not separate issues that we can put in different boxes and treat each different one at a different time. It all

needs to be unpacked and treated kind of at the same time because it's all related.
(47:29)

Recovery could not be relegated to cessation of physical symptoms alone because the ED reached all aspects of the participants lives. When recovery was reduced to cessation of physical symptoms, it reinforced inaccurate, often weight based, stereotypes about what an ED looked like, thus further reinforcing the ED identity.

6.4.2. Effective Treatment Addressed the Whole Person

This subtheme related to the effective delivery of treatment. Overall, treatment was found to be effective when it included all aspects of the person with the ED, meaning underlying causes as well as symptoms were addressed. This experience made treatment accessible, applicable, and specific so that people felt ownership over the treatment process. April referred to the effectiveness of a GP who understood not to discuss her weight in specific numbers, as this was triggering (37:45), a point which Primrose Lou supported (39:21). Clarissa spoke of the importance of having a treatment team who explored all aspects of the ED with her, rather than focusing only on symptom reduction, because up until that point she had little insight into the causes of her ED (50:34). This included looking at the underlying psychological issues but also helping her with healthy exercise with new health concerns (e.g. weak bones, strain on the heart, etc). As Primrose Lou eloquently explained, *“when I found therapies that began to treat my soul, and the person that I was, that's when I started to heal”* (50:21). For these participants, treatment was more effective when it felt personalized and when, as a result, they felt understood. When participants felt that they were being cared for, beyond the symptom remission and into the complex work of untangling the underlying cause of the disorder, they felt that they could trust and buy into treatment.

Participants also felt that effective treatment was specialised to the unique needs of people with EDs. They had the most positive feedback for people who were specialised or

who had a clear ability to understand EDs. Lilianna described beginning her “*real recovery*” once she commenced outpatient treatment and was assigned a specialist psychologist (19:43). Both April and Evangeline had clearly positive experiences with ED specialised dieticians whose sessions re-educated them about nutrition and cooking. These sessions were so successful that both spoke in glowing terms of cooking and trying new food, which was a stark contrast to the rigid, fearful relationship they previously described with food (April, 43:31; Evangeline 6:04). Primrose Lou felt strongly about the importance of specialised nutrition because of successive negative experiences with triggering weight gain whilst an inpatient. She explained that “*this is a disease where food is a repellent, food is unnatural, food is poison. So, to give people food, when their medicine is literally, delicious nutritious food, to give them hospital crap? That's not going to help*” (31:48). Here, Primrose Lou was referring to the unappetizing food that was provided to her during her inpatient stays. For her, it was difficult enough to eat without the added difficulty of unappealing food. In this circumstance, she felt there was a lack of consideration, as people with EDs could not simply begin eating food again, much less unappealing hospital food, because they had been directed to do so. From her perspective, treatment providers needed to be keenly aware that, while there were complexities around food caused by the ED, food may also serve as a form of medicine. Clarissa suggested another area for improvement in specialist ED treatment. She noted that “*I didn't really get taught about how I should exercise or look after my body during recovery either*” (49:13) and that this would have been beneficial because the ED caused unique damage to her bones and joints. In this situation there was a lack of consideration for the possibility that people with EDs would need to know how to healthily engage in exercise after treatment. The lack of education around exercise made it difficult for people with EDs to know what was safe, thus making it easier for them to return to exercise

behaviours used during their ED. For these participants, specialist treatment supported recovery but there was a demonstrated need for further developments within this space.

6.4.2.1. Processing the Eating Disorder Experience with Allied Health

Professionals was Essential to Recovery. Participants spoke readily and at length about their experiences with specific allied health professionals. Their experiences varied from extremely negative to extremely positive, with some participants reporting significant variation across the recovery journey. This meant that individuals did not have consistently positive or negative experiences but instead formed their opinions cumulatively, or, in some cases, based on stand-out interactions with one specific allied health professional.

Participants also discussed the importance of processing their ED experience and recovery with a wide range of allied health professionals. They reported success with therapists (April, 24:04; Nathalie, 26:01; Serena, 21:26; Wendy, 21:14), dieticians (April, 35:52; Wendy, 29:25), GPs (April, 36:26), and art therapists (Wendy, 25:53). Some worked effectively with a treatment team made up of combination of allied health professionals (April, 44:28; Primrose Lou, 54:53). Overall, this illustrated that meaningful connection could be made with any allied health professionals during treatment and recovery and processing of the ED experience was not limited to any one profession. Indeed, insight was not bound by professional boundaries and, while a professional's training was important to this insight, so too were their personal qualities.

Participants reflected clearly on how the personal qualities of allied health professionals had contributed to their recovery. Many participants explained that it was vital for allied health professionals to create a safe treatment environment. In this safe, therapeutic environment, participants felt they were able to tell allied health professionals about their symptoms, which some participants had been hiding from professionals for a significant period of time (April, 44:28; Serena, 31:40), and also about complexities in their lives, such

as self-harm and abuse (April, 24:04). As Wendy eloquently described her group facilitators, “*they had created a space for me to be at my worst*” (50:20). This safe environment fostered a deep trusting relationship between participants and allied health providers (April, 38:52), though this trust did not come easily for some participants. Primrose Lou explained that, “*I didn't trust them easy. I made it very difficult for every single one of them*” (57:10). She further explained that once she felt she could trust her treatment team, she acted differently with them,

And now it's like I feel like I'm my true self with them. I'm gentle. I'm soft. I'm willing and pretty sassy and apparently pretty funny. And it is nice we're establishing those qualities within myself that I then give to my friends... (57:19)

Having access to this true self was incredibly beneficial to allied health professionals who treated EDs, particularly psychologists, as this was the part of the self upon which recovery could be built. In order to go about this uniquely difficult process, psychologists (and other allied health professionals) needed to provide a space for people with EDs to express and explore their identity safely and without judgement. The sense of safety contributed to the ability to express genuine aspects of the self and to the overall success of treatment.

Two qualities that assisted in creating a safe, trusting environment were being able to be empathetic and validating. Participants expressed how important it was for them to have their experience accurately understood by the professionals providing treatment. For April, a dietician's gentle understanding of how April's family's history impacted her eating behaviours and ED overall was one turning point in her recovery (41:42). Serena's psychologist made her feel safe and understood to the extent that Serena felt she could tell her about symptoms that previously made her feel shame,

I know that if I was feeling like I needed to or if I wanted to binge and purge, that if I brought that up with her, she would 100% understand exactly how I felt and what I was going through. (33:17)

Such therapeutic validation allowed symptoms to be approached equanimously. Lilianna spoke of how therapeutic validation from one member of the large treatment team managing her care whilst she was on an inpatient ward helped her to feel hope, *“because, knowing that at least one person believed in me, at least one person understood me, was enough to keep me going”* (15:40). It is noteworthy and concerning that therapeutic validation was so lacking during Lilianna’s stay on a large inpatient ward that only one professional’s validation was significant to her. The experience was shared by other participants, like Primrose Lou, (22:56), whose traumatic experience with inpatient care included physical and emotional abuse from nurses and doctors and was completely devoid of therapeutic validation or care. These negative experiences provided a counterpoint the positive ones. They highlighted how vital therapeutic validation was by demonstrating what happened to treatment when allied health professionals did not provide it.

The importance of encouragement within various therapeutic relationships was also discussed. This encouragement could be quite practical, as April found with her therapist, who guided her into talking to her GP about not being weighed because it triggered checking behaviours (37:45) and her dietician, who gave April effective nutritional and cooking guidance. April noted that this guidance was so effective that, *“I was just obsessed with trying to make new dishes and it became like a thing that I really, really enjoy it and still really enjoy”* (43:00). So, through effective encouragement, she was able to explore new hobbies and skills. Primrose Lou spoke of her entire team’s encouragement in fiercely loyal terms, expressing a commitment to her recovery because *“[t]hey will never give up challenging me. They've never just thrown their hands up and everyone else did”* (54:53). This again demonstrated how important counselling micro-skills were for all allied health professionals, as they helped the client to maintain commitment to therapy. When the professional was committed to the client, the client felt more commitment to the treatment.

Many of these participants had experienced ruptures and missed connections in the relationships with the allied health professionals who treated them, so having professionals who demonstrated commitment to their clients and to their recovery was vital to a successful outcome.

6.4.3. Ineffective Treatment Only Addressed Part of the Person

This subtheme addressed what made treatment ineffective. Overall, treatment was found to be ineffective when the person was not addressed as a whole, but rather, only had part of their disorder addressed- usually the physical symptoms. There were often patterns of being misunderstood, such as when Evangeline was repeatedly misdiagnosed and prescribed the wrong medication, causing her to vomit and have manic episodes (55:44; 58:03). Lina had painful abdominal bloating minimized as being a part of her ED and no relief offered by several allied health professionals during her treatment (42:21). Ebony's ED was misunderstood when she sought treatment. She spoke of feeling psychologically exhausted at the time and wanting to be cared for but was not accepted for treatment because she did not meet the weight-based criteria. Ebony recounted how this made her feel like *"I was so silly to have thought that I could have even engaged in a conversation about [treatment]"* (48:33). Whether the treatment misunderstanding encompassed diagnosis or overall treatment needs, the experience was invalidating, creating the sense that the client's true problems were not being seen by the treating professionals. Instead, the focus on weight reinforced inaccurate beliefs, such as that one needed to be critically thin in order to qualify for treatment and that self-worth was judged based on weight.

6.4.3.1. Rapport was Integral to Relationships with All Allied Health

Professionals. Participants discussed how the rapport they built with allied health professionals overall was built on their assessment of their qualities and skills. As discussed above, participants were very perceptive and insightful about the qualities and skills of their

allied health professionals, because they felt frustration within the therapeutic relationship keenly. For example, when April missed an appointment due to a misunderstanding then was not called by her psychologist until it was too late for her to attend and was also charged for the appointment, April felt the appointments were more about money than about helping her (21:25). Clarissa was acutely aware of how desks, notepads, and other office furniture created physical barriers that were then reflected in the therapeutic relationship, saying that some of these common office features made her feel like she was “*being observed rather than listened to*” (34:21). Similarly, when participants felt that allied health professionals lacked specialisation, they felt that there was a lack of understanding of their ED experience and that the professionals missed the nuances that could provide insight. April’s experience with a dietician who did not pick up on how food tracking was re-triggering her ED (45:23) and Clarissa’s experience with a school psychologist whose approach made Clarissa feel like she needed to present more things that were going wrong in her life (8:03) are indicative of instances where skills did not match the needs of the client. This was contrasted with Primrose Lou’s positive experiences with her GP, who therapeutically refused to engage with Primrose Lou’s eating disordered dialogue on changing goal weight or similar, instead telling her “*Primrose Lou, not productive,*” before redirecting the conversation (40:51). For Primrose Lou this experience made her all the more willing to engage in treatment and to trust her treatment team completely. She explained that she felt they could keep up with her and that she could trust them to emotionally contain her in whatever state she presented in. Though sometimes slow to build, once this trust was established, it strengthened the therapeutic relationship and was formative to positive experiences.

Certain treatment experiences undermined and were formative to overall recovery because they impacted a person’s willingness to establish rapport with allied health professionals. Some participants spoke of avoiding treatment or ending treatment early. Alba

spoke of terminating treatment with psychiatrists who repeatedly failed to understand how to effectively treat her (56:10), while Lina was very specific about which professionals she would have on her treatment team, saying she would never include psychologists again after a series of bad interactions with them (42:37). These incidents undermined the participants' existing rapport with the allied health professionals and made them mistrustful of future engagement. Alba also felt that ineffective treatment shut down the two-way lines of communication between members of the treatment team and herself, such that she felt disempowered and less likely to engage helpfully in treatment (52:04). Sophie felt similarly, describing how the directive nature of some of her treatment kept her from explaining what she was feeling emotionally because she had no one in her treatment team who validated her emotional experience (1:05:17). Other participants described feeling like they needed to be sicker in order to warrant the treatment they were receiving. Primrose Lou was told by allied health professionals that there were people sicker than her on the ICU ward, making her feel guilty for needing a bed (28:57). Serena, meanwhile, endured a pattern of having her serious symptoms, both ED and those that were sequelae of the ED, ignored by members of her treatment team, making her feel that that her kind of ED was not important and that she also needed to reach a high threshold of suffering in order to be noticed (1:00:37). Here, repeated instances of having their experience of illness and suffering invalidated created a situation where it was difficult for the participants to trust future allied health professionals enough to discuss their symptoms. In this way, accessing treatment carried the burden of past negative experiences, which influenced decisions about treatment for the future.

6.4.3.2. With Great Therapeutic Power Came Great Responsibility. Allied health professionals had the potential to wield significant therapeutic power over a psychologically and physically vulnerable client group for whom diagnosis and treatment was particularly important and complex. While there were many instances where this therapeutic power was

used responsibly, there were also instances where this power was abused and misused, which had a negative effect on recovery overall. Within the therapeutic relationship there were ample opportunities for the possibility of abuse. Primrose Lou recounted multiple instances of physical and emotional abuse she endured while she was receiving treatment on an inpatient ICU ward, including being told that she was “*the fattest anorexic they had ever had*” (22:56) and being forced to stay and eat in rooms with patients who were severely emaciated due to cancer and who were incontinent and not able to tolerate food or fluids. She was also told that she was wasting bed space by multiple staff (25:25). She explained that, as a result of these traumatizing experiences and a series of substandard specialist admissions she felt that any desire to recover had been wiped away and that instead, it had resulted in “*putting that disease in my core*” (28:02). It was significant that Primrose Lou placed the responsibility for the change in her recovery trajectory with the allied health professionals who treated her. In her situation, the interaction between the abuse of power by allied health professionals and a psychologically and physically vulnerable person culminated in the ED being strengthened rather than treated. Nathalie also recounted boundary crossing by a psychoanalyst, who saw her on a fortnightly basis for two years and then broke the professional boundaries of the relationship by inviting her to a concert (7:25). This changed her opinion of the psychoanalyst and she stated that psychoanalysis was largely useless for her. Later in the interview Natalie expressed ambivalence about allied health professionals, saying that she felt they did not make the effort to understand their clients (22:52). She did not link this belief to her experience with the psychoanalyst, but instead related how she had repeated experiences with specialists who failed to understand the complex connection between an ED and diabetes (Natalie, 23:30). This repeated invalidation created mistrust of allied health professionals’ ability to understand Natalie’s experience and provide safe

treatment. For both participants described here, the abusive behaviour hardened beliefs against further treatment while also reinforcing the ED.

Participants also described repeated instances of being misunderstood, overlooked, or dismissed by allied health professionals. Serena related how she was not diagnosed or adequately treated for BN despite presenting to her GP with numerous concerning symptoms like fatty deposits on her liver and stomach ulcers that required gastroscopies and colonoscopies (40:13). She described having the sense that *“if I wasn't stick thin and fainting in the living room or things like that, to them it wasn't a big enough issue to address”* (30:54), which contributed to a feeling of anger and betrayal towards the people who were meant to be treating her. Nathalie expressed similar feelings towards allied health professionals who did not understand the link between BN and type one diabetes, which was one of Nathalie's lifelong health concerns and a significant contributor to her ED. She explained,

Because one of those difficult things, when you're a type one diabetic and you're a bulimic, is finding a psychologist who understands the way that they interact, the problems that arise from that. That it's not just as straightforward as I've got no other problems but I'm bulimic. And very often I have to spend so much time. In fact, I did at [redacted- treatment program] and I did at [redacted- psychology clinic], educating a psychologist about what being type one means in terms of your blood sugars, your moods, your ketosis- all of that stuff, because it all impacts on when and how and what you eat in your health terms, let alone if you're bingeing as well.
(20:24)

Nathalie's discussion of living with type one diabetes included accounts of trying to impose control on an ill body that frequently thwarted these attempts. When medical professionals were unable or unwilling to understand her experience, they too were unable to control her illness. Nathalie expressed her frustration with not being a straightforward case; the narrative conveyed a sense of emotional battering, from her experiences with the ED, the type one diabetes, and also with trying to find a psychologist who would understand her. In speaking about her experience with allied health professionals, this sense of battering is evident in the

defensiveness and annoyance of her opinion, *“I think because health professionals are just stupid. But anyway. No, no, really. They just don't see it. They don't see the logic and the reality of those people's lives”* (22:52). Nathalie conveyed clearly that, by failing to understand the client’s experience, a significant barrier was created between clients and allied health professionals.

Serena also reinforced this experience by saying that she felt that because her GP did not seem worried about the symptoms she reported to him, *“for a long time I felt like it wasn't a big deal. Like it was something that maybe I didn't need a lot of help with, or something that wasn't important”* (40:13). Similarly, when Clarissa was initially diagnosed, her GP only provided a diagnosis with a limited explanation of treatment options or explanation of potential origins of the ED, leaving Clarissa feeling depressed, confused, and like she would never get better (30:47). Initial appointments with GPs are generally intended to triage, preliminarily diagnose, and stabilise people with EDs while further treatment options are explored. During this stressful and confusing period it is understandable that Clarissa felt misunderstood, as it is also a period where communication is especially important. That she felt misunderstood suggests that there may have been opportunities for the early treatment process to be explained with greater clarity so that she felt more supported. When allied health professionals misunderstood or overlooked their client’s experiences, they inadvertently created barriers to ongoing treatment, as this fostered distrust, confusion, and even contributed to ED behaviours.

Participants described feeling like the staff were not equipped to handle the complexity of providing treatment to ED patients. Sophie explained that, while she was in an inpatient specialist ward, she and the other patients *“just tended to run circles around the nursing staff, and some of the nursing staff themselves had eating disordered behaviours, which wasn't helpful”* (54:24). Wendy shared a similar experience, saying that she found her

inpatient specialist stay to have the potential to be “*very cult like, and you can get sucked into that really easily in terms of how to get around rules and how to trick the nurses*” (9:23).

Wendy described a shared mentality among some patients that was not recovery oriented but was instead focused on maintaining ED behaviours as much as possible while maintaining the semblance of adhering to treatment. From her experience, it was very tempting to join in with this shared mentality rather than commit to recovery. Primrose Lou told how she was able lose weight during her first inpatient specialist stay and was also able to force an early discharge so she could return to school (27:07-27:44). The ease with which participants felt they could work around staff was significant. All three narratives alluded to how easy they felt it was to trick staff and also to a sense of challenge that was derived from the endeavour. Sophie explained, “*I don't think the staff will ever be intelligent or witty enough to be able to combat 10-30 teenage eating disorder sufferers*” (53:04). From this point of view, an us versus them mentality was evident, where the allied health professionals were pitted against the people they were meant to treat. Experiences like these eroded the trust that the participants also felt should be held between allied health professionals and those in their care. There was a wariness and also a tenuous sense of the power imbalance that existed when those providing treatment were so easily tricked by the treated.

6.4.3.3. Inpatient Treatment was Seen as a Means of Social Control. Inpatient treatment was experienced as a loss of control over the self and a lack of ownership over the treatment process. Lilianna and Lina described how their experiences of inpatient treatment were felt as a means of social control. Both expressed the feeling of being imprisoned (Lilianna, 8:26) and like they had no say in treatment when they felt forced to stay (Lina, 23:12). Lilianna explained how the weight restoration treatment itself became aversive,

I would see people come in and then they would leave, and I wanted to be the one who leaves. I knew that the only way to do that was to gain weight quickly. I just really wanted to go (4:23).

Both described feeling infantilized during treatment, with Lina using particularly vivid language to render the image of how she felt when she was retained for care under the Mental Health Act, *“It was that, kind of, huge doctor with lab coats, and I’m this tiny thing that they’re not even looking at”* (22:13). Here, the doctors were depersonalized white coats and Lina was made small, and insignificant, not even the focal point of their attention as they make decisions about her treatment. Lina further described feeling a loss of self during her inpatient stay, saying that the strict rules around vegetarianism and veganism made her feel like *“I wasn’t allowed to have my morals and my ethics”* (19:11) and that *“I wasn’t able to continue being, like, the last few threads of myself, that I felt I had”* (20:19). Lina’s experience emphasised the importance that identity played throughout treatment, including in the early stages. For her, vegetarianism and veganism were key parts of her identity that were not influenced by her ED. Being forced to eat meals that ran counter to her morals and ethics was felt as an attack on her identity. Given the importance of recovery as an identity re-organisation, this data suggested a more nuanced approach to treatment may be necessary. In these situations, treatment became more aversive than supportive. The people receiving it were trying to complete treatment in order to avoid aversive conditions and to meet the requirements enforced on them, rather than because they felt they were actually starting to recover. This suggested that overly rigid treatment or treatment that focused only on weight restoration may not encourage recovery.

Lilianna provided insightful commentary about how weight gain was enforced during her stay. She explained that she initially denied a nasogastric (NG) tube but when she was not gaining weight fast enough, she complied so that she could move to a more specialised unit quicker (3:03). Lilianna explained that,

To them it was a matter of, ‘Just gain the weight.’ And if I didn’t gain the weight, it seemed like I wasn’t being a good person. Like, ‘You’re not a good girl, you didn’t gain weight this week.’ I really found that really, really not insulting, but I just felt

misunderstood, perhaps. I felt like I had to please these people. It was a very confusing, it wasn't confusing, it was just really depressing (6:45).

Weight was also used as social control when she was not allowed to begin seeing a psychologist until she met a certain weight threshold, with the stated reason being that in a malnourished state she was not cognitively prepared to engage in therapy. Lilianna countered that *"I might not be of rational mind but I can still talk"* (9:10). Treatment for AN commonly notes the cognitive complications can be a result from prolonged starvation, but here, Lilianna suggests that just because these complications were present, it did not mean she was not still able to talk about her experience at the time. The notion that there was no utility in providing therapeutic care during the early stages of AN treatment needs re-examination, as it is not beyond the realm of possibility that discussing the distressing emotions present during refeeding might ease the process.

In all these instances it was noteworthy that the person with the ED had so little control over their treatment. This lack of control was felt keenly and to the extent that it turned the treatment, which was meant to be healing, into an aversive stimulus that was endured and then avoided. The extent of this aversion was made clear by Primrose Lou, who gave thorough descriptions of what she thought IP treatment should look like, including a more seasonal, varied menu and appropriate guided exercise (35:52-36:20). Primrose Lou felt that the increased options this opened to patients were critical to improving recovery outcomes. For the participants in this study, the lack of options gave the sense that inpatient treatment was not focused on their overall care but was instead focused on their weight. This emphasis ran the risk of being counter-intuitive because it reinforced the importance of weight as a means of determining self-worth, which was already a matter of concern for some participants. Taken together, this data supported a more holistic approach to ED treatment.

6.5. Key Findings

Eating disorders were found to meet an identity serving function to such an extent that they became a key part of the person's identity. This impacted recovery, which was found to be an active, ongoing process of identity re-organisation. The findings about interpersonal relationships in this study support those found in the OFG study, namely, that personal boundaries were strictly maintained and that interpersonal relationships could significantly affect recovery. Finally, it was found that there was a keen desire for treatment that addressed all aspects of the ED, not just the relief of symptoms. Overall, this suggested a more holistic and thorough approach to ED conceptualization and treatment.

6.6. Chapter Summary

This chapter examined the results of the second study that comprised this thesis. As with the previous chapter, the overall demographics and results were first reviewed. Following this and an introduction of the themes, the themes and subthemes were discussed at length. This and the previous chapter laid the groundwork for the discussion of these results, which will be carried out in the following chapter.

Chapter 7

Discussion

7.1 Discussion of OFG Results

The use of an online focus group (OFG) with a sample of seven participants who described themselves as being in ED recovery was found to be an effective means of gathering data on ED experiences and recovery. Thematic analysis of the data developed four themes that demonstrated links between treatment and recovery experiences, as well as experiences during the recovery journey and overall long-term recovery. Themes from this study explored the idea that recovery was a highly individualised journey that was purposeful by nature. The dichotomy of physical and psychological recovery was also explored, as was the dichotomy of independence and isolation in the recovery journey. These dichotomies were negotiated on a daily basis, contributing a nuanced understanding of the recovery journey. The themes also explored the relationship of treatment on recovery and how prevailing conceptions of EDs impacted relationships with treating professionals, which in turn impacted the recovery journey.

7.1.1. Implications of Recovery is a Journey Theme

The first theme, that recovery was understood as journey, was supported by existing literature, both within the ED field and in the recovery field overall. Notably, Federici & Kaplan (2008) found in their qualitative study of AN recovery and relapse that recovery was conceptualised as a work in progress that was maintained with sustained vigilance. These sentiments were echoed across the OFG, where participants described recovery as being a daily practice that required consistent effort. Recovery literature established the use of the journey metaphor through analysis of first person accounts of recovery, which sought to establish a definition of recovery and found that many accounts conceptualised recovery as an ongoing journey rather than a destination (Anthony, 1991; Deegan, 2003; Mead &

Copeland, 2000; Ridgway, 2001). This sustained and ongoing nature of recovery was used in the concept of being ‘in recovery,’ as opposed to ‘recovered from’ a disorder. Davidson and Roe (2007) found that the concept of being in recovery allowed for people with psychiatric illnesses to live a fulfilled and meaningful life with the presence of said illness. Participants from the current study described the experience of living in recovery clearly, explaining how they continued to pursue their dreams and goals while managing ED related thoughts; they saw this to be part of the recovery journey.

The purposeful nature of recovery was also well supported in the ED and recovery literature. Multiple qualitative studies found that the individual will to recover was of tantamount importance to ED recovery (Federici & Kaplan, 2008; Lindgren, et al., 2014; Patching & Lawler, 2009; Tierney, 2008a). This finding was further bolstered by evidence from the recovery field, where the importance of individual choice and self-determination has long been supported (Jacobson, 2001; Mead & Copeland, 2000; Noordsy et al., 2002; Ridgway, 2001). The application of the purposeful nature of recovery is especially useful in the early stages of ED treatment, when ambivalence and anxiety are highest and when identification with the ED is strongest. Participants in this study spoke of feeling ambivalent during early stages of treatment and feeling most unsure about recovery at that point. During these stages, an intervention such as motivational interviewing may be successful in gauging motivation to change, as suggested by Arthur-Cameselle and Quatromoni (2014). However, it is also worth noting that use of motivational interviewing with an ED population must be carried out on a symptom by symptom basis, instead of on the basis of the whole disorder (Hötzel, Brachel, Schlossmacher, & Vocks, 2013). This approach, while more detailed and perhaps time-intensive, relates to the identity serving function of the ED, which must be dismantled methodically.

A final notable element relating to the first theme is the relative lack of ambivalence about recovery in the sample. As noted above, the participants did reflect on *previous* ambivalent feelings about treatment, but few participants expressed such feelings about their present prospects or future. This is notable because existing research has found that, while recovery is a positive experience overall, there is a degree of ambivalence at giving up the ED (Lindgren, et al., 2014). It is possible that the participants in this study had progressed past the point in their recovery where this ambivalence was strongest and to a point where they drew more pleasure from previously stressful activities. Based on the responses from the participants from this study and on previous research, these changes can be ascribed to the ability to feel and express emotions, the use of self-care, the development of coping techniques for stressful emotions, and engaging in a social life (Björk & Ahlström, 2008). Addressing these topics in treatment is an area for increased research.

7.1.2. Implications of Recovery Requires the Resolution of Inner Struggles Theme

There was significant existing evidence supporting the theme of recovery requiring the resolution of inner struggles. Both Weaver et al. (2005) and Federici and Kaplan (2008) found that the development of emotional regulation skills were key to recovery. Weaver et al. (2005) linked emotional regulation to the understanding of self, which was seen as key to recovery. This was evidenced in the OFG, where participants explained that recovery involved learning to both access parts of the self that were previously inaccessible due to the ED and to then understand and accept them. The participants in this study explained that this also involved emotional growth as they developed the ability to access, express, and tolerate difficult and confronting emotions. For participants, these emotions would have previously been a reason to use ED symptoms. In recovery, by contrast, participants were able to feel with more greater depth. Federici and Kaplan (2008) provided some context for the development of emotional regulation, as their study found that the ability to tolerate and

express previously inaccessible emotions among an ED population was considered key to recovery's success. This sentiment was repeated by participants in the OFG.

It was in this second theme that the impact of treatment was first raised. Discussion around what happened when participants were misunderstood as they were trying to resolve their inner struggles revealed the importance of therapeutic support. While there was ample discussion in later themes about the relationship between treatment and recovery, it was worthwhile to note that participants raised many similar experiences of having their emotional needs misunderstood or of the ED being misunderstood and how this consequently influenced them emotionally. Some examples of this included the variety of insensitive comments received by participants during the course of their treatment and the repeated conflation of physical recovery with overall recovery. These experiences hindered the recovery process overall because they failed to recognise the participants' emotional pain and extinguished hope instead of building it. The necessity of professionals who were both sympathetic to the experience of recovery and who could provide empathic and informed support was evident. Previous literature has supported this, with Weaver et al. (2005) finding that their sample reported most positive outcomes when the support person was open and receptive. Conversely, there were reports within their sample of treatment being traumatic; while this was not replicated in the OFG, there were reports of negative experiences, suggesting that negative or traumatic experiences in treatment warrant further research.

Overall, this theme laid the groundwork for the first important dichotomy found in this study, that of the difference between physical and psychological recovery. Physical recovery constituted weight restoration and normalisation of eating habits, while psychological recovery encompassed "*everything underneath*" as Hope (4:19) aptly explained. Participants found, through their experiences of treatment, that both areas needed to be resolved but that often, physical recovery was prioritised over psychological recovery,

or, worse, psychological recovery was not addressed at all. This highlighted the peculiar position of EDs as a psychological disorder with acute physical symptoms and the difficulty that this presented for treating professionals, who needed to balance physical risk with trying to deliver complex psychological interventions. The preference of physical or psychological recovery was not determined in this study; some participants noted that it was necessary to be weight recovered in order to begin recovery in earnest, but this only applied to those with AN. What was evident was that allied health professionals who provided empathetic and supportive care and who acknowledged the psychological side to recovery were helpful to recovery.

7.1.3. Implications of Individuals Develop a Keen Understanding of Their Interpersonal Needs Theme

Significant elements of the third theme were upheld in the literature. Participants in this study spoke about developing purposeful relationships as a part of their recovery. These communities of choice may or may not have included family members, who were at times problematic to the recovery journey. Having a developed support network was attributed to positive recovery outcomes because participants felt less isolated. Tierney (2008b) found that when people in recovery were well supported, not just by family but by friends and even online groups, recovery was perceived as being more successful. Developing purposeful relationships outside of the family may be encouraged during recovery to support positive treatment outcomes.

This study also found that participants had a clear understanding of the boundaries they needed to set for their recovery to be successful. The relationships they managed included the purposeful disengagement from others, including family, friends, and people met in treatment. By prioritising their recovery, participants demonstrated keen awareness, not only of their psychological and emotional needs, but of the demands placed on them by

others and how these demands impacted their desire to recover. Research by Arthur-Cameselle and Quatromoni (2014) supported the finding that recovery was improved with self-established boundaries. These authors found that their athlete sample reported more motivation to recover from EDs when they removed themselves from unhealthy social environments.

This finding in turn raised the second important dichotomy found in this study: the tension between isolation and independence during recovery. The third theme illustrated the dichotomy most effectively because in this theme, participants spoke often about having to make daily choices relating to their development of an independent identity without becoming isolated. This was a difficult task, as it first involved developing an identity separate from their ED and, also, at times, from their family and existing peer group. Isolation seemed inevitable due to the lack of understanding among family, friends, and wider community, so the balance between relationships with boundaries and isolation was delicate. As such, recovery was sought on the participant's own terms and with a community of choice. This dichotomy was a relatively new development with little existing support in the research. There were some similarities to findings from Weaver and colleagues (2005), who found that participants reduced contact with family members due to their perceived contribution to the development of the ED. This demonstrated that the purposeful nature of recovery extended to relationships, which were perceived to have lasting effects on recovery. The agency of people with EDs and how they navigate their relationships warrants further research. The risks to recovery are also demonstrated, as the self-examination and development inherent in recovery may force difficult decisions about relationships. Including skills-based therapeutic interventions to improve the ability to handle these decisions may support recovery in the long-term.

7.1.4. Implications of Treatment Impacts Recovery Theme

The elements of the final theme were supported in the literature. The importance of specialised therapeutic relationships to the recovery process was affirmed in this research. These therapeutic relationships could be developed with any allied health professionals encountered during the treatment process and the lack of empathetic care was perceived to have significantly impacted both treatment and recovery. Without a well-established therapeutic alliance, there was increased motivation to return to ED behaviours and little willingness to engage in treatment because of the perception that professionals were not invested. This reciprocal relationship of both practitioners and patients needing to be invested in care was described alongside respectful experiences and was seen as demonstrating that professionals could be strong allies in the recovery journey.

The need for specialised and empathic treatment was demonstrated in previous qualitative literature, which also described instances of hostility and misunderstanding from professionals that was echoed in accounts from the OFG (Tierney, 2008a; Westwood & Kendal, 2011). Some of the extant research focused on the impact that patient characteristics or symptoms have on the ability of staff to provide treatment, specifically the egosyntonic nature of EDs-this being a theoretical construct related to EDs where the primary symptoms of the ED are perceived as both acceptable and in line with desired goals to the individual (Lasègue, 1997). Such research suggested that the egosyntonic nature of EDs may contribute to treatment resistance because the goals of treatment conflicted with the goals of the ED and because, initially, people receiving treatment may not perceive themselves as sick (Westwood & Kendal, 2011). Difficulties in establishing relationships were linked to the egosyntonic nature of EDs and so the clash in goals expanded outwards to how patients were perceived by treating professionals. Pemberton and Fox's (2011) research on the regulation of emotions on an inpatient unit helped to provide a more detailed picture of the relationship between staff and patients. Their research found that the cycle of patients feeling misunderstood was

influenced by poorly educated staff, who could not adequately respond to patients' need for both emotional validation and predictable care. When patients reacted negatively to attempts at care, staff felt rejected by patients, patients subsequently felt dismissed by staff, and this perpetuated an unhealthy treatment environment. The participants in the OFG spoke of being misunderstood and mischaracterised by allied health professionals and also spoke of wariness of allied health professionals overall. They endorsed strongly the need for allied health professionals to have specialised training. The complexity of EDs, inclusive of their egosyntonic nature and the comorbid diagnoses, necessitates specialised treatment so misunderstandings are minimised, and therapeutic relationships can thrive. When this is the case, those receiving treatment feel validated and successful in treatment, and the therapeutic relationship is less strained, as was the experience of multiple participants in the OFG. Additionally, staff who are well educated about EDs are able to manage the confronting behaviours and emotions associated with the disorder with less burn out, meaning their engagement with those under their care can be more validating and empathic.

The impact of treatment on recovery raised the dichotomy of physical versus psychological recovery. This theme brought to the forefront the structural failings of the healthcare system in Australia and world-wide, specifically, how EDs and their recovery are defined. The unique physical and psychological aspects of EDs mean that there is a constant tension in treatment about where resources should be delivered. For the OFG participants, the experience of receiving treatment that was focused primarily on the physical aspects of their disorder to the detriment of the psychological ones was seen as a failing of a treatment system that was supposed to support them. In particular, the experience of treatment appropriateness being determined based on physical symptoms, such as weight, was experienced negatively, as was the experience of recovery being determined based on similar criteria (e.g. weight restoration, cessation of bingeing/purging). While certain aspects of

physical recovery, such as a degree of weight restoration in AN, were accepted as being necessary prior to psychological recovery, the prioritisation of all aspects of physical recovery over psychological was not supported in this study. They instead suggested that both physical and psychological elements of the ED be addressed as a part of treatment.

Existing literature on the egosyntonic nature of EDs presents a persuasive argument for a treatment model that focuses on both physical and psychological elements of the ED. Research by Malson et al. (2011) confirmed the egosyntonic nature of EDs, finding that it became an enduring part of the person's identity, and, as such, recovery was seen as unimaginable because it involved changing an essential (and therefore unchangeable) aspect of the self. Treatment that focused solely on physical symptoms would simultaneously avoid addressing the identity issues while reinforcing the message that weight was the most important aspect of the self, therefore meeting the goals of the ED and affirming the ED identity. This may lead to situations where "patients eat their way out of hospital but quickly relapse" (Tierney, 2008b, p373). Existing research with similar findings pointed out that one underlying issue of EDs related to identity and that psychological work needed to be directed to modifying identity so that it is no longer influenced by the ED (Espíndola & Blay, 2009; Westwood & Kendal, 2011). This literature also noted that treatment needed to work with those receiving treatment instead of against them and suggested using a transtheoretical approach to assess willingness to change on a symptom by symptom basis (Westwood & Kendal, 2011). Results from the OFG agree with this literature, as participants endorsed treatment that addressed issues that caused psychological distress, as well as the physical symptoms associated with the ED. Existing literature found that there was consensus between treating professionals and former patients that both physical and psychological change were necessary for recovery (Noordenbos & Seubring, 2006). However, there was no consensus between these two groups about when recovery occurs; this matter was not explicitly

addressed in this study and warrants further research as it has lasting implications for how treatment is delivered.

7.1.5. OFG Significance

The data from the OFG has implications for how ED recovery is understood and how treatment is delivered. Based on this research, ED recovery was understood to be purposeful, active, and something that people had to want. The use of the journey metaphor by this sample and their conceptualisation of recovery as an ongoing work suggested that ED recovery fits within the existing recovery model, warranting further research into this model's applicability for ED treatment. The purposeful nature of recovery suggested that treatment modalities that access personal responsibility and willingness to change may be appropriate in the early stages of treatment, though, as noted above, this would have to be carried out on a symptom-by-symptom basis. That recovery was seen to occur internally, rather than through the relief of physical symptoms alone, added further evidence to conceptualizations of the active nature of recovery. In order for such internal recovery to occur, there has to be a willingness to engage with treatment or to, at the very least, engage in active self-reflection.

Recovery was found to be impacted by interpersonal relationships, which were actively managed as a part of recovery. This management involved attempting to find balance between being independent in recovery and becoming isolated. Further research into the impact of interpersonal relationships on recovery would clarify how these relationships are perceived by both the person with the ED and the family and friends. Further research could also examine the effectiveness of various skills based therapeutic approaches (e.g. interpersonal therapy, dialectical behavioural therapy) in assisting people in the process of ED recovery to manage their relationships. This would further clarify how support can best be delivered to people with EDs so that they can remain independent in their recovery without feeling so misunderstood that they become isolated.

Finally, the impact of treatment on recovery was notable. The importance of validating and supportive professionals was particularly important and upheld the notion of a reciprocal relationship in specialist ED treatment, whereby well trained and validating professionals were best equipped for care. This suggested that by improving the quality of specialist ED care, treatment outcomes may be improved. Based on the data, this may be best accomplished by focusing on the education of all allied health professionals associated with specialised ED treatment and by widening treatment to focus beyond physical symptoms.

7.2. Discussion of Interview Results

The individual interviews were a successful means of gathering data on the experiences of ED recovery and treatment. Analysis of the data developed three themes that illustrated the relationship between the ED and the self and how this relationship influenced the development and maintenance of and recovery from the disorder. Themes also covered the effect that interpersonal relationships had on ED recovery and how these effects were managed across the recovery journey. Finally, the themes explored the perceived effectiveness and ineffectiveness of treatment and treating professionals. The effect of the biomedical model on both treatment and recovery was noted.

7.2.1. Implications of ED as a Means of Connecting with Self Theme

This study added to the body of literature that examines the purpose of EDs with a particular focus on the role that the ED plays in identity development. This study found that EDs served a number of complex purposes to individuals, including emotion regulation and coping with life stress or complex personal circumstances. In using the ED this way, the ED was characterized as a constant companion who assisted in numbing and reducing the intensity of complex emotions. The function of EDs in emotional coping has been examined in the literature. Numerous studies found that people with EDs reported using ED symptoms such as restriction, bingeing, and/or purging to cope with and suppress emotions that they

found to be toxic or dangerous (Fox, 2009; Fox & Diab, 2015; Lord, Reiboldt, Gonitzke, Parker, & Peterson, 2018). Musolino, Warin, Wade, Gilchrist (2016) found that these symptoms were sometimes perceived as an act of care by people with EDs because the strength of the emotions was felt as being so destructive. The counterintuitive nature of this act is noteworthy. Lavis (2015) suggested that for people with EDs, who had limited means of coping with complex emotions, ED symptoms became a means of care because of the role they played in distress tolerance. In caring for the self through use of ED symptoms, the ED was also cared for and sustained. The caring nature of the ED was discussed in the interviews, where it was characterized as a means of comfort when coping with an abusive relationship and softening the painful edges of reality. Within this construct, difficulties with recovery, such as lack of motivation, oppositional behaviour in treatment, and relapse, can be seen as attempts to care for the self and the ED. This context did not diminish the risk and harm caused by these symptoms but instead suggested a complex relationship between the function of ED and identity.

This study also added to extant literature surrounding the function of control to people with EDs. Participants spoke of how controlling their bodies and weight gave them a sense of mastery over aspects of their lives that felt out of their control. Previous research suggested that body control was used as a surrogate for control over aspects of people's lives because it cannot be interfered with by others (Espíndola & Blay, 2009). By taking as much command of the body through controlling food intake and exercise, command was generalised to other areas of the life and, ultimately, to the sense of self overall (Patching & Lawler, 2009). Living with an ED could also be anxiety provoking because it involved planning for and controlling as many variables in the future as possible in order to meet the ED rules. The results of this study suggested that self-care through the use of symptoms and control were important to the development and maintenance the ED.

7.2.1.1. Role of Identity in ED Development and Continuation. The link between EDs and identity organization has been well-established. This study confirmed existing literature that EDs play a complex role in identity organization, both becoming integral to the self and acting as an entity separate to the self. Though seemingly contradictory, this experience illustrated the complicated psychosocial underpinnings of the ED. In this study, participants identified closely with the ED such that it dominated their sense of self. Existing literature has repeatedly demonstrated that people with EDs identified closely with the ED, such that there was a perceived ceding of control to the ED (Espíndola & Blay, 2009; Fox & Diab, 2015; Patching & Lawler, 2009). Participants in this study spoke at length of the sense that they were trapped or cornered by the ED but that they also needed the ED to function. In this way, the participants in this study demonstrated how EDs can become egosyntonic, where behaviours like excessive exercise, controlling food, and purging, become acceptable goals (Roncero, Belloch, & Treasure, 2013; Vitousek, Watson, & Wilson, 1998). It is noteworthy that participants had conflicted relationships with their ED identity. For some the ED helped develop a sense of self while others used the ED as a source of power. Conversely, some participants felt that the ED was always a part of their identity. For still others there was a sense of alienation from the self or others. These complex relationships have only been partially covered by the literature, which showed that people with EDs both loved and hated their ED (Fox & Diab, 2015) and desired the ED because of the integral purposes it served to the self and despite the pain and distress it caused (Lavis, 2015). This study suggests that the complexity of the relationship between the ED identity and the self extended beyond the love-hate dyad and into feelings like isolation and superiority.

Participants characterized the ED as being separate from the self, both as a means of maintaining distance from it and as a means of giving the ED an identity of its own. The ED was spoken about both as an unwanted guest and a co-conspirator, suggesting various

degrees of acceptance felt toward the disorder. Participants also framed themselves as being taken over by the ED, describing the experience in ways that suggested feelings of being lost and disoriented. Existing literature around the separation of the self from the ED is sparse. Cruzat-Mandich, Díaz-Castrillón, Escobar-Koch, and Simpson (2017) asserted that the ED became a surrogate identity that was centralized around food and body shape and that this identity overtook the authentic self. Malson and colleagues (2011), meanwhile, characterized personhood as stable and found that the ED became a stable version of the self. Here, the self was completely overtaken and supplanted by the ED. Williams and Reid (2012) found that the ED voice was a separate entity that exerted control and also acted as a companion. According to these authors, life was characterized as a struggle against the ED voice, which was both part of the self but also separate from it. The current research aligned more closely with Williams and Reid (2012), as participants spoke of being overtaken by the ED but of still retaining control of their authentic self. This research added to existing literature about the separation between the self and the ED, suggesting that there were various degrees of acceptance felt towards the ED which was still experienced as an overwhelming force. Exploration of the relationship between the ED identity and the self in future research would provide further context for the ambivalence experienced around recovery and treatment. It was not within the scope of this study to examine whether participants experienced a change in their relationship to their ED identity. Understanding how this relationship changes over time is also important because it may open new areas for treatment targeted to the needs of people as they dismantle their relationship with their ED.

7.2.1.2. Role of Identity in ED Recovery. In the same way that the ED was closely linked to identity, so too was recovery. Participants framed recovery as a personal and non-linear journey that required individual motivation for its ultimate success. ED recovery literature repeatedly demonstrated that recovery is not a stepwise process and rather, that it is

ongoing (D'Abundo & Chally, 2004; Hannon et al., 2017). Participants spoke of the adversity they faced in their recovery, which included relapse and moving through periods of acute distress. Similarly, Lindgren and colleagues, (2014) characterized recovery as moving between the poles of recovery and relapse. This research also highlighted the importance of choice in recovery, with the ultimate success of recovery depending on whether there was choice and motivation to achieve it. Previous research demonstrated that motivation for change is an important and positive prognostic factor across the recovery journey (Federici & Kaplan, 2008; Tierney, 2008a). Thus, the characterization of ED recovery in this study as being ongoing, individually motivated, and non-linear is congruent with existing literature.

There was also an identity dimension to recovery, as it was framed as requiring active work to reclaim elements of the self that had been previously lost or usurped by the ED. While the role of identity to recovery has been explored in ED literature, some elements of this study presented new perspectives. The process of identity re-organization was described as revelatory in this study. Strong language was used to convey both the sense of separation from the self and the amazement at regaining the self. There was little research that reported similar results, though Cruzat-Mandich and colleagues (2017) noted that recovery was a transformative process, facilitated by therapy, that taught a person how to recognize internal experiences like thoughts and emotions. This allowed for the successful integration of positive attributes with parts of the self that had been denied or dissociated. Some participants went through a similar transformation process, facilitated by various allied health professionals. Perhaps, the revelatory nature of identity re-organisation found in this study is related to its transformative qualities. It is important to understand how and why recovery was experienced as revelatory because it further suggests that recovery was not a simple process of symptom remission but was instead life changing. Increased understanding around

how and why this was so would assist treatment providers in how to facilitate therapy that engaged this change.

This research also found that recovery involved the reclamation of the self. In this process, aspects of the self were developed or re-discovered. The ED remained a relevant feature of the self, though it no longer exerted as much influence. McNamara and Parsons (2016) posited that, in terms of identity re-organisation, the recovery identity contained elements of the ED instead of being a return to the self that existed prior to the ED. That elements of the ED remained as a part of the recovery identity is logical given that it has been found that the loss of the ED through treatment can be felt as a loss of self (Espíndola & Blay, 2009; Fox & Diab, 2015; Malson et al., 2011). When recovery seemed impossible because it involved becoming a completely different person, the possibility of living in recovery with some aspects of the ED intact (e.g. maintaining certain rules around eating or exercise) as enduring parts of the self could perhaps be more attainable. Still, this does not entirely fit with the data found in the current study, where retention of ED features was felt with ambivalence by some participants because it was a sign that they had not progressed far enough in recovery. Others accepted lingering ED symptomology, such as preferring specific structure to their day and meals, as being part of their identity and something that also could serve as a strength. Identity re-organization in this fashion fits within the recovery model, particularly Davidson and Roe's (2007) conceptualisation of being in recovery, as opposed to being recovered from a disorder. From this perspective, people with a mental illness are able to live a fulfilling life with the ongoing presence of the illness and/or the prospect of relapse. The authors explained that part of what made living in recovery possible was taking steps to minimize the harmful aspects of the illness while simultaneously taking steps to ensure that the person had a life and identity beyond the diagnosis. Participants in the current study found it was particularly important to establish an identity beyond that as a person with an

ED, identifying themselves based on their relationships to others and their career paths. This suggests that the recovery model may be an effective tool for understanding how ED identity operates in recovery.

7.2.2. Implications of Interpersonal Connection Theme

The current study added to existing research on the complexity of negotiating relationships during the recovery journey. Results from this study demonstrated the positive and negative effects that interpersonal relationships could have on ED recovery. Existing literature demonstrated that close interpersonal relationships can negatively affect recovery, especially when they are a source of criticism or pressure (Arthur-Cameselle & Quatromoni, 2014) or when they fail to appreciate the seriousness and complexity of an ED diagnosis (Dimitropoulos, McCallum, Colasanto, Freeman, & Gadalla, 2016). For participants in this study, perceived lack of support and understanding in close interpersonal relationships led to emotional isolation, strict boundary management, and an increased use of the ED for coping. These findings are congruent with extant literature, which found that people with EDs perceived family members as being over-concerned with the food and weight-restoration (Linville, Brown, Sturm, & McDougal, 2012) and that they did not understand the ED (Federici & Kaplan, 2008).

In the current study, interpersonal relationships also exerted a positive influence on recovery by being a source of encouragement and accountability to people with EDs. For participants, support extended beyond practical elements (e.g. transportation, monetary assistance) and was considered especially valuable when it included open communication and empathy. This finding was supported by existing literature, which repeatedly showed that those in ED recovery valued people who provided unconditional, positive support and concern (Arthur-Cameselle & Quatromoni, 2014; Federici & Kaplan, 2008; Patching & Lawler, 2009). Interviewed participants with children felt that their role as a mother had a

positive influence on their recovery because they felt protective of their children and developed an increased sense of responsibility. The role of pregnancy and children as motivators for recovery has been established in previous research (Taborelli et al., 2015; Tierney, Fox, Butterfield, Stringer, & Furber, 2011; Tuval-Mashiach, Ram, Shapiro, Shenhav, & Gur, 2013). Women rationalised the need to reduce ED behaviours in order to protect their unborn babies and to continue putting the needs of their children ahead of their own (Tierney et al., 2011; Tuval-Mashiach et al., 2013). While some women found this change in identity to be empowering or even a respite from their ED, others experienced tension between wanting to return to ED behaviours, especially during times of stress (Taborelli et al., 2015). This tension between the demands of motherhood and the demands of the ED was noted in the current study, where caring for children at the cost of ED behaviours was not without emotional complications. Participants described periods of depression, low self-esteem, and suicidal ideation related to making the choice to care for their children at the cost of the ED. There is evidence to suggest that women with EDs struggle with maternal adjustment in the first three months post pregnancy (Koubaa, Hällström, & Hirschberg, 2008). In the current study, despite difficulties, motherhood was experienced as net positive influence.

The interview data demonstrated that people with EDs strategically managed complex relationships across their recovery journey. Participants reported feeling misunderstood and that, consequently, they felt the need to establish emotional and psychological boundaries with their family members. This experience of feeling stigmatized within the family unit has been identified in recent qualitative literature (Clíodhna, Niamh, Lesley, Megan, & Fiona, 2019; Rich, 2006). Stigma was experienced negatively to the point of being fearful of seeking treatment because of how one would be perceived by family members (Becker, Hadley Arrindell, Perloe, Fay, & Striegel-Moore, 2009; Reyes-Rodriguez, Ramírez, Davis, Patrice,

& Bulik, 2013). Internalized stigma predicted increased alienation and social isolation, which was in turn associated with symptom severity (Griffiths, Mitchison, Murray, Mond, & Bastian, 2018). The relationship between internalized stigma, alienation, and symptom severity suggested the critical role that interpersonal relationships could play in the maintenance of and recovery from EDs. The literature also noted that people with EDs actively resisted internalizing the corrosive effects of stigma, especially those in recovery (Griffiths, Mond, Murray, Thornton, & Touyz, 2015). These efforts of stigma resistance were closely aligned with the results of this study, because they describe the mental processes and behaviours enacted by a person as they work to counteract stigma. Behaviours such as reducing contact with family members and thought processes like creating emotional distance from parents who did not understand the ED diagnosis were a means of decreasing contact with stigmatizing beliefs. As Rich (2006) noted, when a person with an ED was stigmatized, such as when family members interrogated their food intake or weight, they were being primarily understood through a biomedical perspective. This favouring of the physical aspects of the disorder isolated people with EDs from sharing other aspects of their experiences. These interviews added to the literature demonstrating how people with EDs managed the complexities of interpersonal relationships, which can impact their recovery.

7.2.3. Implications of Perceptions of Treatment Theme

In the current study it was found that treating professionals depended heavily on the biomedical model in their diagnosis of EDs and ED recovery. This dependence on a biomedical model negatively affected recovery because it reinforced inaccurate and stigmatizing stereotypes about EDs, which further reinforced the ED identity. The results of these interviews concur with similar studies, which also found that people faced treatment that reinforced weight-based definitions of EDs and recovery (Bannatyne & Stapleton, 2018; LaMarre & Rice, 2016; Lord et al., 2018; Malson et al., 2004; Rance, Moller, & Clarke,

2017; Tierney, 2008b). Similar to the results of the current study, previous research found that when treatment and recovery depended on a mono-perspective like the biomedical model, the scope of practice was limited because the people receiving treatment felt that their individuality within the ED was not recognized (Bannatyne & Stapleton, 2018; Malson et al., 2004). It also created difficulties for people leaving treatment because it promoted a problematic relationship with food and control. This problematic relationship was created because, from a biomedical perspective, following a meal plan was considered compliance (LaMarre & Rice, 2016). Moving into recovery involved an expectation of needing less control over meals (Boughtwood & Halse, 2008; LaMarre & Rice, 2016). So, while treatment provided structure, this structure was limited by its biomedical nature, which was observed in the results of this study. Participants in the interviews noted feeling like they needed to meet certain weight criteria to qualify for treatment and that once they began receiving inpatient treatment, it focused on food intake and weight gain. This came at the cost of examining underlying issues and comorbid disorders.

Participants in the interviews suggested that treatment was more effective when other aspects of the ED, such as the emotional and social, were addressed and that it was also more effective when it was specialized to people with EDs. This meant that underlying causes were addressed along with the presenting symptoms. That treatment should address the whole person has been suggested in previous qualitative literature. Both Krentz and colleagues (2005) and Federici and Kaplan (2008) found that it was necessary to address emotional regulation as a part of treatment because it assisted in integrating and processing emotions and was associated with overall positive change. Supportive relationships have been raised a number of times as being important to recovery (Arthur-Cameselle & Quatromoni, 2014; Hay & Cho, 2013; Matusek & Knudson, 2009). Hay and Cho (2013) noted that because interpersonal relationships could be the tipping point in a person committing to recovery,

using therapeutic approaches, like interpersonal therapy (IPT), that focused specifically on improving relationship quality could be effective. Matusek and Knudson (2009) suggested that recovery was supported by building relationships with spiritual, political, and similar communities and that this could be facilitated in therapy. Being involved in communities unrelated to the ED was found to build an identity separate from the ED and so it was suggested that these relationships could be encouraged as a part of treatment. It is curious to note that there exists such a robust body of literature demonstrating that people with EDs consistently struggle with the model under which their disorders and recovery have historically been defined and treated without any change in the treating field to this model. This research supports existing research that suggests that the existing biomedical model of treatment is not wholly effective for treating people with EDs.

7.2.3.1. Perceptions of Effective Treatment. In this study, participants found that treatment was most effective when it was specialized to meet the unique needs of people with EDs. This finding is in agreement with extant literature, which has demonstrated that, due to the complex nature of EDs, care was more effective when it was provided by a team that has been trained to manage both the psychological and physical presentations (Hay, et al, 2014; NICE, 2017; Yager et al., 2006). While people with EDs wanted their treating professionals to be knowledgeable in the treatment of EDs (Arthur-Cameselle & Quatromoni, 2014; Rance et al., 2017), they also expected professionals to be confident with this knowledge (Gulliksen et al., 2012) and to be humble about gaps in their knowledge (Oyer, O'Halloran, & Christoe-Frazier, 2016). In the current study specialized treatment was characterised as the point at which recovery could truly commence. It was also in specialized treatment that participants described the importance of basic therapeutic microskills to treatment and recovery, such as being empathic, validating, and providing encouragement. The effective use of these skills by any allied health professional helped to build a strong

therapeutic alliance, which increased commitment to the treatment process. The effectiveness of therapeutic microskills in ED treatment has been well demonstrated in the literature (Gulliksen et al., 2012; la Rie, Noordenbos, Donker, & van Furth, 2006; Oyer et al., 2016; Sibeoni et al., 2020). While the complexity of working with people with EDs has been readily acknowledged in this literature, the importance of being empathetic, using a strengths-based approach, having a warm and inviting therapeutic space, and employing shared decision making were also found to be effective skills for allied health professionals (Oyer et al., 2016; Sibeoni et al., 2020). However, Graham, Tierney, Chisholm, and Fox (2020) found that allied health professionals perceived limitations in their ability to work with people with EDs because they had to provide care in a setting that often did not end in immediate recovery. The authors noted that this created a sense of cognitive dissonance for professionals who were accustomed to providing treatment within a model where illnesses had a cure. This dissonance along with stigmatizing beliefs and negative judgements about the client group, were some of the factors that made work with people with EDs complex (Graham et al., 2020). For some professionals, it was difficult to provide unconditional positive regard under these morally conflicted circumstances. Further education and supervision for professionals would ensure that such moral conflict was supported in the workplace and maintaining focus on treating people with EDs effectively.

7.2.3.2. Perceptions of Ineffective Treatment. Participants in this study were acutely aware of treatment that focused too intently on the physical aspects of recovery, as they found it to be ineffective. While they understood symptom remission to be important to recovery, without addressing the psychological issues that supported the ED, participants felt that treatment did not address the matters at the core of the disorder. The effect of an unbalanced focus in treatment has been documented in the qualitative literature, which found that people receiving treatment wanted to be seen as a whole person during treatment, instead

of being judged based on their management of symptoms alone (Rance et al., 2017).

Musolino and colleagues (2016) suggested that treatment focused on symptom remission alone would inevitably be a failure for both the person receiving treatment and the clinician because it was over concerned with need for control over the body and the client. This created a dynamic where the client was often perceived as unmotivated, hostile, and oppositional to treatment without taking into consideration their lived experience of depending on the ED symptoms for self-care. Clinicians, meanwhile, focused on their inability to reinforce the rules and requirements of treatment (Musolino et al, 2016).

Participants in the current study noted experiences with this dynamic, such as when they felt they had to meet physical requirements to be eligible for treatment. These requirements ignored the emotional and psychological suffering that the participants endured because the benchmark for treatment did not include these elements. This reinforced physical stereotypes about EDs and made treatment into an aversive experience that was also felt as a means of social control. Tierney (2008b) discussed such difficulties, explaining that an unbalanced focus in ED treatment meant that people ate their way out of treatment and then promptly relapsed because the underlying psychological issues were never addressed. Participants in this study described similar experiences to the results of Tierney's (2008b) study and to results of the OFG, where participants also found it was necessary for treatment to address the ED's underlying issues. For participants in the interviews, repeated experiences with treatment that did not address these issues undermined their trust in treatment.

This study found that successive negative experiences with allied health professionals and treatment influenced trust and engagement in future treatment. The wide variety in negative experiences described ranged from abusive to being misunderstood and stigmatized to being treated by ill-equipped staff. In the current study, trust was central to all therapeutic relationships. For participants, this understanding was developed due to the number of lasting

therapeutic encounters that lacked trust. Smith and colleagues (2016) similarly found that help seeking among people with AN was influenced by how much trust they had in the allied health professionals. Boughtwood and Halse (2008) found that young women being treated for AN were observant of the quality of the therapeutic relationship between themselves and the treating staff. According to the authors, the young women felt that they were more attendant to the relationship than staff were. Similar to the participants in the current study, the inattentiveness of staff contributed to wariness of and resistance to treatment. The results of the current study suggested that people receiving treatment were keenly attuned to the quality of the therapeutic relationship and that it had an impact on their overall outcome.

In this study, the effects of negative treatment experiences ranged from avoiding treatment, to dropping out of treatment, to being selective about allied health professionals. These effects are supported in the literature (Bannatyne & Stapleton, 2018; la Rie et al., 2006). The literature also raised the issue of how being negatively characterized by allied health professionals impacted the people receiving treatment. A number of studies noted that stereotypical beliefs about people with EDs persisted among treating staff, such as that they are manipulative, treatment resistant, and volatile (Bannatyne & Stapleton, 2018; Rance et al., 2017; Wright & Hacking, 2011). This perceived nihilism from staff about prognosis contributed to feelings of hopelessness and made treatment more aversive and the ED more appealing as a means of coping (Fox & Diab, 2015). A similar effect was found in the current study, where participants described instances of being ignored or misunderstood by allied health professionals, some of whom were cited as making stigmatizing statements about EDs. Pemberton and Fox (2011) explained that managing emotions during inpatient treatment for AN was difficult and sometimes resulted in clashes with staff, who misattributed patient reactions to ED symptomology. The results of the current study are in accordance with Pemberton and Fox (2011), as a similar patient-staff dynamic was described by a number of

participants. In this dynamic, staff were distrusted, described as being both easy to fool, and at times, complicit in people's desire to act on their ED. Others described staff as emotionally distant and as using a punitive approach. That the participants described this dynamic suggested that the ultimate outcome of treatment was influenced by the interaction between the client and the treating professional and that the nature of this interaction was complex. This warrants further research so that interactions between treating staff and those receiving treatment can be more effective.

7.2.4. Individual Interviews Significance

The data from the interviews had implications for how EDs are conceptualized from their development through to recovery. There were also implications for treatment. The relationship between the ED and the self was a finding of particular interest in this study. The finding that the ED was a means of self-care and control for people who needed these tools to manage complex emotions provided depth to the ED experience. It also provided context for treatment, where it may be necessary to find alternatives to the self-care and control functions that the ED has served. Further research is necessary to determine if skills based therapeutic approaches such as dialectical behavioural therapy are applicable and how effective they might be in teaching alternative self-care and control skills.

This research supported findings from the OFG study and from previous literature that recovery is ongoing, individually motivated, and non-linear. This conceptualization of ED recovery has parallels to the recovery model. The current study also found that recovery was an identity re-organization process, a finding that also has parallels to the recovery movement. Taken together this suggested that the recovery model was applicable to ED treatment and warrants further research.

The current study found that interpersonal relationships could have positive and negative effects on recovery. Of note was the role that being or becoming a mother played in

recovery. This change in roles became a source of accountability and encouragement for women with EDs. The tension inherent in this role was also noteworthy, as it came with changes to the body and stress that would previously be managed with ED behaviours. Understanding the role that motherhood played in women's lives gave depth to the recovery experience and warrants further research, as it appears to be a significant motivator for recovery. Also, of note was the means that people with EDs used to manage the effects of emotionally complex or stigmatizing relationships. That these relationships were managed as a means of maintaining recovery is a finding that warrants further research. It demonstrates the agency that people with EDs exercise during their recovery journey.

The biomedical model was perceived to have a negative effect on treatment outcome, based on the results of this study. That it was closely identified with ineffective treatment experiences was notable, especially because this fits with current research. The consistency of the biomedical model being identified as an ineffective model by those receiving treatment raises questions about its continued widespread use. This is especially poignant because the current research found successive negative experiences influenced trust and future engagement with treatment, so in the interest of ensuring the best outcomes for those who receive treatment, examining how treatment is delivered is timely. Also of note was the importance of the therapeutic relationships. These were identified as being critically important to delivering effective, specialized treatment and it was also found that people receiving treatment were closely attuned to the quality of therapeutic relationships. Ultimately, the outcome of treatment was influenced by interaction between the client and the treating professional. It is critically important to understand how people receiving treatment experience it due to the high rates of relapse and treatment drop out and so that treatment can be improved.

7.3. Overall Discussion

Both studies found that ED recovery was purposeful and ongoing. This finding has been well supported by existing literature, both within the ED and recovery fields, as discussed above. In the existing literature, ED recovery was lifelong process that was sustained with constant alertness (Federici & Kaplan, 2008) and necessitated self-determination (Lindgren, et al., 2014; Patching & Lawler, 2009; Tierney, 2008b). This definition was a close parallel to those used in recovery literature, where recovery can be conceptualized as an ongoing journey as opposed to final destination. Participants from both studies discussed feeling that, while major symptoms may have ceased, they would still have some aspects of the ED with them for the rest of their lives. This was similar to Davidson & Roe's (2007) conceptualization of being in recovery. Here, recovery was understood to be the process of living one's life with dignity and hope, while having symptoms of a mental illness and with the risk of relapse. Participants in both studies described an understanding of recovery where they were able to pursue their aspirations whilst managing various residual symptoms of an ED. For some this did include periods of relapse, while for others, it was learning how to manage the ED voice.

Another shared similarity in both studies was the identity aspect of the ED and recovery. The current studies found that the ED became a means of identity organization that could be experienced as a surrogate identity, sometimes in the form of the ED voice. The recovery process was felt as a process of identity reclamation and re-organization. This conceptualization of ED recovery aligned with existing recovery literature. Some theorists described the process as identity reclamation, suggesting that the self is momentarily lost to mental illness (Davidson & Roe, 2007). Some participants described experiencing feelings of being overwhelmed by the ED and that their recovery was a process of reclaiming power from the ED. Other writers suggested recovery was a process of uncovering the essential self, which remained consistent throughout mental illness, though connection to it or

understanding of it may be interrupted or limited during periods of mental illness (Caughey, 2011). Participants described experiences of feeling like their essential self remained intact, though at times, powerless and silent. Deegan (1996) rejected the notion that recovery was a return to normal and asserted instead that the “goal is to embrace our human vocation of becoming more deeply, more fully human” (pg 92). In the current studies, participants spoke of wanting to return to the way their life had been before their ED diagnosis but also accepting that this may not be a reality for them. For some, the unexpected lessons learned along the recovery journey were considered a hard-won benefit and a defining feature of their lives. Still, though recovery was an identity reorganization process by the samples in these studies, it was not always embraced as willingly as Deegan (1996) suggested.

Thus, these studies support the use of the recovery model in defining ED recovery. However, whether the recovery model is applicable to ED treatment overall cannot be determined based on these studies alone. Participants in these studies frequently referred to negative treatment experiences and some discussed what would have made treatment better for them. Overall, negative treatment experiences occurred when participants felt misunderstood, mischaracterized, and when they felt that they were being treated for the symptoms of the disorder rather than for the underlying causes. On the surface, the impact of negative treatment experiences and the necessity of therapeutic relationships may not appear to be related to the recovery model. However, the recovery model endorses a collaborative approach to treatment (Clossey & Rowlett, 2008; Farkas, Gagne, Anthony, & Chamberlin, 2005; Noordsy et al., 2002). For participants in the current studies, the lack of a collaborative approach was felt keenly and endorsed as way to make treatment more successful. Further, they spoke of instances when they experienced treatment delivered in a collaborative manner as being consequential to the outcome of their recovery.

The negative treatment experiences also arose from being treated under a biomedical model that perpetuated physical standards of recovery. These physical standards of recovery fed into the ED identity, instead of supporting a recovery identity. As the literature on this subject has demonstrated, a narrow focus on the physical side of recovery through symptom remission invalidated the richness of client experiences (Federici & Kaplan, 2008) and did not prepare clients for life after treatment because underlying issues were not addressed (Tierney, 2008b). Participants in the current studies felt restricted by treatment provided under a biomedical model. While the problematic nature of the biomedical model does not suggest that the recovery model must be adopted outright, it does suggest that alternatives should be considered. Participants spoke of wanting treatment that allowed them to process all aspects of the ED and to be able to express their true selves. These elements of the recovery model, namely, learning to understand and cope with their symptoms and learning about identity separate from the ED, are applicable to ED treatment (O'Connor & Delaney, 2007). An examination of ED treatment models is called for so that the people receiving care are able to feel like their needs are being met. Despite the mental health treatment being delivered under recovery model in Australia, care as it is delivered to people with EDs does not line up with the model's central principles. That participants in this research endorsed a definition of recovery that aligns with the one used by the recovery model suggested that those receiving care may be conceptually ready for a change in how their care is provided. Further examination of how policy can be changed to suit the needs of those receiving care is necessary.

The current studies found that therapeutic relationships were necessary to the success of treatment and recovery. Therapeutic benefit could be found across the spectrum of allied health professionals who provided treatment to people with EDs, however, there were also aspects of these relationships that did not support recovery. Both of the current studies found

that it was important for treating professionals to be invested in the client's care, which was demonstrated through their specialised knowledge, empathy, and validation of the client experience. A reciprocal relationship formed, where participants felt less motivated to engage in treatment when those treating them were not similarly engaged, supportive, or when the participants felt misunderstood. Previous literature explored the difficulty of providing care to people with EDs, suggesting that it is emotionally complex and draining (Graham et al., 2020). The results of the current studies supported existing literature that found that people with EDs drew significant benefit from treating professionals who were invested in their care (Colton & Pistrang, 2004; Sibeoni et al., 2020; Sly et al., 2014; Zugai, Stein-Parbury, & Roche, 2018). Such supportive relationships were key to treatment provided under a recovery model where care is collaborative. In the interest of assisting allied health professionals to improve their ability to develop these relationships, further resources should be directed towards developing training for people delivering care to those with EDs. Attention should be paid to delivering treatment to all allied health professionals, as any person in the ED treatment team can experience burnout. Training should also continue to be made available to the wider allied health community to decrease the stigma associated with them and improve professionals' ability to provide basic treatment.

Salzmann-Erikson and Dahlén (2017) described nurses who developed a therapeutic alliance with their patients by being open, caring, fair, sincere, and hopeful. The authors suggested that these principles were closely aligned with the recovery model's conceptualization of recovery being personal process of attitude, value, and identity change. Nurses who were invested in the patient's care could work collaboratively to engage them, motivate them, acknowledge their strengths, and also leave them with responsibility (Salzmann-Erikson & Dahlén, 2017). Participants in both studies spoke positively of receiving care from allied health professionals who took a similar approach and subsequently

felt more motivated to continue treatment and to work on recovery. The opposite is also true, with participants describing negative experiences with allied health professionals who were disengaged, poorly informed, and who depended on a biomedical model. Salzmann-Erikson and Dahlén (2017) found that nurses who treated patients from a rigid, biomedical model undermined recovery principle because they tended to depend on generalisations that stigmatized patients. This was supported by several studies that found one-dimensional approaches were perceived as resulting in generalisations developed from the experiences and prejudices of the treating professionals (Offord et al., 2006; Pemberton & Fox, 2011; Wright & Hacking, 2011). By contrast, treatment provided under the recovery model acknowledged the individuality of the client experience and the difficulty of this experience while encouraging growth and development (Davidson & Roe, 2007). That participants in this study had positive experiences with allied health professionals who provided care using collaborative and supportive skills again, does not immediately suggest that the recovery model will be most effective. However, the similarities do suggest that further research is warranted into the effectiveness of the recovery model as an effective tool in providing treatment.

While the applicability of the recovery model in treatment was not explicitly addressed in either the OFG or the interviews, elements of the model were nonetheless raised by the participants. Analysis suggested that the biomedical model was not meeting their needs, that a more holistic approach was necessary, and that their needs may be met by the recovery model. There was scant literature on the topic of the applicability of the recovery model to the treatment of EDs. Dawson, Rhodes, and Touyz, (2014a) found that many evidence-based treatments for AN could be used in conjunction with the recovery model because they shared similar principles. This, however, made no commentary on the applicability of the model to treatment as it is provided in a hospital-based setting or for other

ED diagnoses. Participants in the current studies noted a number of negative experiences with inpatient care that were not consistent with the recovery model, such as being told that they were too fat for someone with anorexia or having their access to basic amenities like WIFI dependent on their ability to gain weight. It has been noted that, while there is a wider societal shift towards providing recovery-oriented care in Australia (Ramon, Healy, & Renouf, 2007), there are particular difficulties with doing this. These include public and private health systems that are largely biomedical in their focus with an organisational structure that maximises efficiencies, cuts costs, and limits how resources are deployed (Dawson, River, McCloughen, & Buus, 2019a). As Dawson, River, McCloughen, & Buus (2019b) noted, while staff at hospitals may be motivated to use the recovery model within the confines of the existing system, the pressure to maximise use of time and resources limited the model's use. While the recovery model could be both time and resource heavy, it was more cost effective because it reduced service dependence, so balancing its use in a hospital setting was a matter of measuring short term versus long term costs (Buus et al., 2019). Thus, while the current research added further evidence to the suggestion that the recovery model has a role to play in ED treatment, further research is needed to demonstrate how applicable it is, both to EDs and within the Australian mental health system.

The current studies also addressed the complexity of interpersonal relationships. Relationships could have a significant effect on recovery to the extent that participants felt the need to maintain strict boundaries as means of self-preservation. The use of boundary management and the resulting isolation are relatively new areas of inquiry in ED research. Research has long focused on the how families influence the development of EDs (Konstantellou, Campbell, & Eisler, 2012). Numerous studies examined parental and family personality traits and psychopathology in relation to EDs (Amianto, Daga, Bertorello, & Fassino, 2013; Goddard & Treasure, 2013; Tafà et al., 2017). Others investigated the

relationship between parental eating behaviours and commented on the development of EDs (Berge et al., 2012; Neumark-Sztainer et al., 2010). Still others explored the role that family environment had on ED development (Berge, Loth, Hanson, Croll-Lampert, & Neumark-Sztainer, 2011; Culbert, Racine, & Klump, 2015; Lampis, Agus, & Cacciarru, 2014). While this research demonstrated that family factors were influential in the development of EDs, the ways that people coped with the stress of families has not yet been addressed in the extant literature. For example, research by Neumark-Sztainer et al. (2010) found that parents' weight talk, dieting behaviour, and weight-teasing all contributed to eating disordered behaviour. In the current studies, participants spoke of similar experiences with their parents and how this contributed to their ultimate decision to put emotional boundaries between themselves and their family members. Similarly Amianto, Ercole, Marzola, Daga, & Fassino (2015) found a number of significant relationships between parental personality and temperament traits and those of their child with a diagnosed ED, demonstrating that parents' personality traits played a complex role in the development of EDs and other psychopathology. In the current studies, participants spoke of the effect that dealing with their parents' difficult personalities had on them. While they did not expand on how they felt they had been influenced by their parents' personalities, it was noted that inflexibility and lack of understanding from parents influenced decisions to maintain firm emotional boundaries.

This research suggested that people with EDs negotiated complex emotional landscapes and had to develop a number of sophisticated coping mechanisms to do so. Another consideration was that all people face various degrees of emotional complexity in their relationships but people with EDs faced an increased level of difficulty. This was due both to the complexity of the disorder and the comorbidities that can make interpersonal relationships challenging for them (Herpertz-Dahlmann, 2015; Hudson et al., 2007), but also

due to the way that EDs impact social and emotional development (Bruch, 1973, 1978; Fox, Federici, & Power, 2012). Recovery was seen to be a process of developing emotionally and psychologically, while also being an identity development process (Davidson et al., 2012). Through recovery, people with EDs learned to handle the complexities of their relationships differently and to develop healthy boundaries based on their emotional needs. This suggested that the ED recovery process was one that may involve not only identity reclamation but also social development. This was supported in recovery literature, where social recovery was outlined as one facet of overall recovery (Jacobson & Greenley, 2001; Whitley & Drake, 2010). Thus, the applicability of the recovery model to ED treatment was further demonstrated. Further research is necessary to examine the role that interpersonal relationships play in ED recovery. Further research would also examine how therapeutic approaches can be used to assist in navigating these relationships and the skills necessary to handle them.

7.4. Chapter Summary

In this chapter, the results of first the OFG and then the individual interviews were discussed in depth. In the discussion of the OFG, the implications of the recovery is a journey theme and recovery requires the resolution of inner struggles theme related to how recovery was defined. The implications of the interpersonal theme related to how people's need for supportive relationships and the lack of these during recovery. Finally, the implications of the treatment theme related to how people felt treatment was more effective when it was specialised to EDs. In discussion of interviews, recovery was perceived to be an identity re-organisation process that encompassed the separation from the ED, which had become an intrinsic part of the self. The implications of the interpersonal connection theme discussed how people used boundaries to manage complex interfamilial dynamics. In discussing the implications of the perceptions of treatment theme, it was again demonstrated that treatment

was most effective when it specialised, both in terms of the treatment itself and the in terms of the person providing the treatment. An overall discussion of the results of both studies suggested that the recovery model may be applicable to ED recovery, stressed the importance of identity to recovery, and examined the need for specialisation and how this related creating supportive treatment.

Conclusions

Improving recovery outcomes among people with eating disorders is a central concern facing the ED field. Given the high relapse rate and long recovery period associated with EDs, determining what makes treatment and recovery successful is important. In this thesis the major aim was to understand the treatment and recovery experiences of participants with EDs and to link these experiences with perceived recovery outcomes. The results from both studies demonstrated that the recovery model was applicable to ED treatment, that people with experiences with treatment and treating professionals impacted overall outcomes, and that interfamilial relationships influenced how people managed their recovery. These substantial findings have implications for the definition of ED recovery, ED treatment, and understandings of the recovery journey.

The results of the two studies that comprise this thesis indicated that ED recovery was understood by participants to be a purposeful and ongoing process. ED recovery was also understood to be a process of identity reorganisation, where a new sense of self was reclaimed from the ED identity. There are parallels between the conceptualisations of ED recovery found here and those used by the recovery model to explain mental illness recovery that suggest that ED recovery can fit within the recovery model. Further examination of these parallels is necessary. While definitions of ED recovery have been examined at length, these have not been formally linked to the recovery model. There are points of difference between the recovery model and ED recovery that warrant further scrutiny, particularly, which symptoms may remain during recovery and how this affects ambivalence, relapse, and resilience. Recovery oriented models of care have been introduced across the mental health sector as Australia has modernised its approach to care (Ramon et al., 2007). Examining how best to implement this model for treatment of a population with specific treatment needs is necessary in order to deliver the most effective and modern care.

The results of this research suggest that treatment was hindered when people felt misunderstood, mischaracterized, and when there was an overdependence on the biomedical model. Treatment was more effective when allied health professionals were invested in therapeutic relationships. This suggested that the current system of care may not be meeting all the needs of the people who receive treatment for EDs and that there may be a gap in service provision at the professional level. The recovery model also has applications here because it encourages a collaborative approach between service users and professionals, which changes the power dynamic to be more equal than the one experienced in the biomedical model. While there has been a societal and policy shift towards the use of the recovery model in Australian mental health treatment (Ramon et al., 2007), it is not effective for the recovery model to be used by individual practitioners or specialist units, rather than by a mental health system as a whole (Dawson, River, McCloughen, & Buus, 2019a). As such, further research into viable alternatives for the biomedical model are required. Further research should include examination of the recovery model as a viable alternative to the biomedical model or at least, a model that may be used in conjunction with it. At the policy level, examination of the effectiveness of the current model of care is necessary, as is an exploration of options for integrating new models of care into the Australian health care system. It will also be important to examine the role that treatment providers play in the recovery journey, as the current research identified the importance of specialised treatment and treatment providers to overall recovery. Based on the results of these studies it was necessary for allied health professionals to have specialised training in ED treatment in order for those under their care to feel understood and ready to trust them. When allied health professionals lacked this specialist training it contributed to feeling of distrust and disengagement from treatment. To this end, examinations of both the experiences of treating professionals and those under their care are crucial. In order to understand how to provide

more effective treatment, researchers may explore how to effectively deliver training to busy allied health professionals and how to improve and maintain the wellbeing of staff who provide treatment to people with complex ED presentations. It will also be important to understand in greater depth how people with EDs experience treatment and treating professionals. Further studies of experience of care should direct more attention to using quantitative metrics as well as further use of qualitative methods.

The two studies comprising this thesis also found that overall recovery was hindered by complex interpersonal family relationships, particularly with immediate family, that needed to be managed. Recovery was helped by supportive, empathic family, friends, and partners. However, boundary management was still necessary, inclusive of limiting contacting with family members and completely cutting ties with them. Methods of managing interpersonal and interfamilial stress is a relatively novel area of inquiry, with this research suggesting that people in ED recovery had sophisticated coping mechanisms in place to manage complex interpersonal dynamics. In a field that has depended on correlational research to relate parental personality traits to ED traits, it is instructive to see how people with EDs experience and cope with the family unit. This finding is useful for understanding the development and maintenance of the ED and how treatment may be most effective. Consideration of how to support and assist family units should be included in ongoing research. Further research should examine how people with EDs and in ED recovery manage interfamilial and interpersonal stress. These findings can be applied in practice to approaches with existing research supporting their use with EDs and that focus on interpersonal skills, such as interpersonal therapy (IPT) or dialectical behavioural therapy (DBT) and to extending to improving the effectiveness of family-based therapy (FBT). Attachment focused therapies have less research supporting their use in ED treatment but some examination of their utility would help broaden treatment options.

8.1. Strengths and Limitations

The studies in this thesis were carried out with two samples comprised of people with varied ED experiences. The use of a broad recruitment strategy that disseminated study information across multiple websites and social media platforms was responsible for the samples being sizable. Sample size resulted in data for both studies being deep and rich. Using a qualitative approach for both studies allowed for a closer examination of the experiences of the participants than would usually be found in quantitative studies. The use of an online focus group (OFG) was also considered to be a strength in this thesis. By using the data from the OFG to inform the development of the questions for the individual interviews, a more detailed approach was ensured. Additionally, the OFG, using a group chat format that was familiar to most participants, was a successful method for data collection because it allowed participants to engage with one another with little social awkwardness.

There were a number of limitations to this research. While the participants represented a variety of ED experiences, the sample lacked variety. The samples recruited predominantly identified as female and white, with one Chinese participant. Participants predominantly identified as heterosexual, with only two noting same-sex relationships in their interviews. The sample of the individual interviews was also not homogenous, having a large age range. This creates difficulties in scaling the research and in developing an understanding of the experiences of people within a homogenous sample. While qualitative studies do not seek to use a representative sample, purposively sampled designs should be used in future research. Some populations for particular attention would be men, racial and ethnic minorities, sexually and gender diverse people, and people in different age brackets. The reliance on self-reporting by participants in this study is another limitation, as it meant that the researcher could not adequately confirm ED and psychiatric diagnoses. The intent of using self-reporting was to avoid an engaging in medicalised definitions of mental illness;

however, this also ignored the reality of EDs existing within a psychological and medical context that does require engaging with diagnostic criteria. Being able to both criticise medically narrow definitions of EDs while still using appropriate ED measures would have allowed the researcher to both confirm the diagnoses of the participants and to develop a clearer picture of the samples.

While the OFG was an effective means of gathering data, there was some attrition due to the duration of the group. Future OFGs will need to balance the number of participants with the possibility of attrition. A sizeable number of participants means group discussion is difficult to manage but reduces the problems of attrition, while a moderate number of participants makes discussion easier to mediate but increases problems of attrition. The use of a second researcher participating in the group would be beneficial in managing group discussion. The use of a focus group as a method of gathering data is another potential limitation, as there can be an overall convergence of the opinion towards the one shared by the majority or by vocal group members. It is possible that OFG participants influenced each other in their opinions and that some participants were more reticent to engage when faced with an enthusiastic and vocal majority. In the OFG, this could have been mediated by using more structure in the session to ensure each participant had the opportunity to voice their opinion. For example, each participant could be asked to submit their response anonymously; subsequently, these responses would be used to begin discussion. Alternatively, rather than using an OFG, another method could have been used, such as an open-ended questionnaire.

The coding in this study was carried out by the author without a participant consensual validation procedure in place. This was due to the volume of work that such a procedure would have required. Had such a procedure been in place, it would have added to the trustworthiness of the coding procedure. In the case of this thesis, the coding procedure was checked at regular intervals by the thesis supervisors to ensure its integrity. This was in

line with supervisory and analysis guidelines. However, the substantial findings of this thesis have implications for the clarification of the definition of ED recovery, understandings of the ED recovery journey, and changes to ED treatment in Australia.

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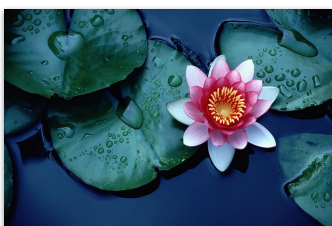
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Appendix A

OFG Flyer

Are you in recovery from an eating disorder?



Discuss your recovery experience!

Two studies are being carried out by researchers from Monash University into the experience of recovery.

These studies aim to expand the understanding of recovery and to improve treatment outcomes for people with eating disorders.

We are seeking the input of people:

- ▶ Who have a previous eating disorder diagnosis
- ▶ Who have received treatment for their eating disorder
- ▶ Who consider themselves to be in eating disorders recovery
- ▶ Who are 18 years or older
- ▶ Who are not currently experiencing suicidal ideation or self-harming

Ways to get involved

Your feedback is extremely valuable. Your participation in one study or the other would be greatly appreciated.

Online Focus Group

- ▶ Open to English speaking participants Australia-wide
- ▶ Recruitment beginning xxxx 2016
- ▶ Group will last up to 2 hours on one day; can be accessed on computers and tablets
- ▶ Will ask questions about your eating disorder experience, treatment, medical and mental health history, and recovery
- ▶ Participants can opt to enter a drawing for a \$30 Coles/Meyer gift card for participating

One on one interviews

- ▶ Open to Australian participants, preferably in Melbourne region but interviews can be arranged over Skype
- ▶ Recruitment beginning xxxx 2016
- ▶ Interviews will be one hour long and will be audio recorded
- ▶ Will ask questions about your eating disorder experience, treatment, medical and mental health history, and recovery.
- ▶ Participants will receive \$20 Coles/Myer gift card for participation

Please contact Capella Meurer if you are interested in participating

Primary researcher: Capella Meurer
capella.meurer@monash.edu

Supervisor: Dr Janette Simmonds
janette.simmonds@monash.edu

Appendix B

OFG Explanatory Statement

EXPLANATORY STATEMENT

Eating Disorders Recovery Experiences

Online Focus Group

Project Title: Recovery and treatment experience among people with eating disorders

Project Number: CF16/2161 - 2016001050

<p>Capella Meurer (primary researcher) Faculty of Education, Psychology Programs Monash University 29 Ancora Imparo Way Monash University VIC 3800 Phone: 9902 4874 Email: capella.meurer@monash.edu</p>	<p>Dr Janette Simmonds Faculty of Education, Psychology Programs Monash University 29 Ancora Imparo Way Monash University VIC 3800 Phone : 9905 2902 Email: janette.simmonds@monash.edu</p>
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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the email addresses listed above.

What does the research involve?

In this study we will be examining the experience of eating disorders recovery as it is told by people who have lived it. People who have been diagnosed with an eating disorder and who consider themselves to be in recovery will meet in an online focus group to discuss, together, how their recovery was impacted by various factors within and outside of themselves. This discussion will involve questions about your mental health, as well as your medical and treatment history; you may choose to reveal as much or as little about this history as they wish. A transcript will be analysed to form a more comprehensive picture of how people with eating disorders experience recovery.

The online focus group (OFG) will take place one day for up to two hours. You will be asked to complete an initial demographic survey, two screening questionnaires, a registration form, and respond to questions throughout this time period and interact with each other in the OFG. The demographic survey will be anonymised and will ask questions about your treatment and medical health history. The registration form will ask for your e-mail address, an alias of your choice, and an emergency contact number that you can be reached at for the duration of the group. This is to ensure that there is a means of contacting you if an emergency arises during the course of the OFG.

Completing the online registration will take up to 20 minutes and participation in the OFG will take up to two hours. There may be a gap of up to two weeks between registration for the OFG and commencement of the group while recruitment takes place. Participants will receive reminders a week, three days, and on the day of the OFG. The OFG will be

conducted online and will not require the installation of any new software on your computer or tablet.

Why were you chosen for this research?

You opted into this study after finding an online advertisement. You opted into the study because you consider yourself to be in eating disorder recovery and you do not currently have any active suicidal ideation. You are older than 18 years of age.

Consenting to participate in the project and withdrawing from the research

(i) In order to participate in this study you will need to complete a digital consent form, which has been included with this e-mail. Completing the consent form will give you access to the OFG.

(ii) You may withdraw from the study within two weeks of the completion of the OFG by sending the primary researcher an e-mail stating that you wish to do so. There are no penalties for withdrawing from the OFG.

(iii) If you wish your responses to either the survey or the OFG to be withdrawn, you must notify the primary researcher by e-mail within two weeks of the completion of the OFG. They will be removed from the record at no penalty to you or the study.

Possible benefits and risks to participants

Benefits to participants and society:

- Opportunity to discuss experience of recovery.
- Chance to contribute positively to eating disorders recovery research.
- Improved overall understanding of how people with eating disorders experience recovery.
- Improved understanding of recovery, which can be applied to improving treatment outcomes among people with eating disorders.

Potential inconvenience/discomfort to participants:

- Discussion of uncomfortable or confronting topics surrounding eating disorders recovery.

Potential risks to participants:

- There is a risk of psychological discomfort through exposure to difficult and confronting topics, which may contribute to thoughts of relapse or suicidal ideation if you are not secure in your recovery at the present time. The risk of this is low but is still possible. Please assess where you are in your recovery to determine if you feel able to participate in this study.
- There is a very slight risk of confrontational encounters with other participants if the OFG discussion becomes heated. This may be distressing and uncomfortable. The primary researcher will be overseeing the discussion to ensure that they are kept civil. Please assess where you are in your recovery to determine if you feel able to engage with potentially unpredictable strangers in the OFG.

Emergency contact information:

Your phone number will be requested to participate in this study. The primary researcher will only use this number to contact you if there is a concern for your welfare. The primary researcher will ensure that your phone number is kept private and will not retain it after the completion of the study.

Services on offer if adversely affected

Crisis information will be available throughout the course of the OFG.

- Butterfly foundation support line: 1800 ED HOPE / 1800 33 4673
- Lifeline: 13 11 14

Payment

Participants will be entered into a drawing win a \$30 Coles/Myer gift card for their participation in the study. Participants may choose not to enter into the drawing.

Confidentiality

When you join the OFG, you will be asked to register under a pseudonym to ensure that your confidentiality within the group is maintained. Once the group is finished, the pseudonym will be changed to a randomly generated code, which will be used to identify your responses within the OFG. This code will not be linked with your e-mail or the pseudonym you chose; these will be removed from the record of the OFG upon its completion. All identifying information in responses made in the OFG will be changed to ensure that your confidentiality is maintained throughout.

All data gathered from the demographic survey will similarly be coded using a random code that will not be linked to any identifying information arriving with the data.

Any academic publications using this response from the OFG or the survey data will use codes and will not provide any identifying information. Quotes may be used from the OFG but no identifying information will be used, so the quotes will not be identifiable.

Storage of data

Data in this study is considered to include the responses to the demographic surveys, questionnaires and the responses made during the OFG.

The data from the demographic surveys and questionnaires will be downloaded from the survey software provider, Qualtrics, and will be stored on the primary researcher's Google Drive account.

The data from the OFG will be downloaded from iTracks servers and will similarly be stored on the primary researcher's Google Drive account. The data will be retained by iTracks, per their data retention policy, for 2 years, after which it will be deleted. Only the primary researcher will have access to the data on the iTracks servers and she will be notified prior to its destruction.

The data will be retained after the completion of the primary researcher's PhD to be used in further research into recovery. If you do not wish for your data to be retained, please notify the primary researcher and your data will be removed from the set and deleted and not used in any subsequent studies.

Use of data for other purposes

Data from this study will be retained for further research on recovery. The data will be retained with the de-identified codes and so will not be traced back to you. This data will only be used for other projects when an ethics board gives approval.

Results

Participants may choose to receive copies of any academic articles written using data from the OFG. The papers are expected to be published within the next two years. An option for receiving these copies is included on the consent form.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer Monash University Human Research Ethics Committee (MUHREC) Room 111, Building 3e Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905 3831	
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Thank you,

Appendix C

OFG Consent Form

CONSENT FORM

Online Focus Group

Project: Recovery and treatment experience among people with eating disorders

Chief Investigator: Dr Janette Simmonds

Student Investigator: Capella Meurer

Co-Investigator: Dr Tristan Snell

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
To complete a demographic survey and questionnaires on the areas of physical health, mental health, eating disorders, and treatment history.		
To take part in an online focus group of up to 12 people.		
To allow a digital record of my data from the online focus group to be retained for use by the student researcher, Capella Meurer, for the duration of her PhD research.		
To allow my data to be retained after the completion of this study for use in further research by the student researcher, Capella Meurer.		
To provide my phone number as an emergency contact number to be used by the student investigator to contact me if there are concerns for my wellbeing during the course of this study.		

Results of the Study

If you wish, you can be sent copies of any academic articles resulting from this study. They will be published within the next two years. If you would like to be receive copies of these articles, please provide your e-mail here: _____

Participant Name: _____

Participant Signature: _____ Date: _____

Participant Phone Number: _____

Appendix D
Demographic Survey

1. How old are you? _____
2. How old were you when you were first diagnosed with an eating disorder?

3. What are your primary diagnoses? _____
4. What are your secondary diagnoses, if applicable? _____
5. Are there any other diagnoses in your history that you feel are important? _____
6. How long do you consider yourself having being in recovery?

7. Have you ever received any treatment for your eating disorder? Treatment is defined as seeing a psychologist, GP, dietician, social worker, or attending specialised treatment at a hospital or clinic.
☐ Yes
☐ No
8. What kind of treatment have you received for your eating disorder? Check all that apply
☐ Psychologist
☐ Dietician
☐ Psychiatrist
☐ GP
☐ Social Worker
☐ Spiritual leader
☐ Inpatient program
☐ Outpatient program
☐ Day program
☐ Group program
☐ Online support group
☐ Other
9. Have you received treatment in any of the following settings for your eating disorder?

- Private psychological practice
- Inpatient specialist eating disorders program
- Outpatient specialist eating disorders program
- Outreach specialist eating disorders program
- Day specialist eating disorders program
- Inpatient general psychiatric ward

Appendix E

Demographic Survey Follow-Up Questions

- 1) How likely is it that you would act on your most recent suicidal thoughts?
- 2) In relation to suicidal thoughts or attempts when did each last occur (as applicable)?
- 3) Currently, do you have one or more people that you would tell if you thought that your suicidal thoughts were a risk?

Appendix F

STORI

The following questionnaire asks about how you feel about your life and yourself since the illness. Some of the questions are about times when you don't feel so good. Others ask about times when you feel pretty good about life.

If you find some of the questions upsetting, and you need to talk to someone – please take a break and talk to a friend or support person.

**The questions are in groups of five.
Read all five questions in a group, and then answer those five questions.
Circle the number from 0 to 5 to show how much each statement is true of you now.
Then move on to the next group.**

When you choose your answer, think about how you feel now, not how you have felt some time in the past. For example:

Q.43 says "I am beginning to learn about mental illness and how I can help myself."

Q.44 says "I now feel reasonably confident about managing the illness."

If you are now fairly confident about managing the illness, you would give a higher score to Q.44 than you would to Q.43, which says you are just *beginning* to learn.

**The questions are about how you feel about your life *on the whole* these days.
Try not to let things that might be affecting your mood just at the moment affect your answers.**

STORI

Read all 5 questions in Group 1, then answer those five questions.

Circle the number from 0 to 5 that shows how much each statement is true of you *now*. Then move on to Group 2, and so on.

When you choose your answer, think about *how you feel now*, not how you have felt in the past.

Group		Not at all true now			Completely true now		
1	I don't think people with a mental illness can get better.	0	1	2	3	4	5
2	I've only recently found out that people with a mental illness <i>can</i> get better.	0	1	2	3	4	5
3	I am starting to learn how I can help myself get better.	0	1	2	3	4	5
4	I am working hard at staying well, and it will be worth it in the long run.	0	1	2	3	4	5
5	I have a sense of "inner peace" about life with the illness now.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
6	I feel my life has been ruined by this illness.	0	1	2	3	4	5
7	I'm just starting to realise my life doesn't have to be awful forever.	0	1	2	3	4	5
8	I have recently started to learn from people who are living well in spite of serious illness.	0	1	2	3	4	5
9	I'm starting to feel fairly confident about getting my life back on track.	0	1	2	3	4	5
10	My life is really good now, and the future looks bright.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
11	I feel like I'm nothing but a sick person now.	0	1	2	3	4	5
12	Because others believe in me, I've just started to think maybe I can get better.	0	1	2	3	4	5
13	I am just beginning to realise that illness doesn't change who I am as a person.	0	1	2	3	4	5
14	I am now beginning to accept the illness as part of the <i>whole person</i> that is me.	0	1	2	3	4	5
15	I am happy with who I am as a person.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
16	I feel as though I don't know who I am any more.	0	1	2	3	4	5
17	I have recently begun to recognise a part of me that is not affected by the illness.	0	1	2	3	4	5
18	I am just starting to realise that I <i>can</i> still be a valuable person.	0	1	2	3	4	5
19	I am learning new things about myself as I work towards recovery.	0	1	2	3	4	5
20	I think that working to overcome the illness has made me a better person.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
21	I'll never be the person I thought I would be.	0	1	2	3	4	5
22	I've just begun to accept the illness as part of my life I'll have to learn to live with.	0	1	2	3	4	5
23	I am starting to figure out what I am good at and what my weaknesses are.	0	1	2	3	4	5
24	I'm starting to feel that I am making a valuable contribution to life.	0	1	2	3	4	5
25	I am accomplishing worthwhile and satisfying things in my life.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
26	I am angry that this had to happen to <i>me</i> .	0	1	2	3	4	5
27	I'm just starting to wonder if some good could come out of this.	0	1	2	3	4	5
28	I am starting to think about what my special qualities are.	0	1	2	3	4	5
29	In having to deal with illness, I am learning a lot about life.	0	1	2	3	4	5
30	In overcoming the illness I have gained new values in life.	0	1	2	3	4	5

Group		Not at all true now			Completely true now		
31	My life seems completely pointless now.	0	1	2	3	4	5
32	I am just starting to think maybe I <i>can</i> do something with my life.	0	1	2	3	4	5
33	I am trying to think of ways I might be able to contribute in life.	0	1	2	3	4	5
34	These days I am working on some things in life that are personally important to me.	0	1	2	3	4	5
35	I am working on important projects that give me a sense of purpose in life.	0	1	2	3	4	5

Group		Not at all			Comple		
		tely			true		
		true now					
		now					
36	I can't do anything about my situation.	0	1	2	3	4	5
37	I'm starting to think I could do something to help myself.	0	1	2	3	4	5
38	I am starting to feel more confident about learning to live with the illness.	0	1	2	3	4	5
39	Sometimes there are setbacks, but I come back and keep trying.	0	1	2	3	4	5
40	I look forward to facing new challenges in life.	0	1	2	3	4	5

Group		Not at all			Comple		
		tely			true		
		true now					
		now					
41	Others know better than I do what's good for me.	0	1	2	3	4	5
42	I want to start learning how to look after myself properly.	0	1	2	3	4	5
43	I am beginning to learn about mental illness and how I can help myself.	0	1	2	3	4	5
44	I now feel reasonably confident about managing the illness.	0	1	2	3	4	5
45	I can manage the illness well now.	0	1	2	3	4	5

Group		Not at all			Comple		
		tely			true		
		true now					
		now					
46	I don't seem to have any control over my life now.	0	1	2	3	4	5
47	I want to start learning how to cope with the illness.	0	1	2	3	4	5
48	I am just starting to work towards getting my life back on track	0	1	2	3	4	5
49	I am beginning to feel responsible for my own life.	0	1	2	3	4	5
50	I am in control of my own life.	0	1	2	3	4	5

Appendix G

SBQ-R



Id/Name: _____ **Gender:** Male Female **Age:** _____

Ethnic Background (Please check only ONE):

- | | |
|---------------------------|---|
| _____ 1. Caucasian/ White | _____ 4. Hispanic/Latino American |
| _____ 2. African American | _____ 5. American Indian/ Alaska Native |
| _____ 3. Asian American | _____ 6. OTHER (Specify _____) |
| | _____ 7. Biracial(_____) |

Education (Please check only ONE)

High School: ___9th/ 10th grade ___11th Grade ___12th Grade ___High School Grad/GED

College: ___ Freshman ___ Sophomore ___ Junior ___ Senior/Graduate

Marital Status (Please check only ONE)

- | | | | |
|-------------------------------|--------------------------|--------------------|-------------------|
| _____ 1. Single | _____ 2. Married | _____ 3. Separated | _____ 4. Divorced |
| _____ 5. Engaged _____ months | _____ 6. Live-in partner | | |

SBQ-R

Instructions: Please circle the number beside the statement or phrase that best applies to you.

1. **Have you ever thought about or attempted to kill yourself? (Circle only one):**

1 = Never

2 = It was just a brief passing thought

3a = I have had a plan at least once to kill myself but did not try to do it

3b = I have had a plan at least once to kill myself and really wanted to die

4a = I have attempted to kill myself, but did not want to die

4b = I have attempted to kill myself, and really hoped to die

2. **How often have you thought about killing yourself in the past year? (Circle only one):**

1 = Never

2 = Rarely (1 time)

3 = Sometimes (2 times)

4 = Often (3-4 times)

5 = Very Often (5 or more times)

3. **Have you ever told someone that you were going to commit suicide, or that you might do it? (Circle only one):**

1 = No

2a = Yes, at one time, but did not really want to die

2b = Yes, at one time, and really wanted to do it

3a = Yes, more than once, but did not want to do it

3b = Yes, more than once, and really wanted to do it

4. **How likely is it that you will attempt suicide someday? (circle only one):**

0 = Never

3 = Unlikely

5 = Rather Likely

1 = No chance at all

4 = Likely

6 = Very Likely

2 = Rather Unlikely

Appendix H

Recruitment Organisations

Online Organisations

- ‘The Science of Eating Disorders’ blog (<http://www.scienceofeds.org/>)
- Recovery Warriors website/blog/podcast (<https://www.recoverywarriors.com>)

Peak Organisations and Service Providers

- The Victorian Centre of Excellence in Eating Disorders (CEED)
- Australian and New Zealand Academy for Eating Disorders (ANZAED)
- National Eating Disorders Collaboration (NEDC)
- Butterfly Foundation

Monash University Based

- Monash Post Graduate Association (MPA) newsletter

Appendix I

Individual Interview Flyer

Are you in recovery from an eating disorder?



Discuss your recovery experience!

A study is being carried out by Monash University into the experience of recovery.

This study will use one on one interviews to explore treatment and recovery experiences among people with eating disorders.

We are seeking the input of people:

- ▶ Who have a previous eating disorder diagnosis
- ▶ Who have received treatment for their eating disorder
- ▶ Who consider themselves to be in eating disorders recovery
- ▶ Who are 18 years or older
- ▶ Who are not currently experiencing suicidal ideation or self-harming

One on one interviews

- ▶ Open to Australian participants, preferably in Melbourne region but video interviews can be arranged
- ▶ Recruitment beginning June 2018
- ▶ Interviews will be one hour long and will be audio recorded
- ▶ Will ask questions about your eating disorder experience, treatment, medical and mental health history, and recovery.
- ▶ Participants will receive \$20 Coles/Myer gift card for participation

Please contact **Capella Meurer** if you are interested in participating

Primary researcher: Capella Meurer
capella.meurer@monash.edu

Supervisor: Dr Janette Simmonds
janette.simmonds@monash.edu

Ways to get involved

Your feedback is extremely valuable. Your participation would be greatly appreciated.

Appendix J

Individual Interviews Explanatory Statement

EXPLANATORY STATEMENT

Eating Disorders Recovery Experiences Interviews

Project Title: Recovery and treatment experience among people with eating disorders

Project Number:

Capella Meurer (primary researcher)

Faculty of Education, Psychology Programs
Monash University
29 Ancora Imparo Way
Monash University VIC 3800
Phone: 9902 4874
email: capella.meurer@monash.edu

Dr Janette Simmonds

Faculty of Education, Psychology
Programs Monash University
19 Ancora Imparo Way
Monash University VIC 3800
Phone : 9905 2902
email: janette.simmonds@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

In this study we will be examining the experience of eating disorder recovery as it is told by people who have lived it. People who have been diagnosed with an eating disorder and consider themselves to be in recovery will be asked to meet the primary researcher for an interview. In this interview, you will be asked to discuss your recovery experience and the factors within and outside yourself that have impacted recovery. This discussion will involve questions about your mental health, medical, and treatment history; you may choose to reveal as much or as little as you wish. A transcript of the discussion will be analysed to form a more comprehensive picture of how people with eating disorders experience recovery.

You will be asked to meet the primary investigator at a mutually agreeable public location for an interview. If no mutually agreeable location can be arranged, the interview may be conducted over Skype. The interview will last roughly an hour in length and will be recorded. You will also be asked to complete two questionnaires and a short demographic survey prior to the interview. These will ask questions about your treatment and physical and mental health history.

Why were you chosen for this research?

You opted into this study after responding to an online advertisement.

Consenting to participate in the project and withdrawing from the research

(i) In order to participate in this study you will need to complete a digital consent form, which has been included with this e-mail. If you cannot complete this digital consent form, a hardcopy will be provided at the time of the interview.

(ii) You may withdraw from the interview within two weeks of completion by notifying the primary researcher that you no longer want to participate. The interview will be halted at no penalty to you or the study.

(iii) If you wish your response to either the survey or the interview to be withdrawn, you must notify the primary researcher by e-mail within two weeks of the completion of the interview. They will be removed from the record at no penalty to you or the study.

Possible benefits and risks to participants

Benefits to participants and society:

- Opportunity to discuss experience of recovery.
- Chance to contribute positively to eating disorders recovery research.
- Improved overall understanding of how people with eating disorders experience recovery.
- Improved understanding of recovery, which can be applied to improving treatment outcomes among people with eating disorders.

Potential inconvenience/discomfort to participants:

- Discussion of uncomfortable or confronting topics surrounding eating disorders recovery.

Potential risks to participants:

- There is a risk of psychological discomfort through exposure to difficult and confronting topics, which may contribute to thoughts of relapse or suicidal ideation if you are not secure in your recovery at the moment. The risk of this is low but still possible. Please assess where you are in your recovery to determine if you feel able to participate in this study.

Services on offer if adversely affected

If this study raises any difficult or confronting emotions, support can be found through the following services:

- Butterfly foundation support line: 1800 ED HOPE / 1800 33 4673
- Lifeline: 13 11 14

Mandatory Reporting

Any disclosure of unreported child sex abuse made during the course of this study must be reported to the Australian Federal Police under the Crimes Amendment (Protection of Children) Act 2014.

Payment

Participants will be given a \$20 Coles/Myer gift voucher for their attendance of the interviews.

Confidentiality

Your interview will be transcribed by a transcription service, who regularly transcribe interviews and confidential recordings. They provide a secure website where audio files are uploaded and, after the transcription is completed, it will be sent to the primary researcher's university e-mail. The primary researcher will check the transcription and, during this process, will remove any identifying information present in the interview, such as names, locations, etc. Your interview will be assigned a randomly generated code that will not be linked to your name or e-mail address; this will protect your confidentiality. If you do not wish your transcript to be transcribed by the transcription service, you may decide to stop the interview at any point with no penalty to you or the study.

All data gathered from the demographic survey will similarly be coded using a random code that will not be linked to any identifying information arriving with the data.

Any academic publications using responses from the interview or survey data will use codes and will not provide any identifying information. Quotes may be used from the interviews but no identifying information will be used, so the quotes will not be identifiable.

Storage of data

Data in this study is considered to include both responses to the demographic surveys and the interviews.

This data will be stored on primary researcher's Monash secure Google Drive account with only primary researchers and her supervisors having access to it. The data will be regularly backed up throughout the duration of the study.

The data will be retained after the completion of the primary researcher's PhD to be used in further research into recovery. If you do not wish for your data to be retained, please notify the student researcher and your data will be removed from the set and deleted and not used in any subsequent studies.

Use of data for other purposes

Data from this study will be retained for further research on recovery. The data will be retained with the de-identified codes and so it will not be traced back to you. The data will only be used for other projects when an ethics board gives approval.

Results

Participants may choose to receive copies of any academic articles written using data from the OFG. The papers are expected to be published within in the next two years. An option for receiving these copies is included on the consent form.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Building 3e
Research Office
Monash University VIC 3800
Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905
3831

Thank you,

Appendix K

Individual Interviews Informed Consent

CONSENT FORM

One-on-one Interviews

Project: Recovery and treatment experience among people with eating disorders

Chief Investigator: Dr Janette Simmonds

Student Investigator: Capella Meurer

Co-Investigator: Dr Tristan Snell

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
To complete a demographic survey and questionnaires on the areas of physical, mental health eating disorders, and treatment history		
To take part in a one-on-one interview on the topic experience of eating disorder treatment and recovery experiences, totalling up to one hour in length		
To allow the audio of my interview to be transcribed by a Monash University approved transcription service		
To allow my data to be retained after the completion of this study for use in further research by the student researcher, Capella Meurer		

Results of the Study

If you wish, you can be sent copies of any academic articles resulting from this study. They will be published within the next two years. If you would like to be receive copies of these articles, please provide your e-mail here: _____

Participant Name: _____

Participant Signature: _____ Date: _____

Appendix L

OFG Research Schedule

Topic A : Personal understanding of recovery

1. How do you define eating disorder recovery?
 - What does this definition mean to you? How has this definition been helpful?
 - Where did this definition come from?
 - Can you give me an example of what it means for your life - how it has influenced your decisions?
 - How do you act now that you are in recovery- how do you behave, think, or feel differently?
2. Has this definition changed during the course of your recovery journey?
 - What influenced this change? What was happening? How did you feel about the change? What difference did it make in your recovery?
 - What has kept it steady- if no change or once the definition has solidified. What difference has it made?
 - If people have disagreed with you- what has kept you steadfast in your opinion? How has that felt?
3. Did your treatment team (allied health professionals) always have the same views of recovery as you did?
 - How have you discussed recovery with your recovery team?
 - What have been the points of difference? How did you resolve conflict? How did this feel (how did you manage/cope)?
 - What have been the points of similarity?
 - Is it helpful to have similar concepts of recovery to the treatment team? What makes you say that?

Topic B : Internal conditions for recovery- how has recovery been impacted by personal conditions

1. How have your family and social relationships impacted your recovery journey?
 - Who has been involved and integral to your recovery? How have they helped you?
 - Have you met new people along your journey who have changed or impacted you? Why do you think they have had this impact?
 - Have any losses (changes in relationships, deaths, distancing) impacted your recovery? How has that felt (how have you managed/coped)?
2. What has helped you to maintain your recovery?
 - Have you connected with any role models within or outside the ED community? What about them has resonated with you? What messages have appealed to you and why? How have they sustained you and your recovery?
 - Do you have any spiritual or religious beliefs? What about them has impacted your recovery?
 - How have you understood any experiences of relapse- if you have had any? What was happening in your life? How did you feel about it? How did you manage?
3. Have your values and attitudes changed through your recovery journey?
 - How can you tell that there has or has not been a change? How do you feel about it?
 - How is this change reflected in your daily life? What does it look like when you are acting in line with your values?
 - Do you hold any values particularly strongly? Why? How has this impacted how you live your life?

Topic C: External conditions for recovery- how has treatment influenced recovery

1. Please describe any stand-out experiences, either positive or negative, that you might have had during your treatment for your eating disorder.
 - What makes these stand-out? How did it/they make you feel?

- How did you handle (negative) experience? What were your actions? Who did you talk to?

How did you cope? How did you feel?

- What impact do these experiences have, if any, on your recovery?

2. What are your opinions of the allied health professionals who have been involved in your treatment?

- What has influenced this opinion?

- Has this impacted on when and how you accessed support?

- How open are you with this opinion? Does your treatment team know?

3. In your opinion, what do you think treatment should consist of to ensure it is beneficial to those with eating disorders?

- In light of this, what do you see for the future of eating disorders treatment? What do you hope to see?

Topic D: Additional

1. Is there anything that you would like to add on the topics of recovery and eating disorders treatment? Or anything that you thought I would ask but did not?

Appendix M

Online Conventions

- Please try to stay on the topic being discussed. Avoid posting irrelevant links, comments, or pictures as these will interfere with the analysis process.
- Please respect the opinions and experiences of other group members, who will be coming into this group with different experiences and from around the country and world. If you disagree with an opinion or experience, please do so respectfully. Acknowledge that others have different perspectives and experiences.
- Please remember that humour and sarcasm does not always translate over the internet, so some things may be misinterpreted by other group members.
- To the best of your ability, maintain each other's confidentiality. Please refrain from discussing anything sensitive raised in this focus group with peers and family members. This maintains the confidentiality and trust of group members.
- The use of emoticons (:-) :-/ etc) and text short-hand (lol, wtf, omg) will confuse the interpretation process. Please avoid using these in this group as much as possible.
- Flaming, trolling, and baiting other group members will not be tolerated. If it is witnessed, group members will be issued one written warning. If the behaviour continues, the group member will be removed from the group. Posts that are purposefully inflammatory will be removed. Please contact Capella with any concerns.

Please report any glitches in the group. If there are any difficulties, with posting or receiving replies, send Capella a message.

Appendix N

Individual Interviews Research Schedule

Core Questions

- Can you explain what prompted you to begin on your recovery?
 - What does recovery mean to you?
 - Why is it meaningful?
- Can you tell me about the progress of your psychological recovery?
 - How was this addressed?
 - How did this contribute to recovery?
 - What happened when physical recovery was prioritized over psychological recovery?
 - How did this feel?
 - How did this contribute to the recovery experience?
- Can you tell me how your personal relationships may have influenced your recovery?
 - How did your relationships change during your recovery journey?
 - How did you feel about these changes?
- Can you tell me how experiences you had in treatment may have impacted your overall recovery?

Ancillary Questions

Recovery is a Journey

- Can you tell me about any difficult choices you had to make during your recovery?
- Can you tell me about any specific skills that have made your recovery possible?

Recovery is a Goal

- Can you tell me about the goals you set yourself during your recovery?

- Who did you see yourself becoming?
- What did you see yourself doing that was different from how you had been living?
What did you see staying the same?
- Can you describe where you see your recovery taking you?
- Can you describe your ultimate recovery goal?
- How did your goals change?
- What led to the change? How did it come about?
- How did you maintain your motivation to stay with these goals?

Treatment Impacts Recovery

- Can you tell me, what in your experience, makes for a supportive allied health professional?
 - What about one who isn't supportive or is a hindrance to recovery?
- What can you tell me about the professionals who helped you the most along your recovery?
 - What about those who helped the least?
- What can you tell me, based on your experience, makes for successful treatment?
 - What kind of treatment helped you the most in your recovery? Why?
 - What elements made it successful? Why?
 - What kind of treatment helped you the least in your recovery? Why?
 - What elements made it unsuccessful? Why?

Appendix O

Human Ethics Certificate of Approval



MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number: CF16/2161 - 2016001050

Project Title: Recovery and treatment experiences among people with eating disorders

Chief Investigator: Dr Janette Graetz Simmonds

Approved: **From:** 5 October 2016 **To:** 5 October 2021

Terms of approval - Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. **Amendments to the approved project (including changes in personnel):** Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

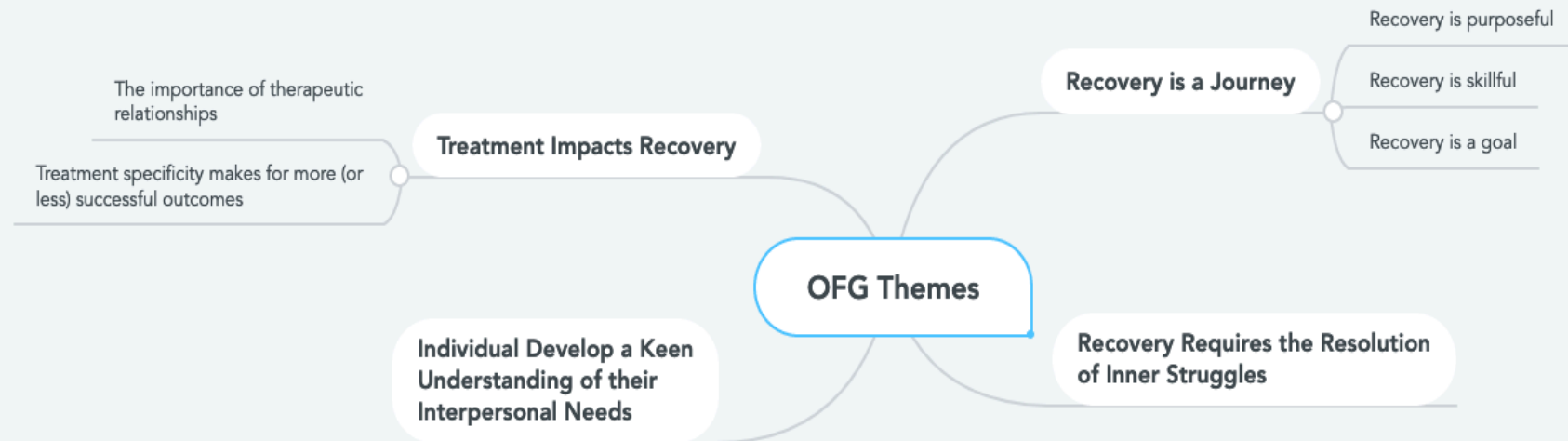
Professor Nip Thomson
Chair, MUHREC

cc: Ms Capella Elisabeth Meurer, Dr Tristan Snell

Human Ethics Office
Monash University
Room 111, Chancellery Building E
24 Sports Walk, Clayton Campus, Wellington Rd, Clayton VIC 3800, Australia
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@monash.edu <http://intranet.monash.edu.au/researchadmin/human/index.php>
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix P

OFG Thematic Map



Appendix Q

Individual Interviews Thematic Map

