

**Disordered Eating in a Digital Age:  
Narratives of Withdrawal from Pro-  
Ana/Mia Forums by Regular Site  
Users**

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I promise that the hibernating is temporary!

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## Abstract

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Background & Aims: Studies estimate that over 500 live Pro-Ana websites are in existence (Hansen, 2008). Broadly speaking they advocate that eating ‘disorders’ are a ‘life-style’ choice rather than a mental health problem requiring treatment (Bardone-Cone & Cass, 2007). To date, content analyses (Borzekowski, Schenk, Wilson, & Peebles, 2010; Harshbarger, Ahlers-Schmidt, Mayans, Mayans, & Hawkins, 2009), covert observations (Brotsky & Giles, 2007) and experimental designs (Bardone-Cone & Cass, 2007; Jett, LaPorte, & Wanchisn, 2010) have been used to investigate the impact of the Pro-Ana movement on individuals. Findings suggest that the sites can maintain and worsen eating difficulties and pose a significant obstacle to recovery. Yet remarkably, no study has investigated accounts of Pro-Ana withdrawal and its associated impact. This study sought to address the literature gap.

Methodology: Six women formed the sample (two British, four American). All identified themselves as previously using Pro-Ana sites regularly and also reported experiencing eating difficulties. Using semi structured interviews; Pro-Ana experiences were explored, focusing particularly on site disengagement. Narrative inquiry enabled the content, structure, context and performative aspect of all accounts to be considered.

Analysis & Findings: A brief narrative summary was presented for each participant, along with the emerging storylines across accounts. The strongest storyline of coming to Pro-Ana was aspirations for further weight loss and a search for a connection. The strongest storyline of withdrawal involved a quest for recovery, though accounts varied widely in agency surrounding this act and for a small proportion disengagement was actually a sign of things getting worse. Notably, storylines of strengthening different identity aspects and connecting with different social support systems featured heavily in most recovery accounts. The findings are discussed in relation to their clinical implications, the strengths and weaknesses of the project and direction of further research.

## Chapter 1: Introduction

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*'Every tale is told from a particular vantage point' (Goffman, 1974)*

In line with Goffman's notion that the position taken to view the landscape determines the tale that can be told, I wish to begin by orientating you to the position where I stand and present relevant aspects of my own tale. To do this, I will start the chapter by stating why I believe the Pro-Ana/Eating 'disorder' movement to be a worthy topic of study (Tracy, 2010). I will then outline my own epistemological position, which inform both how the study has been conducted and how this doctoral thesis is presented. I will then introduce the relevant literature surrounding the Pro-Ana movement. This includes the concepts of eating 'disorders', including how they have been understood through the dominant, western-medical-narrative. I will then consider how the stigma associated with an eating 'disorder' diagnosis, coupled with western ideals of beauty/slenderness, may have contributed to the Pro-Ana movement coming about. In doing this, the political and historical narratives surrounding the movement are considered. This is followed by a systematic literature review, where I critically review the Pro-Ana research conducted so far. The aims and objectives of my project are then presented, together with the gaps in the existing literature.

### **1.1 Personal Significance**

My interest in this area was born out of my own relationship with food, image and a brief use of Pro-Ana websites prior to clinical training.

As a child, I really enjoyed the act of eating. I was frequently found over indulging and joyfully staring at my body's many imperfections. Yet, as I grew older, I began comparing myself to my peers and the beautiful slim women that littered social media, wondering if only thin women were valuable. By my early twenties my body had become my project and

exercise my new obsession. In the months that followed, I went from seeing myself as someone who was ‘big’ and ‘sturdy’, to someone ‘slim’ and ‘athletic’, a view reinforced by others. I was soon going to the gym for many hours a day, seven days a week and I paid close attention to what I ate; I started to feel valuable! Yet as my weight began to plateau and I still enjoyed the act of eating and all the benefits of this new slimmer physique. I looked to the internet for ways I could continue the downward trend. In doing this, I stumbled upon Pro-Eating ‘disorder’ websites.

I soon realised that my own internal struggle with beauty or rather value, was a common story and it was then that I first became curious about the journeys of others to the Pro-Ana sites. I was also interested in the rather novel idea that eating ‘disorders’ might be considered a ‘life-style’ choice, rather than a mental health problem that needed to be fixed or cured. I noticed the support, solidarity and normality with which eating difficulties were discussed on the sites and this led me to wonder how individuals broke away from this community, particularly when disclosures of eating difficulties offline appeared so stigmatising.

## **1.2 My Epistemological Position**

My research has been heavily influenced by the postmodern movement and a social constructionist perspective. Postmodernism challenged the once dominant notion that an external reality exists beyond our selves, which can be known about and objectively measured to reveal absolute truths (Harper & Thompson, 2011). This movement led to a surge in popularity of the constructionist viewpoint that all knowledge is relative; constructed and reconstructed through multiple emerging realities (Gergen, 2009). These realities are thought to be created through language and the interactions we have with others (Burr, 2015). This means that our knowledge and beliefs are subject to change; bound by context, culture and time in which they existed (Gergen, 2009; Polkinghorne, 1991).

These ideas extend to constructions of ourselves and identities; as Hollway and Jefferson (2008) claim, ‘there is more than one I in identity’ and the degree to which these ‘identities’ can be accessed are contextually and relationally dependent. Ideas of multiplicity within individuals, within stories and within lives, have guided my understanding of the ‘identities’ I present to you in this thesis (Burr, 2015).

### **1.3 Language Use**

In line with my own epistemological position, I see language as a pivotal device in constructing meaning. For this reason, I wish to share some of my own decisions regarding the choice of terms that I have adopted.

Firstly, I have decided to combine a third person academic style of writing with a first person more personal, colloquial tone. Whilst the latter is more unusual I wish to be transparent when presenting my own views and remind the reader of my presence and the inevitable influence that this will have on the stories told and the interpretations made (Webb, 1992).

I have chosen to present some words like ‘recovery’ with a single inverted comma, to draw attention to the multiple and sometimes disputed meanings that these words can hold. I have also avoided using the words ‘anorexic’ or ‘bulimic’ (unless used in authors’ quotes) as I believe that this can feed into the notion that people are single stories, which undermines the idea of multiplicity within individuals presented earlier.

I have been mindful of the pathologising medical discourses that I believe exists within the field of mental health and the sense of disempowerment that labels can hold for some individuals. For this reason, I have been reluctant to include the word ‘disorder’ within the document. Yet following much reflection and lively conversation with my supervisory team I have chosen to use the term with caution. Adopting it in line with my participants, who all

identified themselves to have experienced an eating ‘disorder’. I have also reflected upon my reluctance to use the term within Appendix A and also shared my own construction and understanding of the word.

Finally, there has been some variability in the literature regarding how certain Pro-ED or Pro-Ana terms have been applied. Older studies have tended to use the term ‘Pro-eating disorder’ or ‘Pro-ED’ which in many ways seems more appropriate than a ‘Pro-anorexia’ or ‘Pro-Ana’ label since high numbers of this online community seem to identify more with bulimia than anorexia (Giles, 2016). However, newer studies have tended to use the latter ‘Ana’ term. One of the key reasons for this as noted by Giles (2016), is that the restrictive nature of anorexia is often aspired to and seen as a state of purity rather than bulimia which is associated with a loss of control and often viewed as failure. For this reason, I have struggled to know which term feels the most appropriate to use when referring to the sites. I have been consciously aware of this struggle and have decided to, again be guided by my participants; almost all of whom referred to them interchangeably as Pro-eating ‘disorder’ and Pro-Ana. For this reason, I have adopted this slightly messy stance too.

#### **1.4 Literature Review: Providing Pro-Ana Context**

The following section considers the available literature on eating disorders and the Pro-Ana movement. It is separated into a number of sections. The first presents research on eating ‘disorders’, their definitions, perceived causes, treatments and the commonly held narratives in western society about beauty. The second section considers how the Pro-Ana movement came about, offering some historical and political context to the reader. The third section reviews the research conducted on Pro-ED forums to date. The research is split into studies which have investigated the sites themselves, as well as studies which have investigated the Pro-Ana users. The later type of research forms the systematic review.

### **1.4.1 Introducing Eating ‘Disorders’: Definitions, Classifications and Epidemiology**

When it comes to defining, and classifying the numerous eating ‘disorders’ thought to exist in western society, a number of different, ever-evolving systems have been proposed. These include the Diagnostic and Statistical Manual, fifth edition (DSM-V) (American Psychiatric Association (APA), 2013) and the International Classification of Diseases, tenth edition (ICD-10) (World Health Organisation (WHO), 1992). Both are routinely used to diagnose eating ‘disorders’ across the West and such labels help to ensure treatment provisions can be accessed by those in need (National Institute for Clinical Excellence (NICE), 2004). Yet broadly speaking the term ‘eating disorders’ refers to a collection of syndromes where individuals are perceived to have abnormal attitudes towards food, leading to changes in their eating patterns and behaviours (NICE, 2004).

The two most commonly cited are anorexia nervosa and bulimia nervosa (Belangee, Sherman, & Kern, 2003). Anorexia is characterised by an excessive fear of becoming fat, which drives fasting behaviours and leads to emaciation. Here weight is maintained at 85% or under what would be expected (Abraham & Llewellyn-Jones, 1997; Luck et al., 2002; Patton, Selzer, Coffey, Carlin, & Wolfe, 1999). Bulimia is characterised by similar fears but involves recurrent episodes of binge eating and compensatory behaviours like purging, fasting or excessive exercise (McAdams et al., 2004). Here dietary restriction cannot be maintained in the same way as anorexia and individuals typically fall into the healthy or over-weight ranges (NICE, 2004). The last ‘atypical’ category, accounts for the highest proportion of diagnoses and is commonly referred to as Eating ‘disorder’ Not Otherwise Specified (EDNOS). It is a highly heterogeneous category, reserved for those who do not fulfil the full criteria for anorexia or bulimia (APA, 2013; WHO, 1992). For example, an individual may purge less frequently than specified for bulimia or a person’s weight may remain just above the 85% bench-mark required for anorexia, leading to an EDNOS diagnosis. What is interesting is the

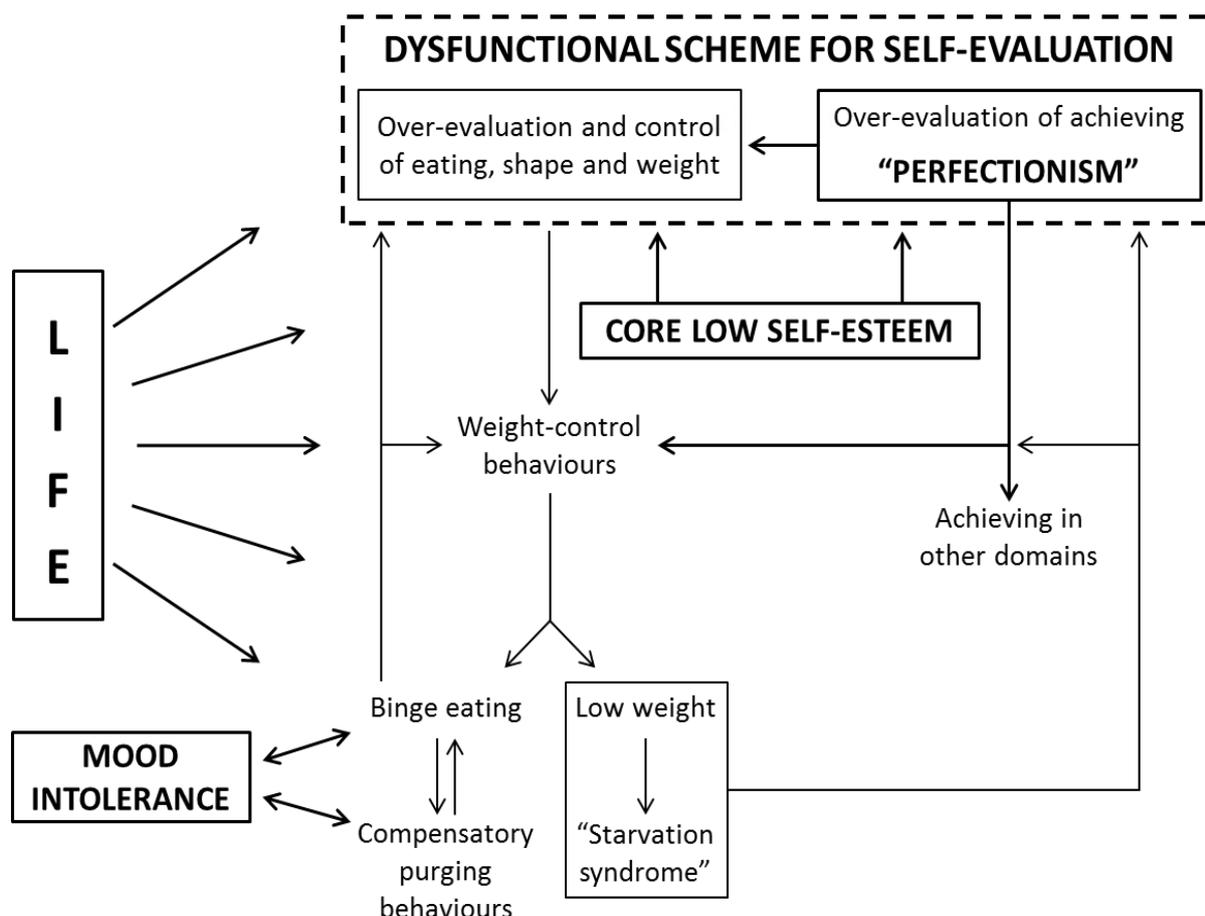
high degree of overlap and transient nature with which individuals can move between these classifications. It is estimated that 50% of individuals with a diagnosis of anorexia will go on to develop bulimia (Bulik, Sullivan, Fear, & Pickering, 1997) and many circle between anorexia and EDNOS over the course of their life-time (NICE, 2004).

Though subtle differences in the risk factors and aetiology of these diagnoses have been cited (Collier & Treasure, 2004; Norring & Palmer, 2005) many authors claim that there is a high degree of overlap between conditions, as noted in Fairburn's creation of the Transdiagnostic Eating 'Disorder' Model (see figure 1) (Fairburn, Cooper, & Shafran, 2003; Fairburn and Bohn, 2005). Given that a discussion of these differences is beyond the scope of this thesis, the population will be largely spoken about as one homogenous group but key differences highlighted between the conditions, when deemed particularly useful by the author.

In terms of who develops eating 'disorders', adolescent, white, western, middle class, women are seen to be most at risk (Striegel-Moore & Bulik, 2007). Yet establishing the prevalence of these 'disorders' in this group, or any other, has proved challenging. This is in part due to recorded incident figures in the general population being reasonably low and practically it is difficult to screen and continuously track a sufficiently large enough sample group (at least 100,000), to enable accurate estimates to be made (Hoek, 2016). Instead incident studies have relied on records held in hospital and mental health facilities which are likely to be a gross underrepresentation of the true figures. Particularly as the shame and secrecy which often surrounds receiving an eating 'disorder' diagnosis and limited access to treatment provisions, especially for EDNOS diagnoses, means many battle in silence and these incidences go unrecorded (Keski-Rahkonen & Mustelin, 2016).

However, a few good studies assessing lifetime prevalence rates do exist. Estimates within the general population range from around 0.5% for anorexia to 3% for EDNOS in western

women (Hoek, 2006; Keski-Rahkonen et al., 2007). A recent study suggested that around 1.6 million people in the UK are likely to live with a diagnosed or undiagnosed eating ‘disorder’; 10% are thought to have anorexia, 40% bulimia and the remaining 50% fall into the atypical category (Joint Commissioning Panel for Mental Health, 2013). Alarminglly these perhaps conservative figures have been steadily climbing, which many attribute to the West’s growing obsession with obtaining thinness (Hawkins, Richards, Granley, & Stein, 2004; Pollack, 2003). Moreover, the eating ‘disorder’ epidemic is not confined to the UK with another 11 million individuals thought to be affected in America (Wade, Keski-Rahkonen, & Hudson, 2011). Yet outside of these two countries, few others have rates recorded, this is particularly true for Asia, Africa and the Pacific Islands (Hoek, 2016).



**Figure 1: (Fairburn, Cooper, & Shafran, 2003) Transdiagnostic Model of Eating ‘Disorders’**

Fairburn et al., (2003) claimed that the core attitudes and ‘maladaptive’ behaviours expressed by individuals diagnosed with anorexia, bulimia and atypical eating ‘disorders’ were largely similar. Within this model they conceptualised eating ‘disorders’ as ‘cognitive distortions’ that resulted from an individual’s over-evaluation of shape and weight in terms of their self-worth and a minimisation of other aspects contributing to an individual’s self-worth, like successful relationships or occupational achievements.

It is suggested that individuals become fixated with concerns surrounding their shape and weight, which leads to continued checking behaviours and the development of beliefs that they look ‘fat’ and ‘repulsive’. Overly-critical comparisons with others are positioned as maintaining an over-concern in these areas and lead to low self-esteem. This leads individuals to try and restrict their calorie intake and follow strict dietary regimes (leading to anorexia type presentations). However, many are unable to adhere to the level of restriction aspired to and subsequently binge on large quantities of food. Misconceptions surrounding the effectiveness of purging behaviours as a means of compensating the effects of binges reinforce these behaviours (leading to bulimia type presentations).

Within this model, low self-esteem, interpersonal difficulties and perfectionism are seen to maintain eating ‘disorders’.

**1.4.2 Aetiology and Chronicity**

The first eating ‘disorder’ to become recognised and classified was anorexia. ‘Sufferers’ were seen as young, weak, women, on the edge of puberty. They were positioned as being frightened by the prospect of adulthood and had starved themselves in an attempt to return to their childlike existence of innocence and parental dependency (Bruch, 1973; Chernin, 1983). Since this psychodynamic interpretation was made, both the number of recognised ‘disorders’ and explanations for their existence has diversified. The aetiology of all eating ‘disorders’ is now commonly considered to be multifactorial resulting from a complex interplay of biological, psychological, environmental and social factors (Collier & Treasure, 2004). Heritability estimates range from 0.28-0.84 across anorexia, bulimia and EDNOS (Bulik,

Sullivan, Wade, & Kendler, 2000; Kendler & MacLean, 1991; Wade, Bulik, Neale, & Kendler, 2000) with perfectionism, impulsivity, low self-esteem, stressful life events, family discord and sexual abuse, all seen as risk factors in the development of an eating 'disorder' (Rikani et al., 2013). Others argue that the contradictory messages held in western culture and its increasing preoccupation with beauty and physical form have contributed to increased incidences. On the one hand tabloids dedicate huge spreads to the latest must try diet (in time for the holiday season) while at the same time shaming celebrities for losing too much weight, with photos of their angular figures claiming that they look unhealthy and need to eat (Brumberg, 2000; Ward, 2007). The cycles of fasting, bingeing and purging could thus reflect the confusing messages held within society.

Yet regardless of the perceived cause, the serious nature of these conditions cannot be denied. Anorexia has the highest mortality rate of any other mental health problem (Gremillion, 2003). It is estimated that around 10% of individual diagnosed with the condition will die within the first 10 years of receiving a diagnosis (Sullivan, 2002). For the remaining 90%, studies suggest that less than half (47%) go on to make a full recovery, 34% make some improvement but 21% remain chronically unwell (Steinhausen, 2002; Sullivan, 2002). The mortality rates of bulimia, tend to be lower (Rikani et al., 2013) but the physical and psychological impact are well documented in both difficulties. A wide range of medical complications like anaemia, endocrine system dysfunction, electrolyte disturbances, osteopenia/osteoporosis, heart disease and organ failure, can follow (Mitchell & Crow, 2006). The severity of such complications is thought to depend on the amount and speed of weight loss, duration of eating 'disorder', age of individual and intensity of any purging behaviours. Common psychological difficulties include feelings of guilt, shame and social isolation as well as high rates of depression, anxiety and personality 'disorder' diagnosis (Rikani et al., 2013). Worryingly, a large meta-analysis which combined the results of 42 published studies

which examined eating 'disorder' mortality rates, found that after medical complications, suicide was the leading cause of premature deaths in this population (Sullivan, 2002). It is estimated that 10-20% of individuals with a diagnosis of anorexia and 25-35% of individuals with bulimia have made at least one suicide attempt (Dalle Grave et al., 2007). For these reasons, there is a need for timely and effective treatments.

### **1.4.3 Treatment and Recovery from Eating 'Disorders'**

NICE advocates talking therapies as the treatment of choice for eating 'disorders', with Cognitive Behavioural Therapy (CBT) and Inter Personal Therapy (IPT) recommended for adults (NICE, 2004). Family therapy is also recommended for children and adolescence (NICE, 2004). Currently, the treatment guidance for bulimia and anorexia are different. For anorexia, it is recommended that most patients should be cared for in outpatient services. If inpatient re-feeding is believed to be required, treatment should be delivered alongside psycho-social interventions. For bulimia, self-help approaches should be used first then therapeutic interventions like CBT, IPT or for adolescence, family therapy used afterwards (NICE, 2004).

However, studies show that the success rate for these programmes is very low. Around one third of individuals who receive NHS treatment will still meet diagnostic criteria for an eating 'disorder' 5 years later (Polivy & Herman, 2002) and 20% remain chronically ill their whole lives (Steinhausen, 2002). Some have blamed this outcome on the poor content of treatment programmes, which arguably focus too much on weight restoration rather than understanding the emotional and social difficulties which may have led to have an eating difficulty (Rich, 2006). Others note that the provision of help comes too late (Dias, 2013); with many individuals being turned away from services because their eating 'disorder' was not deemed severe enough to warrant treatment. By the time they became eligible, it was much harder for

them to recover. The likelihood of recovery is worsened still, by many inpatient treatment stays being short term. This is particularly problematic for Americans, where the standard treatment stays paid out by medical insurance companies rarely last over 30 days, despite research consistently showing that this duration is rarely long enough to create a stable environment for recovery (Grasfield, 2015). Given these findings, there has been a growing emphasis placed on trying to understand the development of eating ‘disorders’ with a preventative, rather than curative focus.

#### **1.4.4 Summary**

As reflected in the literature the term eating ‘disorders’ is an umbrella term which encompasses three heterogeneous ‘disorders’; anorexia, bulimia and EDNOS (NICE, 2004). The shame and secrecy that surrounds receiving a diagnosis, along with the variability in how incidences are both reported and classified across countries, if at all, make it difficult to determine the exact prevalence rates (Hoek, 2016). There are few ‘high-quality’ studies in existence but generally rates appear to be on the increase across most parts of the West. How professionals have come to understand the development of these ‘disorders’ has changed over-time and a bio-psycho-social explanation is now favoured by most (Collier & Treasure, 2004). To date, research into eating ‘disorders’ has primarily focused on studying populations with anorexia and to a lesser extent bulimia with notions that the findings can be generalised to the other conditions. Treatments have also been confined mostly to these two groups, with few people diagnosed with EDNOS receiving care (NICE, 2004). This may be caused by anorexia’s high mortality rate and the high degree of physical and psychological suffering that results from this ‘disorder’ in particular. A number of talking therapies have been advocated by NICE but with stretched provisions and a high proportion failing to recover, there has been a growing emphasis placed on prevention and trying to understand how eating difficulties develop, rather than solely treat them.

### **1.4.5 Narrative of Beauty and Eating ‘Disorders’**

Though reported rates of anorexia (restrictive sub-type) have stayed fairly stable since its initial classification, leading some researchers to claim that desired weight-loss has little to do with chasing the current slim body ideal (Schmidt & Treasure, 2006) the prevalence of all other eating ‘disorder’ classifications has been steadily climbing. Many have cited the Wests growing preoccupation with thinness, as a possible reason for this (Turnbull, Ward, Treasure, Jick, & Derby, 1996). As a result, the dominant discourses surrounding weight and shape will now be discussed and the dominant discourses around eating ‘disorders’ will then follow.

#### 1.4.5.1 Notions of Beauty

In the West notions of female beauty have changed over time and the bias appears to be increasingly towards women achieving slim lean bodies which are held in high esteem and associated with control and order (Williams & Reid, 2007). Today food is not only seen as a source of fuel but also has a wide range of values attached to it. High calorific foods are seen as ‘sinful’ and ‘bad’ while healthier options are viewed as ‘morally superior’ (Brumberg, 2000). With this in mind, perhaps it is no wonder that an increasing number of women are going on to develop extreme eating behaviours. However, while there is stigma and shame attached to being viewed as overweight or fat, this also the case for individuals who are very underweight (Kelly & Carter, 2013). This perhaps leaves women to walk a tight rope in their quest for beauty.

#### 1.4.5.2 Notions of Eating ‘Disorders’

To date the discourses around eating ‘disorders’ have largely been biomedical, psychiatric and pathologising. They have ignored the cultural pressure on women to achieve often unattainable beauty standards, portraying these women and in particular those with anorexia, as irrational and in denial (Dias, 2013). Experiences have been medicalised and the emphasis

has always been on ‘fixing’ or ‘ridding’ individuals of their ‘mental illnesses’ (Gailey, 2009). Corrigan and Watson (2002) claimed that the ‘mental illness’ label provides individuals with a double misfortune, as the general public fail to understand both the course and impact of the illness but also discriminate openly against these individuals. In a UK survey, a third of surveyed respondents felt that those with eating ‘disorders’ had themselves to blame for their condition and reported having difficulty talking and empathising with sufferers (Crisp, 2005). In the USA, a similar story emerged (Stewart, Keel, & Schiavo, 2006).

#### **1.4.6 Evolving Nature of Eating ‘Disorders’: The Emergence of Pro-ED Ideas**

The dawn of the internet in the late 90’s offered a new medium for thin ideals to be spread, compounding the eating ‘disorder’ epidemic further. Yet it also offered an alternative space for women to come together and discuss their eating and body issues (Dias, 2013). According to the literature several factors have given online communication its appeal (Suler, 2004). Firstly, it provided anonymity, online disclosures can feel as though they have been made in a vacuum, they cannot be easily linked to people’s off-line lives. This further allows for some dissociation, where the need to be mindful of the possible negative repercussions by sharing was eased. Online communications also offer invisibility, because at the time of interacting individuals are not usually seen or heard so the personal risks involved with disclosures can feel lessened. Finally, it provided asynchronicity, as conversations do not occur in real time individuals can develop more thoughtful responses and lesson the likelihood of making social errors (Suler, 2004). Moreover, according to Fox, Ward, and O’Rourke (2005), the creation of the internet allowed women to share in their struggles and offer non-judgemental support away from the scrutiny of others. In this way, Dias (2013) noted that cyberspace had the potential to offer individuals a ‘sanctuary’.

In the years that followed different types of eating ‘disorder’ websites emerged. Those developed and run by health professionals and charitable associations (e.g. BEAT) which take a pro-recovery stance and those developed and run by people with eating ‘disorders’/difficulties themselves. Websites developed by individuals themselves often take quite polar positions. They either advocate for ‘recovery’ and weight restoration (like the charities), or reject this idea all together (Chesley, Alberts, Klein, & Kreipe, 2003). Those sites rejecting pro-recovery are termed pro-eating ‘disorder’ websites, or more commonly referred to as Pro-Ana or Pro-Mia sites after their respective eating ‘disorders’; anorexia and bulimia (Dias, 2013).

Taking a narrow definition commonly used by the media these sites advocate that eating ‘disorders’ are a life style choice, rather than a mental health condition that needs to be ‘treated’ (Bardone-Cone & Cass, 2007). The more extreme sites contain rules governing eating behaviours or assertions that, if the desire to eat is not resisted, the individual is worthless. However, there is great diversity amongst these sites. Some take a much more liberal stance where there is a willingness to accept an individual as they are and support them to continue with their ‘disordered’ eating in the safest way possible, until the individual decides or feels ready to pursue ‘recovery’ options (Csipke & Horne, 2007).

In 2006, it was estimated that there were 500 live sites in existence outnumbering pro-recovery sites by 5:1 (Giles, 2016; Hansen, 2008; Wilson, Peebles, Hardy, & Litt, 2006).

Though collating this information has proven difficult due to the diversity in which the Pro-ED label has been used in order to classify sites.

#### **1.4.7 Who Uses the Sites?**

Using online surveys, a small number of studies have sort to profile users (Csipke & Horne, 2007; Peebles et al., 2012; Ransom, La Guardia, Woody, & Boyd, 2010). In a study where

151 individuals completed a survey posted on a mental health charity webpage and various Pro-ED sites, 97% of Pro-Ana users were reported to be female, with most living in either the UK (60%) or USA (25%). Their ages ranged from 13 to 49 years old, with the majority being aged 22 or younger (69%) and a high proportion aged 16 to 19 (41%) (Csipke & Horne, 2007). Similar demographics have been reported by a number of other studies (Peebles et al., 2012; Ransom et al., 2010), though are of course subject to reporter bias and the possibility that subjects may have provided false information to conceal their identity. Interestingly though it has been claimed that many users would not reach the criteria to receive an official eating 'disorder' diagnosis (Bardone-Cone & Cass, 2007) and only a third stated that they had ever received formal care for an eating related difficulty (Peebles et al., 2012). What these women appear to have is a desire to explore extreme weight-loss and to connect in relation to an internal struggle.

#### **1.4.8 Summary**

Ideas of beauty throughout the West have changed over the last thirty years. The size of the ideal women has shrunk. Slim, lean bodies appear to hold the most value (Chojnacki, Grant, Maguire, & Regan, n.d.; Williams & Reid, 2007). Those viewed as overweight have been positioned as having low morality, being lazy and sloth like but those viewed as grossly under-weight have also been subject to scrutiny (Brumberg, 2010; Kelly & Carter, 2013). The discourse around eating 'disorders' have been largely medical and pathologising focusing on a need to 'fix' individuals and inviting very little empathy from the general public. With the birth of the internet, cyberspace offered a new way for women to connect and support each other with eating struggles. This led to an online pro-eating 'disorder' movement (Dias, 2013). Although the websites created by this group vary, broadly speaking they support individuals to continue to engage in 'disordered eating; offering tips and tricks on weight loss techniques as well as advice on how to conceal this from loved ones and health care

professionals. Notably, most Pro-Ana users appear to be female and in their late teens and early twenties, with only one-third receiving formal care for an eating difficulty and most failing to meet the eating ‘disorder’ diagnostic thresholds set by the ICD-10 and DSM-V (Bardone-Cone & Cass, 2007; Csipke & Horne, 2007). Nevertheless, these women have a desire to explore extreme weight loss.

#### **1.4.9 Providing Historical Context: How the Pro-ED Movement Came About**

Many explained the explosion of these sites across the internet as a revolt against dominant stigmatising discourses in society (Crowe & Watts, 2016; Dias, 2013; Giles, 2016). Some claim that the failure to take into account other causes for behaviour, aside from medical narratives like sexual and physical abuse, oppression, discrimination, violence, trauma and harassment have caused women to create a forum where these can be heard and privileged (Herman, 2015; Kearney-Cooke & Striegel-Moore, 1994; Thompson, 1994). Through forming an online community where individuals post pictures and celebrate each other’s successes, users work towards altering the dominant and perhaps only heard viewpoint that they are failures, need ‘fixing’ and should be ashamed of their bodies. The sites offer an alternative narrative redefining the term ‘anorexia’ outside medical and other professional discourses, rejecting notions that they are ‘victims’ or ‘suffers’ and positions themselves as a strong, elite group of humans who have successfully mastered how to govern their bodies (Nordlund, n.d.).

In line with this idea, Ward (2007) claimed that the Pro-Ana movement has been about resistance; resistance to the pathologising medical discourses surrounding eating ‘disorders’, to the threat of hospitalisation, the threat of therapy and resistance to commonly held beliefs of what ‘recovery’ should look like, namely weight restoration. He argued that for some it could also represent resistance against dominant ideals of beauty, in the sense that many sites

encouraged continued control and aspirations of weight loss long after socially desirable weights had been achieved. In this sense, while Pro-Ana sites can be viewed as a strict brutal regime in the pursuit of 'beauty' it is a beauty that they have taken ownership of, re-authored and reconstructed where women can embody this lifestyle completely and it can be accepted and embraced.

This notion that Pro-Ana sites have come about due to a rejection of commonly held beauty ideals is in line with third wave feminist theorists (Bordo, 2004; MacSween, 2013; Malson, 2003; Pollack, 2003). It has been suggested that in creating a body that is seen as revolting to most men, who are perceived to value a curvier feminine frame, women are able to assert their independence and power from an oppressed society, where they are too often sexualised and objectified (Brumberg, 2000; Ward, 2007). What is perhaps most surprising is that the Pro-Ana revolt seemed to have slipped under the radar, evoking very little negative attention until the turn of the millennium.

#### **1.4.10 Narratives of Pro-Ana Sites, Laws and Regulations**

In 2001, *Cosmopolitan* magazine labelled Pro-Ana 'the world's most dangerous secret society'. Shortly after the article was released Yahoo shut down 115 sites in a four-day window and other search engines quickly followed suit (Reaves, 2001; Way, 2015). By 2002 the sites were demonised throughout the media, health professionals were warning of the dangers associated with their use and researchers had started to covertly investigate what was on the sites (Giles, 2016) perhaps hoping it would shed more light on eating 'disorders' themselves. This hostility and surveillance from the outside world drove many sites underground (Dias, 2013; Yeshua-Katz, 2015). They started to drop the 'Ana' and 'thin' terms from their titles and added disclaimers to sites warning people of the dangers of entering (Mulveen & Hepworth, 2006). Yet despite these actions providers continued to shut

down the Pro-Ana sites. Giles (2016) claimed that this led to a new era which some described as 'Ana-Lite'. This occurred from 2002-2007 and put simply the sites diluted their ideas down in order to gain acceptance. They also began to spread across the West and sites began appearing in Germany, Spain and France (Giles, 2016). In 2008 legislation was passed in France to allow hefty fines to be imposed on modelling agencies who employed extremely thin models and Valerie Boyer, a right-wing parliament member created a bill to force the closure of all Ana sites, however the bill did not pass and if anything, the number of sites rose (Allen & Sparks, 2015; Way, 2015). This appeared to be due in part, to new forms of social media and diversification of the sites. Blogs replaced traditional sites and members were connecting through LiveJournals or Vlogs on YouTube. Myspace, Facebook, Twitter, Flickr and Instagram also brought new opportunities to host 'thininspirations' and appeared to be less vulnerable to censorship (Boero & Pascoe, 2012). This led to some of the old more stringent Pro-Ana ideals being reclaimed (Giles, 2016). In 2012 Pinterest and Tumblr announced a new ban on this material and Instagram deleted all hashtags titled Pro-Ana but this did not have the desired affect and new hashtags have been created and circulated (Barnett, 2012; Indvik, 2012; Ryan, 2012). A recent study found that there were as many live sites now post-ban (Casilli, Pailler, & Tubaro, 2013).

This has led many governments and clinicians to shift focus; rather than trying to eradicate the movement they have more recently sought to understand it by conducting research. The majority have either done this by studying the Pro-Ana sites themselves through content analyses or covert observations (Borzekowski et al., 2010; Brotsky & Giles, 2007; Harshbarger et al., 2009). This has often involved using publicly accessible material as data, either by analysing the general content on each site or downloading text from non-password protected message boards (Brotsky & Giles, 2007). Alternatively, research has been

conducted more overtly with Pro-Ana participants, either through qualitative questioning of their experiences or by using experimental designs to look at the impact of use on individuals.

#### **1.4.11 Summary**

Many view Pro-Ana sites as a movement of resistance. Resistance to the pathologising dominant discourses held within society that fail to take into account common causes of ‘disordered’ eating like trauma, abuse and oppression. Resistance to threats of hospitalisation, ‘recovery’ and specifically weight restoration as well as resistance to conforming to common ideals of beauty as weight loss are typically encouraged long after socially desirable weights have been met (Dias, 2013). Until the turn of the century this movement existed largely under the radar but since it was branded ‘the world’s most dangerous secret society’ in 2001, it has received a lot of negative press. Health professionals have warned of the dangers associated with use, politicians have tried to pass laws shutting the websites down and some host sites like Yahoo have even done this (Reaves, 2001; Way, 2015). Yet despite the attack on the Pro-Ana movement, it has survived, with hundreds of sites thought to be in existence (Hansen, 2008). As a result, the focus has shifted from trying to eradicate the movement to trying to understand it. This has led to two types of studies being conducted: Those that looked at what was written on the websites through content analysis and covert observations; and those that interacted with participants who used the sites, through surveys, qualitative interviews and experimental designs. The former will now be briefly discussed and the later shall become the focus of the systematic review.

#### **1.4.12 Research into Pro-Ana Forums**

##### 1.4.12.1 Content Analysis

Researchers have sought to understand the movement by examining content typically contained on the sites (Borzekowski et al., 2010; Harshbarger et al., 2009; Juarascio, Shoaib

& Timko, 2010; Lapinski, 2006). Despite the Pro-Ana websites varying widely in their stance, many have been found to share common features; most notably with a ‘thininspiration’ photo gallery and a ‘tips and tricks’ section (Hepworth, 1999).

‘Thininspirations’ tend to be photographs of ultra-thin, often emaciated models, celebrities and sometimes Ana followers. Photographs of Kate Moss, Mary Kate Olsen and Nicole Richie are routinely used. ‘Thininspirations’ can also include quotes, like Kate Moss’s tag line, ‘nothing tastes as good as skinny feels’ (Dolan, 2003). These posts are thought to inspire food restraint.

In the ‘tips and tricks’ section participants share weight loss ideas (Juarascio, Shoaib, et al., 2010). Harshbarger et al. (2009) examined this aspect of nine websites and identified three common themes, on this part of the site. The first theme of calorie restriction and dieting tips, accounted for 28% of the website content, advice included:

*‘When you get the urge to eat rinse your mouth with strong mouthwash or brush your teeth. Food will not taste so good then’*

*‘Pick one food for the day like an apple. Cut it into eight slices. Eat two slices at breakfast, two slices at lunch, two at dinner and you will have two left for a snack!*

*This way your body thinks it is eating four times that day, but in reality, you only had one apple’.*

The second theme concerned tips that distracted from hunger, this accounted for 14% of the content, for instance:

*‘When you want to eat something, you should not, make a list of all the reasons you should not and read it twenty times’.*

The third theme centred on ‘deception’, put simply, ways to conceal weight-loss and its impact from health professionals and loved ones. This accounted for 11% of the content, for example:

*‘Put change in your pockets. Ladies some coins in your bra to add weight. You won’t have to take off your undies before being weighed’*

*‘Wear nail polish to hide the discolouring in your nails from lack of nutrition’.*

The authors argued that whilst some of tips were seen as aggressive and dangerous, taken in isolation most were benevolent. It was the combination of restriction and concealment tips that posed the most concern (Harshbarger et al., 2009).

A widely-cited content analysis of 180 active Pro-Ana sites found that 79% of sites contained interactive features (Borzekowski et al., 2010). Examples included bulletin boards and chat rooms where users talked to each other directly, sharing ideas, advice and experiences. Some of the interactive spaces enabled visitors to join fasting groups or buddy up with another member. Here individuals often mentored each other on how to obtain the lowest weights. This study also found that 91% of sites were publicly available with a very small proportion having restricted access to the main interface (Borzekowski et al., 2010).

Some websites also had song lyrics, poems, autobiographical stories, information about treatment and general information about the physical and psychological changes associated with anorexia, and/or other eating ‘disorders’ (Juarascio, Shoaib et al., 2010). More blog-like websites tended to display diary entries usually from the site owner with the function of keeping others regularly up to date on their own calorie intake, moments of weakness and pledged recommitment to the Ana lifestyle (Giles, 2016). In many of these sites ‘disorders’ were personified and referred to simply as ‘Ana’ or ‘Mia’ (Lieblich, Tuval-Mashiach, &

Zilber, 1998). The sites tended to have aspects that were similar to some religions, drawing on discourses of faith and obedience, with most listing ‘Creeds’ or ‘Thin commandments’ which represented a set of rules that users were expected to practice and follow (Harshbarger et al., 2009) for instance:

*‘Thou shall not eat without feeling guilty’.*

#### 1.4.12.2 Covert Observations and Interpretations

Studies using methods of covert observations will now be discussed. Upon entering the sites, most users introduced themselves to the community by statistics. This was typically their age, height, current weight, heaviest weight, lightest weight and goal weight (Fox et al., 2005). Researchers examining group interactions found that the way in which an individual positioned themselves at this point regarding why they had joined the community and what they hoped to achieve, was central to determining whether they would be embraced and welcomed or rejected and shunned (Brotsky & Giles, 2007). There was an emphasis on keeping the site free from ‘wannabes’ or rather ‘wannarexics’ who confused the eating ‘disorders’ with ‘fad’ diets and a desire to maintain an elite community (Yeshua-Katz, 2015). Yet there was also some degree of variability regarding who was accepted across the websites. In Brotsky and Giles’ 2007 covert study, a researcher constructed a single Pro-Ana persona, joined 12 websites and gained access to their associated chat rooms, blogs and email groups for a two-month period. In doing this, the researcher experienced great variability in the responses from community members some were extremely hostile, others very supportive. This cast further doubt on the idea that there was a single unifying Pro-Ana philosophy and instead suggested that support was conditional upon fitting into a set of unspoken, often illusive group norms. Yet once accepted members appeared to be fiercely loyal.

From analyses of user discussions, it seemed that the need for online support was driven by the user's unwillingness or inability to share their experiences with loved ones (Brotsky & Giles, 2007). This impression is consistent with Dias (2013) study, who used discourse analysis and identified common Pro-Ana narratives as feeling miss-understood, isolated, out of control and having opposing ideas about on the one hand wanting to go public with their struggle, but on the other avoid publicity. Their accounts suggested that they feared the response that they may receive from others.

Brotsky and Giles (2007) noted that parents were frequently positioned as 'force-feeders' who failed to engage with and understand user's 'psychological difficulties' in a similar vein to health care professionals who were regarded as treating the wrong symptom. Yet by far the highest numbers of negative comments made by site members were self-directed.

*"But for me I have started it as a way to deal with a bigger problem which was my depression and suicide ideation. Then it spiralled out of control and into this whole other uncontrollable problem of its own proportion".*

Consistent with some self-harm theories this last statement positions anorexia as a problem that started out as a coping strategy before becoming a problem in its own right (Grasfield, 2015). It appears that some users felt that they had no alternative but to adopt this coping strategy which often became a bigger problem than the first difficulty that they were trying to cope with.

Despite these deep and passionate interactions researchers also noted that the content of members' discussions could often be mundane concerning boyfriends or popular culture. This suggested perhaps that the main function of these sites was social rather than informational (Giles, 2016). Moreover, although a key concern raised by health professionals was the promotion of the shared ethos that eating 'disorders' were a 'life-style' choice rather than a

mental health condition, when it came to users discussing anorexia and bulimia their meanings, origins and perspectives on ‘recovery’, a vast array of positions were held, both within each site and between them (Brotsky & Giles, 2007). Ana was referred to as a ‘disease’, ‘disorder’, illness and lifestyle, often interchangeably and also in combination of all (Brotsky & Giles, 2007). Indeed, shared behaviours seemed to trump having a shared lifestyle ethos. Notably in a grounded theory analysis of message boards it was found that when an individual felt in control Ana was positioned as a good thing, a friend. However when users felt out of control it was seen as the enemy, a foe (Williams & Reid, 2007). These findings mirror the general ambivalence towards ‘recovery’ identified in the work of Serpell, Treasure, Teasdale, and Sullivan (1999).

In the systematic reviews below I will discuss the studies which have actively spoken to users to try to understand what led them there and what impact site use had.

### **1.5 Systematic Review**

The systematic review is comprised of nine peer reviewed journals which have either explored 1) individual accounts of how people came to learn about and repeatedly use Pro-Ana sites, 2) qualitative or quantitative research that examined the impact of use 3) individual accounts that explored how people were able to withdraw from the Pro-Ana sites 4) qualitative or quantitative research that examined the impact of withdrawal (see Appendix C for search strategy). Given the small amount of research published using individual accounts and examining the impact of use/withdrawal, it was felt that all available work should be included but the quality of studies should be considered (see Appendix E). A summary of each study including their main findings are in Appendix D. Akin to the theoretical position which drives the study, I invite the reader to consider the review as being one ‘perspective’ of many on the subject matter (Gilbert & Mulkey, 1984).

### **1.5.1 What Leads People to Pro-Ana?**

Studies suggested that a high proportion of users discovered the sites through internet search engines, the media, chatrooms, journals or friends (Csipke & Horne, 2007; Ransom et al., 2010; Rodgers, Skowron, & Chabrol, 2012). Themes of belonging, connection and opportunities for improved weight loss, were consistently identified as an initial draw to Pro-Ana sites (Collyer, 2014; Csipke & Horne, 2007; Gale, Channon, Larner, & James, 2016; Ransom et al., 2010; Rodgers et al., 2012). These findings mirror that of the covert studies which interpreted discussion boards (Brotsky & Giles, 2007), though hold ethical advantage, as participants gave informed consent for their data to be used in the research.

Most studies have been quantitative, using self-report surveys and Likert scales in a bid to investigate ‘reasons’ for members first coming to the Pro-Ana community (Gale et al., 2016). Notably, there has been a high degree of consistency reported across studies samples, regarding the cited value of weight loss opportunities. With 52%-59% of samples citing it as a pull towards the sites (Peebles et al., 2012; Ransom et al., 2010; Rodgers et al., 2012).

There has been much more variation regarding the claimed importance of social support. In a small study comprised of 64 participants, 75% of the sample cited support as a key reason for using the sites, compared to just 26% in a much larger survey of almost 1300 Pro-Ana users. One reason for the discrepancy may concern the subtle differences in the wording of survey questions. For instance, Peebles et al. (2012) asked if support was the ‘main reason’ for Pro-Ana use, compared to Ransom et al. (2010) who asked if it was ‘a reason’ for use. Thus, it is possible that whilst many view social support as a draw, they did not position it as the main reason. Furthermore, it is possible that the differences could be accounted for because participants were recruited from subtly different Pro-Ana sources; in Ransom’s case forums and in Peebles’ case websites. Forums may have provided more opportunities for

communication and the sharing of experiences, attracting a different type of user and perhaps those who value social support more highly (Peebles et al., 2012; Ransom et al., 2010).

Whilst both highlighted perceived support as a draw, one advantage of the Ransom study in particular, was the detail in which this support was investigated. In contrast to Peebles, which encompassed just a few items on a questionnaire, Ransom used an entire measure. Ransom also went on to investigate how perceived offline support differed from age matched controls, who were not using the sites. The findings suggested that Pro-Ana users reported significantly lower levels of global support in offline relationships and also in relation to their biggest life stressor, which many stated was their eating 'disorder'. Of course, it remains unclear whether pre-existing poor offline support led users to the sites, or if there was a shift in support as a by-product of continued Pro-Ana use. Further investigation is needed and caution should be taken by those generalising findings with such a small sample.

### **1.5.2 What is the Impact of Use?**

Both qualitative and quantitative studies have investigated the impact of using these sites on individuals, identifying a number of benefits and draw backs.

#### 1.5.2.1 Quantitative Studies

Quantitative studies have frequently reported an association between Pro-Ana use and heightened image and eating related concerns (Csipke & Horne, 2007; Peebles et al., 2012; Ransom et al., 2010; Rodgers et al., 2012). In a sample of 150 Pro-Ana users, 32% reported an adverse impact on their body attitudes following use, 46% reported weighing or measuring themselves more often and 50% claimed that the sites were helping them restrict, fast or purge (Csipke & Horne, 2007). These findings have been replicated in a much larger study and a dose response relationship reported (Peebles et al., 2012). Put simply, those who spent more time on the Pro-Ana sites reported high rates of 'disordered' eating. However, casual

inferences cannot be made using these paradigms and at times, the findings and potential implications of the research have been over stated by authors.

The first study which claimed to provide a causal link of Pro-Ana use leading to adverse consequences, was Bardone-Cone and Cass (2007). Here 235 college students were randomly allocated to one of three conditions, either viewing the Pro-Ana site, a mock fashion site, or home décor site, for a 25-minute period. Mood, cognitions and eating attitudes were assessed both immediately before and after participants viewed the sites. The study found that there was a significant reduction in self-esteem and self-reported attractiveness, in those that viewed the Pro-Ana sites. They were also more likely to ruminate about their weight, perceived themselves to be more overweight in relation to others and showed higher rates of negative affect, compared to the other two groups (Bardone-Cone & Cass, 2007). However, the lack of follow-up data makes it difficult to determine if any changes were long lasting. It is also unclear, whether these changes in cognitions, led to any behavioural changes. This was investigated by Jett et al. (2010). Using a similar paradigm and sample size, it was observed that one off Pro-Ana site exposure in healthy college students led to a weekly reduction in calorie intake by 84% of the sample. 60% claimed to have reduced their intake by 2500 calories per week, 33% by 4000 calories per week. Perhaps even more worryingly, 28% reported being unaware that this reduction had happened. At a three week follow up point almost a quarter of participant reported that they were still restricting their intake and stated that they planned to continue using the weight-loss methods discovered whilst on the site.

Collectively these findings suggest that Pro-Ana sites may influence thoughts, feelings and behaviours which are more indicative of ‘disordered’ eating. However, given the ‘crude’, artificial nature of the experimental studies, further research is needed regarding the exact

processes that may led to this proposed change, with longer follow-up periods and conducted in more naturalistic settings.

#### 1.5.2.2 Qualitative Studies

Some researchers have employed qualitative interviews, to try and gain richer insights into user's experiences than has previously been afforded by quantitative methodologies (Crowe & Watts, 2016; Fox et al., 2005; Gale et al., 2016). Here Pro-Ana users often reported a sense of catharsis and relief in being able to share their struggle with others online, they reported improved their mood (Collyer, 2014; Williams & Reid, 2012). The type of support was positioned as 'uniquely non-judgemental' and in this way appeared to act as a 'haven' for many women; offering them liberation from the negative views of the offline world (Crowe & Watts, 2016; Fox et al., 2005).

Although it has been reported that these sites only offer support in relation to restriction, some participants reported that they had received encouragement to eat, to accept their body and to communicate their distress with loved ones (Ransom et al., 2010). While these were seen as the perceived benefits there is perhaps a more sinister side. Many participants did report learning new restriction behaviours that they claimed they would not have thought of on their own and stated that it acted as a barrier to gaining support offline, which could impact 'recovery' (Collyer, 2014). One of the most concerning impacts of regular use appeared to be a normalisation of 'disordered' eating and a minimisation of the dangers associated with extreme weight-loss methods shared among the community. This is captured in the quote below of a Pro-Ana member:

*'You ever seen that 'how to look good naked' on TV? This fashion designer Gok Wan finds these really fat women and helps them get comfortable with their bodies. These are seriously fat women, that's not healthy either but no one mentions that, so when*

*he does it it's somehow ok. Well we're just like Gok, but in reverse. We help people feel good about being thin, but we get crucified for it.* (Crowe & Watts, 2016)

It is notable that only three studies have used qualitative interviews as a means of understanding individual Pro-Ana experiences (Crowe & Watts, 2016; Fox et al., 2005; Gale et al., 2016). While the demographics of participants was richly described in one study (Gale et al., 2016), it barely featured in the other two which limits our understanding of how these findings situate in relation to the experiences of other Pro-Ana members (Crowe & Watts, 2016; Fox et al., 2005). This is seen as a significant limitation to the existing work that has been conducted so far.

Nevertheless, despite the many limitations in the existing body of research, the findings from both quantitative and qualitative studies has led many to claim that accessing Pro-Ana sites can create, worsen and maintain eating related difficulties. As a result, it seems reasonable to argue that disengagement from these Pro-Ana sites may be a necessary step in enabling individuals to recover and warrants further investigation.

### **1.5.3 How do Users Disengage with the Sites?**

Remarkably what has been completely overlooked in the literature so far is any study looking at how regular Pro-Ana users were able to disengage from this online community and what impact this withdrawal had on their lives. The lack of research may be due to the difficulties associated with reaching this population or in realising how to identify and capture positive outcome indicators. These are notoriously harder to measure than barriers, as they are more complex and likely to present in a narrative form (Garrett, 1997). Yet the value of this kind of study and its potential cannot be denied as it could offer clinicians and the public a valuable window into the struggles of living with eating difficulties within a digital age. Specifically, it could shed further light on the appealing features of the Pro-Ana community, which may be

important for clinicians to be aware of, in order to understand the power of the sites influence. By seeking to hear the stories of those who have experience of trying to disengage from Pro-Ana and also considering how their accounts are co-created, a far richer understanding of the withdrawal process and its associated impact could be uncovered.

#### **1.5.4 Research Recommendations Based on Literature Gaps**

A number of recommendations have been made, regarding the direction of future research. According to Grasfield (2015) whilst much research has already been conducted into eating ‘disorders’, the majority has been quantitative. Thus, understanding the experiences of those living with eating difficulties through qualitative methods has often been overlooked, with few high-quality studies produced. He argued that if future studies could shift their focus and ideally use a narrative lens, new, unique, intimate insights may be provided. Conversely, Rodgers et al. (2012) argues that the focus should shift to understanding the Pro-Ana communities. Specifically, studies looking at what led members to join the sites as well as leave and seek ‘recovery’. To date there have been no published studies that have looked at what enabled people to withdraw from the Pro-Ana community and how this withdrawal impacted lives. Finally, Bardone-Cone and Cass (2007) argues that Pro-Ana research should not just involve those with a diagnosed eating ‘disorder’ but also those without, as a huge number do not meet the DSM-V or ICD-10 criteria. These ideas have shaped the direction of the thesis that I will now present.

#### **1.6 Study Aims**

The study aims to address gaps in the Pro-Ana literature by conducting qualitative interviews with those who have regularly used Pro-Ana forums; with a focus on better understanding not

only what led individuals to join this community but also how they storied the disengagement process and any impact it had on their lives.

To my knowledge this is the only study that has sought do this. It will also not privilege the accounts told by those who have an official eating ‘disorder’ diagnosis as a large number of users are either undiagnosed or would not meet diagnostic criteria (Bardone-Cone & Cass, 2007). Therefore, anyone who considered themselves as having experienced eating difficulties and to have regularly used the Pro-Ana sites will be eligible to take part. In order to consider the situational, societal and cultural factors which might be impacting on how individuals are able to tell their story I will use a narrative analysis methodology. This methodology, although thought to hold value in this field (Grasfield, 2015) has never been conducted in relation to exploring interview accounts of the Pro-Ana community.

### **1.7 Research Questions**

- 1) How do regular users of Pro-Ana forums narrate their experiences of how they came to regularly use the sites and subsequently disengage from them?
- 2) How do people narrate the impact this journey has had on them (relationship to self and others overtime and relationship to food and eating over time)?

Within this question, particular attention will be paid to:

- 1) The content of the narrative
- 2) How the story is told (in terms of structure, performance and context)

## Chapter 2: Method

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*'If we understand the world narratively... then it makes sense to study the world narratively'*

*(Clandinin & Connelly, 2000, p.17)*

The chapter opens with details of the study's methodology. This includes its epistemological position, the rationale for using qualitative approaches and in particular, narrative inquiry. An overview of the research design is then presented, key ethical considerations discussed and an explanation of the procedure and the process of analysis provided. It is my intention that the reader has enough information to adequately assess how suitable the approach and chosen analysis are, whilst also considering the steps taken to ensure the project's credibility and rigor.

### **2.1 Methodology**

#### **2.1.1 Qualitative Research**

Up until now most studies investigating the Pro-Ana movement have adopted a quantitative approach; concerned with finding casual relationships and absolute 'truths' (Burr, 2015).

These approaches have been criticised for reducing human experience to numerical outcomes (Krahn & Putnam, 2003). With such a strong focus on precise measurement and objectivity, quantitative methods are not well placed to explore the subjective and complex nature of how individuals make sense of their experiences, in the context of their social lives (Riessman, 1993; Wells, 2011). Qualitative methodologies are much better placed to do this. In order to determine which qualitative approach should be selected, both the research question and the projects epistemological position were considered (Pearce, 2010).

### **2.1.2 Epistemological Position**

As noted in the introduction, the philosophical position of social constructionism underpins the study. Constructionists claim that individuals create their own meanings of the world, through their social interactions with others and the environment (Gergen, 2009). The meanings, knowledges and beliefs a person holds are therefore shaped by their culture, context and the language which is available to them (Burr, 2015). Such contexts will invite individuals to narrate their accounts in differing ways, leading some discourses to be privileged, silenced or seen to offer points of resistance (Squire, 1991).

Social constructionism also acknowledges that any account is a co-constructed story; influenced by the social interactions between the interviewer and interviewee, their perceptions of each other and the research objectives (Stokoe & Benwell, 2006). As well as the multiple voices of culture and context embedded within it and perhaps versions of events told by loved ones, who may have contributed to the sense making of these tales (Frank, 2012; Goodley, 1996; Lyons & Chipperfield, 2000). Furthermore, it recognises that any account will be bound by time and space; that different stories will be told to different audiences, in different contexts and at different points in time (Pearce, 2010). The resulting interview is thus not seen as a fixed account of ‘truth’ but an ever-evolving construction of an ‘experience’ as expressed in language within a particular relational and socio-cultural context.

### **2.1.3 The Case for Narrative Inquiry**

Narrative inquiry (NI) refers to a collection of methods used to interpret storied language (Wells, 2011). The approach has origins in anthropology, sociolinguistics and the social sciences (Riessman, 2008), which has led to an array of definitions and frameworks being put

forward to investigate human experiences through narrative forms (Squire, Andrews, & Tamboukou, 2008).

According to Gergen (2009) a narrative is a story of events, placed in a sequential order to convey meaning to a specific audience and for a specific purpose. Narratives may be seen to offer audiences insights into two realms. 1) The realm of experience, where speakers convey how they have experienced certain events and infer their own meanings onto these experiences; and 2) the realm of narrative means, which considers the devices used to construct these accounts (Bamberg, 2010). Therefore unlike other forms of qualitative analysis (such as Interpretative Phenomenological Analysis (IPA) and Thematic Analysis), which primarily concern themselves with the content of *what* is said (Lyons & Coyle, 2016), NI goes beyond this and is also concerned with *how* the speaker constructs their story, *why* the tale is told in that way and for what ends (Riessman, 2008; Wells, 2011). Therefore, when considering narratives of how Pro-Ana users come to regularly visit and gradually disengage from the sites, it is possible to analyse not only what is explicitly stated but also consider the dialogic-performative aspects of their account, which may provide richer, more meaningful insights (Riessman, 2008).

Another strength of NI is that it considers how the local and broader context may impact the constructed narrative (Wells, 2011). This is consistent with the studies epistemological position. The local context refers to the interactional relationship between the interviewer and interviewee and the broader context refers to the cultural, historical, medical and political context in which the account is situated (Frank, 2012). Within this study, it could be possible to examine, how individuals position themselves in relation to the broader societal narratives about eating ‘disorders’, Pro-Ana sites and Pro-Ana site users and also how they position themselves in relation to me, the interviewer.

It is further argued that NI recognises that individuals make sense of themselves and their identities through narrative form (Bamberg, 2010; Gregg, 1991; McAdams, Josselson, & Lieblich, 2001; McAdams & Ochberg, 1988). As new circumstances, experiences and information arise, new individual and group identity narratives emerge (Bruner, 2004). Humans engage in a continuous process of constructing and reconstructing who they are, through the stories they tell and others tell about them. In this sense, identities are seen to be relational and fluid (Bruner, 2004). NI can therefore be seen to provide unique opportunities to consider which identities are being performed and claimed within the accounts and for what purpose.

Although a range of qualitative methodologies were considered, including Grounded Theory, IPA, Thematic Analysis and Discourse Analysis (Lyons & Coyle, 2016). It was felt that NI was most suited for capturing the studies epistemological position and research questions. Specifically looking to investigate both the content of Pro-Ana disengagement accounts, along with considering how the socio-political context may impact what was shared and how the account was performed. No other approach seemed better placed to do this.

## **2.2 Design**

### **2.2.1 Sampling Strategy**

Participants were recruited using a purposive sampling frame; a method commonly used in qualitative research (Oliver & Jupp, 2006). Initially I hoped to recruit 8-10 participants but time constraints, difficulties with recruitment and a desire to thoroughly analyse the data, meant that this recruitment target was reduced. Six female participants formed the final sample, two British and four American. Although this is relatively small, Wells (2011) notes

that for narrative studies involving complex and detailed analyses samples as small as five can be sufficient and allow for a more in-depth examination of the data.

The inclusion criteria for the study is outlined below, along with a rationale regarding why it was adopted:

Participants had to answer yes to the following statements:

1. Be aged eighteen or over
2. Have a history of eating difficulties
3. Previously logged onto pro-eating ‘disorder’ sites, regularly
4. Now either reduced their use of these sites or stopped logging onto them altogether

Item 1: Given the potential distress that might be experienced by participants reflecting on their journey into and out of the Pro-Ana community, setting a lower age limit of eighteen seemed appropriate. Furthermore, some narrative researchers claim that the ability to make sense and construct a series of self-defining stories is a complex skill that requires both reflection and formulation. These skills are not thought to develop until individuals reach their adult years (McAdams & Janis, 2004), adding weight to an age limit of eighteen being employed.

Item 2: The term ‘eating difficulties’ rather than ‘eating ‘disorder’ was used, as to not ignore the stories of individuals who consider that they struggle with body image but fall outside the thresholds set by the DSM and the ICD. Indeed, studies estimate approximately 60% of Pro-Ana site users, do not reach diagnostic threshold (Bardone-Cone & Cass, 2007).

Item 3 and 4: As the research aimed to understand how Pro-Ana disengagement was narrated, it felt important to recruit participants who were immersed in that culture and identified as ‘regular’ users but had now stopped or significantly reduced their visits to these sites in order

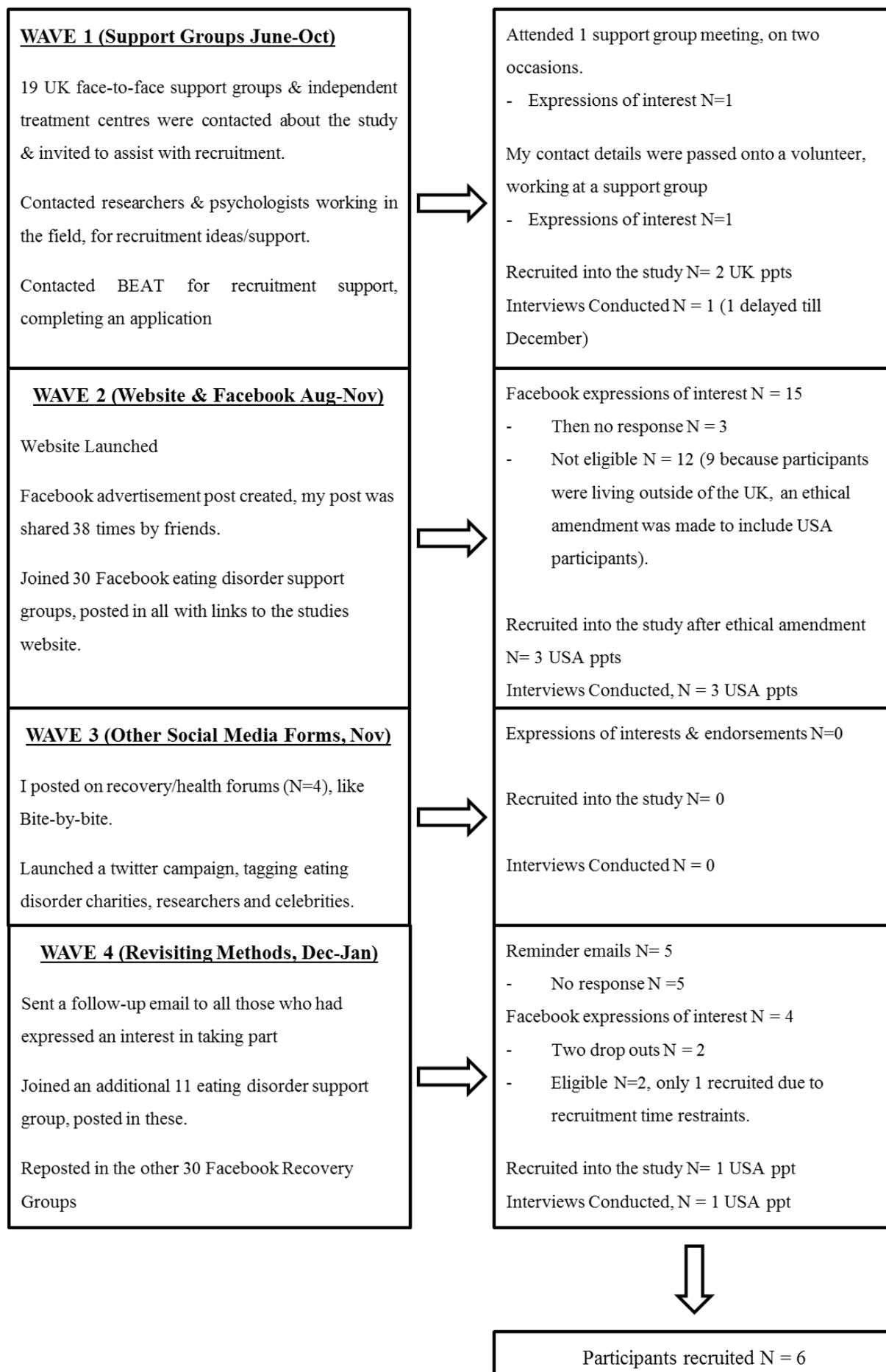
to understand how they made sense of how this change in behaviour was possible. Akin to the studies epistemological position, I did not feel comfortable adopting stringent criteria of what qualified as either 'regular' or 'reduced' use, as this would privilege certain stories over others. Thus, what was considered to be 'regular use' and 'reduced use' were self-defined by the participants.

### **2.2.2 Recruitment Procedure**

Participants were recruited via support groups listed on the BEAT website (N=2) and online Facebook Recovery Groups (N=4). There were four recruitment waves, which took place between July 2016 and January 2017. See figure 2.

### **2.2.3 Sample**

Prior to any interviews being conducted, participants were asked to provide demographic and background information concerning their eating difficulties and Pro-Ana usage (see table 1a, 1b and 1c). Face-to-Face and Skype (video conferencing) interviews were conducted for both British and American participants respectively. As noted by Deakin and Wakefield (2014), Skype provides 'an opportunity to talk to otherwise inaccessible participants', offers a convenient way to maximise research budgets and 'gives participants, a greater freedom to participate, without the need to travel'. However, it is not without draw backs, Seitz (2016) claims that these methods involve a loss of intimacy between the researcher and participant. This can affect rapport which is an essential ingredient in minimising social distance and enabling rich stories to be narrated. Nonverbal forms of communication and paralinguistic cues can also be harder to detect (Markham, 2006).



**Figure 2: Recruitment Waves**

**WAVE 1:** Initially nineteen UK support groups and independent treatment centres were contacted and invited to take part in the study (either advertised via BEAT or found using the google search engine). Three replied to my email. One agreed that I could attend a monthly group meeting and discuss my research with their service users, the other two did not wish to be involved with the study, though one organisation did agree to forward my email on to a volunteer who was known to have used the Pro-Ana sites. This individual was subsequently recruited into the study and an interview conducted in December 2016. There was a delay due to her study related commitments. On attending the monthly support group in August, it was unusually quiet and no service users in attendance fitted the studies eligibility criteria. I asked if I could return after the summer holidays and attended the October group meeting. One participant expressed an interest in taking part after this second meeting and an interview was arranged and conducted later that month. I contacted a number of eating “Disorder” researchers working in the field for advice relating to recruitment and subsequently decided to complete an application for research supported by BEAT. However, due to delays in the proposal being processed, other recruitment avenues were explored. (Wave 1, participants recruited N = 2, interviews conducted N =1).

**WAVE 2:** In the second recruitment wave I launched a website. I posted links to the site on my personal Facebook account and the post was subsequently shared by 38 friends. This yielded no participants. I also joined and posted about the study in 30 Facebook eating “Disorder” recovery groups, providing links to my website. Fifteen people expressed interest in taking part: three were not eligible and a further nine were American, which made them also in-eligible. Following this, I made an ethical amendment and decided to expand my search criteria to include participants based in the USA. Of the nine American’s who had initially expressed interest, three responded to the follow up email. Interviews were scheduled and conducted for these three American participants in November 2016. Of the three British people who initially showed interest, no one responded to my follow-up email. (Wave 2, participants recruited N= 3, interviews conducted N=3).

**Figure 2 (cont.): Recruitment Waves**

**WAVE 3:** In the third recruitment wave I posted about the project on recovery forums like, bite by bite and tweeted about it to well-known charities, recovery groups and celebrities, who have spoken publicly about their experience of eating difficulties, to see if they could endorse the project. No endorsements occurred via twitter. Two participants did express interest in the study during this period, it is unclear how they came to learn about the project but did not reply to my follow up email regarding participation (Wave 3, participants recruited N=0, interviews conducted N=0).

**WAVE 4:** In an effort to recruit further participants, a follow up email was sent to all those who had expressed interest in the research but I had not heard from and study advertisements were re-posted in the 30 Facebook Recovery Groups I was a member of. I also did a fresh Facebook search and joined a further 11 new Facebook eating “Disorder” support groups and posted in these too. This resulted in four American participants expressing interest over Facebook. Due to time constraints, I decided to just recruit and interview one participant. I created a first come first serve list, the top two participants on the list, scheduled interviews but pulled out just before I was due to conduct them. The final participant (third on the list) was subsequently recruited and the interview took place in January 2017. This gave a final sample size of six. The remaining participant on the reserve list was thanked for their time but informed that recruitment to the study had now closed.

**Table 1a: Basic participant demographic information, from the pre-interview questionnaire**

Pseudonym	Age	Gender	Ethnicity	Social Class	Highest Qualification	Geographical Location (at time of interview)	Recruitment Source
Heidi	36	Female	White Caucasian	Working Class	BA & MA (complete)	USA	Facebook Support Group
Emma	26	Female	White	Middle Class	PhD (In progress)	USA	Facebook Support Group
Kirsty	22	Female	White British	Middle Class	PGCE (in progress)	UK	UK Support Group (attended)
Lucy	38	Female	White British	Working Class	Bsc Hons (in progress)	UK	UK Support Group (Email Inquiry)
Kendra	22	Female	Hispanic/Latino	Middle Class	BSc Hons (in progress)	USA	Facebook Support Group
Samantha	20	Female	Indian	Middle Class	BSc Hons (in progress)	USA	Facebook Support Group

**Table 1b: Reported Pro-Ana Usage Data**

Pseudonym	Age First Visited Pro-Ana/ED Sites	Age Last Visited Pro-Ana/ED Sites	Peak Site Use	Peak Hours Spent on Site Per Week	Duration of Peak Site Use	Have you posted / chated to others on the sites?	Are you visiting the sites now?
Heidi	Age 22	Age 33	Weekly, sometimes daily	4-8 hrs per week	Almost 2 years	Yes.	Not at all.
Emma	Age 15	Age 23	Daily, multiple times	8-15 hrs per week	Several months	Left Blank	In the past year I have searched the hastags 'skinny' or 'anorexia' on Instagram a few times. This has been the extent of it.
Kirsty	Age 15	Age 21	Daily, multiple times	3 hrs per week	Left Blank	No.	Not at all but I do use recovery pages on facebook daily & am obsessed with anything about eating disorders on YouTube.
Lucy	Age 32	Age 35	Daily, multiple times	21-28 hrs per week	Several Years	Yes.	Not at all.
Kendra	Age 14/15	Age 22	Daily, multiple times	7-14 hrs per week	Weeks/Month on & off	Yes	Not at all.
Samantha	Age 14	Age 18	Daily, multiple times	20-25 hrs per week	11 months	Yes	Not at all in the last year.

**Table 1c: The Nature of Reported Eating Difficulties**

Pseudonym	Description of Eating Difficulty	Age of Onset	Official Diagnosis	How would you describe your eating difficulty now?
Heidi	Since the age of 5 I have struggled to have a healthy relationship with food. On & off I have viewed it as something that I had to earn. I have also been in places in my life where I could binge and purge on over \$100 in an evening.	Age 5	Yes. Anorexia & Bulimia	I am currently struggling with my desire to restrict. I have been ill and lost about 50lb due to my illness. I have begun to receive compliments on my size and weight loss and it is compromising my ability to fight the ED thoughts?
Emma	My official diagnosis began at age 15, which was Anorexia. I currently have a diagnosis of EDNOS but consider myself in recovery. It has affected me more at different times in my life than others: at the worst time it affected me physically to the point that I was hospitalised with heart problems, electrolyte imbalances and immobility of my limbs. It all effected me socially for a long time.	Age 12	Yes. Anorexia (binge/purge subtype) & now EDNOS	I am mostly better: I consider myself in recovery, but still see a therapist. I still struggle with body image issues and fantasise about losing extreme amounts of weight but do not engage in disordered eating for the most part. I do avoid meal planning and grocery shopping and engage in some unhealthy habits in those behaviours but not to a point that it would be considered clinically significant.
Kirsty	I have had a restrictive eating disorder for about 7 years. This was diagnosed as 'eating disorders' & I have not had a more specific diagnosis. From my own research I have both anorexia and bulimia and go through episodes of one and then the other. I am 22 now and still really struggling.	Age 15, things became unmanageable, but childhood onset	Yes. Type not specified by Drs	Its very complicated and messy. I have been attempting to recover as soon as things went downhill. Although my eating disorder was picked up really quickly & I have received support, I was reluctant to fully engage with the treatment and spent years bouncing back from trying to recover and trying to be ill. I relapsed really badly in 2016, this validated my ED for me as I always felt since I had not really been thin, I didn't have a real ED and that I certainly couldn't be anorexic. Even though my weight has been restored, I struggle with my ED constantly and am in the midst of a relapse currently. I hope to recover one day.
Lucy	I was in a cycle of restrictive eating followed by a phase of bingeing and purging. It affected me by not being able to function. I became isolated from the outside world. I lost my friends and wasn't able to carry on working.	Age 8/9, then again early thirties	Yes. Type not specified	I consider myself well and managing the eating disorder, so it is not ruling my life anymore.
Kendra	I have had an eating disorder since I was a teenager. It affects you in ways you can never imagine, my health deteriorated greatly to the point where I was always sick and weak. I pushed friends and family away and isolated myself with my illness. I do not have a strong immune system and my stomach is more sensitive to certain food.	Age 14/15	Yes. EDNOS	I am not fully recovered. Most of the time I eat good but sometimes not enough, other times all I can think about is my old eating habits again. I have to say I am much better now physically, mentally and emotionally. I like to say my eating disorder comes and goes. There are months I can go without falling into old habits and then one day I just stop eating and so on.
Samantha	Physically I have bone thinning and a tremmor. I am currently under the care of a dietician, therapist, psychiatrist & physical therapist. AN also led me to begin self-harming.	Age 11	Yes. Anorexia (restrictive subtype)	Not recovered though in recovery. Eating more with no attempts to restrict. Weight restored & maintained for a year. I am no longer counting calories but still restrict fluids heavily.

### **2.3 Ethical Considerations**

The study received ethical approval from the University of Hertfordshire (See Appendix F). As participants were not recruited through the National Health Service (NHS), additional approval from the National Research Ethics Service, was not required.

In accordance with the British Psychological Societies (BPS) Code of Ethics (2010) , key ethical concerns associated with the research, are discussed below.

#### **2.3.1 Informed Consent**

Given the stigma and shame many report in speaking about their eating 'disorder' (Crowe & Watts, 2016) and the largely negative societal discourses that surround Pro-Ana sites (Dias, 2013; Giles, 2016), I wanted to give individuals the opportunity to learn more about the study at their own pace, in an unpressurised, anonymous way before they agreed to take part. To facilitate this I constructed a study website (see Appendix K). This explained the broad aims of the research and requirements for participation.

Those who then expressed an interest in taking part by email were sent an information sheet to review and given the opportunity to ask additional questions about the study. A second opportunity to ask questions was also given verbally, at the start of each interview. The aim was that the transparency of the research would help participants make well informed decisions, regarding participation.

#### **2.3.2 Confidentiality**

The confidential nature of the study was made explicit on the studies website (FAQ section), information sheet and verbally to participants at the start of their interview. They were informed that all personal information would be stored securely on a password protected laptop, accessible only to the researcher and that extracts from their interview may be used in

the study's write-up. Participants were assured that any identifiable information would be omitted and a pseudonym used in order to maintain participant anonymity. It was explained that due to personal nature of their stories it would not be possible to guarantee that the stories would not be recognisable to those who were very familiar with their lived experiences. This is a common difficulty faced in qualitative studies (Elliott, 2005).

### **2.3.3 Participant Well-being and Risk Issues**

Due to the personal and potentially sensitive nature of the topic protecting participant well-being remained a central concern at each stage of the study.

With regard to advertising the study despite this form of recruitment being well used in other study's (Csipke & Horne, 2007; Peebles et al., 2012), I felt a tension between wanting to provide individuals with enough information about the research to enable them to make an informed decision about participation and advertising the existence of sites which as a group are known to be ambivalent about 'recovery' (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013). In order to minimise this risk, I thought carefully about my wording when posting into ED Facebook groups and the website. The website also included reference to relevant supportive organisations, such as BEAT & an NHS website.

Prior to consent, participants were informed that although the focus of the interview was on how disengagement from these sites was possible and having the opportunity to reflect on this, may, in itself be therapeutic, the interview may also elicit some unexpected distress. At the start of the interview participants were reminded that they could take breaks, choose not to answer certain questions or stop the interview and withdraw at any point.

If a participant became visibly distressed, I paused and when appropriate checked that they were happy to continue. As the interviews closed, I asked participants how they had found

the process of sharing their experiences and gave them space to reflect on the feelings evoked. Participants were given a debrief sheet (see Appendix J) at the end of the interview, which provided contact information for organisations that could provide ongoing support and my own contact details should participants wish to discuss any study related issues further. I also contacted them several weeks later to find out how they were feeling. No ongoing difficulties were reported as a result of study participation.

## **2.4 Procedure**

### **2.4.1 Preparation for Interviews**

In preparing for the interviews I reflected a great deal on how open I wished to be about my own image struggles and experience of using the sites. I also spoke with members of my supervisory team about this issue. On the one hand I recognised the stigma and shame attached to the disclosure of eating difficulties and that these can arguably fuel continued secrecy, leaving many people feeling that they are alone or abnormal. I did not wish to perpetuate the stigma cycle further by being silent myself. I also recognised that ethically, a power imbalance existed and if I asked participants very personal questions, they should be afforded the right to ask why I was interested in this research. However, I did not want the process to become an overly-indulgent cathartic space. I felt strongly that this was not appropriate. I was also mindful that any disclosures I made could impact on the stories my participants felt able to share.

After much consideration, I decided to offer a space at the start of each interview where I asked each participant if they had any questions for me in relation to the research project, or why I became interested in the area. All but one participant took up this invitation. I shared that I had struggled with image and eating difficulties in my early twenties, utilising exercise

to lose weight and had stumbled across the sites looking for more weight loss ideas. To position the research in a broader context, I spoke more generally about my interest in western ideas of beauty and the value of the female form, along with my surprise in realising how little research had been done into the impact of use and withdrawal from these sites, from the viewpoint of those who regularly used these websites.

#### **2.4.2 Collecting Stories: Creating an Interview Framework**

To help elicit rich and meaningful stories a narrative interview framework was created. There are several approaches to conducting NI which determine the line of questioning used.

Historically, the approaches which have been privileged have either focused on the content of what was said during a narration (Lieblich et al., 1998) or considered the structural aspects of how the story unfolds (Labov, 1972, 1982). Yet more recently, there has been a growing tendency to consider the performative aspects of how a story is told (Bamberg & Georgakopoulou, 2008; Riessman, 2002, 2008), especially when considering someone's sense of self (Bamberg, 1997). As a result, although the schedule was influenced by reading from a number of authors (Bamberg, 2004, 2007; Bamberg, 1997; Daly, 2007; Gregg, 2006; Lieblich et al., 1998; McAdams, 1985; Mishler, 1984; Squire, 2008; Squire et al., 2008), the framework itself was primarily influenced by the work of Riesman, (1993, 2002, 2003, 2008). She is well known for not only considering the content and structural aspects of an account but also its performative features.

I began with a very open question which provided minimal structure and was designed to give participants both the space and control to construct their own story (Wengraf, 2001).

*'I'm interested in hearing about your relationship with Pro-Eating 'disorder' websites? How you came to learn about, use and reduce your use of these sites. I'd like to hear about the events or experiences that have been important to you, along*

*this path. I want to give you time and space to tell me about this, in as much detail as you can. It is up to you where you begin. I just want to hear your story, there's no right or wrong answer and anything you think is important I will want to hear'.*

This was followed by a series of prompts, relating to aspects of the research topic (see Appendix M), this ensured that the key topic areas were covered by the end of the interview. This included understanding 1) how individuals came to use the sites, 2) how this impacted them, 3) how a change in use came about 4) how this change impacted them. Of particular interest was the relationship to self, others and food. I engaged in active listening, asked follow-up questions which sought to deepen and expand the account being told (Kvale, 2008). The order and precise way in which prompts were asked varied across participants but their existence, coupled with the verbal and non-verbal responses I gave, often unconsciously during this process, will have undoubtedly shaped the co-construction story developed (Wells, 2011).

## **2.5 Analysing the Narratives**

### **2.5.1 Interview transcription**

Before I turned the verbal narrations into textual representations, I considered what level of transcription detail would be appropriate for my research study; I recognised that there would be an inevitable loss of richness during the transcription process, which would leave a 'partial, incomplete and selective' representation of our conversations (Riessman, 2002). I decided to adopt a popular approach used by Poland (2002) which involved capturing words verbatim but also some of the conversational characteristics, like pauses, sighs and laughs (See Appendix N). This helped me to analyse some of the performative aspects of the narratives.

In a bid to hold onto richness that may not be available when I listened to the recordings, I also made reflective audio notes immediately after every interview session. The content included reflections on participant's facial expressions, eye contact and emotive feelings evoked within me at what I considered to be key points of their story.

I feel strongly that the first point of analysis begins at the level of transcription (Wells, 2011) and so I transcribed all six interviews myself.

### **2.5.2 Process of Analysis**

Once the transcription phase was complete, I listened back to each interview recording while reading its transcript. This helped me to become more immersed in the narrative. I also listened to my post-interview audio reflections, adding further comments and reflections to the transcript (where I felt that these had been lost from the text). I then read each transcript four times, I paid close attention to the narratives' content, structure, performative aspects of talk and the contexts in which stories were shared (Riessman, 1993; Wells, 2011). As suggested by Riessman (1993), I initially read for structure, then performance before I considered the content and context of the narrative. These readings were guided by the questions below. Reflections were made at every stage of analysis.

#### **Content (Lieblich et al., 1998; McAdams, 1993; Riessman, 1993, 2003)**

- 1) How do individuals narrate their experience of both coming to use Pro-Ana forums and trying to disengage from them?
- 2) How do individuals narrate what effect both site use and disengagement has had on them?

#### **Structure & performance (Bamberg, 2004, 2007; Bamberg, 1997; Gregg, 2006; Mishler, 1984; Riessman, 1993, 2008)**

- 3) How is the account organised?
- 4) Why does the informant develop their tale in this way, with this listener?
- 5) What aspects of the self are expressed in these narratives?
- 6) How does the narrator strategically make identity claims through the account?
- 7) What other identities are performed or suggested?

### **Context and broader cultural narratives (Daly, 2007; Squire, 2008)**

- 8) How do individuals position themselves, relative to themselves through time?
- 9) How do they position themselves in relation to the broader societal narratives about eating 'disorders', Pro-Ana sites and Pro-Ana site users?
- 10) How do they position themselves, in relation to me (the interviewer)?

Once the process was completed for all six transcripts, a short summary was written for each participant. These captured the main storylines of their narratives, in relation to the above questions. They were written in a third person tense, to ensure that it was clear that this reflected my interpretation of the accounts (Saukko, 2000). I then compared and contrasted the accounts to establish broad over-arching stories as well as points of divergence. All accounts were then re-read to establish if these stories were reflected in the narrative accounts.

### **2.5.3 Self-Reflexivity**

Feeling privileged to be on a doctoral training programme that values reflection, I have thought extensively about how societal labels serve to guide our understanding of mental health difficulties. Like many (Collyer, 2014) I see eating 'disorders' as existing on a continuum, where it is easy to shift from body image concerns viewed as socially acceptable, to more extreme concerns and unusual behaviours which are often, all too quickly pathologised and 'othered'. Having immersed myself in the Pro-Ana literature I have been

disappointed at the level of 'othering' within the researcher realm. This has led me to try to conduct a research project with my participants, rather than on them.

Yet this has not always been a straight forward process. I have for a long time believed that positioning the sites as just harmful is over simplistic, where the complexities of connectedness in experiences are not adequately captured and a more balanced position is needed. I have now read extensively around the topic regarding the impact of regular use and it has on occasion been difficult to hold onto this more open position and not join in on the 'othering' or vilification of the sites. These tensions are explicitly stated to acknowledge my ongoing tussle with the nature of the research topic. According to Spencer and Ritchie (2012), such practices are not only central to social constructionist studies but this level of transparency adds to validity and credibility of the study's findings.

I kept a reflective diary throughout my research process, which has included reflections on project ideas, my own emotive response to certain texts, as well as feelings pre-and-post interviews and during the transcription/analysis phase.

## **2.6 Credibility and Rigour of the Research**

When it comes to assessing the quality of the qualitative research produced here, the standards commonly used in quantitative study's, namely objectivity, reliability and validity do not hold. Instead, the research's credibility, rigor and pragmatic use must be considered (Riessman, 2008; Yardley & Smith, 2008).

To assist the reader with the assessment process, transparency is required at every stage of the research process (Riessman, 2008; Yardley & Smith, 2008). I have sought to do this in a number of ways. To clearly demonstrate how narrative interpretations have been made, I have included a full transcript and how this was analysed (see Appendix O and P). I have also

wove quotes throughout the main body of the results section, to further illustrate how my own interpretations have been developed from the transcript. Finally, in recognising that my interpretation is one of many and will be influenced by own realities, beliefs and personal knowledges (Gergen, 2009), I have explained to the reader not only what led me to become interested in the topic and what values I hold but also what impact these may have had on the analysis produced.

Finally, to ensure the research is of pragmatic use, I have considered the socio-political position in which the research is situated within the introduction and the clinical implications of the findings within the conclusions. I intend to submit the findings to a peer reviewed journal and an abstract to any relevant upcoming mental health conferences. Although the epistemology position of the study does not require member reflection on the accounts I have produced, it is recognised that the product is my interpretation of a co-constructed narrative. I have asked all participants whether they would like to receive a written summary of the findings. All agreed and thus the findings will also be disseminated amongst participants.

### Chapter 3: Analysis & Discussion

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*'We speak our identities, we become the stories through which we tell our lives'*

*(Mishler, 1999)*

The intention of this chapter is to offer an interpretation of the six participant Pro-Ana narratives, with a particular focus on withdrawal storylines. To maintain anonymity, pseudonyms have been used throughout and additional identifiable information altered. The analysis has been split into two distinct sections: The first provides an introduction to each participant, including an overview of their narratives. The second section details the emerging storylines, across the participants as a collective.

Akin to Squire's (2005) claim that it is important to consider the context in which a story is situated. For each individual participant, I have chosen to begin by providing some brief demographics, setting the scene of the interview. I have also included their written response, to a pre-interview Pro-Ana questionnaire. A narrative summary then follows; this contains quotes from the interview, serving to illustrate the presence of certain storylines and claimed identities, as seen by the researcher.

In the second section, the similarities and differences across participant accounts are considered, together with ideas concerning how the accounts sit in relation to existing research and dominant societal, cultural and contextual discourses. There are three areas of collective focus, these include stories of coming to Pro-Ana, moving away from Pro-Ana and reflections on the type of narratives told. Although it may seem somewhat surprising that 'coming to Pro-Ana' storylines have been included in a study which sought to investigate withdrawal, it was observed that many narrators positioned these two aspects of the narrative as being tightly intertwined.

Participants' quotes are shown in italics.

### **3.1 Introduction to the Participants**

#### **3.1.1 Kirsty**

Kirsty was a 22-year-old, white British, female, who at the time of the interview lived with her parents in south-east England. Kirsty found out about the study after hearing me speak about it at a local eating 'disorder' support group that she attended. Within the group Kirsty had appeared timid and shy, saying very little and was observed to become upset when asked by another member if she knew what had caused her eating difficulties. As a result, I was pleasantly surprised when she elected to take part in the study. The interview took place in a village hall, close to Kirsty's home.

In her pre-interview questionnaire, Kirsty reported receiving a diagnosis of '*eating 'disorder'*' at age 15 but nothing more specific. From her own research, Kirsty identified as having experienced both anorexia and bulimia, going through episodes of one and then the other. Kirsty traced the onset of her difficulties into her childhood but noted that things became unmanageable around age 15. This coincided with her starting to use the Pro-Ana sites. From this point, she reported visiting the sites multiple times a day, three hours a week, for around two years. Kirsty stated that she was no longer using the sites. She described her eating difficulties as; '*complicated and messy*' where she had '*bounced back and forth between trying to recover and wanting to be ill.*' Kirsty reported that for the last six months she had been trying to recover from anorexia and had recently started private counselling. She was studying to become a primary school teacher at the time of the interview.

### 3.1.1.1 Narrative Summary (Kirsty)

Kirsty's narrative began tentatively, offering brief descriptions of how her eating 'disorder' came to exist; though her account steadily grew in depth and detail, which may suggest an initial apprehension or discomfort in speaking. This was consistent with Kirsty frequently positioning herself as someone who '*wasn't very open*'.

Kirsty's account drew on multiple stories of using her body to express herself instead of words.

*'I liked dancing a lot because I didn't have to say anything I could just express myself with my body (.) which I think is a big thing for me (.) in my eating 'disorder' and also in like self-harm (.) like not needing to say anything but if I can change my physical appearance I can show someone that I'm not okay'.*

(909-914/920)

She described learning about the sites through a chance conversation with a classmate and coming to the sites for motivation to be thin. She claimed that the Pro-Ana images represented what she wanted to be and believed that obtaining a new identity could make her happy. Kirsty positioned the sites as providing her with another way to '*punish*' herself and '*self-destruct*', when she felt angry. Yet she also positioned the sites as giving her a way of '*bettering*' herself - being able to restrict in ways that others could not.

However, as the narrative unfolded Kirsty described finding the sites increasingly '*teen focused*', '*inauthentic*' and '*trivial*', worrying that if anyone found out she was using the sites, it would discredit the severity of her 'disorder'. She drew on discourses prevalent within the eating 'disorder' community of the sites being for '*wannarexics*' and in doing so, described feeling like a '*fraud*' and a '*fake*' in relation to having an eating 'disorder' because

she *'was just online'*. Kirsty claimed that for this reason *'it wasn't a massive effort to stop going on them'* and actually represented a time where she could *'prove (.) I can do this on my own'*.

She positioned her desire for 'recovery' as coming about much later due to a number of significant events and a readiness for change. These events included going to University and needing to invest energy into her degree. She ran a dance squad where one of the members had an eating 'disorder' which she was actively trying to fight and Kirsty admired this. She also found a Facebook 'recovery' page which was *'deeper'* and seemed to resonate more with her experience. Kirsty described returning to the sites, during her most recent relapse but explained at this time, she was *'quite a low weight anyway'*, with people offline asking *'Oh are you anorexic?'*, so positioned herself as not needing the motivation on offer.

There seemed to be a strong narrative of shame woven throughout her account. This was illustrated by Kirsty when she spoke about her experiences through soap characters at times or, repeatedly used the words *'just'* to minimise the importance attached to viewing the sites and leaving them. Such narrational activity served to provide distance from Kirsty and her story, as well as depersonalising it; this suggested that talking about her own experiences may be something that she had found difficult. Towards the end of the account, Kirsty performed a much more reflective persona; she claimed that the existence of the sites needed to be taken more seriously. This provided a strong counter narrative to the one used at the start of her account, which positioned the sites for wannabees.

*'I think it needs to be taken a lot more seriously... (.) and not just seen as erh like a kind of fad that girls do (.) and (.) ...I think I have been guilty of in the past ... I don't know how to put it (.) like they-they don't really have an eating 'disorder' they're like there just looking at these websites (.) like it would make me feel quite angry (.) I*

*guess because I didn't want to be one of those people (.) erm (.) but now I see them as kind of places (.) where people who are really ill go(.)'*

(819-831/920)

### **3.1.2 Heidi**

Heidi was a 37-year-old, white American, female, who lived in California at the time of the interview. She had found out about the study after she saw it advertised on a Facebook support group. The interview took place over Skype, in Heidi's back garden. She was renting a room in what she termed, her '*ocean side oasis*', many miles from her family.

In her pre-interview questionnaire, Heidi reported receiving both anorexia and bulimia diagnoses and traced the onset of her eating difficulties to age 5. She wrote that at different stages of her life she had struggled to have a healthy relationship with food, sometimes viewing it as something '*she didn't deserve*' and '*needed to earn*', whilst at other points, binging and purging '*on over 100 dollars*' worth of food in one evening'. Heidi wrote that she began using the Pro-Ana/Mia sites aged 22 and at its peak she visited the sites for 4-8hrs a week, across a 2-year period. She wrote that she last visited the sites in 2013. Heidi was studying for a drug and alcohol counselling certificate at the time of the interview.

#### 3.1.2.1 Narrative Summary (Heidi)

Heidi's account had a somewhat chaotic and disorganised style. It often jumped around, making it difficult to keep track of the sequence of events and hold onto the narrative thread. This gave the impression of a story that was not straightforward to tell but was complex and still being made sense of. Pro-Ana sites were only briefly mentioned and instead the narrative was dominated by stories of trauma and a need to dissociate from difficult emotions through self-harm, alcoholism, drugs and 'disordered' eating.

Heidi began by her recounting childhood memories of feeling so overwhelmed by food options that she would cry and also refused to have her photograph taken, she stated that she felt *'too fat'*.

She positioned herself outside of the typical aetiology narrative, where eating difficulties emerged during adolescence and instead painted a picture of a much earlier struggle.

Heidi's strongest narrative of how she came to Pro-Ana concerned her ex-fiancé. She claimed he had written a list of everything that was wrong with her, which included Heidi being too much like her mother. She described this comparison as *'a dagger to the heart'* and said *'he was referring to my size'*.

Heidi estimated weighing 210lbs at this time. She positioned herself as coming from an overweight family and holding a strong desire to be seen as different to them. Heidi conveyed the impact of this comparison in-particular as she frequently referred to it throughout the interview.

*'I always kept going back to that list (.) that fucking list (.) you're like your mother'*

(348/1066)

*'maybe he would have married me (.) if I wasn't like my mother(.)... if I would have lost this weight'*

(412-4/1066)

Her account portrayed a young woman who struggled to feel worthy and initially sort the sites out, as a weight loss tool, yet with it found *'a community of support'* which helped her to manage *'all that pain'*.

Heidi positioned herself as playing a minor role in the Pro-Ana disengagement process; holding little agency herself, but instead gave this to the medical professionals involved in her care. Heidi claimed that after being admitted to an inpatient unit, she had to attend an AA recovery group and started connecting with this community. Heidi's narrative suggested that once emotional support was provided elsewhere, she visited the Pro-Ana sites far less, only to see if new weight-loss tips had been added.

*'I had another community of people I was connecting with (#) that understood me on a different level', 'I would go every once in a while (.) to see if there was anything new out there (#) but it was always pretty much the same'.*

*(636-8, 613-8/1066)*

Heidi's account highlighted how being discharged from the unit and disengagement from the Pro-Ana sites, did not automatically lead to recovery. She drew on common societal discourses of positive comments associated with weight-loss, as well as negative comments associated with any weight gain, serving to reinforce her learnt Pro-Ana behaviours.

Heidi claimed that obtaining a job in the rehabilitation unit she used to attend, and being actively involved in running an eating 'disorder' recovery group, helped her to enter a better place. Heidi positioned herself now as doing battle with the eating 'disorder', where she tries to avoid material which may trigger a relapse and stays connected to a recovery community. There is much more agency in her current story. Though she was observed to weave an overall narrative of resilience and survival, she painted a picture that some battles had been fought and won, like sobriety, whereas others, like her eating difficulties were ongoing and could easily be lost. For instance, she performed as if she had a fragile self, regarding the progress made.

*'I have to be super (.) super careful (.) I've had to block certain people that I honestly care about (#) I just can't see the pictures (.) I can't see the stories'.*

(774-7/1066)

### **3.1.3 Lucy**

Lucy was a 39-year-old, white British, female, who lived in South-East England at the time of the interview. She had been facilitating a local eating 'disorder' support group and was forwarded my details from another member, whom I had contacted about participant recruitment. Although Lucy expressed interest in the project in July, we did not meet until December due to her University study commitments. The interview took place in her living room, in the middle of the day. There was no one else at home.

In her pre-interview questionnaire, Lucy reported receiving an eating 'disorder' diagnosis in 2011, though she did not specify what type. She wrote that it involved experiencing cycles of very restrictive eating, followed by binging/purging. She noted that her eating 'disorder' went into crisis at age 31, though traced the onset of her eating difficulties to be around age 8/9. Lucy wrote that she first began using the Pro-Ana sites at age 33 and this lasted for a few years. At its peak, she would log on multiple times a day, for around 3-4hours. She reported to be no longer using Pro-Ana sites and identified herself to be '*well*', stating that the eating 'disorder' '*is not ruining my life anymore*'. Lucy wrote that she was studying for a degree in psychology at the time of our interview.

#### 3.1.3.1 Narrative Summary (Lucy)

Lucy presented herself as a thoughtful, considered and reflective individual. This was illustrated in both the construction of her narrative, with often lengthy pauses and tentative

openings to follow up question, as well as the smaller stories she positioned herself within. Her strongest narrative seemed to be of 'self-transformation'.

Lucy initially positioned herself in '*an extremely dark place*' when she found the sites. Her partner had '*walked out*', she had given up a full-time job and been wrongly reported for benefit fraud. Lucy described how these events made her increasingly '*paranoid*', claiming that no-one could be trusted and she started to lock herself away, she stated that she isolated herself from friends and family. As her narrative unfolded was observed to paint a picture of someone deeply depressed who had used restrictive eating to cut off from her emotions. She identified herself as having always been over-weight and spoke about how her body started to change as she restricted her eating. Lucy explained that when she would see friends or family, they congratulated her on the weight loss. Within this storyline, the praise seemed to validate that she was good at something, so she sought to become better at it, controlling her food intake further. She spoke of stumbling across the Pro-Ana sites when she began searching the internet for information on eating 'disorders', wondering if she might have one.

Lucy positioned the content of the sites as resonating with her experiences. She positioned the users as providing complete understanding and much needed emotional support. This idea of feeling '*completely understood*' online was referred to many times throughout the account and often contrasted with multiple stories of feeling increasingly misunderstood offline. A turn in her narrative came after she had been in therapy and read a book which externalised the eating 'disorder' and personified him as '*Ed*'. She spoke of this helping her to gain distance from certain thoughts and behaviours which she no longer saw as normal and increasingly saw as '*destructive*' on the Pro-Ana sites. She punctuated her narrative with playful stories of '*going upstairs to shut Ed in my airing cupboard*'. Her account suggested that '*there was no conscious decision*' to leave the community, she just started to see things differently and her use of the sites gradually decreased.

During this part of the account she spoke of an internal struggle, where she tried to help other Pro-Ana members recover with her. She shared her new understanding of her eating difficulties on-line but noted that there was little interest in this way of thinking and she reported realising that her connection to the community was adversely impacting her own recovery and she needed to step away. In doing this her preferred identity seemed to be of a kind, nurturer who wanted to help others, yet someone who had persistence and strength in a fight to recover and was not afraid to put herself first.

Her account suggested that recovery had not been an easy process but Lucy claimed that starting a degree had added structure to her day and given her a new area of focus. Lucy spoke passionately of wanting to graduate and stated that she felt that this could only happen if she stayed well. Her narrative ended by telling stories of being in a new loving relationship, where she was rediscovering how to cook and developing a love of food. This was in stark contrast to the lonely isolated individual her narrative had portrayed when it began. She continued to speak of a strong desire to help others, which she seemed to be achieving by facilitating a local recovery support group, engaging in charity fundraising events for BEAT and educating her friends and family about eating 'disorders' and their impact. Her overarching narrative seemed to be one of a quest (Frank, 1995), where she had come out the other side a '*stronger*' person for her experiences and her preferred position was of an educator and positive role model.

### **3.1.4 Samantha**

Samantha was a 19-year-old, Indian American female, who lived in Missouri at the time of the interview. She learnt about the study after seeing it advertised on a Facebook support group. The interview took place over Skype, in Samantha's bedroom, at her College halls of residence. There was a technical fault towards the very end of the interview and a delay of a

few minutes before the internet connection and our conversation resumed. This did not appear to adversely affect the interview flow.

In her pre-interview questionnaire, Samantha reported having received a diagnosis of anorexia (restrictive subtype) at age 18. She identified herself as being physically affected by osteopenia, and she had developed an essential tremor which she associated with the diagnosis. She traced the onset of her eating difficulties to age 11 and stated that she first began using the website age 14. At its peak Samantha reported visiting the websites multiple times a day, for around 20-25hrs a week, across an 11-month period. She claimed to have last visited the sites a few months ago. Samantha stated that she is weight restored but considered herself to be in recovery rather than recovered she struggled to eat balanced meals and not restrict her fluid intake. She wrote that she was currently under the care of a dietician, therapists and psychiatrist at the time of the interview. Samantha was also studying for a diploma in nursing.

#### 3.1.4.1 Narrative Summary (Samantha)

Samantha began her account by providing some context regarding how she came to the Pro-Ana sites. She positioned herself as someone who had always experienced mental health difficulties and by age 11 had a strong desire to end her life, this led her to search the internet for methods to die. She drew on her Indian heritage and parental values to explain why committing suicide was not an option but described finding a you-tube video on anorexia, where the main character had become progressively sicker and she '*wanted that*' for herself. Samantha described how the Pro-Ana sites, referenced by the video, enabled her eating '*disorder*' to '*bloom*'. She positioned her family as ignoring the signs that she was becoming '*sicker*' and told multiple stories of respected members of her community becoming increasingly worried about her health, each had tried to make her parents listen.

Samantha claimed that people understood her within the Pro-Ana community and told stories of how she had developed close relationships online, where she felt supported and heard. Her account suggested that although the sites initially '*legitimised*' the existence of her eating 'disorder', their competitive nature often made her feel like a failure in '*developing*' one. She positioned this as being the reason why she had briefly left the community, with the intention of finding out what worked for her, in terms of improving her eating 'disorder' to enable her to come back '*stronger and smaller*'.

Samantha's account was full of rich descriptions concerning the inner working of the Pro-Ana community. This involved describing the importance associated with selecting the right user name and wording the first few posts, to ensure that she was accepted rather than rejected by the community. She took up the role as an educator and positioned me as the learner, as she explained how on her return she was able to move up the ranks to become an '*advanced warrior*'<sup>1</sup>, mentoring others users. These stories were perhaps told to further legitimise her position as my educator but also to illustrate just how 'skilled' she had become at restriction.

Samantha claimed that her parents eventually took her to an inpatient centre which led to an enforced break from the Pro-Ana sites. Although she spoke of having every intention to go back online after she had left the centre, Samantha described the act of re-feeding as enabling her to think more clearly.

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<sup>1</sup> Advanced Warrior: This was a term used by Samantha, to reflect the high rank position she held within the Pro-Ana community. It was described as a position that she had earned through restrictive eating and had been given by her peers in recognition of her Pro-Ana successes. She reported that there was only one level above it '*Sage*', though she claimed that many died before achieving this status. She described how people moved up as '*wiser or weaker*' member within the community and that those who held an advanced warrior status were '*looked up to, almost as a mentor*'.

*'with my brain being fed I was able to talk to people (.) get help and therapy that I needed (#) and erm (.) explore some of the deeper issues that came along with actually developing my eating 'disorder''*

*(131-135/956)*

She also spoke of forming a close bond with another patient, who confided that other girls viewed Samantha as 'triggering'. This seemed to be deeply upsetting to Samantha, who painted a picture of someone who was seriously contemplating recovery and trying her best to navigate a difficult process. These two events were positioned as pivotal in her decision to give recovery her full attention for six-months.

Her stories in the last part of the account, suggested a coming and going to the Pro-Ana community, where she occasionally set up new profiles for brief periods of time before shutting them down again. She explained that she felt that she no longer belonged there but positioned herself as an introvert who often struggled to develop close friendships offline and missed the ease in which this was possible in the online world. Samantha was observed to place herself more readily, (though not exclusively) in a chaos narrative, where struggles were positioned as on-going and often beyond the teller's control (Frank, 1995).

### **3.1.5 Kendra**

Kendra was a 23-year-old, Latino American, female, who lived in North America. The interview took place over Skype, in Kendra's bedroom. She had found out about the study after seeing it advertised on a Facebook support group.

In her pre-interview questionnaire, Kendra reported that she had received a diagnosis of EDNOS at age 17 and traced the onset of her eating difficulties to age 15. She wrote that she had been forced into therapy by people who cared and stated that her eating 'disorder'

affected her in ways you could never imagine. She reported that her health greatly deteriorated and she still suffers the consequences with a weakened immune system and sensitive stomach. Kendra stated that she is not fully recovered and does not know if she ever will be but tries to keep the eating 'disorder' under control. She noted that she first started using Pro-Ana at age 15, where she would visit a site for a couple of weeks and then her use would die down until she found a new one. At its peak, she logged on for 7-14hrs per week. Kendra reported last visiting the sites 6-months ago.

#### 3.1.5.1 Narrative Summary (Kendra)

Kendra's narrative was tentative and somewhat disorganised. She was observed to position herself in many stories where it had been difficult to '*open up*' and '*let people in*' and I wondered if this was impacting on her narrational style.

Kendra's account portrayed an overweight teen, who engaged in a fairly typical period of dieting, but after her weight plateaued she turned to the internet for additional 'help'. She claimed that she didn't go straight to the Pro-eating 'disorder' sites; it was a '*slow process*' which started out as looking for '*healthier recipes*'. As the storyline unfolded Kendra described how the eating 'disorder' slowly crept up on her and made her feel increasingly '*isolated*'. Kendra claimed that for a long time, she denied of its existence. She positioned the sites as being useful in providing weight loss ideas and support from '*people who had the same mentality*' but she contrasted this with stories concerned with the burden of listening to other people's difficulties '*I didn't want to have to listen to everyone else's problems*', particularly when '*my eating 'disorder' was taking energy from me*' and stated that she often felt under scrutiny '*everyone just assesses you*'. The narrative constructed in this way, perhaps legitimised why she used the sites intensely for a brief period and would then step away, before the cycle repeated, '*it was like every day for a couple of weeks and would then dwindle down*'.

Kendra described how her deteriorating health eventually caused a '*big argument*' with her boyfriend and she decided to go to therapy, she feared that she may otherwise be admitted to hospital and '*tube fed*'. Although she positioned herself as having agency in this decision, using the term '*I decided*' she went on to present herself as being very ambivalent towards recovery and frustrated by the constant monitoring from her family

*'I would be served my plate and I would have to eat it (.) and then I would not be allowed to go to the rest room afterwards... I was being force fed, without being force fed'.*

(545-7,549-50/1396)

Her account suggested that a loving relationship with her boyfriend, along with a close relationship with her therapist, whom she positioned as '*never giving up*' and whom Kendra stated insisted she take a more proactive role in her own recovery, enabled her to get much 'better'. In the closing narrative, Kendra suggested that with a reduced desire to restrict and more support, the need for the Pro-Ana sites faded. However, she stated that recovery is '*not one straight road*' and positioned herself within an ongoing battle, which included some inevitable '*small relapses*'. She seemed to accept that this was simply part of her journey but for the most part, her preferred self-seemed to be of a responsible adult who now had little time for the Pro-Ana sites.' *I'm older....I don't have time to be chatting with people...I go to work & have responsibilities'.*

### **3.1.6 Emma**

Emma was a 26-year-old, white American, female, who lived in Alabama at the time of the interview. She had found out about the study after seeing it advertised on a Facebook support group. The interview took place in Emma's living room over Skype. No-one else seemed to

be home. The interview was interrupted once, towards the end of our conversation, due to technical difficulties but was quickly resumed.

In Emma's pre-interview questionnaire, she wrote that she had received a diagnosis of anorexia (binge/purge subtype) around age 15 and had a current diagnosis of EDNOS, though considered herself to be in recovery. Emma noted that the effects of her eating 'disorders' had been variable and at its worse, she had been hospitalised for heart problems, electrolyte imbalances and immobility of her limbs. She traced back the onset of her eating difficulties to age 12 and stated that she had begun using the Pro-Ana sites by age 15. At its peak, she reported logging onto the sites for up to three hours a day, five days a week, for several months at a time. She wrote that she had last visited the sites two-three years ago. Emma stated that she was studying for a PhD in clinical psychology at the time of the interview.

#### 3.1.6.1 Narrative Summary (Emma)

Emma's narrative had a thoughtful, coherent style and was ordered chronologically. Her strongest narrative was of a naïve, lost girl, searching for connection and a place to belong. She drew on dominant psychological discourses, such as the eating 'disorder' initially serving to keep her family together, *'when I was very sick everything settled down and the focus was on me and my parents were together (.) there was no drama or big explosive fights'*.

She also spoke of wanting her body to stay as *'a little girl's'*. Emma presented an account where her divorced parents became increasingly pre-occupied with their new marital-relationships and became distant from her. She positioned herself in this storyline as feeling alone *with* her eating 'disorder' and described how visiting the sites provided her with a *'sense of community'*, *'understanding'* and *'competition'* in helping her to maintain a low weight. Her account was consistent with low weight being associated with care.

Emma claimed to actively seek out the Pro-Ana sites, after seeing them referred to on Myspace. She painted a picture of withdrawing into an online world, where new weight loss behaviours were learned, and a new bar for restriction set and reinforced. However, there was a narrative change. Emma then moved to tell stories of loved ones becoming frustrated with her condition and they turned away from her, namely her long standing best friend. She also spoke of how, when she got a job as an au-pair she was provided with the new experience of being part of a family that was very different to her own. Specifically, she started to question her ideas of womanhood. It seemed that she could eat, be healthy and still worthy of care. Emma claimed that a collection of significant moments led to '*the realisation*' that this '*cannot be who I am*'. Her account suggested that '*as the urge to be thin decreases, so too does the urge to look at these Pro-eating 'disordered' websites*'.

Throughout the narrative, Emma performed an identity of great 'strength' in both having an eating 'disorder' ('*I felt stronger and superior because I could do this thing that humans aren't supposed to do*'); and also in giving it up ('*I made the choice to not let it be my identity anymore*'). The amount of agency she positioned herself as having in the recovery process, varied throughout the narrative and seemed to steadily grow. In doing this, Emma storied herself as moving from a powerless to powerful position. The development of the account in this way had the effect of initially striking sympathy for her plight to the audience, followed by admiration that she had succeeded despite the odds being stacked against her.

### **3.2 Emerging Storylines**

This section outlines interpretations of the emerging storylines across participant accounts. Given my own epistemological position, I see these accounts and storylines as being co-constructed rather than a window into someone's interior mind or lived experience. As a result, they will have been influenced by my presence as the researcher, the follow-up

questions I posed and the beliefs and knowledges I may already hold. For this reason, I recognise that the reader may derive different meanings from the text, and I invite them to use the emerging storylines posed as 'listening devices' rather than perceiving them to offer a 'unifying view' (Frank, 1995).

Though the data-set was incredibly rich and diverse I have chosen to focus on storylines concerned with how participants came to Pro-Ana as this seemed relevant to their later stories of withdrawal as well as the storylines of withdrawals themselves. This was in-line with the studies research question. In order to situate the study within a wider research context literature on the Pro-Ana movement and literature concerning eating 'disorders' and recovery have been woven into the analysis, providing an integrated analysis and discussion.

**Table 2: Collective Plots and Pro-Ana Storylines**

<u>Shared Plots</u>	<u>Storyline</u>
<b>Driving down a new road: Coming to Pro-Ana</b>	Aspirations of further weight-loss, for Ana and I  A search for connection and a place to feel better
<b>Driving away from Pro-Ana: Withdrawal</b>	Ana takes the driver’s seat  - A need to go it alone, feeling like a fraud  Taking control of the wheel  - Outside control helps loosen Ana’s grip - Others take control of the wheel: opening the door on change  - A choice: I reclaim control of the wheel - The moment: a shift in motivation happens - A shift in social support - A shift in identity  The comfort of Ana when in control of the wheel: can her grip ever be severed?
Reflections on the type of narratives told	

**3.2.1 Driving Down a New Road: Coming to Ana**

As the interview began participants were asked about their journeys through Pro-Ana; specifically, about the events and experiences which they perceived as important in how they came to learn about, use and stop using the sites. All participants, bar Lucy, started their accounts with contextual descriptions of how their eating ‘disorders’ developed, followed by what was missing in their offline world which then led them to Pro-Ana sites. This trajectory

in an 'illness' narrative of opening with stories of onset, is typical of western narratives (Greenhalgh & Hurwitz, 1999). Lucy opted to start her account slightly differently, she opened hesitantly with a story that concerned her first encounter with a Pro-Ana site. She provided the surrounding context of what was absent in her offline life later which went against the more expected chronological sequence.

According to existing literature, the most frequently cited reasons for going to the Pro-Ana community is 'a wish for rapid weight loss' and a search for 'connection or belongingness' (Rodgers et al., 2012; Wilson et al., 2006). These marked two of the strongest storylines seen to emerge.

#### 3.2.1.1 Aspirations of Further Weight Loss, for Ana and I

All six participants claimed that a desire for further weight loss was a central reason for initially going on or returning to the Pro-Ana sites. Most drew on clinical discourses particularly associated with anorexia, where the possession of a thin body was seen as a means of self-expression (Serpell, Neiderman, Haworth, Emmanuelli, & Lask, 2003; Serpell, Teasdale, Troop, & Treasure, 2004; Serpell et al., 1999). All resisted dominant feminist discourses where the drive for obtaining weight-loss is attributed to the pressures of gendered, cultural ideals of beauty (Bordo, 2004; Gilbert & Thompson, 1996; Orbach, 1985; Orbach, 1993). Instead they claimed restrictive eating was helping them to make an external expression of emotional pain and communicate this more overtly to others. The Pro-Ana sites were positioned by these women as providing an additional tool to help them achieve this more effectively.

This storyline was particularly strong in Samantha's narrative. She spoke of using her body to express what her mouth could not; specifically, to her parents. She positioned herself in a severely distressed mind-set where suicide was contemplated but told multiple stories where

the act itself would have been perceived as '*sinful*' by her parents and those in her community. Her account was constructed in a way to suggest that the development of an eating 'disorder' as a means to end her life, would bring less shame on her family so was sort out. In this way, the Pro-Ana sites were portrayed as providing Samantha with an additional device for restriction in order to communicate her distress to others.

*'I wanted attention from my family (.) specifically I wanted them to know that I wasn't ok (.) I couldn't walk up and say 'mum and dad I have (.) I wanna kill myself' (.) suicide is considered awful (.).... it's considered sinful..... if I couldn't say it with my mouth I was going to say it with my body'.*

*(Samantha, 141-8/956)*

Kirsty also expressed both desire and frustration in her struggle to communicate distress through her body:

*'I kinda wish that I kind of wasn't a normal weight when I was younger hheh (.) sounds like an odd thing to wish but I mean just as in (.) so I could express what was happening a bit more'.*

*(Kirsty, 513-6/920)*

The reason for her distress and to whom she wished to communicate it is omitted from the account. In response to a prompt question, she later portrayed a family in chaos, with a long history of serious mental health difficulties, and host of '*big personalities*' which appeared to suggest that there may have been limited space for Kirsty's voice to be heard, leading her to express herself physically. She claimed to have come to Pro-Ana initially in the hope that the sites would '*motivate*' her to become thinner and presumably communicate the distress more overtly.

The benefits of weight-loss in eliciting care were spoken about by Emma who claimed that the 'concern' and 'attention' she gained from others after an unexpected sickness caused her to lose weight and 'hooked' her in. This marked a stark contrast to Kirsty and Samantha whose accounts suggested that they had yet to be seen by others.

*'I think it also served the function of keeping family problems at bay because when I was very sick everything settled down (.) and the focus was on me (.)and my parents were together (.) there was no drama or big explosive fights... which made me feel empowered'.*

*(Emma, 738-44, 746/1163)*

Emma's narrative suggested that finding the sites provided her with 'many more tricks' and 'set a new bar' for restriction; this resulted in increased weight loss which, in turn, elicited more care and helped to maintain this care. Again, the sites were positioned as a tool to achieve rapid weight-loss and a reason for her to seek the Pro-Ana community out.

The remaining accounts of Lucy and Kendra were more divergent. Both positioned themselves as stumbling across the sites: Kendra while looking for healthier eating recipes online and Lucy while searching the internet to determine the presence of a suspected eating 'disorder'. Kendra positioned herself as initially being overweight and wanting to lose some extra kilos before she eventually reached a plateau and upon discovering the sites spoke of becoming particularly curious about the weight loss tips there. Conversely, while Lucy told multiple stories of feeling a sense of mastery and skill in relation to the weight-loss she had achieved before coming to the sites, the community was positioned as providing her with more weight-loss ideas. Using them seemed to strengthen these internal positive feelings of mastery.

Taken together these narratives suggested that all of the women who sought out the Pro-Ana sites did so looking for new weight-loss methods and of the two who positioned themselves as stumbling across the sites by chance, they claimed to return for this reason. Most women spoke of weight-loss as being a way to either communicate internal pain to others, end it or both. This is consistent with eating 'disorder' literature which suggests these individuals often struggle to tolerate internal distress, but seek to inhibit their own emotional expression in order to maintain close relationships, leading to an inward attack (Corstorphine, Mountford, Tomlinson, Waller, & Meyer, 2007; Geller, Cockell, Hewitt, Goldner, & Flett, 2000; Hambrook et al., 2011). For the remaining participants weight-loss appeared to be associated with increased mastery following praise from friends (Branch & Eurman, 1980; Garner & Bemis, 1982; Vitousek, Watson, & Wilson, 1998; Vitousek & Ewald, 1993) and initially desirable following dieting (Shisslak, Crago, & Estes, 1995). Notably Samantha was the only person to speak about developing an eating 'disorder' through the sites, everyone else positioned themselves as having one already but sites worsened symptoms.

#### 3.2.1.2 A Search for Connection and a Place to Feel Better

Present in all accounts were storylines of 'connection'. All were observed to position themselves as becoming misunderstood and isolated in offline relationships. Members of the Pro-Ana community were positioned as 'understanding' and providing an emotional connection. The accounts, constructed in this way, set up an easily understandably rationale for using the sites, which in the context of the negative political and media discourses surrounding Pro-Ana, could perhaps allow individuals to be making an understandable rather than 'irrational' decision. These narratives of connection conformed to those found in other Pro-Ana qualitative studies, which have suggested that the sites provide a sanctuary away from the scrutiny of others (Crowe & Watts, 2016; Dias, 2013; Fox et al., 2005; Gale et al., 2016).

For instance, Lucy described feeling increasingly *'frustrated'* because those around her *'weren't understanding'* the difficulties she was trying to communicate. She positioned herself as feeling like an *'alien'* and in *'turmoil'*. The only place she spoke of feeling *'normal'* or *'not ill'* was online. Here she said, *'I could be myself'*. This *'alien'* to *'normal'* comparison served to give weight to the narrative in regard to the quality of connection she received online and the necessity of them.

*'I kinda went in and I could just relate to everything(.) that they were saying (#) and at that time in my world (.) no one kinda understood- I didn't feel understood (.) I almost felt (#) that I was an alien that I just didn't fit in anywhere... I think it's where I belonged and that's where I felt comfortable that almost (.) I didn't feel like I was in turmoil there*

*(Lucy, 41-58/115)*

This was mirrored across many accounts.

*'it became another resource for me to feel not so alone and listened to...it almost felt like coming home to a place where people got me'.*

*(Samantha, 193-5/956)*

Kendra also claimed that in the outside world *'people didn't quite understand (.) they would just judge'*. Phrases like *'coming home'* and *'they would just judge'* may again evoke more compassion from audiences in legitimising the need to go online and the perceived value in doing so.

What was portrayed as being unique about the support available amongst the Pro-Ana community was a sense of understanding, with *'acceptance'* not *'challenge'*. This storyline was captured with Emma's description of the sites.

*I didn't get that shocked reaction I got a more accepting reaction (.) and like in hind sight of course that was not a healthy acceptance (.) erm but when your fifteen and hurting and have this 'disorder' (.) acceptance is acceptance'*

*(Emma, 395-4001/1163)*

She also used active voicing (Wooffitt, 1992) in reference to the challenging comments made by those in her off-line community. '*What do you mean you're fat?*', '*What do you mean you've only had you know this much to eat today?*' The use of active voicing in reference to off-line challenges was also evident in Kendra's account, for example '*why are you not eating?*' as well as Lucy's '*You need to just sit down and eat a proper meal*'. The tone used by all was punitive and seemed to express a frustration and exacerbation from the viewpoint of those around them. This experience from loved ones of not 'knowing' how to help, has been commonly cited in the literature (Brotsky & Giles, 2007).

Most of the accounts, (Emma, Kendra, Heidi & Samantha) described withdrawal into an online world, at the expense of maintaining relationships with loved ones off-line.

*'I kind of withdrew into this world via the internet (.) where I didn't (.) seek out support in positive ways because I was getting support in negative ways'*

*(Emma, 449-51/1163)*

*'there comes a point when people start to notice (.) they may not notice at first but you know after a while whenever you don't look healthy (#) then everybody notices(.) and (.) I realised that people did try to help me but I pushed them away(.) A: Okay (.) K: and instead I substituted them for the people in the pro eating 'disorder' sites''*

*(Kendra, 468-76/1396)*

*my closest relationships were on line with people who had pictures of erm cartoon characters or erm actors from shows as their picture...when asked about my friends(.) when I first began therapy (.) and talking about my Pro-Ana sites (#) I couldn't name their legitimate names but I could name(.) twenty or thirty user names*

*(Samantha, 495/956)*

*'besides the community and all of that which was great (.) ya know (.) those sites-those were my friends (.) those were the people I talked to'*

*(Heidi, 475-7/1066)*

Kirsty and Lucy's accounts were somewhat different. Although Kirsty initially claimed that the sites '*made her feel part of her community*' she then moved to naming them as '*inauthentic*' leading to withdrawal.

*I maybe found the sites a bit inauthentic (.) like I didn't feel that the sites were really authentic (.) or I started to question (.) like who was making them? (.) or (.) I felt that it was really forced?*

*(Kirsty 460-4/920)*

In contrast, Lucy positioned herself as having lost friends through divorce and depression before she joined the sites. She claimed '*I became completely isolated so that was my only (#) place of support*'. One might suggest that the narrational activity provided a strong counter narrative to the dominant political discourses around Pro-Ana, which view the sites as solely dangerous (Giles, 2016), Lucy claimed that she had gained something valuable within this space. This is very different from the accounts above, which suggest Pro-Ana substitution, perhaps leading audiences to be more sceptical that resource gains were positive.

### 3.2.2 Driving Away from Pro-Ana: Withdrawal

The way that individuals constructed their accounts of withdrawal varied greatly. This contrasted with the more uniform ways of storying entry into Pro-Ana. Some participants richly described their journey through the Pro-Ana community necessitating few researcher prompts. Others provided a brief over-view of their journey to the sites but appeared more unsure about how to narrate stories of withdrawal, they invited additional questioning and asked me '*were there specific questions you had?*'. The storylines also differed as to whether participants returned to the Pro-Ana sites after initially moving away from them. For some, their accounts of Pro-Ana use seemed to be very much positioned in the past, for others, there were frequent and short returns to the sites during times of relapse, with several claiming that this was simply part of their recovery process. Interestingly Samantha's account suggested separate episodes of withdrawing from the Pro-Ana sites, which she attributed for different reasons; as a result, her narrative appears in more than one withdrawal storyline.

It is notable that Kirsty's account is mostly absent from this section. Although she positioned herself in withdrawal and recovery storylines her account suggested that these two events were unrelated and for this reason only the former (narrated reasons for withdrawal) have been discussed here. This is at odds with the remaining accounts, where withdrawal and recovery were positioned as being linked.

From the six accounts, two distinct withdrawal storylines seemed to emerge 1) Withdrawal; a sign of the 'disorder' gaining in strength and power 'Ana takes the drivers seat' 2) Withdrawal; a sign of the 'disorder' losing strength and power 'Taking control of the wheel'. Each had a number of sub-plots (see table 2).

### 3.2.2.1 Withdrawal – Ana Takes the Driver’s Seat

#### 3.2.2.1.1 A Need to go it Alone, Feeling like a Fraud

According to the literature, individuals with both bulimia and anorexia are often positioned as being in denial about the severity of difficulties and claim that they are not ‘sick’ enough to warrant treatment (Vandereycken & Van Humbeeck, 2008). Those with anorexia tend to only be admitted to treatment centres following concern from loved ones and obvious emaciation, and those with bulimia are much more likely to slip under the radar and not enter services (Bruch, 2001). These discourses were present here.

Both Kirsty and Samantha positioned themselves as feeling like a *‘fraud’* in relation to developing an eating ‘disorder’ and suggested that this was their primary reason for withdrawing from the Pro-Ana sites. Samantha positioned the act of having to learn about and use other people’s weight loss tips as serving to negate the presence and severity of her own eating ‘disorder’ *‘I felt like I had developed an eating ‘disorder’ based on other people’s advice’*. ‘She described wanting to have a break from the Pro-Ana community in order to understand what worked best for her.

*‘I didn’t feel like my anorexia was legitimate (.) and I wondered if I took a break from the sites if I would be able to figure out what’s best for me (.) versus trying everybody else’s tips and tricks (1)’*

*(Samantha, 50-3/956)*

The word *‘break’* seemed to suggest an intention of returning to the community, before Samantha described her Pro-Ana use as *‘gradually building up’* after *‘a couple of months’* *abstinence’*. Such language was perhaps indicative of Samantha positioning her need for Pro-Ana as paralleling an addiction. This notion has been hotly debated in the literature (C Barbarich-Marsteller, W Foltin, & Timothy Walsh, 2011), with similarities concerning the

physical highs that can be induced from starvation and the need to carry out behaviours at any cost. Samantha's account told in this way may serve to evoke sympathy in her audience, returning to the sites was not her fault or perhaps even a choice.

Unlike Samantha who appeared to position the break as allowing her to potentially come back a stronger and more legitimate Pro-Ana member, Kirsty claimed that those with 'real' eating 'disorders' would not need to use the sites at all.

*'I felt like it was a fake eating 'disorder' because it was online (...)... I wanted to prove that I didn't need that....I don't really think it was a positive thing (...) at first (...) when I stopped using it (...) I think it was more of a (...) I want to be completely on my own? (...) and prove that I can do this on my own'*

*(Kirsty, 128-34/920)*

By constructing the narrative in this way, Kirsty discredited the idea that she had an eating 'disorder' while she used the Pro-Ana sites, creating a need to 'go it alone'. She appeared to express both shame and embarrassment in using Pro-Ana as a weight loss tool, with comments like *'I almost tried to forget that I did it'*. She told multiple stories of worrying that others would find out and negatively judge her, she seemed very aware of the negative socio-cultural discourses around site users, which perhaps served to offer one explanation to the audience as to why she did not confide in others.

*I felt like I would be really judged (...) and also people would just think I was stupid (...) and because like (...) I knew it was stupid (#)*

*(Kirsty, 578-9/920)*

The ease in which Kirsty described being able to step away from Pro-Ana is very different to the addictive language used by Samantha, to perhaps account for how the community drew her back in.

### 3.2.2.2 Withdrawal: Taking Control of the Wheel

Perhaps unsurprisingly the remaining accounts of withdrawal were described using recovery storylines. Yet they differed in an important way, namely in whose decision it was to withdraw from Pro-Ana and how much agency or power they had in this process. For some participants, they positioned withdrawal as an active choice whilst others described having an enforced break imposed upon them, through inpatient admissions. This later scenario was the case for both Heidi and Samantha.

#### 3.2.2.2.1 Outside Control Helps Loosen Ana's Grip

Heidi positioned the sites as providing her with much needed emotional support following the multiple traumas she reported to have faced within her life. She described no longer being able to use this resource once she was admitted as the inpatient facilities. She stated that as part of her treatment programme she was forced to attend alcohol and drug addiction recovery groups. Heidi claimed that eventually she opened up and connected to members of the recovery community; connections she maintained after discharge.

*'We had to go to meetings everyday (.) I had to go (.) within the house everyone sort of had different things (#) I went to AA for alcohol and CA for cocaine (.) so then I started learning about the steps (.) and that community (.) then it forced me to get a sponsor*

*(Heidi, 524-533/1066)*

*'After I got back from rehab, I got more connected with the recovery community with AA I there (.) started using that community so was less on those sites'*

*(Heidi, 484-7/1066)*

Heidi's account suggested a reduction in Pro-Ana use because her support needs were met elsewhere. She would however check the sites occasionally to identify any new weight loss tips.

*'I didn't need to go....I would go every once in a while to see if there was anything new out there...but it was pretty much the same...so that's how it faded but I think it was coz of that three month break (.) that was forced upon me basically'*

*(Heidi, 612-20 /1066)*

Like Heidi, Samantha also positioned the sites as providing her with emotional support. She portrayed her treatment stay as a hard process, where at times she longed for the Pro-Ana community but started to see some benefits after following a weight restoration programme.

*'Treatment was very helpful; my brain being fed (.) I was able to talk to people (.) get the help and therapy that I needed and erm explore some of the deeper issues that came along with actually developing my eating 'disorder' '*

*(Samantha, 656-9/956)*

Her account drew on dominant medical and psychiatric treatment discourses, that by nourishing her body and brain she was able to connect with thoughts and feelings that up until then she had avoided. The use of these discourses had the effect of seeming to support the necessity of her inpatient admissions and re-feeding being enforced, before she was herself able to take action. The feeding of her brain was positioned as enabling her to open up

during therapy and start to navigate some of the deeper issues, with more agency and power in her own recovery. According to Schmidt & Treasure's (2006) cognitive-interpersonal maintenance model of anorexia, emotional avoidance is one of the key factors in the maintenance of anorexia and research has suggested that it is often highly valued by those diagnosed with the condition, often acting as a barrier for recovery (Treasure & Schmidt, 2013).

Although Samantha claimed to return to the Pro-Ana sites upon entering an outpatient programme, she stated '*when I got out it just didn't appeal to me nearly as much (.) I wasn't in nearly as deep with the eating 'disorder''*.

Both accounts suggest that an enforced period of abstinence, following an inpatient admission led to a reduction in Pro-Ana use after participants were discharged. Heidi's narrative suggested that this reduction was caused by her emotional needs being met through other means (inpatient addiction support groups). Samantha's narrative suggested that this reduction was caused by the physical changes associated with re-feeding which enabled her to access therapy and ensured that the impact of the eating 'disorder' was reduced when she left treatment. This appeared to result in a reduced pull to Pro-Ana.

#### 3.2.2.2.2 Others Take Control of the Wheel: Opening the Door on Change

Notably, neither Samantha nor Heidi claimed that their inpatient stay and enforced Pro-Ana break led them to recover, or were even observed to position themselves as recovered. Yet both accounts are constructed in such a way that they suggest that it made it easier for them to start to 'open the door on change'.

In Heidi's narrative, being forced to step away from Pro-Ana led her to look for support in other places and engage in an AA recovery group. She later set up an eating 'disorder' anonymous support group and she now has plans to do some trauma focused therapy. Her

account suggested that her initial admission gave her a taste of what sources of recovery support could be available which she has gradually built upon to construct a new recovery based community around her. In constructing the account in this way, she moves from a more chaos to quest based narrative (Frank et al., 1991).

*'right now I have a therapist (.) a dietician (.) erm (.) and I'm also going to be actually starting on Monday with a therapist that does....EMDR but she also does Kinesthetic work and things like that (.) coz I also know that those are things that I need to deal with still (.) like the trauma issues (.) and so (.) but I have the support of my therapist the dietician and all those people (.) and my community (.) I have an EDA meeting that I started two years ago '*

*(Heidi, 734-45/1066)*

*'I'm at a place now where I'm taking care of myself and working on me (.) my ultimate goal is that I wanna hold space for people'*

*(Heidi, 797-8/1066)*

These new and growing sources of support are positioned as having helped Heidi to enter a different head space. Her account suggests that addressing her eating 'disorder' has been hard *'the eating 'disorder' (#) I mean that's just been a fight'* but it is a fight for recovery that she is now actively engaged in.

In Samantha's account, she described how inpatient admission not only enabled her to nourish her body and brain in order to deal with the deeper issues surrounding her eating 'disorder' onset but having others around her who were entering recovery, led Samantha to start contemplating if recovery was something that she too could obtain.

*'I talked to a lot of the girls who had left before me (.) the girls that I was closer with and they were doing great and part of me began to wonder (.) if I could maybe get there whether it took another treatment centre or sheer determination'*

*(Samantha, 673-7/956)*

Although Samantha described returning to the Pro-Ana sites after she left the inpatient centre and subsequently joined an outpatient programme, her account was constructed to suggest that she had come out of the process a different person, who was less immersed in the Pro-Ana world. Consequently, when she had a chance conversation in which she was told that she had been referred to as '*triggering*' by other patients, the decision to give recovery her full attention, only seemed possible because of the events and abstinence that came before it.

*'I had a conversation with a girl I am still very close to from inpatient erm(.) about the other clients that were there and at that point we were all very positive about each other's recoveries erm(.) and she told me things that girls had said behind my back about how I was triggering.....to hear all the damage I had done erm I decided at that moment that I was going to give it six months erm(.) and if I couldn't do it that I was allowed to relapse'*

*(Samantha, 691-6,698-700/956)*

As an audience member, I was left wondering whether this '*triggering*' reference was particularly pertinent to Samantha, given the stories she has told prior to this. Notably, earlier on in the account Samantha had appeared to express a great deal of remorse in relation to mentoring other Pro-Ana site users to become '*sicker*', in her role as an 'advanced warrior'. She painted a picture of someone who no longer wanted to be seen as a person who made others more unwell. She had already tried to make amends for her previous actions which

may have been 'triggering'. Constructing the sequence of events in this order has left me wondering if the comment had connected Samantha to an old version of herself that she no longer wanted to be associated with, when sighting this strong desire for change.

*'Towards the end of my time there I started to realise how sick everyone else was online (.) I couldn't see it for myself (.) erm that I was just like them (.) erm (.) but people who had messaged me (.) and asked for this advice (.) I would try my best to conceal healthy eating (.) and getting in two thousands calories a day.....in the language of the site (.)....it was almost me trying to make up (.) pay a penance for all of the people I had worsened (.) made sicker (.) and all the people that had talked to me and helped me get sicker too'*

*(Samantha, 424-34/956)*

Both Samantha and Heidi's storylines suggested that a combination of enforced abstinence from Pro-Ana, coupled with exposure to a recovery environment; enabled them to gain more distance from the Pro-Ana community and make later changes.

#### 3.2.2.2.3 A Choice: I Reclaim Control of the Wheel

For the remaining participants, Lucy, Kendra and Emma, their narratives of Pro-Ana withdrawal were told using recovery storylines, with no enforced break. Their accounts were strikingly different to Heidi's and Samantha's because they contained more agency, using words like, '*I realised*' or '*I decided*' to explain how recovery and withdrawal were possible. Although the value of psychology professionals was spoken about extensively in both Kendra's and Lucy's storylines, their accounts attributed withdrawal to their own actions, rather than it being enforced on them by medical professionals. In doing this, the locus of control for change and any perceived 'successes' were perhaps more readily given to themselves, rather than those involved in their care (Rotter, 1966).

#### 3.2.2.2.4 The Moment: A Shift in Motivation Happens

All three women were observed to construct accounts in which there was a growing readiness for change and preparation for action (Prochaska & DiClemente, 1984; Prochaska & Velicer, 1997). According to the trans-theoretical model of change individuals do not make black and white decisions regarding behaviour changes but gradual progress through a series of stages. The women were observed to construct accounts which suggested that they had progressed through the pre-contemplative and contemplative phases in order to prepare themselves for action (Prochaska & DiClemente, 1984; Prochaska & Velicer, 1997). They then each described how a specific moment tipped the scales and enabled them to decide to enter recovery. Within Lucy's storyline she spoke of a realisation that there was more to life than being thin, expressed through a felt sense of change within her body.

*'it was like this fiery thing inside me just sparked (.) and (1) I was like yeh (#) there's more to life than being skinny'*

*(Lucy, 691-3/1115)*

For Emma, a realisation that it would cost her important relationships, rather than enable them, as it had done in the past with eliciting care from her parents.

*'If I was gonna have the kind of friendships and relationships and experiences in life that I wanted (.) (voice cracks as if about to cry) then the eating 'disorder' couldn't be central to who I was because I have lost a best friend (.) the best friend I ever had (.) and I think that was a big turning point for me (.) was that realisation'*

*(Emma, 772-80/1163)*

For Kendra, a realisation of how much the eating 'disorder' was hurting her boyfriend and her therapist she stated that she needed to provide more input into recovery.

*'My therapist said it's my job to help you (.) not my job to make you and that really helped and motivate me to (.) make myself try to give some input into recovery (.) because I said I was saying I wanted to recover (.) and I was kind of trying (#) but I wasn't giving it my one-hundred percent (#)..I had to give more'*

*(Kendra, 841-8/1396)*

Notably, these participants were observed to place themselves in stories where this readiness for change had only been made possible by the women resourcing themselves through shifts in social support and shifts in identities.

#### 3.2.2.2.5 A Shift in Social Support

All three spoke about the importance of finding alternative sources of support. For Emma, this seemed to come through a change in work and living arrangements. She described becoming increasingly close to the mother of the family she was a nanny for and her storyline expressed shock that women could be *'thin and lovely'* but also still *'love food'*. She was observed to repeatedly use the phrase *'shocked to my core'* in relation to this, perhaps communicating to her audience that up until now, her thinking was more black and white.

*'the mum of that family and I got really close and erm (.) she is like gorgeous and thin and lovely (.) but she is a healthy person (.) and loves food and I admired her so:: much and I wanted to be like her so:: much (.) it literally shocked me to my core (.) that she liked food, (.) and would openly talk about liking food and (.) ya know she exercises but in a healthy way (.) ya know just because she cares about her body not because she is trying to lose weight kind of thing (.) and so I had this new model that (.) I mean was completely (.) like I can't tell you how many times I was shocked (.) to my core'*

(Emma 538-51/1163)

Emma's account positioned herself as becoming increasingly integrated into their household she subsequently took on their ideas and values around food, eating and health. Emma claimed that having this '*role model was a big deal*'. Her account went on to suggest that by the time she left for college she was actively trying to recover and wanted to establish '*different support systems*' that had nothing to do with her eating 'disorder'. This decision to enter recovery appeared to come about due to the threat of losing her best friend. Emma's narratives sequenced in this way, positioned the drive for thinness, eating 'disorder' and with it the need for Pro-Ana, as moving further and further behind her. In the extract below her use of the word '*shenanigans*' could be seen to trivialise and mock the eating 'disorder', it's power over her diminished through the existence of new social support resources and a creation of a new life.

*'there's no time for eating shenanigans...I've made so many friends and like got into so many things that I know wouldn't have been possible (.) or I wouldn't have had the energy or motivation to do (.) erm (2) had my eating 'disorder' had been a big part of my life (.) '*

(Emma, 836, 841-6/1163)

Emma's account was dominated by stories that concerned the value of creating new friendships outside of the context of her eating difficulties. Lucy in contrast positioned herself as returning to her old source of support and '*coming out the closet*' with her struggle. She drew on sexuality discourse by using this term, which perhaps suggested taking a position of pride to combat previous feelings of shame that can often be associated with having to hide aspects of oneself in these discourses (Rasmussen, 2004).

During her account, she also spoke of the value of moving to an online recovery space, using a private Facebook page with other people from the Pro-Ana sites who were also in the recovery process.

Kendra's account was somewhat different to both Lucy's and Emma's. Omitted are many references to friends and family which perhaps suggested that these sources of support were unavailable to her. Instead, the support from a new boyfriend and therapist were positioned as pivotal in helping her to enter recovery. She opened her withdrawal storyline with less agency than the other two women, claiming *'when I started therapy (.) I didn't want to recover' 'I was just following my Drs'*. Yet her account moved to suggest that their continued *'care'*, *'persistence'* and *'patience'* enabled her to open up and want to get better. She then positioned herself as making a decision to stop losing weight and stop using the sites.

*'after a while being in therapy and me opening up and also with the support you know that I was getting from my boyfriend mostly because he really encouraged me to go to therapy... having him having him by my side to support me and at the same time the support from my therapist made me wanna get better (.) so whenever I started to try whenever I actually decided you know ok I'm going to stop trying to lose weight and start trying to eat more that is when I started you know when I realised I had to stop using the pro eating 'disorder' sites'*

*(Kendra, 613-6,619-26/1396)*

The narrative constructed in this way, where two individuals are narrated as enabling her to shift her mind-set away from Pro-Ana and into recovery perhaps served to show just how significant she experienced their impact to be. During the account, she referred to this decision to enter recovery many times:

*'Well (.) I am going to try and gain weight and you know be healthy (1) and try to eat more so why do I need to log into the sites',*

*(Kendra, 631-3/1396)'*

*'Even though I was scared to gain weight (.) I had already taken that decision... so once you make that decision when you log onto those sites you don't feel the same'.*

*(Kendra, 660-1, 662-3/1396)'*

This narrational activity, where 'I' and 'my' were used so frequently, perhaps served to show that although she experienced their support to be immense, the decision to withdraw from Pro-Ana was her own. Towards the end of her account she stated;

*'I would have thought that I would miss talking to those people (.) but I didn't. I felt no connection to them anymore'*

*(Kendra, 985-7/1396)*

This perhaps suggested that Kendra had developed a different mind-set, reinforcing the narrative that changes had been made within therapy, which further supported a story of recovery.

#### 3.2.2.2.6 A Shift in Identity

Both Emma and Lucy spoke in detail of experiencing shifts in their identity. This was not present in Kendra's account and I am left wondering if both Emma's and Lucy's backgrounds in studying psychology equipped them with a narrational device to make sense of their experiences which was less readily available to Kendra. Though the identity talk conducted by Emma and Lucy is subtly different; Emma's account suggested a realisation that there

were other aspects to her identity, whereas Lucy's suggested a realisation that the eating 'disorder' was not her identity.

Emma positioned herself as making a number of life changes, trying to find her identity in, '*other things*'. She spoke of '*setting boundaries*' with her family, going '*off to school*' and surrounding herself with new people. She claimed that through these actions her '*sense of worth shifted? a lot (.) it didn't (.) need to-I just (.) I dunno how to verbalise it but it didn't need to be around my weight and it didn't happen over-night.*' Emma suggested that a collection of situational changes enabled her focus and feeling of worth to move away from her weight. Her account portrayed this as a slow gradual process where the specifics regarding the internal processes were somewhat intangible for her to describe.

She went on to claim that when her eating 'disorder' moved from being her whole identity to just one small part, it was less important for others to '*get it*', like they had done on the Pro-Ana sites.

*'I think having people understand how it affected my life (.) like I got in those Pro-ED communities (.) was more important when the eating 'disorder' was my identity (.) so when I started finding my identity in other things (1) that mattered less'*

*(Emma, 687-92/1163)*

Although Emma positioned herself as making a choice to withdraw from the sites and enter recovery it is a 'choice' in which she repeatedly expressed a struggle to recover, with stories of pretending to be okay.

*'I think I made the choice to not let it be my identity any more (.) and some of that was like a lot of times me just faking it (.) like I'm gonna pretend that I don't have an*

*eating 'disorder' (.) ... so a lot of it was like pretending a lot of it wasn't who I was until that became a reality.'*

*(Emma, 806-10, 813-5/1163)*

In contrast, Lucy's account painted a picture of someone who, whilst in therapy could not see how recovery could work for her, until reading a book entitled 'A Life Without Ed'. She claimed '*this book was my brain*' and positioned herself as being gripped by its content '*I finished it within two days*'. What Lucy appeared struck by, was the author's ability to personify and externalise the eating 'disorder', using a metaphor,

*'I liked the metaphor she was using (.) so I gave (.) so my eating 'disorder' became Ed', 'that gave me something to fight (2) that kind of separated (.) where I was one'.*

*(Lucy, 667-71/1115)*

During this part of the narration Lucy was observed to become more animated, in pitch, tone and pace, moving forward in her seat, as if readying herself to perhaps engage in a fight with Ed in her living room. She claimed '*I thought my eating 'disorder' had my identity*', which suggested a realisation that it did not. Her account constructed in this way served to give Lucy much more agency. She moved from a powerless, passive position, through using the word '*had*' as if imprisoned, to a much more powerful, attacking one, where she was going to claim her identity back. She spoke of how the metaphor enabled her to separate out thoughts.

*'I was able then to pick out which were the eating 'disorder' thoughts and which were my thoughts',*

*(Lucy, 678-80/1115)*

She claimed to bring the metaphor into therapy, which seemed to enable a different type of conversation, where the blame was positioned outside of Lucy.

*'She would say (.) I think Ed is in charge at the moment (.) let's get Lucy back in charge'.*

*(Lucy, 843-4/1115)*

Lucy then told multiple stories of being in charge, *'I was like right (.) I'm going to run the British 10k'* perhaps serving to strengthen this new preferred identity where Lucy was her own person.

Both draw on discourses of effective treatment, which fall in line with the existing recovery literature that externalisation (White, 1990; White & Epston, 1990; White, 1988) and individuals strengthening other aspects of themselves (Hayes, 2004; Juarascio, Forman, & Herbert, 2010), can enable meaningful change.

### 3.2.2.3 The Comfort of Ana: Can Her Ties Ever be Fully Severed?

Though all participants were observed to position themselves in recovery by the end of the interview, several accounts suggested a coming and going towards Pro-Ana. Samantha's account most strongly portrayed this.

*'now that I'm here at university I(.) it's not a struggle to stay in recovery but the sites still has some appeal (1.) erm (#) in that I'm an introvert it's hard to make (.) friends erm but I mean (.) when I went back a couple of months ago I have nothing in common with those girls anymore ... I made another account erm got the usual hatred that a newbie gets (#) it was very surreal for me to be back in that place and to know that within weeks I could be in relapse'*

*(Samantha, 703-8, 709-12/956)*

She performed an ongoing struggle, she positioned herself as an introvert who missed the ease with which connections could be made online and struggled to develop offline support systems. This perhaps suggested some fragility in the progress that had been achieved and the pull of the sites leading to a relapse.

Kendra also spoke of returning to the sites; she described this as occurring more during the early part of her recovery and as a response to feeling scared about gaining weight but claimed that nothing further happened, as her ultimate goal was not to lose weight.

*'I would still log into them occasionally when I when I guess I felt the need to see something I don't know how to explain it it's like(.) when I started to recover(.) I would(.) you know you gain weight so sometimes you get scared you are gaining weight and you are like but I don't want to gain weight all these years I've been trying to lose weight and to stay skinny ...like when you see those numbers go up and when you know that you are eating more you are consuming more calories it sends you into a panic sometimes and so there were times wherever it sent me into a panic and you know I just logged into those sites'*

*(Kendra, 639-45, 646-50/1396)*

The panic associated with gaining weight throughout recovery was also woven throughout Emma's account, though she did not speak of returning to the sites.

*'I still go through a phase where I think a lot of being thin (.) for me right now it serves the function of anxiety reduction (.) like when I get very anxious I can think about numbers and plan a weight loss regiment (.) and it calms me down a lot (#) and obviously that's not the most super amazing thing ever but erm I think in those times*

*(.) I do feel the urge to (.) erm (.) I don't necessarily feel the urge to look at Pro-ED websites (.) coz I think those would make me very angry'*

*(Emma, 593-603/1163)*

### **3.3 Reflections on the Type of Narratives Told**

According to Frank (Frank, 1995; Frank, 1997; Frank et al., 1991) narratives typically fall within three structures; restitution, chaos and quest. He claims '*these are the skeletons on which many stories of illness are fleshed out*'. Notably, all bar one participant used a quest narrative to frame their personal stories. They positioned themselves as being in a '*battle*' '*fight*' or '*struggle*' with an eating 'disorder' and the purpose was to overcome it. According to Frank (1995) in quest accounts, individuals meet adversities head on, recognising that damage may have resulted but hold on to the belief that something can be gained through their experiences. These usually refer to personal qualities the illness has given them, or gifts in understanding which can be passed on. For example, Lucy described coming out a '*stronger*' and '*more compassionate person*', who wanted to help others and raise awareness '*I'm going to help people with this now (.) people need to understand*' facilitating support groups and raising money for eating 'disorder' charities. Emma too positioned herself as becoming '*very compassionate....and pretty damn resilient*' helping her to become '*a good friend now*' and a '*very healthy*' influence on those around her. In a less overt way, Kirsty positioned herself as gaining a more understanding persona

*'I think I have been guilty of in the past of thinking about the other people on those websites as (.) like wannabe anorexics (.) but now I see them as kind of places (.) where people are just really ill'*

*(Kirsty, 803-/920)*

She appeared to call for societal action on how eating 'disorders' and the Pro-Ana movement have been viewed, *'I think the sites needs to be taken a lot more seriously'*. The accounts varied regarding the degree to which these eating 'disorder' and Pro-Ana 'battles' had been fought and won. For instance, Heidi and Samantha situated themselves in an ongoing battle. The enduring and chronic nature of severe mental health difficulties like eating 'disorders', may make it important to tell stories of hope which encompass personal growth and resilience in order to sustain a recovery mind-set but given the high degree of relapse amongst this population there could be a need for some to tell stories which are tentative in claiming a resounding victory or defeat (Frank, 1995).

From the first half their accounts, it seemed that both Samantha and Heidi were going to present chaos's narratives. These narratives are characterised by plots which suggest life can never get better (Frank, 1995), however both went on to describe experiencing some personal gains through their struggles, which enabled them to *'give back'* to others. Respectively, writing in an online magazine and *'holding space'* for others in support group meetings. Upon hearing these narratives, I wondered if these earlier stories were told to honour the degree of struggle each reportedly faced and also to help place the chaos further behind them before they told more quest based stories.

Storytelling is thought to play a vital role in repairing narrative wreckages, as the self can be steadily reclaimed through the act of telling and Frank claims it is not untypical for accounts to slowly move from chaos to quest (Frank, 1995; Frank, 2012). These perhaps offer two examples of narratives undergoing this re-authoring of experiences process.

The last participant Kendra appeared to position herself more readily in a restitution narrative. She saw herself as altered by her eating 'disorder' experiences, both physically and mentally but attempting to go return to a healthier version of herself. The focus of these

stories are concerned with what can be re-claimed, rather than gained through a quest (Frank, 1995). Although parts of her narration appeared hopeful of continued progress, she contrasted this with an uncertainty as to whether recovery could ever be completely achieved for her.

*'Since I started therapy it's been like five years and I've still not fully recovered...you know some people are able to get fully recovered (#) but many others just live with the process of it(#)'*

*(Kendra, 1260-2, 1266-8/1396)*

Kendra went on to delineate out the physical, mental and emotional impact of eating 'disorders', which suggested that whilst she looked well physically she continued to struggle mentally. Through doing this she resists the more reductionist categorisation of dominant discourses in which individuals are positioned as 'sane' or 'sick' and creates a middle ground, positioning herself with some ongoing difficulties.

## Chapter 4: Conclusion

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*I think the greatest gift you can ever give someone is your attention (Moyers, 1993)*

This research aimed to hear the stories of those who had regularly used Pro-Ana sites, with a particular focus on their experiences of withdrawing from the sites. The intention was not only to consider the content of narratives but also the structural, performative and contextual aspects of accounts. In the last chapter I will summarise the findings of this research, discuss how these may inform clinical practice, consider the strength and limitations of the study and make recommendations for future research. Finally, I will offer some personal reflections on the research process.

### **4.1 Summary of Findings**

Before providing a summary, it may be advantageous to revisit the study's initial research questions:

'How do regular users of Pro-Ana forums narrate their experiences of how they came to regularly use the sites and subsequently disengage from them?'

'How do people narrate the impact this journey has had on them (relationship to self and others overtime and relationship to food and eating over time)?'

#### **4.1.1 Narrations of Coming to Regularly Use Pro-Ana**

There was some variation in the stories told by narrators regarding how they came to use the Pro-Ana sites. Two women positioned themselves as stumbling across the websites but most positioned themselves as actively seeking them out after Pro-Ana was referenced on social media forums, in a chatroom or by a class mate. Notably, all spoke of the ease at which the sites could be found, entered and the community joined. The strongest storyline of what led

individuals to the sites and/or repeatedly return seemed to be a desire for improved weight-loss. A search for connection was a further storyline that was present in many of the accounts. This mirrors the small body of existing qualitative and quantitative Pro-Ana research (Crowe & Watts, 2016; Fox et al., 2005; Gale et al., 2016; Peebles et al., 2012; Rodgers et al., 2012; Wilson et al., 2006).

#### 4.1.1.1 Aspirations of Further Weight-Loss

Most narrators painted a picture of having pre-existing eating difficulties or 'disorders', where there was a strong drive to lose weight, or a desire to maintain an already low body weight. Four women positioned their eating 'disorders' as being a means of self-expression and a way of communicating their distress to others. They were observed to resist dominant feminist discourses of gendered pressure to obtain slim physiques in the quest for beauty and instead drew on clinical eating 'disorder' discourses. For instance, within the clinical literature this form of self-expression has been cited as a commonly perceived positive outcome for restrictive eating in individuals who have been diagnosed with anorexia in particular. (Serpell et al., 2003; Serpell et al., 2004; Serpell et al., 1999).

The weight-loss tips and tricks section which feature in most Pro-Ana sites was positioned to offer an additional tool in helping individuals to express themselves more effectively. In the remaining two accounts, participants spoke of gaining a sense of mastery associated with losing weight, which they claimed was further enhanced when they found the Pro-Ana sites. The sites seemed to offer these women new ways to 'better themselves' through continued weight-loss. Perceptions of mastery have also been implicated in the maintenance of restrictive eating in a number of other studies (Branch & Eurman, 1980; Garner & Bemis, 1982; Vitousek et al., 1998; Vitousek & Ewald, 1993).

#### 4.1.1.1 A Search for Connection and a Place to Feel Better

Present in all accounts were storylines of connection. The findings here seem to mirror the existing work of (Dias, 2013), who suggested that Pro-Ana sites can offer women a 'sanctuary' as they report feeling increasingly isolated and misunderstood in their offline world. What appeared unique about the type of understanding provided among the Pro-Ana community was that the members seemed to provide 'understanding' without challenge to eating 'disordered' behaviour. The value of 'acceptance' was repeatedly storied across accounts and often contrasted with the challenges present by loved ones offline. In this way, the sites were positioned to offer women the freedom to become more immersed in their eating 'disorder'/difficulty.

#### **4.1.2 Narrations of Impact**

Several women told stories of the sites initially legitimising the existence of an eating 'disorder' but then told stories of how the sites normalised 'disordered' eating to such an extent that participants started to believe that they were not that 'sick', or 'sick' at all. Many positioned themselves as gradually eating less over the course of using the sites and went on to richly describe the weight-loss methods they discovered there. This is consistent with findings from quantitative studies, which suggest the Pro-Ana use can adversely impact eating behaviours (Jett et al., 2010; Peebles et al., 2012). The tips the women spoke of gaining mostly concerned how to avoid eating food and detection from loved ones or health professionals in relation to reported changed behaviours.

Several participants situated themselves within storylines where they appeared to express an increased level of mastery regarding food restraint, by using tips and tricks from the sites. This was particularly present for one participant who had disclosed receiving a diagnosis of anorexia (restrictive subtype), and described being admired by those who's presentation was

more akin to bulimia. Those who disclosed bingeing and purging behaviours more readily recounted times of feeling like a failure when on the sites, as they reported not being able to obtain the desired purity of restriction. These differences in experiences which appear to result from presentation of the two diagnoses, has also been cited by Giles (2016).

Most accounts suggested that there was a gradual retreat into an online world, at the expense of maintaining offline connections and this was positioned as leading participants to become increasingly immersed in the eating 'disorder' and for it to become a more central aspect of their identity.

#### **4.1.3 Narrations of Disengaging from Pro-Ana**

Participants showed greater diversity in how they narrated the disengagement process. Some claimed to have lots of agency in making a decision to leave the community, others very little. The accounts also differed around the meaning participants seemed to ascribe to disengagement. For some, withdrawal was closely intertwined with moving towards a recovery mind-set. For others, it appeared to represent a sign of eating difficulties actually 'worsening'.

##### 4.1.3.1 A Sign of Eating Difficulties 'Worsening'

Two participants stated that they felt like a fraud in relation to developing an eating 'disorder' whilst on the sites and their narratives suggested that this led to a disengagement decision. One narrator was observed to trivialise the sites claiming they were for 'wannabee's' and reported that if she had an eating 'disorder', she should be able to go it alone. The other, positioned herself as needing some time away from the sites to figure out which tips and tricks worked best for her, before coming back to the community a seemingly more legitimate member.

#### 4.1.3.2 A Sign of Recovery Possibilities

Perhaps unsurprisingly, the remaining storylines positioned withdrawal as being closely associated with recovery. How the narratives differed, was the degree of agency participants gave themselves in relation to the withdrawal process. In the accounts of two participants, withdrawal was not seen as a choice but an enforced action, by medical professionals, which led to some positive changes post discharge. One participant described becoming more connected with substance misuse recovery groups at the treatment centre because the social support provided by the Pro-Ana community was not available. She appeared to position this break from the sites as being the catalyst for future changes she would go on to make in her life, though claimed this was not a *'linear'* process. For the other, a weight-restoration plan coupled with therapy was positioned as ensuring she was not so *'entrenched'* with the eating 'disorder' when she left the centre and thus reported that there was a reduced pull to the sites. For these two women, enforced breaks were observed to open the door on change.

The remaining participants storied their experiences in a way that suggested that they had more agency in the decision to enter recovery and withdraw from the Pro-Ana community. Their accounts suggested a gradual movement through the stages of change model and increasing propensity or readiness for change (Prochaska & DiClemente, 1984; Prochaska & Velicer, 1997). They each then richly described experiencing a moment of 'realisation', which resulted in action. Their accounts suggested that this decision became possible, when there was a change in circumstances through shifts in social support and a strengthening of other identity aspects. Across the narratives there were examples of how this was achieved, such as going to college, strengthening new offline relationships and developing therapeutic resources.

#### **4.1.4 Narrations of Impact**

Most accounts positioned the impact of withdrawal as enabling participants to gain more distance from the eating 'disorder', which was portrayed as becoming less central to their lives. Most participants richly recounted stories of becoming increasingly connected to others in their offline world; either forming new relationships or re-connecting with existing ones. They also described experiencing shifts in their identity, where other aspirations outside of weight-loss became strengthened. This break from the Pro-Ana community and movement towards recovery was positioned, in many narratives, as a way of enabling the women to also alter their view of the sites and Pro-Ana users. For instance, one participant spoke of now seeing the community as '*destructive*' and another that they were run by individuals who were '*sick*' and '*lonely*'. For the two accounts where withdrawal was not associated with recovery, it was less clear what the impact was. One narrative suggested that once they left the community, restrictive eating and weight-loss continued and was not positioned to have much impact at all. In the second account, withdrawal was portrayed as offering some space to try out the new weight-loss techniques before coming back to the community '*stronger*'. Again, the impact was scarcely spoken about during this part of the narration.

I will now move to discuss the impact of these findings for clinical practice and beyond.

## **4.2 Implications for Clinical Practice**

### **4.2.1 Inside the Therapy Room**

For many women, they positioned their eating difficulties and drive for thinness as being a form of self-expression and communicating distress. This suggests that a focus of therapy could be to help individuals find different ways of expressing themselves and new ways to

communicate within their support systems. However, this system is constructed whether it be through family or friendships.

Arguably one of the most significant findings was that storylines concerning a drive for thinness and search for a connection were central in individuals both coming to Pro-Ana sites and also withdrawing from the sites. It seemed that when other aspects of identity were strengthened and individuals were able to feel appreciated and supported within their offline world, they were less inclined to use the Pro-Ana sites. A narrative technique known as externalisation (White, 1988) was positioned as pivotal in enabling one participant to gain agency in order to fight the 'disorder'. For another it seemed that her values of becoming a psychologist and role model to younger members of her adopted family helped the eating 'disorder' become a smaller part of her identity. Both these accounts suggest that if an individual does enter psychological therapy ideas from narrative therapy and acceptance and commitment therapy may be particularly valuable (Hayes, Strosahl, & Wilson, 1999; White, 1990; White & Epston, 1990; White, 1988).

An example of how externalisation could be implemented during one-to-one therapy or perhaps in an inpatient group setting is to ask individuals collectively 'What's the biggest impact Pro-Ana is having on you?' 'How does Pro-Ana influence your view of yourself, others around you, your hopes dreams and ability to move forward?' 'Are there tricks and tactics that Pro-Ana uses to try to draw you in and influence you?' 'Is it okay that Pro-Ana has these influences on your life?' 'Why else isn't this okay for you?' 'What would it mean to you and yourself, if it was possible to resist Pro-Ana's lure?' (White, 1988, White, 1990; White & Epston, 1990).

Woven throughout many storylines, was implicit and explicit expressions of shame and embarrassment in using the Pro-Ana sites. One storyline in particular suggested great concern

that if professionals knew that she was using them, it would invalidate the severity of her struggles. For this reason, it is important that clinicians familiarise themselves with both the Pro-Ana literature and content of websites. If clinicians are able to become more aware of the tips and tricks commonly featured on the websites to hide weight loss behaviours, they may be better able to detect symptoms earlier, thoughtfully intercept and also help educate families to recognise changes in behaviours too. Given that several studies suggest that early treatments yield better outcomes (Dias, 2013; Grasfield, 2015), this may be an important clinical recommendation. It will also be very important for clinicians to offer a non-judgemental, supportive response to any disclosures that are made, given the strong narrative of shame identified here.

Another striking finding was that Pro-Ana withdrawal was not only associated with 'recovery' but also the notion of individuals wanting to become 'sicker'. For this reason, it will be important for clinicians to remain curious about how individuals view the Pro-Ana sites and what withdrawal means to them, rather than perhaps automatically assuming that it is a sign of individuals moving towards a 'recovery' mind-set.

The findings also suggested that Pro-Ana sites may hold particular appeal to individuals who identify as having anorexia (restrictive subtype). One participant who identified herself to have this diagnosis, told stories of feeling admired by others, perceived to possess a skill or talent for restricting, that others looked up to. This admiration storyline was also referenced to by two others. Given this positive reinforcement, it is likely that the pull to the sites/forums for these individuals may be particularly strong, compared to those who identify as experiencing bingeing and purging which is seen as far less desirable action by the community, indicating a loss of food control. Clinicians working with those who have anorexia should be particularly mindful of the feelings of success or self-worth an individual could feel that they will lose, if they step away from the Pro-Ana world. Clinicians should

perhaps ensure that alternative stories of worth and success are thickened with the client (White, 1990; White & Epston, 1990), both inside and outside the therapy room so that this potential 'loss' can be minimised.

Two women positioned themselves as being in 'recovery', but still visiting the Pro-Ana community infrequently. Though they both richly described it as being a place where they no longer felt they belonged. One described missing the ease with which friendships could be made online which occasionally led her to return, the other described how gaining weight whilst in 'recovery' could sometimes cause her to panic, particularly in the early phases, so she would return to the sites as a form of anxiety reduction. Notably both claimed that nothing would occur beyond this and they positioned themselves to be committed to 'recovery'. Given this finding, it will be important for clinicians to recognise that leaving Pro-Ana may for some, be a transitional process and one that they may never fully enter out of. For this reason, therapists will need to stay curious about the intention individuals have when they returned to the sites, so that they can perhaps be further supported during ongoing interventions to reduce the need to revisit. Clinicians should also recognise that if no changes in 'disordered' eating behaviour occur occasional use may not be a 'red flag' and serious cause for concern.

#### **4.2.2 Beyond the Therapy Room - Blue Sky Thinking**

There have been numerous attempts to police and shut down Pro-Ana sites (Giles, 2016). Yet despite this, over 500 websites are thought to be in existence (Hansen, 2008; Wilson et al., 2006). The ease with which sites can be found, accessed and joined was referenced across all accounts, perhaps leading to the question of what can be done to police these sites even better, or to deter creators from launching the sites altogether? However, as claimed by Csipke and Horne (2007), I wonder too if 'internet savvy individuals will always stay one

step ahead'. Therefore, instead of seeking to criminalise and stigmatise the creators and users of these sites any further, which makes it more difficult for individuals to speak about their experiences, perhaps clinicians, politicians and the wider public, should turn their attention to trying to understand what needs these sites fulfil. Many narrators claimed feeling increasingly isolated and misunderstood in their offline worlds. As a result, perhaps we as a society need to reflect on how we conceptualise eating 'disorders' and seek to hold a more compassionate position, where we continue to try and help someone make sense of their experiences. This may lessen the perceived need of individuals to use the Pro-Ana sites.

Campaigns like *'time to change'* and eating 'disorder' awareness week, may help to reduce the stigma around disclosures of eating difficulties and thus Pro-Ana (Henderson et al., 2012). As a result, there could be value in further investing in this type of campaign. Given that societal discourses have been seen to position the sites as 'dangerous' through to 'pre-teen fads', clinicians may also have a role in helping to break these stigmatising ideas (Giles, 2016). Action could however be taken at every level, with more psychoeducation about eating difficulties in schools, more pastoral care and diligence taken in media reporting. Only when needs are fulfilled elsewhere, will the use of the sites start to significantly decrease.

Finally, though the women did not draw on feminist discourses of beauty ideals driving weight-loss, several told stories of their weight-loss being admired and positively endorsed by those on and offline. This storyline is consistent with ideas from Bordo (1993) that socially constructed attitudes towards thinness may be manipulating consumers into believing there is an ideal body size, which if achieved provides worth. Young, electronically savvy women, may represent a sub-culture most at risk from this consumerism. Perhaps we need therefore to consider the cultural messages that exist in relation to size. The media also needs to be held accountable so that the type of body that women inhabit is not seen as their sole

source of worth. New messages need to be reinforced concerning health and not size. Each of us may need to take a pebble and throw it in the pond.

### **4.3 Evaluation of Study**

#### **4.3.1 Strengths**

Given that most of the research investigating the Pro-Ana movement has been quantitative; the use of qualitative methodologies is a significant strength of this study and adds to a small body of literature investigating user experience, helping rich, meaningful datasets to emerge. The choice of NI may be particularly relevant because it considers how dominant discourses challenge and allow certain stories to be told. Considering the social and political attack this movement has endured and the shame and stigma associated to the disclosure of eating difficulties, NI seems an appropriate methodology to thoughtfully, investigate the research questions. To my knowledge, it is also the only study to do this.

It also appears to be the only study which has sought to investigate withdrawal from the perspective of those in the Pro-Ana communities. The findings can thus be considered novel and offer a platform from which future studies can be undertaken.

Although the small sample size and epistemological position of the study, means that findings cannot be generalised to all individuals who identify as having eating difficulties and use the Pro-Ana sites. Recruiting internationally and including individuals who are ethnically and culturally diverse means that the study affords new insights and opportunities in understanding how Pro-Ana use could potentially impact a whole range of individuals. To date most studies investigating experience have done so from the position of white, western, women, limiting new discourses and knowledges from being constructed. The inclusion of

participants from minority backgrounds could be a strength of this study and also suggest avenues for future research.

#### **4.3.2 Limitations**

Initially, my intention was to recruit 8-10 participants, yet due to time constraints and difficulties with recruitment, this figure was reduced to six, such a reduction will have affected the diversity and richness of the data. It is also worth considering, if so many people are affected by eating difficulties and have used the sites, why it was so challenging to recruit into the study? Details were posted in over forty Facebook groups, sometimes on more than one occasion, tens of UK support groups were contacted regarding recruitment support and over 200 hits occurred on the studies website. I have developed several tentative hypotheses to account for this. Firstly, several participants made reference to continuing to 'do battle' with their eating difficulty and the need to be careful regarding the type of information they exposed themselves too, fearing that it may trigger a relapse. It is possible that these re-triggering fears were prevalent across the wider online Pro-recovery community and prevented individuals from wanting to take part, even if they thought the study was worthwhile. This could also explain why so few monthly support groups from the UK showed an interest in taking part too. Alternatively, perhaps the stigma and shame in admitting to using these sites exist within the eating 'disorder' community as well as outside of it. One participant drew on a strong discourse of shame, believing that others saw the sites as a *'pre-teen'* fad (Giles, 2016). It is possible that a portion of eligible participants held similar views, being too embarrassed to admit to using the sites by signing up. Lastly, it may be that individuals felt ambivalent about the study or did not think that they/others would gain much from participating in it. Though, this would go against comments made by the six individuals that participated, all of whom thanked me for engaging in important research.

Notably, all participants engaged in a one-off interview. Whilst there is of course value in the findings, richer data may have been gathered by using multiple interviews. For instance, Hollway and Jefferson (2000) claim that a second interview can enable individuals to construct more detailed accounts. Interviewees can also be seen to have more power in the process, being able to look back and continue certain conversations on, whilst leaving others alone (Squire, 2007).

Another limitation is that the study had an all-female sample. Whilst eating difficulties are seen to be more prevalent in women, pressure to obtain the 'perfect physique' exists for all individuals. These have not been explored and further research should be conducted in this area to determine the differences and similarities between different sexes. Moreover, recognising that sexuality exists on a continuum it may be that certain individual profiles pose a greater risk of eating difficulties and likelihood of Pro-Ana use. For example, many gay and trans men, report feeling under a great pressure to maintain very slim frames, perhaps increasing the likelihood of engaging in 'disordered' eating, compared to the average heterosexual male (Strong, Williamson, Netemeyer, & Geer, 2000; Strother, Lemberg, Stanford, & Turberville, 2012).

Finally, while the ability to conduct Skype interviews opened up possibilities in being able to contact an out of reach American population, it also added some complexities in analysing the data. This mostly concerned the cultural differences between UK & USA participants. All USA participants had a skype interview and all UK participants a face-to-face interview. In reviewing my reflective notes, it seemed apparent that USA participants spoke in far richer emotive detail about their experiences, It is difficult to unpick whether the study's and with it researcher's distance afforded them a greater level of 'freedom' in which to share their story, or whether the stiff upper-lip culture of the UK prevented richer interviews from unfolding. It may be useful to investigate potential communicative or cultural differences further.

#### **4.4 Suggestions for Further Research**

There are a number of avenues for future research. Firstly, due to recruitment difficulties and tight time frames, only a small number of participants were included in the study. As a result, understanding of what enables regular users of Pro-Ana sites to step away from this community may be further enhanced by repeating the study with a larger sample.

It is also notable that all the participants had received an official eating 'disorder' diagnosis, despite this not being a necessary inclusion criterion. This means that the experiences of a large proportion of those who use Pro-Ana sites, specifically those who do not meet diagnostic thresholds but identify as having eating difficulties, are not represented. There may be benefit in investigating similarities and differences across these two groups by conducting more research with this population.

Whilst an advantage of this study is that it has included the stories of those from different ethnic groups (an Indian American and Latino American), rather than solely the white, middle-class Caucasian stories, which dominate most research populations, it will be important for future studies to seek to hear the stories from more of these individuals.

Understanding their experiences of the Pro-Ana community may hold clinical implications that are currently unknown.

Given the finding that American participants appeared more open during their interviews, it may be valuable for researchers to investigate potential cultural differences more thoroughly when conducting further research in the arena, as well as considering the role of Skype.

Finally, the interview schedule was comprised of a broad range of research topics and it is possible that with more detailed, in-depth questioning thicker storylines may have developed. For this reason, there may be value in conducting a series of interviews with each participant

to better understand Pro-Ana withdrawal experiences. This may also provide much richer insights into aspects of identity and self-characterisation. There may also be value in collecting Pro-Ana narratives across time, to better study how personal experiences are narrated differently as individuals move through time.

I will now close with some personal reflections on the thesis process.

#### **4.5 Personal Reflections**

It has been claimed that high quality qualitative research can only be produced, when one considers how the researcher presence has impacted the data and wider research process (Emerson & Frosh, 2004). Yet perhaps there is also value in considering how the research process, impacts the researcher?

When I started doctoral training, one of my own preferred identities was of a 'quantitative researcher'. I held tightly to the view of 'absolute truths' and 'singularity' within people. My experiences of working as a trainee psychologist and the teaching at Hertfordshire University have led me to continually question these beliefs. It has been a complex, challenging and uncomfortable process of epistemological self-discovery. Upon seeing the increasing value of qualitative methodologies and opting to use NI, I felt a mixture of excitement and terror. There is no fixed way of conducting analyse here (Riessman, 1993); no SPSS syntax safety net to fall back on and ensure I generate the 'right' answer, with a very low probability of making a type one error. Instead, there are narrative accounts, coloured pens, subjectivity, and endless interpretative possibilities. Though this new mode of analysis has been hugely anxiety provoking, it has afforded me the opportunity to closely attend not only to the content of what is being said but also to consider the contextual, performative and structural aspects that exist within accounts. I believe that this has helped me to gain a far richer understanding

of the experiences of those using and trying to disengage with the Pro-Ana sites, than may have been afforded by most (if not all) other methodologies. Conducting this research has also enabled me to thicken a new qualitative identity, which I hope to hold onto post training.

Given that my primary intention as an interviewer in this context, was not to provide a therapeutic intervention but to simply listen to stories I was struck by how many participants thanked me for 'just' listening. They stated that they had gained something valuable from having their narratives heard, reminding me that the act of bearing witness can in itself be a powerful intervention (Birch & Miller, 2000). I hope that I can continue to hold on to this knowledge post training, when I busy myself with trying to find 'solutions', when simply noticing and opening up conversations with gently curiosity, maybe enough.

Finally, the topic held some personal significance for me and this has been both challenging and enlightening to reflect more deeply upon. I have felt so very privileged to have heard stories from participants who seemed so open and generous with sharing their own experiences, despite the shameful, stigmatising discourses which I believe still surround the use of these sites and were often alluded to by the women themselves. That it has undoubtedly enabled me to take more risks in sharing parts of my own story here and helped connect me to a somewhat courageous version of myself; recognising that struggles reflect just one aspect of who we are. After all, a single story need not be the only story.

#### **4.6 Closing Remarks: An Evaluation**

As noted in the methods chapter, I have sought to present a high quality qualitative research project which has rigour and credibility. I have used the guidelines from Elliott, Fischer, and Rennie (1999) to evaluate what has been achieved as I have done with other studies included in the systematic review (see Appendix E).

I have sought to 'own my perspective', by stating how I became interested in the Pro-Ana movement. I specified my theoretical orientation, weaved multiple reflective sections throughout the chapters and appendices, which include internal points of tension and discussions of how certain beliefs or values, will undoubtedly have impacted on the piece of work created.

I have endeavoured to situate the sample by providing basic demographic data, as well collecting more detailed data from the interviewee's concerning their reported eating difficulties and Pro-Ana site use. I have also provided a recruitment flow offering further insights into how the sample was formed.

I have attempted to 'ground my interpretations within the data', by embedding quotes throughout the analysis, including the provision of line numbers for larger extracts, so readers can clearly see where in the account data was drawn. This is considered important in NI to illustrate the narrative unfolding over time, as well as highlighting the chronology of events which may support certain interpretations, such as the existence of chaos type narrative whose form is often non-linear.

The analysis has undergone several 'credibility checks'. A member of my supervisory team, with expertise in using NI, read through my first two analysed transcripts offering feedback and further points of reflection to extend the work. Multiple discussions were had with different supervisory members regarding the emerging themes, which ones should be chosen and how best to present them. Document drafts were submitted and amendments made following feedback from those with expertise in narrative inquiry and eating 'disorder' research.

Finally, it was my intention to present to you my understanding of the narratives, in a way that achieved an overarching story of 'coherence', whilst also preserving the nuances of the

data. In this way, I hope to have provided you with a data-interpretation road map, which resonates with you the reader and offers new 'knowledges'.

## Chapter 5: References

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## Appendices

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### Appendix List

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**Appendix A: Reflections on Eating 'Disorder' Diagnoses: 'A Note to my Reader'**

I have now read many articles in the field of eating 'disorders', visited a whole host of Pro-Ana and Pro-Recovery forums, as well as reflected extensively on conversations I have had about 'ED diagnoses' on training, with my supervisory team and with those who have experienced eating difficulties. Nevertheless, I still find it very difficult to hold a clear position around the 'disorder' vs. life-style debate. This tension was perhaps reflected by a less than clear introduction concerning my position on the debate. This was deliberate! I wanted you, the reader, to join me in asking yourself whether all eating difficulties need a label or, whether all eating difficulties truly reflect a choice. For me it's messy, complex and confusing but so it should be; as being wedded to either position seemed to invite a whole host of problems. As a result, I have included both sides of the argument because I see both as holding value.

I believe like everything in life, that eating difficulties exist along a continuum, rather than the being to discrete categories of 'well' vs. 'unwell' or 'normal' vs. 'disordered'. I do think that the construction of 'disordered' exists (at the far end of this spectrum). I have seen that for some, diagnoses are needed. They can be helpful in validating that a struggle is real and enabling vital access to services. Quantifying someone's experience in this way, can therefore be useful, in fact it can be more than this, it can be life changing. I also recognise that if one views eating 'disorders' as anything but a serious mental health problem, then the continued funding of care by the National Health Service or private insurers may become in serious jeopardy. This could have serious ramifications on survival rates and leave people unable to access much needed and wanted treatment.

Whilst the severity of eating 'disorders' is very much acknowledged, I also believe that western society and the general population are perhaps too quick to apply labels, an often-

powerless label that for some fail to capture the complexities of an experience. Instead it pathologises it. As labels do not always enable access to care provisions, in fact the vast majority of those are not perceived to be 'sick' enough to warrant care. For this group of people, I am left wondering, why do we as society do it....why do we apply these labels so readily? To be naturally thin and mindful of what you eat in restaurants, leads to the automatic assumption that you must be 'anorexic'. To disclose eating a reasonably large amount of food in a very short window and spending a few hours at the gym burning seems to automatically make you 'bulimic'. And with these labels a high degree of 'othering' seems to follow. The old *'I am normal, they are 'disordered', 'I am well, they are unwell'*.

I have felt that in reading about EDs and the Pro-Ana literature that there is a lot of 'othering' in relation to this 'well/normal' and 'unwell/'disordered' idea too. Although I have tried to avoid it, I have found myself joining it at times. Given the extreme nature of what is written on some of the sites, at times, it was difficult not too. I have sort of oscillated between idea a) do not pathologise everything, not everyone and every action needs a label (is there no room for an a-typical experience?) and b) but my gosh, this idea seems so worrying, perhaps we need a label here, in order to get much needed help?

I wonder if on reflection, the difficulty comes perhaps in knowing where this boundary sits and who applies it. Who am I or anyone else, to say what is disordered and what is a difficulty or in fact a choice? That's the struggle I have perhaps been grappling with. So, it may be relevant for you, the reader to know that I have been guided by participants. All of which identified themselves with a label. They spoke about their eating difficulties often in relation to 'my anorexia' or 'as an anorexic', and as I have sort to provide a document which is reflective of their story and be true to my own ideas, I have attempted to show you my struggles and perhaps explain why certain terms have been used, which may be at odds with my belief and the desire to provide perhaps a slightly different 'greyer' discourse.

**Appendix B: Reflections of My Journey to Narrative Inquiry**

*'Research is rarely a linear process' Dr Helen Ellis-Caird 2016*

When I began this research project, although I was interested in how regular users of Pro-Ana websites were able to withdraw from these Pro-Ana sites. I thought about the question in quite a concrete way. I felt sure that there would be certain undiscovered factors which if in place, could make disengagement from the Pro-Ana community possible. I hoped to uncover what these factors were, by interviewing previous site users and to use grounded theory to develop a new explanatory model of disengagement. I had already assumed that disengagement from the Pro-Ana world would mean engagement in the recovery world. Consequently, I thought that the study would not only provide information about how Pro-Ana disengagement was possible but also shed light into the complex process of recovering from an eating 'disorder' in today's world. This information could be beneficial for clinicians, sufferers and the wider public. Looking back, (now March 6<sup>th</sup> 2017) those seem like very distant and perhaps somewhat naive memories.

I smile to myself now. I constructed a website as a recruitment tool, detailed the rationale for my project, posted about it on various social media sites and attempted to set up meetings with UK support groups. Yet I was struck by how difficult it was to recruit into the study. There was a wall of silence in so many directions! I remember posting about the study on Facebook eating 'disorder' support groups, before it was quickly being removed by an admin team member. One admin contacted me to say participants were not 'Guinea-pigs'. This was followed by an email from another group member who told me that the process was not as simple as disengaging from the sites in order to recover. It was not linear! There were no factors! It was complex and messy. This turned out to be a very important email. It invited me to reflect on how I had approached the research and encouraged me to think about human

experiences on a much deeper level; much more than I ever have before (and I pride myself on reflection). With this, I really started to question, my own 'knowledges', belief systems and understanding of the singular and concrete nature of 'truths'.

Indeed, the more I thought about the research and spoke with those who had received eating 'disorder' diagnosis, the more interested I became in people, their stories, identities, the spoken/unspoken storylines they used to position themselves in relation to medical discourses, I could go on.... With the help of Saskia, this led me to re think the project and I planted my head well and truly in narrative inquiry text books and journal articles. In the weeks that followed I put in an ethics application and the start of the most wonderful love affair with narrative inquiry methodology began. Shortly afterwards I recruited my first participant into the study.

## **Appendix C: Literature Search Strategy**

### **Stage 1: An Initial Exploration**

The search began, with a review of the relevant articles held at the University of Hertfordshire's Learning Resource Centre: preliminary database searches were also conducted through Google Scholar and Scopus, to survey the current Pro-Ana literature. The following search terms were used:

'Pro-Ana' OR 'Pro-Mia' OR 'Pro-ED'

AND

'Websites' OR 'Online' OR 'Internet'

### **Stage 2: Following-Up References**

From the relevant references identified: key authors were noted and key articles sorted. If access to a full text was not available through the University of Hertfordshire, an inter-library loan was requested, via the British Library.

### **Stage 3: A Detailed Systematic Literature Review**

Informed by searches conducted so far, a more detailed, systematic review of the literature was carried out over an 18month period, using the below search criteria:

#### **Inclusion criteria**

- Studies exploring individual accounts of how people came to learn about and repeatedly use Pro-ED sites?
- Research (qualitative/quantitative) examining the impact of Pro-ED websites use on individuals
- Studies exploring individual accounts of how people were able to, step away from these Pro-Ana forums.

- Research (qualitative/quantitative) examining the impact of withdrawing from Pro-Ana forums, after regularly using them.

#### Exclusion criteria

- Research assessing the content of Pro-Ana online forums
- Studies focusing solely on the impact of general media (TV/magazines) rather than Pro-Ana online forums
- Generic eating 'disorder' research, which does not focus on Pro-Ana online forums
- Research focusing on pro-recovery forums or general mental health websites
- Research with school aged children
- Non-English articles

To ensure that all relevant papers were retrieved, Boolean and Truncation options were used, in conjunction with the following search terms:

#### Search Terms:

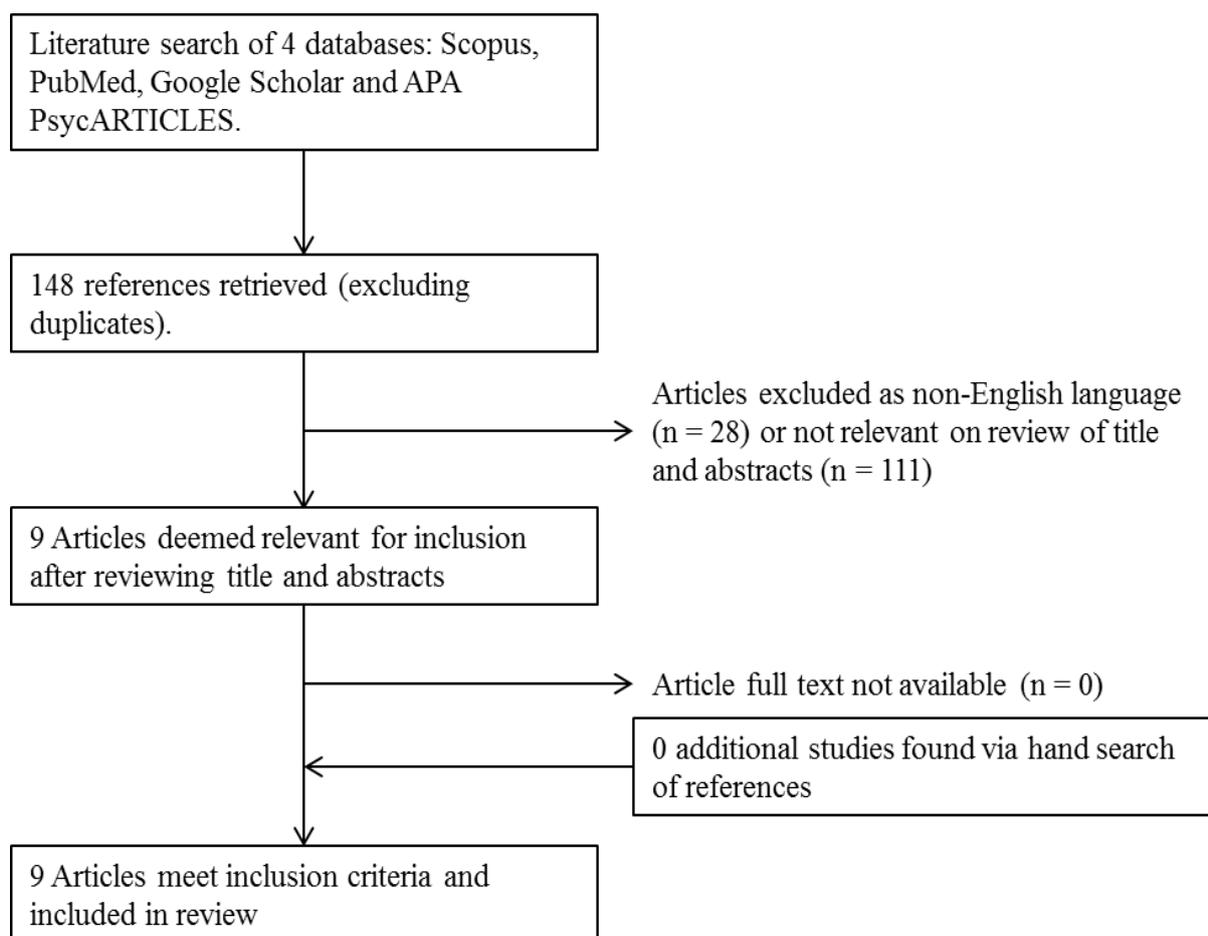
'Pro-Ana' ; 'Pro-Mia' ; 'Pro-ED' ; 'Pro-Anorexia' ; 'Pro-Bulimia' ; 'Pro Eating 'disorder''  
'Web' ; 'Virtual' ; 'Cyber-space' ; 'Online' ; 'Forum' ; 'Blog' ; 'Thinsp' ; 'Social Media' ;  
'Internet'

The reference lists of relevant articles were also searched by hand to generate further studies which may have been missed. New articles were identified up until March 2017, using the following search engines:

#### Search Engines

- Scopus
- PubMed
- PsycARTICLES
- Google Scholar

**Figure 3: Details the search process.**



General Web Searches

At various points, more generic sources of information were needed to inform specific parts of the study. This involved searching the world-wide web for:

- NICE Guidelines
- Department of Health guideline

**Appendix D: Table Summarising Studies Included in the Systematic Review**

Author	Csipke & Horne (2007)	Bardone-Cone & Cass (2007)
<b>Aims</b>	To better understand the function of Pro-Ana/Mia sites from those who use them. Specifically, do they provide emotional support, a way of gaining information or motivation for weight-loss from others?	To investigate the perceived affective, cognitive and behavioural consequences of exposure to a Pro-Ana website. Clear hypothesis that viewing a Pro-Ana website would have negative effects on affect and cognitions, compared to two control groups.
<b>Participants</b>	N= 151 ppts, 97% female, age range 13-49, mean age 22yrs. Place of residence: 60% UK, 25% USA, 3.5% Australia & Canada, 3% the Netherlands and 1 ppt from Germany, Mexico, Korea, Uruguay and Puerto Rico. 84% reported having an Eating Disorder, 29% Anorexia, 15% Bulimia, 15% Co-morbid & 17% EDNOS, 5% unspecified problems. 46% also reported self-harm, 37% anxiety & 24% depression.	235 female undergraduate volunteers from an introductory psychology course formed the sample. Mean age 18.37 years. 88% Caucasian, 5% African American, 1% Hispanic, 2% Asian, 3% Biracial
<b>Methods</b>	<u>Design:</u> Online survey & correlational design. <u>Recruitment:</u> Links to study posted on charity websites and Pro-ED websites. <u>Self-report</u> <u>Measures:</u> Eating Attitudes Test-26 (indexed possible eating difficulties) & Pro Anorexia Website Survey (indexed attitudes towards the sites & impact of use). A variety of question formats were used, including free text & rating scales. <u>Analysis:</u> Pearson's correlations, t-tests and chi2.	<u>Experimental Design:</u> 24 female undergraduates were randomly assigned to one of three conditions 1. The pro-Ana website (created by researchers) 2. Control condition (female image using average sized models) 3. Control condition home decor website. Deception used to mask intentions of study. Participants completed pre-post questionnaires, following a 25 minutes website viewing block. <u>Measures:</u> Positive and negative affect schedule (PANAS), State Self-esteem scale (SSES), Appearance-modified general self-efficacy Scale, Perceived weight status. <u>Analysis:</u> One way ANOVA and post hoc comparisons were conducted. Means, standard deviations and effect sizes reported.
<b>Findings</b>	Majority of users identified as having an eating disorder, with a mean score of 45 on EA T-26, supporting this. Half visited sites once per day. Motivation for logging or concerned sustaining or instigating disordered eating. Trend data was found for usage worsening body image and participants reported that the sites helped maintain disordered eating and discouraged recovery. Also, greater feelings of emotional support after use. A profile of two types of ppts emerged, passive ppts who silently browsed for tricks and tips, active ppts who were more likely to use chatrooms and gain emotional support.	Participants exposed to Pro-Ana websites had greater negative affect, lower social esteem & lower appearance self-efficacy scores than those in the control groups. They also significantly higher scores on measures relating to likelihood to exercise, thinking about weight, engagement in more image comparison and perceived themselves as heavier. There were no significant differences in BMI or cognitions between groups, prior to website exposure.
<b>Implications &amp; Practice Recommendations</b>	Sites may provide emotional support but also worsen body image and disordered eating, particularly for those passively surfing. Although attempts have been made to shut down the sites, site developers have stayed one step ahead and clinicians should seek to better understand the needs Pro-Ana sites fulfil. A key therapeutic challenge for recovery is to avoid feelings of loss of something valuable. The challenge is to strengthen other parts of an individual's identity so that they do not die along with their eating disorder.	Effects are after a single viewing- it is unclear whether repeated viewing produces same responses. Possible that repeated use exacerbates but may also desensitise. The authors claim a causal link between the use of Pro-Ana and increase of negative markers relating to body image. They suggest that Pro-Ana sites may contribute to the cognitive changes associated with anorexia or at least help maintain them. <u>Improvements and possible further research / future implications:</u> 1) Assessment of the effects of longer term exposure. 2) What parts of pro-ED websites give the most negative impact (e.g. tips and tricks section vs. chat rooms)

Author	Peebles et al., (2012)	Crowe and Watts (2013)
<b>Aims</b>	To investigate the demographics and self-reported eating behaviours of Pro-Ana members and the degree to which website usage correlated with problem severity and quality of life scores. Compared to members of Pro-Recovery sites.	The aims are not explicitly stated, though the intention of the research appears to be hearing the experiences of those using Pro-Ana sites.
<b>Participants</b>	Recruited adult users of websites with Pro-ED content. Inclusion: over 18 years old. 1291 participants (38.64% of initial survey hits). 97.13% female, 85.21% white, 89.16% unmarried, 58.71% student, 27.89% employed, 45.2% diagnosis of AN, 20.0% BN, mean age 22, 77.73% self-harm, 58.85% depression diagnosis. In the past, 23.73% reported being overweight and 34.17% reported being obese. 67.62% had never been in treatment and 87.09% were not currently being treated. 39.20% had never had a formal ED diagnosis. Mean age of dieting onset 13 years. Disease duration mean 7.6 years.	Online interviews took place with Pro-Ana participants across four websites, though no demographic information was provided, including the sample size and it is unclear how the recruitment process took place.
<b>Methods</b>	<u>Design:</u> Cross-sectional study. 550 sites met criteria, 296 sites contacted. Others excluded. Clear inclusion criteria: Declaration website was pro-ED, disclaimer or warning from website, use of term "thinspiration", information on 'disordered' eating (tips and techniques). Exclusion criteria: Only English language sites used, members had to be > 18. No deception, informed consent, ppts completed online survey containing 193 items. <u>Measures:</u> The Eating Disorder Examination Questionnaire (EDEQ) and Eating Disorder Quality of Life measure (EDQOL)	A mixed method approach was used. This involved analysing posts from message boards and also conducting interviews with Pro-Ana users. <u>Measures:</u> Semi-structured interviews (unclear the exact questioning employed).
<b>Findings</b>	Descriptive statistics provided: Pro-ED/Ana participants, n= 556. Mean age of first Pro-Ana visit = 18.9 years, mean time spent on Pro-Ana = 10.5 hours in the last 30 days. Pro-recovery participants n=735 age first visited 19.3 years, hours per week in last 30 days 2.3. Pro-Ana 29.01 felt extremely supported vs 6.6% Pro-recovery, 8.68 Pro-ED vs 35.5% Pro-recovery not at all supported.	An association between the level of pro-ED website usage and both disordered eating and quality of life was found. Authors claim that Pro-ED website usage remains an important predictor of EDE-Q scores, when other commonly reported predictors are considered. Heavy Pro-Ed users differed significantly from light users with particular concern for those that spend > 16 hours per week on these websites. More website usage was strongly associated with higher levels of disordered eating on EDE-Q and more severe impairment on the EDQOL.
<b>Implications &amp; Practice Recommendations</b>	The reported average age of visiting pro-ED websites was higher than the reported onset age of other disordered eating behaviours and years after participants felt their eating disorder had begun. The authors claimed that this suggested website visitation was not a predictor of developing an eating disorder but may predict more risky behaviours in those participants with eating disorders later on.	Just 1/3 of participants had received formal care for disordered eating. This may suggest poor screening and diagnosis of eating disorders and that pro-ED website users are seeking support online. <u>Improvements and possible further research / implications:</u> 1. The need to consider the internet more often for intervention and study due to its ease of access. 2. There is a greater need to listen to online health seekers to determine whether there are self-help sites or educational modules that these people would find useful.

Author	Jett et al., (2010)	Rogers et al., (2011)	Gale et al.,(2016)
<b>Aims</b>	To investigate whether exposure to pro ED websites influences eating behaviours in a sample of college women.	To assess disordered eating among the members of a French language online Pro-Ana community and explore self-reported reasons for becoming a member, perceptions of support provided, nature of information given and perceived influence on viewers.	To explore the underlying functions and processes relating to first accessing and then continuing to use Pro-Ana sites, with a clinical population
<b>Participants</b>	Female students with BMI>18 and no history of an eating disorder formed the sample.	Recruited from forums on 8 different websites. 29 participants, all female, mean age 17.4 years (12-23), all French residents. 6= students, 18 = school, 4= employed, 2 = unemployed. Data collected late 2007 - early 2008	7 female participants were recruited through NHS services. Six were white British, one was from central Europe. All reported experiencing eating difficulties for between 6 and 24 years. All had received a diagnosis of anorexia and also bulimia at various points in their lives.
<b>Methods</b>	Using an randomised control trial (RCT) design, participants were exposed to either Pro-ED websites, health/exercise websites or tourist information websites for 1.5hrs. Following this, participants completed quantitative and qualitative measures to assess eating behaviour including calorie intake, food diary and strategies for food intake reduction.	Investigator posted a message on forums explaining study with contact email. Informed consent or assent from all participants. Participants responded by email to a number of open ended questions. <u>Measures:</u> Eating Attitudes Test (EAT) - 40 (French translation). Also responded to questions regarding motives for joining pro-Ana website, satisfaction, their definition of pro-Ana movement, advice they had received and which parts they had chosen to follow.	A semi structured interview was used to explore participant experiences. Grounded theory was then used to construct a model of the data.
<b>Findings</b>	Participants who were randomised to the pro-ED websites were found to have a significant reduction in caloric intake and an increased use of food reduction techniques, 1 week later, compared to those in the control conditions. This reduction continued in a third of these individuals 1 week later.	Only descriptive statistics provided. Participants scored highly for disordered eating. Main motives for joining these sites were 1. Wish for rapid weight loss or support to maintain motivation for weight loss 2. Social support and a sense of belonging. Perceived benefits included; 1. Emotional benefits of being listened to, sense of sameness, belonging and finding inner peace. Overall sense of satisfaction with membership. Large majority identified anorexia as an illness - 3 described anorexia as a lifestyle choice.	Five key themes were identified within the interviews. 1) Fear, many reported a great deal of anxiety in relation to recovery and expected weight gain. 2) Most reported an ambivalence to recovery and though many cited the risks of using certain tips and tricks, the risks to themselves were often minimised. 3) Most reported feeling a sense of achievement in relation to weight loss, often comparing themselves to others. 4) Shame and stigma was present in many interviews. 5) Continual use was seen to maintain disordered eating and implicated in social isolation.
<b>Implications &amp; Practice Recommendations</b>	Authors claim a causal link between exposure to Pro-ED websites and a reduction in calorie intake and food reduction behaviours in healthy participants, even after very short periods of exposure. They suggest that the sites may contribute to the development of eating disorders.	The age range in the study emphasises concerns around adolescent's internet use. Highlights the importance of online support group. Supports the notion that Pro-Ana websites encourage weightloss and weight control practices. Improvements and possible further research / implications: 1. Exploration of motivations to join pro Ana sites and leave pro-Ana sites and how this relates to recovery.	The implications for clinical practice are richly explored, these include clinicians continuing to hold an empathetic stance, consider the readiness for change, ways to develop trust and safety in the therapy room so use can be discussed. There are also recommendations for similar studies to be conducted international and with a more heterogeneous sample.

Author	Fox et al., (2005)	Ransom et al., (2010)
<b>Aims</b>	To analyse the Pro-Ana movement in order to develop an anti-recovery explanatory model for anorexia, and contrast it with medical, psychosocial, sociocultural and feminist models.	To investigate both the positive and negative behaviours advocated on pro-ED forums and users' perceptions this. In addition, to investigate the perceptions of support received off line.
<b>Participants</b>	20 participants were recruited for in-depth interviews from one website. No further information is provided on the sample.	Data was collected from 60 forum members, taken from 15 forums (each containing over 50 members). All participants female aged 14-30 years old. Participants from the United States (51%), United Kingdom (22%), Canada (7%), Australia (3%), and Asia (2%).
<b>Methods</b>	A mixed methods approach was used. Some participants choose to reply to questions left by the researcher on message boards, others choose to respond directly to the researcher which led to in-depth online interviews. All information was then triangulated. <u>Measures:</u> Questions asked appeared to fall into 5 broad categories, 1) Definitions (what is happening to me). 2) Aetiology (what is the cause of my difficulties). 3) Incident patterns (why has it affected me now?). 5) Prognosis (what course will it take). 6) Treatment and management (what treatment do I want? what do I fear).	15 websites which took a Pro-ED rather than Pro-recovery stance were recruited into the study. Member data was compared to age matched controls who used non-eating focused forums. <u>Measures:</u> included body mass index, eating attitudes test, presence of clinical diagnosis, treatment history, disordered-eating behaviours, Forum usage and social support.
<b>Findings</b>	The state of anorexia was depicted as aspirational, a complex interplay of factors was seen to have led to difficulties, many users positioned the sites as offering a sanctuary and claimed it offered non-judgemental support that was useful and novel. Most positioned their difficulties as a symptom of a more deeply rooted problem and drew on feminist and cultural discourses to explain it.	Forum users perceived less support than control subjects. Pro-ED websites were found to encourage 'disordered' eating behaviours.
<b>Implications &amp; Practice Recommendations</b>	These are poorly described and few research practice links made. The focus is instead how participants position themselves to privilege and resist certain societal discourses. <u>Improvements and possible further research / implications:</u> 1) More information on participant demographics would assist integration with other pieces of research in the field.	These are explored: specific focus on how learning points and challenges that exist in the offline world can be applied to families. <u>Improvements and possible further research / implications:</u> 1) Increase number of participants to improve validity of conclusions.

**Appendix E: Table Evaluating Quality of Studies Included in the Systematic Review**

Author	Cspike & Horne, (2007)	Bardone-Cone & Cass, (2007)
<p><b>1. Explicit Scientific Context &amp; Purpose -</b> <i>Relationship of study to literature - Clearly stated aims and research question</i></p>	<p>Good: Clear introduction &amp; literature gap identified. Aim of the study written up, along with 4 clear hypotheses.</p>	<p>Introduction takes into account current literature and current knowledge. Aims of study and hypotheses recorded.</p>
<p><b>2. Appropriate Methods -</b> <i>Does the design &amp; recruitment strategy appropriately address the aims?</i></p>	<p>Partly: Whilst the study did have some free text elements, a qualitative methodology would almost certainly have allowed for a more detailed, richer, understanding of user experiences, which was the studies initial aim.</p>	<p>Partly: previous research was cited to suggest that viewing community of pro-anorexia websites to be females 13-25. However the recruited sample were aged 18-23. This maybe too narrow and cuts out age at which onset possibly occurs i.e. 13/14 years.</p>
<p><b>3. Respect for Participants -</b> <i>Have ethical issues been considered e.g. informed consent?</i></p>	<p>Partly: 1) As recruitment adverts were posted on general mental health websites, vulnerable, naive ppts could have been altered to the existence of pro-ed sites, 2) Some ppts were under age 16 and therefore both child assent and parental consent should have been sort but it is unclear if both were obtained.</p>	<p>Partly: Study used deception however extensive psychoeducation debriefing given to participants. No indication of follow up of participants to check adverse effects. No indication of whether informed consent was obtained and whether this indicated as some information concealed. Ethics approval obtained.</p>
<p><b>4. Specification of Method -</b> <i>Is there transparency in how the data has been collected?</i></p>	<p>Yes but some concerns: There is a detailed methodology with designated recruitment, procedures and measures laid out. However, it is unclear how the PASW questionnaire was developed and the study may have benefited from further transparency in relation to this.</p>	<p>Yes with some concerns: Clear referencing of how artificial website was created and why an existing site was not used. Adequate explanation of measures used and their validity. No description of how participants were randomised or if this randomisation was concealed from the authors.</p>
<p><b>5. Appropriate Discussion -</b> <i>Have the authors understanding of the findings and their implications been explored -Has the evidence for and against arguments been explicitly stated?</i></p>	<p>Yes: Some theory practice links were made, however this only featured in the conclusion as a token gesture and much more could have been made of the ideas. Also, a high proportion of participants had co-morbid difficulties e.g. anxiety, NSSI etc, which may have acted as confounding variables, these were identified but the influence on outcomes not included in the analyses or explicitly discussed. Also some facets e.g. self-esteem, were only measured with a single item on the PASW tool, reducing the findings reliability in relation to this.</p>	<p>Yes: Good links to interpret results in practical terms. Good review of study limitations including ecological validity and long term effects including whether they translated into actual harm.</p>
<p><b>6. Clarity of Presentation / Writing</b></p>	<p>Coherent flow, with tables and appendix of self-revised measure.</p>	<p>Coherent flow, with appendix of content on website.</p>
<p><b>7. Contribution to Knowledge -</b> <i>clear statement of findings - credibility of findings - findings related to Research Question - How valuable is this knowledge</i></p>	<p>Good: The first and to date only study looking at differences among pro-ana users. Clear links are made back to the aims and hypotheses in the discussion and several limitations of the study have been identified and how this effects the conclusions that can be drawn. Some avenues of future research also stated.</p>	<p>First large study to use an experimental design and claim causality. Validates this as an important area of study.</p>

Author	Peebles et al., (2012)	Crowe and Watts, (2013)
<p><b>1. Explicit Scientific Context &amp; Purpose</b> - <i>Relationship of study to literature - Clearly stated aims and research question</i></p>	<p>Yes: Clear explanation of aims and research questions. Established niche for purpose of research.</p>	<p>Current thinking and research explained in introduction. No clear aims expressed.</p>
<p><b>2. Appropriate Methods</b> - <i>Does the design &amp; recruitment strategy appropriately address the aims?</i></p>	<p>Partly: Good quality cross-sectional study however in order to confirm causality a randomised control study design would have been needed. Clear descriptive statistics and explanation of findings in tables. Risk of reporting bias and selection bias which is unavoidable in this type of study. Given that the sample size was so large (almost 1300 participants) a power analysis would have been useful to ensure the study was not overpowered, increasing the likelihood of making a type 2 error.</p>	<p>No clearly defined search or inclusion criteria is evident.</p>
<p><b>3. Respect for Participants</b> - <i>Have ethical issues been considered e.g. informed consent?</i></p>	<p>Yes: Ethical approval confirmed. An age limit of &gt;18 years, employed. Transparency with participants.</p>	<p>Unclear: Ethical approval not stated. Largely observational design, examining message boards. However, the researchers does interview some Pro-Ana users and it is unclear if informed consent, through debriefing has occurred.</p>
<p><b>4. Specification of Method</b> - <i>Is there transparency in how the data has been collected?</i></p>	<p>Yes: Good transparency including documented search criteria and participant demographics. Clear explanation of how participants were recruited including incentives (none used).</p>	<p>Major concerns: Poor explanation as to how websites were chosen and how participants and their quotations were selected. Open to reporter, selection and recall bias. This may be a result of the aims being poorly stated.</p>
<p><b>5. Appropriate Discussion</b> - <i>Have the authors understanding of the findings and their implications been explored -Has the evidence for and against arguments been explicitly stated?</i></p>	<p>Good discussion highlighting areas of further research. Good review of limitations including lack of confirmed causality and increased risk of recall bias and selection bias.</p>	<p>In depth exploration of data with links to challenge psychological/ medical theories.</p>
<p><b>6. Clarity of Presentation / Writing</b></p>	<p>Good flow with clear methods and aims.</p>	<p>The paper lacked an over-arching structure and the findings were presented somewhat ambiguously, without a dedicated section.</p>
<p><b>7. Contribution to Knowledge</b> - <i>clear statement of findings - credibility of findings - findings related to Research Question - How valuable is this knowledge</i></p>	<p>First large study of its type to investigate the dose response relationship between time spent on Pro-Ana sites and the severity of self-reported disordered eating behaviours. Notably, only associations rather than causality can be claimed.</p>	<p>Given the poor layout and some methodological issues as detailed above, the study has limited credibility.</p>

Author	Jett et al., (2010)	Rodgers et al., (2011)	Gale et al., (2016)
<b>1. Explicit Scientific Context &amp; Purpose -</b> <i>Relationship of study to literature - Clearly stated aims and research question</i>	Place in context of existing research clearly stated and included clear aims and outcome measures.	Clearly stated aims and methods to fulfil research question.	The aims and research question are clearly stated, along with a rationale for conducting the study, given the gap in existing literature.
<b>2. Appropriate Methods -</b> <i>Does the design &amp; recruitment strategy appropriately address the aims?</i>	Good: Randomised controlled design so causality can be established with concealment and blinding to reduce confounding and bias. No explanation of randomisation process found as only methodological weakness. Good methodical design as ensured appropriate validated measures of clinically important outcomes (calorie intake) and appropriate multipoint follow-up.	Good: Methods appropriate including both validated questionnaire to assess eating concerns and open ended questionnaire to further explore motivations.	Partly: Appropriate use of qualitative methods to explore research question with a clearly documented recruitment strategy. However the sample size is very small for a grounded theory study. Which is a likely consequence of studying a hard to reach population.
<b>3. Respect for Participants -</b> <i>Have ethical issues been considered e.g. informed consent?</i>	Yes: Ethical approval granted. Post intervention care and follow-up provided. However due to interventional nature of study there is a chance of continued harm to participants after the study has ended.	Yes: Ethical issues considered. No intervention to cause harm. No deception used to recruit participants or collect data.	Yes: Participants were only recruited once they were at a certain point in their recovery, presumably to reduce the likelihood of triggering any relapses. Both University and NHS ethical approval was sought and gained. Informed consent, withdrawal and debrief were all written about.
<b>4. Specification of Method -</b> <i>Is there transparency in how the data has been collected?</i>	Yes: Clear recruitment and concealment of randomisation from investigators. Participants blinded to nature of study. Clearly documented source of participants.	Yes: Clear recruitment via specific websites. Unclear selection criteria of which sites to recruit from.	Yes: There is transparency regarding how the data has been collected and enough information provided to ensure that the study could be easily replicated.
<b>5. Appropriate Discussion -</b> <i>Have the authors understanding of the findings and their implications been explored -Has the evidence for and against arguments been explicitly stated?</i>	Yes clear exploration of findings and their use in the context of the existing research.	Yes clear implications of the data described and weaknesses of findings explored.	The discussion is cohesive and thoughtful. Theory practice links and explored as well as the limitations of the study and recommendations of future work.
<b>6. Clarity of Presentation / Writing</b>	Very clear design including aims and analysis	Clear presentation of methodology and findings	The paper is clearly written and guides the reader through the research journey.
<b>7. Contribution to Knowledge -</b> <i>clear statement of findings - credibility of findings - findings related to Research Question - How valuable is this knowledge</i>	Good contribution to knowledge as giving a clear causal link and a demonstrable clinical effect.	Good contribution to existing knowledge base with useful rich data in the form of more quantitative data.	The findings are clearly stated, along with links back to the projects aims and how the study fills the preexisting literature gap. Given the detailed description of how the findings could be used to effect clinical practice. The knowledge gained does appear valuable.

Author	Fox et al., (2005)	Ransom et al., (2010)
<p><b>1. Explicit Scientific Context &amp; Purpose</b> - <i>Relationship of study to literature - Clearly stated aims and research question</i></p>	<p>Yes: the purpose of analysing the Pro-Ana movement is to generate an explanatory model of anti-recovery anorexia.</p>	<p>Aims well stated and clear research methods outlined.</p>
<p><b>2. Appropriate Methods</b> - <i>Does the design &amp; recruitment strategy appropriately address the aims?</i></p>	<p>Partly: Useful qualitative design when considering the research aim, allows rich collection of data. However, there is no explanation on participant demographics or even if they had an anorexia diagnosis. This limits the usefulness of any findings reported.</p>	<p>Partly: Use of multiple ED forums to try and enable spread of participants. Limitations include a small success of recruiting participants. In addition selection bias as self selected participants. Possible bias in control samples despite good age, gender and cultural matching as taken from an undergraduate student pool suggesting possible educational and socio-economic differences could be included and therefore not adequately controlled for.</p>
<p><b>3. Respect for Participants</b> - <i>Have ethical issues been considered e.g. informed consent?</i></p>	<p>Yes: Good review of ethical considerations including open data gathering by non-concealed researcher.</p>	<p>Yes: Investigators open and honest with website moderators and with participants. No intervention so limited harm for participants.</p>
<p><b>4. Specification of Method</b> - <i>Is there transparency in how the data has been collected?</i></p>	<p>Some concerns: Difficult to see the inclusion and exclusion criteria for forming results and obtaining the research participants.</p>	<p>Yes with some concerns: Data is presented transparently with good demonstration of case vs control demographics. However issues stated above in terms of selection bias based on controls were all undergraduates.</p>
<p><b>5. Appropriate Discussion</b> - <i>Have the authors understanding of the findings and their implications been explored -Has the evidence for and against arguments been explicitly stated?</i></p>	<p>Detailed discussion of findings and related to current psychological theory.</p>	<p>Appropriate discussion including relation to current research. Good analysis of limitations of study also provided</p>
<p><b>6. Clarity of Presentation / Writing</b></p>	<p>Somewhat ambiguous presentation of the methodology and findings, though an excellent literature review was outlined.</p>	<p>Clear design of study with good flow.</p>
<p><b>7. Contribution to Knowledge</b> - <i>clear statement of findings - credibility of findings - findings related to Research Question - How valuable is this knowledge</i></p>	<p>Some contribution to knowledge pool due to richness of data collected and novel nature of the study. Though applications of results beyond this group are difficult due to the small, unknown sample.</p>	<p>Decent contribution to knowledge base as focusing on both protective and harmful aspects of pro-ED forums.</p>

**Appendix F: University of Hertfordshire Ethics Approvals**



**UNIVERSITY OF HERTFORDSHIRE**  
**HEALTH AND HUMAN SCIENCES**  
**ETHICS APPROVAL NOTIFICATION**

**TO** Ashlyn Firkins  
**CC** Dr Keith Sullivan & Dr Saskia Keville  
**FROM** Dr Richard Southern, Health and Human Sciences ECDA Chairman  
**DATE** 2/8/16

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Protocol number: **LMS/PGR/UH/02454**

Title of study: Investigating the thought processes and values of those who use eating forums compared to those who do not, and also making sense of how disengagement from pro-eating disorder websites can be possible

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 2/8/16

To: 1/9/17

**Please note:**

**If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete.**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.



**HEALTH AND HUMAN SCIENCES ECDA  
ETHICS APPROVAL NOTIFICATION**

**TO** Ashley Firkins  
**CC** Dr Keith Sullivan & Dr Saskia Keville  
**FROM** Dr Richard Southern, Health and Human Sciences ECDA Acting Chairman  
**DATE** 03/11/2016

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Protocol number: aLMS/PGR/UH/02454(2)

Title of study: Investigating the thought processes and values of those who use eating forums compared to those who do not, and also making sense of how disengagement from pro-eating disorder websites can be possible.

Your application to modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification: The extension of recruitment avenues to include participants based in the USA

This approval is valid:

From: 03/11/2016

To: 01/09/2017

**Please note:**

**Any conditions relating to the original protocol approval remain and must be complied with.**

**Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.**

**Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.**

**Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.**

**Students must include this Approval Notification with their submission.**

**Appendix G: Participant Information Sheet**

UNIVERSITY OF HERTFORDSHIRE

FORM EC6

**PARTICIPANT INFORMATION SHEET (INTERVIEW)**

**Investigating the thought processes and values of individuals with Eating Difficulties, who access different types of eating related websites. And understanding how disengagement from websites thought to maintain eating difficulties, is possible.**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us for clarification of anything that is not clear or for any further information that you feel that you would like, to help make a decision.

Please do take your time to decide whether or not you wish to take part

**What is the purpose of this study?**

The study aims to explore how individual's with eating related difficulties came to use and subsequently withdraw from pro eating 'disorder' websites (Pro-ED, Pro-Ana & Pro-Mia sites).

Many studies have found that using Pro-ED websites can adversely affect individuals, reducing self-esteem, calorie intake and body satisfaction. And that individuals who recovered from eating 'disorders'/difficulties, had stopped using these websites.

Despite there being some evidence that website disengagement might be key to recovery, few studies have actually spoken to those who have used the sites to explore and understand how they came to use the Pro-ED websites and identify the key factors or turning points which they believe made withdrawal possible.

It is hoped that if mental health professionals can better understand what factors enable withdrawal from the websites, we might be better able to support individuals in recovery when accessing health services.

### **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

### **Are there any age or other restrictions that may prevent me from participating?**

You must be aged 18 or over.

You must have experienced eating related difficulties and in the past used Pro-ED websites regularly, and either be using them less now or stopped using them all together.

### **How long will my part in the study take?**

You will be asked to participate in a one off interview, lasting around 1hr.

Interviews will be conducted up until March 2017.

### **What will happen to me if I take part?**

If you would like to take part in the study, you will need to contact myself, (the researcher, Ashlyn Firkins). I will then contact you to provide more information about the study, answer any questions that you might have and hopefully schedule an interview date and time.

Interviews can be flexibly conducted across a variety of locations. During the interview, I will ask you about your experience of using and trying to disengage with Pro-ED websites.

I may also ask you to complete a small questionnaire about your experiences, prior to the interview. The interview will be a one off and no further participation will be required.

### **What are the possible disadvantages, risks or side effects of taking part?**

During the interview, I will ask you to think about the impact that using and disengaging from Pro-ED websites, has had on you. The personal nature of these questions and sharing of such information could be distressing. Every effort will be made to minimize any distress caused by being sensitive, taking breaks or if necessary, discontinuing the interview.

At the end of the interview you will have the opportunity to ask me any questions or raise any concerns about the research interview. I will also provide a debrief information sheet about who to contact for further support if desired.

### **What are the possible benefits of taking part?**

Although you may find talking about your experiences helpful, taking part in the research may not directly help you. However, the aim of the study is to help us better understand the impact Pro-ED websites can have on individuals, and how others can be supported in the future to disengage with them, which is thought to positively impact recovery. Therefore, the study may expand practitioners understanding of these websites, the disengagement and recovery process, which could potentially develop future interventions and help other people with eating related difficulties.

**How will my taking part in this study be kept confidential?**

Where possible all identifiable information such as names and addresses will be removed from electronic or hard copy documents. Your identity on records will be indicated by an ID number rather than your name.

Where this is not possible, such as keeping consent forms, the documents will be kept securely. This data will be retained until October 2017, when the project is due to end and then all personal documentation destroyed.

Recordings will be kept on a secure computer and deleted immediately when no longer needed. No personal identifiable information will be held on the recordings.

**Audio-visual material**

An audio recording device will be used to record all interviews. These recordings will not contain any identifiable information but a unique ID code. The files will be transferred onto my personal computer, within 48hrs of the audio being created and password protected. The file will then be deleted from the recording device but stored on the computer for the duration of the study (until October, 2017). It will then be destroyed.

**What will happen to the data collected within this study?**

*The data will be collected using both electronic and hard copy forms:*

- 12.1 The data collected will be stored electronically, in a password-protected environment, until October 2017, after which time it will be destroyed under secure conditions;
- 12.2 The data collected will be stored in hard copy by myself, Ashlyn Firkins, a trainee clinical psychologist, in a locked cabinet until October 2017, after which time it will be destroyed under secure conditions;

**Will the data be required for use in further studies?**

- 13.1 The data will not be used in any further studies.

**Who has reviewed this study?**

This study has been reviewed by: The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority. The protocol number is **LMS/PGR/UH/02454**.

**Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing or by email:

Ashlyn Firkins (Trainee Clinical Psychologist

Email: [a.firkins@herts.ac.uk](mailto:a.firkins@herts.ac.uk)

Academic Supervisors:

Dr Saskia Keville

Email: [s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)

Dr Keith Sullivan

Email: [k.sullivan3@herts.ac.uk](mailto:k.sullivan3@herts.ac.uk)

Address: Ashlyn Firkins/Dr Saskia Keville/Dr Keith Sullivan, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, AL10 9AB.

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar.**

**Thank you very much for reading this information and giving consideration to taking part in this study.**

**Appendix H: Example Advertisement Social Media Post**

Hi there,

\*\*\*Research Opportunity, can you help\*\*\*

I'm a clinical psychologist in training and doing some post-doctoral research for the University of Hertfordshire, into the area of eating 'disorders'/difficulties.

Specifically, I'm interested in understanding the stories of how individuals who previously used websites that see anorexia or bulimia as a life style choice, rather than a MH problem, stopped using the sites or reduced their use and what impact this has had on their life.

I'd like to write up a small number of these stories into a doctoral thesis and hopefully submit an academic paper to be published at the end of the year, hopefully to enable health professionals to have a better understanding of difficulties individuals face and how to improve support.

The interviews take around 1hr and can be done over Skype at flexible times.

I have conducted 5 interviews so far and have 1 spot left.

If you are interested in taking part, please email me at [uheatingresearch@gmail.com](mailto:uheatingresearch@gmail.com)

Or for more information please see the study website: [www.uheatingresearch.org.uk](http://www.uheatingresearch.org.uk)

Best wishes

Ashlyn Firkins

**Appendix I: Participant Consent Form**

UNIVERSITY OF HERTFORDSHIRE

FORM EC3

**PARTICIPANT CONSENT FORM (INTERVIEW)**

I, the undersigned [*please give your name here, in BLOCK CAPITALS & then your signature*]

.....

of [*please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address*]

.....

hereby freely agree to take part in the study entitled [*insert name of study here*]

**Investigating the thought processes and values of individuals with Eating Difficulties, who access different types of eating related websites. And understanding how disengagement from websites thought to maintain their difficulties, is possible** (UH Protocol number LMS/PGR/UH/02454)

- 1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), the names and contact details of key people and as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long.
- 2 I understand that my participation is voluntary and I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.
- 3 In giving my consent to participate in this study, I understand that participation will involve my interview being audio-taped, with use of anonymised verbatim quotation.
- 4 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: How it will be kept secure, who will have access to it, and how it will or may be used.
- 5 I understand that my participation in this study may reveal findings that could indicate that I might require medical advice. In that event, I will be advised to consult my local doctor. I also understand that if there is any indication of unlawful activity or non-medical circumstances that would, or has, put others at risk, the University may refer the matter to the appropriate authorities.

**Appendix J: Participant Debrief Sheet UK and USA**

UNIVERSITY OF HERTFORDSHIRE

**DEBRIEFING INFORMATION SHEET****Disengaging from Pro-Eating 'disorder' Websites: what makes this possible, through the eye  
of previous site users?**

Thank you for agreeing to participate in the study and generously giving up your time to be interviewed.

The study aimed to explore the experiences of those who had eating related difficulties and regularly used pro-eating 'disorder' websites but had been able to reduce their use or stop using the sites altogether. Specifically, it was interested in identifying the factors which made withdrawal possible.

Experiments have been done in this area looking at the effects of college students viewing Pro-ED websites, compared to self-help websites, on their mental health and psychological wellbeing. Research has also looked closely at the content of website forums and message boards. To date, the research suggests that Pro-ED websites can have a negative effect on how people feel about themselves and view their bodies. This in turn, seems to adversely impact their recovery. However, there is little research talking directly with people who have used Pro-ED websites. It is hoped that by better understanding the factors that enable disengagement, we will be better able to support individuals with eating related difficulties.

**Sources of help and comfort**

The personal nature of the interview means that you may have found talking about your experiences difficult. It is quite natural to feel low or upset immediately afterwards. However, if these feelings persist and you become troubled by them, there are a number of sources of support:

Your friends and family are likely to be immediate sources of support.

If you have given your consent, your GP will be aware that you have taken part in this study and you could make an appointment to talk to them about how you feel following your participation in the research.

There are also a number of national organisations that offer support. You may find some of these useful, for example:

**Beat** (tel. 0845 634 1414; <http://www.b-eat.co.uk/beat-cymru/>; [help@b-eat.co.uk](mailto:help@b-eat.co.uk)).  
Beat provides help lines, online support and a network of UK-wide self-help groups to help adults and young people in the UK beat their eating 'disorders'.

Beat's aims are:

To change the way everyone thinks and talks about eating 'disorders'

To improve the way services and treatment are provided

And to help anyone believe that their eating 'disorder' can be beaten

Beat do this by:

Challenging the stereotypes and stigma that people with eating 'disorders' face

Campaigning for better services and treatment

Providing information, support and encouragement to seek treatment and recovery

The Beat Adult Helpline is open to anyone over 18 who needs support and information relating to an eating 'disorder', including sufferers, carers and professionals.

The Helpline is open Monday - Friday 10.30am - 8.30pm and Saturdays 1pm - 4.30pm.

**The Samaritans** (tel. 08457 909090; [www.samaritans.org](http://www.samaritans.org)). The Samaritans is a national charity and the co-ordinating body for the 201 Samaritans branches across the UK. The Samaritans aims to help alleviate emotional distress and has a helpline which is open 24 hours a day for anyone in need.

You are also welcome to contact me again to discuss any aspect of your participation in this study, to ask questions or share any concerns you may have.

**Contact details:**

Name: Ashlyn Firkins

Email address: [a.firkins@herts.ac.uk](mailto:a.firkins@herts.ac.uk)

Address: Ashlyn Firkins, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, AL10 9AB.

If you have further concerns that you would like to raise about the research you can also contact my academic supervisors:

Dr Saskia Keville

Email: [s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)

Dr Keith Sullivan

Email: [k.sullivan3@herts.ac.uk](mailto:k.sullivan3@herts.ac.uk)

Address: Dr Saskia Keville/Dr Keith Sullivan, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, AL10 9AB.

**Thank you again for taking part in this research study.**

UNIVERSITY OF HERTFORDSHIRE

## DEBRIEFING INFORMATION SHEET

### (INTERVIEW) (USA Citizens)

Investigating the thought processes and values of individuals with Eating Difficulties, who access different types of eating related websites. And understanding how disengagement from websites thought to maintain their difficulties, is possible.

Thank you for agreeing to participate in the study and generously giving up your time to be interviewed.

The study aimed to explore the experiences of those who had eating related difficulties and regularly used pro-eating 'disorder' websites but had been able to reduce their use or stop using the sites altogether. Specifically, it was interested in identifying the factors which made withdrawal possible.

Experiments have been done in this area looking at the effects of college students viewing Pro-ED websites, compared to self-help websites, on their mental health and psychological wellbeing. Research has also looked closely at the content of website forums and message boards. To date, the research suggests that Pro-ED websites can have a negative effect on how people feel about themselves and view their bodies. This in turn, seems to adversely impact their recovery. However, there is little research talking directly with people who have used Pro-ED websites. It is hoped that by better understanding the factors that enable disengagement, we all will be better able to support individuals with eating related difficulties.

#### **Sources of help and comfort**

The personal nature of the interview means that you may have found talking about your experiences difficult. It is quite natural to feel low or upset immediately afterwards. However, if these feelings persist and you become troubled by them, there are a number of sources of support:

Your friends and family are likely to be immediate sources of support.

You could also make an appointment at your local health clinic, to see a doctor and discuss how you are feeling more generally and if you may benefit from additional support. Or, if you are attending higher education, you could contact your college health clinic for advice and/or counselling.

In addition to this, there are also a number of national organisations that offer support. You may find some of these useful, for example:

#### **NEDA (The National Centre for Eating 'disorders')**

<https://www.nationaleatingdisorders.org/> ;

NEDA is the leading non-profit organisation in the USA, providing support to individuals and families effected by eating 'disorders'. It provides specialist information and can direct you to local services and programs that exist in your area and you may be able to access.

The helpline (1-800-931-2237) is open 5 days a week (Monday-Thursday 9am-9pm and Friday 9am-5pm). It is available for anyone to call. Alternatively, you can chat online to a staff member using their instant messaging service or in an emergency text \*NEDA\* to 741741 and an advisor will get back to you.

### **Eating 'disorder' Hope**

Eating 'disorder' Hope is an organisation which provides practical resources on how to get help, find a specialist and articles on the eating 'disorder' treatment options.

It also includes a directory of all the profit and non-profit organizations working in the US and also internationally (<https://www.eating''Disorder''hope.com/recovery/external-resources>).

You can phone the helpline (1-888-274-7732), or, fill in the contact us form for more information and advice <https://www.eating''Disorder''hope.com/about/contact-us>

You are also welcome to contact me again to discuss any aspect of your participation in this study, to ask questions or share any concerns you may have.

### **Contact details:**

Name: Ashlyn Firkins

Email address: [a.firkins@herts.ac.uk](mailto:a.firkins@herts.ac.uk)

Address: Ashlyn Firkins, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, AL10 9AB.

If you have further concerns that you would like to raise about the research you can also contact my academic supervisors:

Dr Saskia Keville

Email: [s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)

Dr Keith Sullivan

Email: [k.sullivan3@herts.ac.uk](mailto:k.sullivan3@herts.ac.uk)

Address: Dr Saskia Keville/Dr Keith Sullivan, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, UK AL10 9AB.

**Thank you again for taking part in this research study.**

**Appendix K: Screen Shots of Recruitment Website**

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## Eating Attitudes Research

Recruitment for a doctoral project, conducted by the University of Hertfordshire

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[HOME](#)   [THE PROJECT](#)   [TAKING PART](#)   [ONLINE QUESTIONNAIRES](#)   [FAQ'S](#)   [CONTACT US](#)

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### Home page

Welcome to the Eating Attitudes Research Website.

My name is Ashlyn and I'm a trainee clinical psychologist at the University of Hertfordshire.

I am interested in understanding how people recover from an eating difficulties & eating disorders, like anorexia or bulimia. I am also interested in how social media affects our eating attitudes more widely. As a result, I have decided to do my doctoral project in this area. This website has been developed to provide you with more information about the project and how to participate in this research, should you wish too.

Please click on the 'Project' or 'Taking Part' tab for more information.

*Please note that if you are concerned about the impact of eating difficulties on your health it may be worth consulting with your local doctor or charity support groups in your area, such as BEAT for UK website visitors & the NEDA for USA visitors.*

## The Project

Over the last decade, there has been a sharp increase in the use of social media. A wealth of information now lies at our finger tips. Celebrity stories of yo-yo dieting, clean eating plans and fitness regimes to get the 'perfect body', are everywhere. The Western ideal that 'thinner is better' seems stronger than ever. There are now hundreds of websites which view eating disorders like anorexia and bulimia as a lifestyle choice, rather than a mental health difficulty. For every 10 of these websites, there is only 1 pro-recovery site and many individuals in treatment, are still regularly using these forums.

A small but growing number of studies have started to look at the impact of regular use on people's life and wellbeing. Some claiming that often, in order for people to recover and to achieve a healthy relationship with food and exercise, they need to stop using these sites.

Yet until now, few researchers have investigated this research area, by interviewing people with lived experience of using the sites. It is hoped that with a better understanding of how the disengagement process is possible, professionals would be better able to support people with eating difficulties, who want help. This research may contribute towards this.

### The project aims:

- to complete 1hr interviews with individuals who have regularly used these pro-eating disorder websites in the past, but have now reduced or stopped their use.
- to better understand people's experiences, including their ideas of what made it possible to reduce/stop using these websites.
- to publish this research and disseminate findings in order to help others.

If you are interested in taking part, please click the 'Taking part' tab.

**If you do not meet the inclusion criteria/are unable to participate in the interviews, you could help by filling in a questionnaire, please click on the appropriate 'online questionnaire' tab to learn more.**



Photo credit: Danielle Helm, published on Flickr

## Taking Part

To be eligible for an interview, the following must be true:

1. You are aged 18 or over
2. You have a history of eating difficulties
3. You previously logged on to pro-eating disorder websites regularly
4. You have now either reduced your use of these websites, or stopped logging on altogether
5. You are willing to take part in a 1 hour interview. I will ask about your experiences of using the sites, what enabled you to disengage and the effect this may have had on your life.
6. You are available Thursday-Sunday for an interview (times and locations are flexible and skype interviews are possible)

If you answered 'yes' to all the statements above, please click the 'Contact us' page to learn more and book an interview slot.

**If you do not meet the inclusion criteria/are unable to participate in the interviews, you could still help by filling in a questionnaire, please click on the 'online questionnaire' tab to learn more.**

## Online Questionnaires

As a supplement to the study, I am also interested in understanding more about the values and thought processes, of people who do and don't have eating difficulties and do or don't use pro-eating disorder and/or pro-recovery websites.

To investigate this, I am asking people to complete an online questionnaire.

To be eligible to take part, the following must be true:

1. You are aged 18 years or over
2. You are able to access the internet using a smart phone or computer, for around 20-30 minutes to complete the questionnaire

*Please note: If your aged 18-17 your parents must give consent for you to take part in the study.*

Click on the link below to read the information sheet and complete the consent form and questionnaire:

[UH Eating Research Online Questionnaire](#)

If you have any questions about this part of the study, please get in touch using the 'Contact us' page and a researcher will get back to you.

**Thank you for taking the time to learn more about this research.**

Photo credit: Danielle Helm, published on Flickr

## FAQ's

*Please note, these FAQs only concern the interview part of the project.*

*For queries about the online questionnaire, please get in touch using the 'Contact us' page.*

### **Who can participate?**

If you are aged 18 or over, have a history of eating difficulties and used to regularly log on to pro-eating disorder websites but have now either reduced your use of these websites or stopped using them altogether: you are eligible to take part.

You must also be willing to take part in an interview lasting around 1hr, where I will ask you about your experience of using them and what enabled you to disengage from them. As well as the impact disengagement may have had on your life. You must also be available Thursday-Sunday (Times and locations are very flexible and skype interviews are possible)

### **What will happen to me if I take part?**

If you would like to take part in the study, you will need to complete our 'form' on the contact us page. I will then send you an information sheet, answer any additional questions you might have and arrange a time for us to meet for the interview. This should take around 1hr to complete. You will not be required to do anything else.

### **What are the possible disadvantages, risks or side effects of taking part?**

During the interview, I will ask you about your experiences of using and disengaging from pro-ED websites. This may be upsetting for some people. Every effort will be made to reduce any discomfort by being sensitive, taking breaks or if necessary, stopping the interview. You can also withdraw at any time without giving a reason. At the end of the interview you will have the opportunity to ask me any questions or raise any concerns about the research interview. I will also provide contact details of charities who offer further support, if desired.

**I don't want to participate but I want help with my eating difficulty and I'm not sure where to turn?**

Please note that if you are concerned about the impact of eating difficulties on your health it may be worth consulting with your local doctor or charity support groups in your area, such as BEAT for UK website visitors & the NEDA for USA visitors.

**What are the possible benefits of taking part?**

Although you may find talking about your experiences helpful, taking part in the research may also not directly help you. However, the aim of the study is to understand how people reduced or stopped using these sites, so we can hopefully help others to do this. This could be used to develop better treatments and help others recover from eating related difficulties.

**Will my data be kept confidential?**

Absolutely, the interview is strictly private and confidential. All identifiable information such as names and addresses will be removed from electronic or hard copy documents. Where this is not possible, such as keeping consent forms, the documents will be kept securely. This data will be kept until October 2017, when the project is due to end and then destroyed. No identifiable information will feature in the study write up.

**Who has reviewed this study?**

This study has been reviewed by: The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority. The UH protocol number is LMS/PGR/UH/02454.

## Contact Us

If you are interested in taking part in the interview, please get in touch by emailing me at: [uheatingresearch@gmail.com](mailto:uheatingresearch@gmail.com)

I will get back to you as soon as possible.

*Please note: The 1hr Interview, can be conducted flexibly across a range of times (Thursday-Sunday) and locations, as well as via Skype. If you can, please state the days and times that tend to work best for you within the email.*

**Who can I contact if I have any questions?**

If you would like further information, please complete the contact form on the 'Taking Part tab' or email me:

**Ashlyn Firkins (Trainee Clinical Psychologist)    email: [a.firkins@herts.ac.uk](mailto:a.firkins@herts.ac.uk) / [uheatingresearch@gmail.com](mailto:uheatingresearch@gmail.com)**

Academic Supervisors:

Dr Saskia Keville    email: [s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)

Dr Keith Sullivan    email: [k.sullivan3@herts.ac.uk](mailto:k.sullivan3@herts.ac.uk)

Address: Ashlyn Firkins/Dr Saskia Keville/Dr Keith Sullivan, Health Research Building, School of Life and Medical Sciences, College Lane Campus, Hatfield, University of Hertfordshire, AL10 9AB.

## **Appendix L: Pre-Interview Questionnaire**

Thank you for agreeing to participate in the Eating Attitudes Study.

Below are some questions we would like you to complete ahead of our interview.

The questions are asked so that I can gain a clearer picture of who you are as a person, and your use of Pro-ED sites, prior to our interview. All of your answers are strictly private and confidential.

Please answer as honestly as you can, and provide as much information as you think relevant.

Please email the completed questionnaires to [uheatingresearch@gmail.com](mailto:uheatingresearch@gmail.com), at least 24hrs before your scheduled interview.

Many thanks, Ashlyn.

Your gender

Your date of birth

Your ethnicity

What social class would you identify as belonging to [e.g. middle class, working class]?

What is your profession and highest qualification obtained?

Where did you learn about this study?

\_Could you say a little about the eating difficulty you have? Whether you received an official diagnosis and how the difficulty has affected you?

Age of difficulty onset?

When did you first start using Pro-ED sites?

When was the last time you visited these sites (if relevant)?

At its peak, how often were you visiting Pro-ED sites? And for how long did this pattern of use last [e.g. daily for 1 month]?

During this peak time, how long were you typically spending on these sites each week [please specify in hours or minutes, e.g. 2hrs per week]

Please list some of the sites you regularly visited?

Did you post/chat to others on the sites?

\_How often are you visiting Pro-ED sites now, if at all?

How would you describe your eating difficulties now [e.g. recovered, not recovered, difficulties worse or better etc]?

**Appendix M: Interview Schedule**

**Opening Question: I'm interested in hearing about your relationship with Pro-Eating 'disorder' websites? How you came to learn about, use and reduce your use of these sites. I'd like to hear about the events or experiences that have been important to you, along this path.**

**I want to give you time and space to tell me about this, in as much detail as you can.**

**It is up to you where you begin. I just want to hear your story, there's no right or wrong answer and anything you think is important I will want to hear.**

'You said that you first started using Pro-ED sites around age \_\_\_\_\_'

1. What else was going on in your life around this time?
  - how did you view yourself?
  - Others?
  - Food?

What led you to use the sites / what did you hope they would give?

2. How did regularly visiting the sites effect your life?
  - Were there times you noticed, that it effected how you felt about yourself,
  - your relationships to other people
  - how you felt about food?
  
3. It seems that something changed and you began visiting the sites less, could you tell me more about that? / What was happening around the time you stopped visiting the sites as much/at all?
  - Can you tell me about any key moments that you feel enabled you to use the sites less? /
  
4. How has this change effected your life?
  - how you felt about yourself,
  - Your relationship to other people
  - How you feel about food

Possible: When you first started using the sites, you said X was happening.....Had things always been like that earlier in your life.....When you experienced a difficulty, or got distressed as a child, how did you manage that? How did others respond?

CHRONOLOGY: And then.....what happened next.....

DETAIL: You mentioned\_\_what was that experience like for you / could you tell me that part of the story in a bit more detail /Can you tell me more about how you felt about.... / what happened when..

CLARIFICATION: I'm a bit unsure about\_\_\_\_, could you tell me more about it.

EXPLANATION: Can you tell me more about that...../ Before we wrap up, can we go back to.....I would be really interested to her about.....

FINISHING

- Is there anything we haven't spoken about that you think is important for me to know?
- Now that the interview is coming to an end, how did you feel about the process of talking today?
- Do you have any questions for me?

**Appendix N: Transcription Symbols Key**

Simplified and adapted from Poland (2002)

Transcription symbols	Example	Explanation
[square brackets]	A: then [I said] B: [yeah] exactly	Represents overlapping speech
= equals sign	A: then I said= B: =yeah exactly	Represents 'latching' where there is no perceptible gap between the end of one person's speech and the beginning of another's.
(2) (.) (#)	A: It was like this (#) her came out (.) and (.) then (2)	Number in brackets represents pauses in seconds. (.) represents a brief pause of 0.1 seconds, like a catch between words. (#) represents a pause longer than (.), but less than 1 second.
Hyph-	A: She wa-no she di-did it	A hyphen indicates a broken off utterance in a stutter
: colon	A: She was so::: wrong	One or more colon indicates an extension of the preceding sound.
<u>Underline</u>  Capitals  °degrees°	A: I couldn't <u>believe</u> it, HOW COULD SHE? I °trusted° her	Underlying indicates an emphasis on the word or part of the word.  Capital letters indicate words spoken louder than the surrounding talk.  An degree symbol ° preceding the word indicates it is spoken quieter than surrounding talk.
?  .	A: What was it then?  A: What was it then.	? indicates rising intonation at turn completion.  . A period after a word indicates falling intonation at turn of completion

,	A: What was it then,	, a comma indicates low-rising intonation at turn completion, suggesting continuation.
;	A: What was it then;	A semi colon indicates a slight fall intonation at turn completion
“speech marks”	A: She just said “yeah”	Speech marks indicate the speaker imitating another person
(xxx)	A: Yeah I could (xxx)	Indicates inaudible speech
((double brackets))	A: Hahahaha! ((laughs))	A non-speech element such as laughter or a descriptor
[square brackets]	[Name] was going to	Square brackets indicate deliberately omitted text, for example names, for confidentiality purposes.

**Appendix O: Transcription Example (Examiners Copy Only)**

To protect anonymity this transcript has been removed and was only available in the examiners copy, to illustrate how ideas had been woven together.

**Appendix P: Analysis of Transcript Example**

**Analysis Stages**

**Part 1**

**Audio reflections on the interview**

Context

- This was my third interview. It had felt a little tricky for Emma and I to arrange an interview time slot and although we had penned one in, I had not received Emma’s pre-interview questionnaire 24hrs before our scheduled Skype call, so sent a chaser email later that day. I had not heard anything by the time I logged on to skype at the agreed time and was somewhat unsure if the interview was going ahead.
- Emma was running late, she quickly emailed to say that she would fill in the questionnaire now and perhaps we could still talk.

- I waited online, it was around eleven, I'd been up since 6.30am with a long commute to work. I had managed to fit in a gym session and my own personal therapy session that evening, before logging onto Skye but was feeling increasingly tired. I feel asleep at my desk and stirred around midnight, just as she came on-line.
- I quickly refreshed my emails and opened the questionnaire, it was complete.
- I felt a bit nervous, I wanted the interview to be good. Given the small sample size I felt that it was even more important that I did a good job as the interviewer but I felt very tired and wondered if I would be able to listen and be as present in hearing her story as I would like.
- I swallowed some water and called her using Skype.

#### Interview

- Emma was very personable and the clarity with which she spoke about her experiences and degree of articulation meant that my role as an interviewer, felt an easy one.
- I wondered if her profession (a trainee clinical psychologist) and identifying herself as someone who had engaged in quite a lot of therapy, had enabled Emma to really process, understand and perhaps distance herself from her story, so that she could tell it in this way.
- Her difficulties appeared to be placed very much in the past, sort of a narrative of 'this was me then', but I'm a different person now.
- The main storylines seemed to involve care, being noticed and gaining control, in what sounded like very chaotic family environment.
- I was struck by the degree of connection she reported to find on the sites, and the value she attributed to understanding with 'acceptance' rather than understanding with 'challenge'. This acceptance only seemed to be available to her within this community and there were moments I felt really touched and connected to the content of her story.
- I was also struck by her phrase 'the sites set a new bar for restriction'. There seemed to be so much power conveyed through this type of language.
- It seemed from her account, that there were a number of small but significant moments that led to a decision to enter recovery. Once this decision was made, her narrative suggested that the need to log on to the sites, went with it. For Emma, Pro-Ana appeared to hold a very important role in the maintenance of eating difficulties.
- The relationship breakdown with her long standing best friend, seemed to be positioned as a particularly important turning point. As she started to cry, I suddenly noticed how different it felt to 'be with' someone in the 'room' when you were communicating through a laptop. I found myself giving more audio cues than I would normally do if I were sat next to someone, perhaps to remind her of my presence. I wonder if this will be apparent in the later part of the transcript.

#### **Part 2**

#### **Analysis of the Transcript**

#### **Summarising Aspects of Content, Structure, Performance and Context**

1) How do individuals narrate their experience of both coming to use Pro-Ana forums? What is the Impact? What is the strongest narrative being told?

- Her account suggests that Emma developed eating difficulties/an eating 'disorder' before she used the Pro-Ana sites. This seems apparent by her positioning the onset of her eating difficulties to have started fourteen years ago and before she had '*regular access to the internet*'
- Emma storied herself as seeking out the sites, after seeing references to Pro-Ana on myspace and then googling the term herself.
- She positions the sites as proving her with 'motivation' not to eat, 'tips' she would never have thought of and a sense of competition between other members, which kept her coming back and maintained a low weight.
- Stories of Pro-Ana competition were contrasted with stories of Pro-Ana understanding. Particularly understanding without challenge. She referred to the community as being a 'safe space', where she could become more 'immersed' in her eating thoughts and behaviours.
- Her account suggested an impact of causing her to 'withdraw' into an online world and changing her eating patterns, particularly using the concealment tips and normalising these more secretive actions and behaviours.
- Emma also recounted how a 'function' of the eating 'disorder' was that it kept family problems away elicited care in what appeared quite a chaotic environment. Pro-Ana was positioned as enabling her to lose more weight and thus receive more care.

2) How do individuals narrate trying to disengage from them? What is the Impact? What is the strongest narrative being told.

- Emma positions disengagement as a decision in which she has lots of agency (there appeared to be a realisation that now the cons outweighed the pros).
- There is lots of identity talk in this part of the account, specifically strengthening other aspects of herself and really focusing on the direction she wanted to move in life.
- Her account suggests lots of situational changes e.g. going to college, creation of a new family, change in network of friends where her eating difficulties were not known.
- Her strongest narrative is one of quest (becoming a better person for her experiences).
- The narrative suggests that once a decision to enter recovery occurred, she no longer wished to be thin so there was no need to go on the Pro-Ana sites. The explanation appeared to be a logical one for her and language contained little emotion.

3) How is the account organised? Why does the informant develop her tale in this way, with this listener? What is the narrative doing? Whose story is it, for whom is it constructed?

- The account is organised chronologically, moving from the onset of her eating difficulties, to present day.
- Emma offers a clear, conscience, easy to follow and well-structured narrative.
- It starts with her eating difficulties onset perhaps to paint a picture of severity and demonstrate the sites did not cause her eating difficulties but worsened ‘‘disorder’ed’ behaviours.
- It is very much her story and one that I believe based on how it is told and the clarity of her answers, recounting detailed stories with ease.
- I wonder if some of her stories are told to remind Emma of her own strength and also told to her loved ones, to show how far she has come and to honour their presence/degree of impact that they appear to have had on Emma.

4) What aspects of the self are expressed in these narratives? How does she/he strategically make identity claims through the narrative performed? What other identities are performed or suggested? How do individuals position themselves through time? **Performance of identity (multiple identities). How does the person want me to see them? What kind of person do they want me to think/feel that they are? What is the preferred self?**

- She appeared to initially perform quite a fragile self (feeling lost, trying to find a place that she belongs, creating an impression of not really being noticed within her family).
  - o Recounting it was ‘very chaotic’, telling stories of both parents, splitting and remarrying a number of times and going ‘back and forth’ between homes.
- But this moves to an identity built in strength in being able to restrict, telling stories in which she felt superior and also performing strength in being able to step away from the sites quite easily. Recovery was positioned as a struggle but stepping away from the sites was not.
- Her stories often contain quite a high degree of reflection, with comparisons of this is what I thought then and this is what I think now. As well as psychological understanding of the reasons for eating ‘disorders’ developing and I wonder if she wants to show herself to have undergone a transformation and position herself as being on a journey of understanding her own experiences.
- Her preferred self, seems to be someone who is thoughtful, compassionate and resilient.

5) How do individuals position themselves to the broader societal narratives about eating ‘disorders’? **What cultural resources does the story draw on, or take for granted?** How do they position themselves to Pro-Ana sites and users?

- Emma’s account draws on commonly used clinically used ED onset discourses i.e. ‘I was hitting puberty and I wanted my body to look like a little girl’ and I got a lot of attention, a lot of concern, which I hears pretty common and can kind of mark the onset’.

- She also draws on clinical treatment discourses where anorexia can become central to someone's identity, and if it is possible to strengthen other aspects, recovery is more likely to occur.
- She draws on some political discourses. I.e. a hardship of gaining access to treatment and how these websites might be underdoing all the good work of people taking it seriously ('we have so many people who are advocating for policy change... to cover treatment for eating 'disorders' and I don't know what that looks like in the UK but it's very difficult, but then on the flip side we have people in the US who are saying oh no but this is a choice this is a lifestyle'. 'You're fighting against yourself').
- She was observed to largely resist overt feminist discourses.
- The sites are positioned initially as offering a community of support and haven of understanding.
- Emma positions the members as being both friends and foes. She positions herself as admiring and looking up to members who she aspired to be like but also told a story of keeping her friends close and enemies' closer.
- There was lots of description, surrounding the competitive nature of the sites and eating 'disorder'. She notes 'I want to keep tabs on you guys to make sure I'm the skinniest'.

6) How is the audience effecting what can and cannot be told?

- She was the only person who asked no questions about my own experience. For this reason, I was probably able to make a more curious stance during the interview and probably more about the sites and its impact, whereas in other interviews knowledge was often assumed.