# A Grounded Theory Analysis of the Forms of Support on Two Online Anorexia Forums

Ву

Sarah Catherine Lewis

## A DOCTORAL THESIS

Submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy

at

Loughborough University

September 2014

#### **Acknowledgements**

I would first like to thank my supervisors, Paula Saukko and Line Nyhagen, for everything they have done for me over the last four years. I honestly couldn't have asked for better supervisors, you have both been so supportive of me, and I appreciate the time and energy you have given to me. Paula, thank you for your honesty, for the great advice and for constantly pushing me to expect more from myself. Line, thank you for your enthusiasm, for the pep talks and your thoughtful criticism. You have both shaped me as a researcher, and I am very grateful to have been your student.

My sincerest thanks go to Karisa Krcmar and Annette Knight from the counselling and disability service, this thesis would have looked very different without the help and support you have both given over the years.

I would like to thank the Economic and Social Research Council for the funding to conduct this research. I would also like to thank the two communities that took part in this research, ANA and REC, especially those who were involved in interviews, without each one of you this thesis wouldn't have been possible. Perhaps a bit unconventional, but I would like to thank the thesis itself, as it has been source of stress and joy over the last four years, and enabled me to put my energy into something productive when times were tough.

PhD friends! My thanks go to, Emma, Jo, Pauline, Dana, Georgie, Michael, David, Jane, Roxana, Pawas and Alena. Thank you for all the jokes, the wise words, lunches, nights out and everything in between. Special thanks go to Emily Harmer, my PhD spirit guide, for constantly reassuring me that everything was going to be 'fab' and believing in me. To Erica Kucharcyzk, thank you for putting up with my constant catastrophizing and always bringing me back to reality. Thanks to Stefanie Gregorius for the long lunches and supportive words. To lain Hannah, thank you for your encouragement and humour. Jenny Gordon, you have been so supportive, and for that I am truly thankful. Harriet Brabbin, thank you for the tacos, the nights in and of course the many driving lessons.

To my parents, Filly and Dave, I think it's fair to say you've put up with more than your fair share during the last four years, and you will never know how incredibly grateful I am for everything. Martin Lewis, thank you for always understanding how much my 'homework', 'story', 'novel', 'blog', means to me, and for always encouraging me to push on even when things felt bleak. You have been a constant source of support over the past four years, listening to my worries and giving great advice, I wouldn't have been able to do this without you. Finally to Lindsay Hughes, how do I sum up how important you are in just a few sentences? You have been integral to the completion of this thesis, you are unwavering in your belief in me, you always listen to my woes (even if you've heard them a million times before) and you are an excellent friend. Thank you so much for everything.

#### **Abstract**

This thesis analyses the support given on two online anorexia forums, one has a proanorexic stance, and one is pro-recovery in orientation. The aims of this research are, to
explore these online environments as supportive places, to gain an understanding of *how*support operates on online anorexia forums, to reveal what elements influence the *form*support takes and to gain insight into how these environments are experienced as
supportive by members. In order to meet these aims, an online ethnographic and
grounded theory approach was taken to the study. This involved immersion in the online
cultures of pro-anorexia and pro-recovery more broadly, as well as, a year of nonparticipant observation of the two communities studied and online interviews with
members. The ethical implications of gaining access to and researching marginalised
online communities are also discussed at length, with this research taking an adaptive
approach to ethical decision making.

The first empirical chapter of this thesis begins by analysing members' critique of the DSM diagnostic criteria for anorexia. This analysis highlights the similarities between the two communities, as both reject the criteria due to its focus on the physicality of the condition. However, the communities are shown to be distinctly different in their interpretation of the notion of choice in eating disorders. Members of the pro-recovery community are encouraged to embrace the choice they have to get better, while members of the pro-anorexia community are united in their belief that their "hard wiring" negates any agency or choice with regard to their eating disorder. These differing understandings of choice are shown to create two site ethoses, the 'recovery spirit' and the 'sickness mentality', which shape what is constituted as supportive on the sites and members are required to conform to in order to be eligible for support.

The second empirical chapter moves on to consider the *forms* of support on both sites, which are shown to be closely related to and influenced by the site ethoses. On the prorecovery community support takes the *form* of challenging, which is the open critique of members' eating disorders thoughts and behaviour. This form of support does not comply with traditional support typologies, and functions as a norm on the site.

Challenging is normative as it, regulates behaviour, creates a sense of responsibility

among members and ensures members are held to account. The *form* of support present on the pro-anorexia community is also normative, but does not take on the prescriptive tone of the pro-recovery site. The main tenet of the norm of non-judgemental support requires members to respond without judgement to one another's posts, creating a fluid and inclusive support environment while maintaining the boundaries of the community and highlighting unacceptable behaviour.

The final empirical chapter uses the Bakhtinian (1994) concepts of dialogue and monologue to further explore support on these two forums. Through analysing interaction and the expression of voices, this thesis reveals the simultaneous presence of dialogue and monologue on these forums, which contributes to the creation of two distinct support environments and reveals further forms of support. The recovery community is shown to have dialogic interaction but a monologic expression of voices, which facilitates an interaction-focussed support environment. Interaction-focussed support is a *form* of support that is focussed on listening to and problem-solving for the individual seeking support. While the pro-anorexic community is characterised by monologic interaction and a multivocal expression of voices, which reveals another *form* of support: self-focussed support. Self-focussed support allows members to focus on their own support needs, creating a space where being able to vent is prioritised and support is read into messages rather than being overtly present. These forms of support are shown to be complementary to and reaffirm the previously discussed concepts of 'recovery spirit', 'sickness mentality', challenging and non-judgemental support.

Through the outlined analysis, this thesis contributes to knowledge on online support and online anorexia forums, by providing an in-depth comparison of two online anorexia forums, highlighting the conditionality of support in online environments, illustrating that support can take a variety of forms in online anorexia forums and displaying the influence of existing discourses on these spaces.

### **Table of Contents**

Acknowledgements	i
Abstract	ii
Table of contents	iv
Table of figures	vi
Chapter One- Online Anorexia Forums: An Introduction	1
Chapter two- Ethical Considerations: Gaining Access to Sites of Study	27
Introduction	27
Questions of power and 'vulnerability'	29
Approaching the communities	31
Public spaces or private settings?	34
Informed consent	36
Anonymity	42
Use of data	44
Conclusion	46
Chapter three- Researching Online Anorexia Forums	48
Research Design	48
Accessing Online Anorexia Forums	51
Non-participant Observation	54
Interviews	59
Authenticity in Online Research	67

Analysis	71
Point of Departure	75
Chapter four- Defining Anorexia: The role of Diagnosis and Choice in the o	reation of site
ethoses	76
Introduction	76
Wider Literature on the DSM	77
Diagnosis and Choice in the Literature on Online Forums	81
Two Communities, One Understanding of Eating Disorders	86
The role of choice in creating site ethoses	96
REC-The 'Recovery Spirit'	98
ANA- The 'Sickness Mentality'	108
Discussion	118
Chapter five: Challenging and Non-judgemental support: illustrating the f	orm and
normative constraints of support	121
Introduction	121
The Wider Literature on Online Support	122
Online Anorexia Sites and Support	126
Challenging Support: The Construction of Support on REC	129
Non-judgemental Support: The Construction of Support on REC	145
Discussion and Conclusion	161
Chapter Six (section 1) Introduction- Communicating Support: Monologue	and Dialogue
in Online Anorexia Forums	166

A review of the literature on Computer-Mediated Communication, d	ialogue and
monologue	167
Chapter Structure and Rationale for Themes	174
Charles of Associated Total Associate Construction Constr	
Chapter six (section Two) Analysis- Communicating Support: Dialogic and Mo	_
interaction on ANA and REC	177
REC: Interaction as Dialogue	177
ANIA internation of Manalague	100
ANA- interaction as Monologue	189
Communicating Support: Monologue and Dialogue in Online Anorexi	a Forums- A
Summary	201
Chapter six (section Three) Analysis- Communicating Support: 'Monologic Co	onsensus' and
Multiple Voices on REC and ANA	203
REC-The monologic Expression of voices	203
NEC THE MONOIGE Expression of Voices	203
ANA- The multivocal expression of voices	218
Discussion and Conclusion	228
Conclusion	222
Conclusion	232
References	243
Appendices	264

## Table of Figures

Figure 1: A visual display of dialogue and monologue on ANA and REC.......175

#### Chapter one

#### Online anorexia forums: An introduction

My first experience of an online anorexia forum was in 2008, I was a Master's student at the University of Liverpool, and conducting research into community as part of a qualitative research methods module. I spent a month observing a forum on LiveJournal, known as 'anorexia24/7', which at the time was advertised as the biggest pro-anorexia community online. I made observations, I analysed the data, I wrote and submitted the essay and eventually I left the field. Leaving the field site was difficult, I had become immersed in the stories of these women: the Australian medical student who posted frantically about chewing and spitting out food and was on the verge of being sectioned; the American college student who had refused to see her psychologist anymore because she ate a full meal; and the Canadian teenager who was purging blood. Not only was I invested in individual stories, but I was intrigued by the community itself, the rules which were not formalised but were by and large adhered to, the way members spoke about their eating disorder, what the community meant to them, the group mentality that clearly existed and the people that did not quite fit in. My experience of observing a proanorexia site left me with a sense that there was 'something there' and I wanted to understand that better.

This thesis marks my attempt to better understand online anorexia forums, which I define as any forum established to facilitate the discussion of eating disorders, this includes, forums that are pro-anorexic in their orientation (sites which discuss the reality of anorexia but do not encourage recovery) and forums that take a strict pro-recovery stance (sites that intend to facilitate an individual's transition into and maintenance of a recovery orientated mind-set). This project has changed shape over the course of data collection and analysis. Initially I was interested in how adolescents' use of the site impacted on the way support was given. As anorexia is frequently diagnosed during adolescence (NCCMH, 2004), and the majority of users of pro-anorexia sites in particular are young women aged between eighteen and twenty-four (Borzekowski et al., 2010), it seemed likely that adolescents were the main sources of support on these sites. As I became more familiar with the two sites under study, a pro-recovery forum (referred to

as REC throughout this thesis) and a pro-anorexia forum (known as ANA throughout this thesis), I began to realise that while support would be an enduring theme in this study, adolescence would not. Through non-participant observation of ANA and REC, it became apparent that support was not influenced by age, members were unaware of the age of their peers, as the disembodied online space removes social cues. Instead I began to see that support was a binding or unifying feature on both sites, using grounded theory as a method of analysis allowed me to see what was emerging from the data and explore this further. After approximately nine months of observation I began conducting online interviews with members of both ANA and REC, using video chat, audio chat, email and instant messenger services. Using the categories that had emerged from the analysis of the forum data as a starting point interviews touched on issues surrounding eating disorders, members' access to support (both online and offline) and what the terms proanorexia and pro-recovery meant to them. The interviews added depth to the analysis, corroborated some of the emergent findings and provided an opportunity to hear members' views on the community they were part of.

Through exploring the broad aims of this thesis, which are, to explore support as an element of online anorexia forums, to gain an understanding of *how* support operates on online anorexia forums, to gain an understanding of what elements influence the *form* of support given on online anorexia forums, to gain insight into how members experience online anorexia forums as supportive. I believe I have managed to draw out the 'something there' that interested me as a Master's student. Through the analysis detailed in the upcoming chapters I have explored the depth and nuance of support that exists in these online environments. Therefore this thesis contributes to knowledge by (1) providing an in-depth comparison of the support given on two different types of online anorexia forums. This comparison has highlighted differences and similarities that exist within these online support environments. Interestingly, these two communities will be shown to be more similar than they are different, suggesting that the concepts and forms

\_

<sup>&</sup>lt;sup>1</sup>Herring (2004) offers a six point criteria for analysing an online environment for community, but effectively problematises the need for an objective definition of community, stating that community is a sense or an experience that members have. Members of both ANA and REC describe and refer to these forums as communities, and so while I acknowledge the debate that surrounds this concept, referring to these forums as communities emulates participants perception of these environments and is methodologically appropriate as one of the aims of this study is to gain an understanding of the experience of being a member of an online anorexia forum.

of support examined in this thesis can be applied to settings more broadly, and are not just confined to online anorexia forums. Related to this, this thesis (2) illustrates that there is no one form of support given in an online support environment. As will be shown in the three analytical chapters, support works in different ways on individuals sites and at all levels of interaction. While this thesis shows that online anorexia forums are places of support, it also shows (3) support in these environments to be conditional and regulated. Members of both ANA and REC are required to adhere to the site tenets in order to be eligible for support from the community. So, while support is the main purpose of both communities, it is not given without conditions. Finally, this thesis (4) illustrates the impact of existing discourses on anorexia and mental health on the support provided in online anorexia forums, which shows the boundaries of online and offline to be blurred. These four key contributions will be elaborated on over the course of this introduction, and related to the literature to illustrate how this thesis advances existing knowledge on online support and online anorexia forums.

The rest of this chapter will be dedicated to reviewing the literature on feminist approaches to eating disorders, online support and online anorexia forums and providing an overview of the contents of this thesis.

# A review of the literature on feminist approaches to anorexia, online support and online anorexia forums

In this section I will review the existing academic literature concerning feminist approaches to eating disorders, online support and online anorexia forums. The aim of this focussed literature review is to discuss and give a grounding to the academic context of this thesis, while relating existing literature to my own research. Relevant literature from a variety of disciplines and standpoints will also be discussed throughout the analytical chapters.

#### Feminist approaches to anorexia

This study of online anorexia forums has been influenced by a variety of medical, psychological and feminist approaches to anorexia. The medical and psychological standpoints on eating disorders (anorexia more specifically) are perhaps more familiar

than the feminist model, due to eating disorders being considered the remit of doctors and clinical psychologists, and thus reduced to physical and mental symptoms (Bordo, 1993). Feminist approaches to eating disorders seeks to place these conditions in their cultural context, in order to expose how culture can produce eating disorders rather than just contributing to or triggering them (Bordo, 1993). The reoccurring themes in this body of literature are: femininity (Malson, 1998; Hepworth, 1999), the family (Bruch, 1978; Orbach, 1984, 1993; Thompson, 1994), the body (Bordo, 1993; Orbach, 1993; Hepworth, 1999), consumption (Bordo, 1993), and the thin ideal (Malson, 1998; Bordo, 1993; MacSween, 1993; Orbach, 1993). While these themes are relevant to this study in shaping an overall understanding of anorexia, there are key aspects of this literature that are more salient to this study, they are: the critique of the medical discourse and narrative therapy.

I will first briefly summarise how anorexia is made sense of in some of the feminist literature. Although these understandings are presented separately, there is crossover between stances and scholars rarely draw on one aspect of social life when discussing understandings of eating disorders. The family is frequently discussed in the feminist literature, and shapes understandings of anorexia. Bruch (1978) and Orbach (1984,1993) can both be seen as highlighting (or overemphasising) the role of the mother in anorexia. For Bruch (1978) the mother is an overbearing presence in the anorexics life who is thin obsessed, denying the daughter agency to make her own decisions. Orbach (1984, 1993) takes a similar stance to Bruch (1978) in emphasising the socialisation of daughters by mothers in creating an environment in which anorexia can exist. For Orbach (1984, 1993) the mother is repressed, casting uncertainty and anxiety onto her daughter while preparing her for a life of gendered domesticity. A key criticism of this understanding of anorexia is the focus on the mother and neglect of the role of fathers or siblings (MacSween, 1993). Further to this, Thompson's (1994) work highlights the intersections of race, class, gender and the family, making Bruch (1978) and Orbach's (1984, 1993) concept of the overbearing/repressed mother appear reductive and idealised. For some scholars, anorexia can be seen as the internalisation of the western thin ideals, which are pervasive in society and usually aimed at women. This understanding leads to scholars critiquing the objectification of women in western society and the intense scrutiny that

the female body is placed under (Orbach,1993; Chernin, 1984; Bordo, 1993). However this particular stance has been critiqued as overly individualistic, a critique also levelled at biomedical discourse (Saukko, 2008; 2009). Scholars such as Malson (1998) and Hepworth (1999) discuss anorexia in terms of femininity, with women being seen as having no other expression of femininity except through their bodies, the restriction and control associated with anorexia and self-starvation are therefore seen as exaggerated displays of western femininity. With MacSween (1993) suggesting that women are caretakers of their bodies and objects sculpted for the approval of men. Understandings of anorexia are not prescriptive in this body of literature, but can be seen as attempting to place anorexia in its social, historical and political context and move beyond the physical or biomedical understandings that dominate discourse on eating disorders.

The feminist literature on eating disorders has critiqued the medical model of anorexia (Bordo, 1993; MacSween, 1993; Malson, 1998; Gremillion, 2003; Hepworth, 1999) and has influenced this thesis by providing an understanding of the cultural, social and political meaning behind the pathologisation of eating disorders. Feminist scholars have problematized the 'discovery' of anorexia in the nineteenth century, and the notion that all historical cases of self-starvation can now be attributed to anorexia, stating that these ideas assume that the meaning of self-starvation is ahistorical and universal, and therefore is a denial of the social and cultural meanings associated with food and eating (Macsween, 1993; Brumberg, 1988). Malson (1998) in particular describes the emergence or 'discovery' of anorexia as a discursive event, which was only possible due to the gaps that existed in medical discourse of the Victorian and Georgian era and the social and cultural environment of the time. In this period femininity itself was being medicalised, through the pathologisation of hypochondria and hysteria, women were being positioned as medically (and also politically) unstable and in need of intervention. This pathologisation of anorexia continues to the modern day, with discourses on the condition evolving so that rather than having one understanding of anorexia there are many medicalised 'truths' (Malson, 1998). The impact of this medicalised/pathologised discourse of anorexia on individuals with the condition is that they are framed as powerless, the condition is seen as a shortcoming of their own, as it is divorced from the social conditions surrounding its development (Malson, 1998). The implications for this in

a clinical setting are stark, anorexics must further internalise the pathologisation of their condition, in order to be successful in treatment (Gremillion, 2003). Being confined to this medicalised discourse the anorexic is unable to move beyond it, or even express their experience of anorexia in their own terms, as they are always seen as 'unstable', too sickly to articulate anything other than illness (Saukko, 2009). In terms of online anorexia forums and this study, these particular ideas are salient, as these forums are working to establish a discourse on anorexia that is not divorced from the medical model (as aspects of this discourse are embraced) but rather is not consumed by it. This will be shown in this study through the refutation of the Diagnostics and Statistical Manual for Mental Health (APA, 2000) diagnostic criteria for anorexia on the two sites studied and the way both communities interpret members' ability to choose to be eating disordered.

One treatment option discussed in feminist literature on eating disorders is narrative therapy (Saukko, 2008; Gremillion, 2003). Narrative therapy is a therapeutic approach that emphasises the narrative or story of an individual, this narrative is explored through specific ways of talking about eating disorders that separate the self from the eating disorder (Maisel et al, 2004). In narrative therapy, the self is seen as constructed through life events, social structures and the culture in which an individual lives and there is not thought to be one 'true' self (Hoskin and Leseho, 1996; Maisel et al, 2004). In viewing the self in this manner, narrative therapy departs from traditional approaches to treating eating disorders. This is because traditionally, in the treatment of anorexia, the self is considered unitary, so at the core the self is always the same, regardless of external circumstances (Hoskin and Leseho, 1996). Due to this concept of the unitary self the anorexic is treated as if there is something inherently wrong with them, with treatment focussing on refeeding, and addressing intrapersonal issues (Saukko, 2008; Gremillion, 2003). Contrary to this, in order to address the issues that arise, narrative therapy suggests techniques such as externalisation (separating the self from the eating disorder), deconstructive questioning (asking questions that expose the eating disorder as separate from the self) and adopting different language (language that supports an anti-eating disorder mindset) (Maisel et al, 2004). Narrative therapy features in this study because the way in which the recovery community support one another is reminiscent of this technique, as they encourage members to separate themselves from their eating

disorder and also to critique eating disordered thoughts and behaviour (their own and other members). Walstrom (1999, 2000) in her study of a recovery community also found that narrative therapy techniques were used by members, further illustrating the scope for narrative therapy in online support contexts. However, it is necessary to acknowledge that members of the studied recovery community are not consciously using the techniques of narrative therapy in order to provide support, rather, as a community they have developed ways of supporting one another, which mimic the techniques of narrative therapy.

In summary, the feminist literature on eating disorders provides a useful critique of the medical model, and uses a more holistic approach to look at the production of eating disorders, citing the role of culture as essential in understanding these conditions. Within this holistic approach narrative therapy is important as it provides an alternative treatment that encompasses and explores the role of culture in the treatment of individuals with eating disorders. My own research complements this body of literature, as it brings to the fore the communities' critique of the DSM-IV and illustrates how this shapes understandings of eating disorders and contributes to the creation of site cultures. Further to this, in chapter five I show how one of the forms of support given on REC is reminiscent of narrative therapy, and how this contributes to this specific support environment.

#### <u>Literature on online support</u>

The literature on online support is varied in its focus, what is consistent is that the much of the literature looks at the support given in online forums, newsgroups and listservs. In order to coherently discuss this wide body of literature, studies will be grouped into three sections: Studies which look at the type of support; studies that assess the impact of support; and studies that relate support to issues of community. Before turning to the literature on online support it is necessary to define what is meant by support. Online support groups have proliferated since the late 1990s, and now exist for a wide array of issues. Online support groups for health conditions are particularly popular (Adler and Adler, 2013) and take various forms from asynchronous to synchronous, moderated, unmoderated or professionally monitored (Attard and Coulson, 2010; Kaplan et al.,

2011). Support is given online through various formats, including email lists, blogs, forums and social media, it is also prevalent in online spaces where the main purpose is not support (Coulson et al., 2007; Wellman and Gulia, 1999). There is no one definition of online support, however, some of the consistent features described by scholars are; the sharing of information, facilitating expression, discussion of feelings and personal experiences, and the development of relationships (Eysenbach et al., 2004; Chung, 2013; Barak et al., 2008; Evans et al., 2012). The lack of a definitive stance on what constitutes online support is complimentary to this study, as throughout this thesis support will be shown to be fluid, and to take on differing forms depending the online environment in which it is given and the way in which interaction is analysed.

Turning first to the literature that discusses the type of support that is offered in online spaces, broadly speaking this body of literature looks at the content of support, rather than how support is provided in online spaces. Type of support is generally assessed through the use of Cutrona and Suhr's (1992) social support behaviour code, which places support-intended communication into five main categories, which are: emotional support (sympathy, understanding, concern), esteem support (compliments and validation), informational support (suggestions, advice giving, teaching), network support (advancing the individuals social network) and tangible aid (provision of physical assistance, help with practical tasks). Although designed to code offline support, this social support behaviour code has been successfully applied to support given in online contexts and studies have shown that a variety of support types are visible in online environments including: informational, esteem and emotional support (Eichhorn, 2008; Winzelberg, 1997; Coulson et al., 2007; Coulson, 2005; Evans et al., 2012; Stewart-Loane and D'Alessandro, 2013). Despite support being given in an online environment, where members of communities are likely to be dispersed geographically, it has also been shown that tangible aid is present on online forums (Baym, 2010; Coulson et al., 2007; Bakardjieva, 2003, Coulson, 2005). Interestingly, the type of support members seek or offer has been shown to change over time. Stewart-Loane and D'Alessandro (2013) show that new members of an online community for people living with ALS (Amyotrophic Lateral Sclerosis) begin using the forum by seeking informational support, and as they became more established members their active support seeking reduces, and instead

they offer other members emotional and network support. What form of support is provided on a site has also been shown to be influenced by the gender of those who access the site. Seale et al. (2006), in their study of two cancer support forums, one breast cancer and one prostate cancer, found that women sought expressive or emotional support, while men sought informational support. This body of work establishes that online environments are also supportive environments. Members are able to offer and receive meaningful support, which is comparable to the support offered in offline contexts.

The impact of online support has been assessed using a variety of analysis methods, and the results are more varied than the studies conducted on form, which generally adhere to the above outlined typologies. In order to present this body of work in a coherent manner, they will be discussed in two broad categories: studies that reported positive impact and studies that reported negative impact. While I have categorised the studies in this way, there is cross-over between them. McKenna and Bargh (1998) conducted a three part study of newsgroup messages on marginalised (concealed, eg. drug use, homosexuality, bondage), marginalised (inconcealable, eg. Obesity, cerebal palsy, stuttering) and mainstream interests. They found that group participation had the impact of identity 'demarginalisation' for members of the marginalised (concealed) newsgroup, making them more accepting of their stigmatised identity and more likely to reveal it to an important person offline. Stewart et al. (2011) also report positive effects of online support group use, the authors developed a group for adolescents living with spina bifida and cerebral palsy with the intent of observing if online participation decreased members' sense of social isolation. The main findings were: an increase in confidence; improved coping strategies and a decrease in loneliness. Malik and Coulson (2008) also found that membership of an online support group reduced members' sense of social isolation. Conducting thematic analysis on questionnaire data collected from members of an online support group for infertility; they also found members reported improved relationships with their romantic partner. Each of these studies show that online support, while provided in a virtual space, has wider reaching implications, with members of online support groups experiencing significant positive impact from their involvement.

The real world impact of participation in an online support group is not always reported as positive. Hinton et al. (2010) are clear that participation in an online support group for infertility had multiple negative consequences. These included, the normalisation of negative feelings; avoidance of situations and withdrawal from friends with children; and obsession with infertility (their own and that of other members of the group). Obsession was also noted as a negative consequence of involvement with online support by Malik and Coulson (2008- outlined above), as was distress. Further to this misinformation has also been posited as a negative attribute of online support group use (Sherman and Greenfield, 2013) and is a criticism often levelled at online anorexia forums (Juarascio et al., 2010; Norris et al., 2006; Borzekowski et al., 2010; Rouleau and von Ranson, 2011).

Finally, I will summarise the literature that touches on how the support provided online creates a sense of community, group dynamics or cohesive sense of support. Beginning with Rodriquez's (2013) study of an online forum for early onset Alzheimer's disease, the author found that constructing illness narratives were essential for the creation of a sense of self (which was under threat due to the diagnosis of dementia) but also contributed to creating a sense of community. Interestingly, it was through sharing stories of social isolation as a result of dementia, that members of the online forum created a sense of shared understanding, solidarity and support enabling them to give advice, encouragement and offer one another condolences. Wright (2000) used grounded theory of forum data and a questionnaire to study the communication themes that promote the provision of social support in SeniorNet, an online forum for older adults. The prominent communication themes were: promoting community support, advice disguised as self-disclosure and shared events. These themes allowed members to create an environment in which they could offer and receive support to deal with the issues faced in later life. Advice-giving has been a feature of both of the previously discussed studies, and has been investigated by Veyreda and Antaki (2009), Smithson et al. (2011) and Morrow (2006). Smithson et al. (2011) set up an online forum for young people who self-harm in order to study information sharing online. Through conversation analysis, they found that members gave unsolicited advice and that the advice given was mundane or 'safe', suggesting that fears surrounding advice-giving are unfounded. Veyreda and Antaki (2009) looked at unsolicited advice-giving on a bipolar disorder

forum, and using conversation analytical methods found that the provision of advice would often be at odds with the kind of advice the poster sought and also that this acted as a initiation for new members. Further to this, the authors suggested that advice-giving in this manner also is telling of the communities' construction of bipolar disorder, with members offering advice on the understanding that biomedical diagnoses, and the medical professionals capable of making them carry authority which must be respected in order to access the community (Veyreda and Antaki, 2009). Morrow's (2006) study of advice-giving in a forum for people living with depression highlights the delicate nature of advice-giving online, and the ways in which members position themselves as competent when seeking advice in order to preserve face. Advice-givers in this study also worked to make advice palatable and preserve the advice seekers self-image by framing the advice with other information, while at the same time also positioning themselves as knowledgeable and equipped to give advice (Morrow, 2006). These studies illustrate that something as standard as advice-giving can be indicative of online community norms, and the support that is provided in online support environments.

Turning now to dominant site discourses, a range of online forums have been studied and have been shown to have particular site ethoses that influence the support given on the site and the way in which it is acceptable for members to use the site. Alexander et al. (2006) contend that not all support groups are created equal, and that the support that is given is related to the unique support environment and context created by the group. This was shown through the content analysis of forum data of four online support forums and questionnaires carried out with site members. This finding is shown in the literature, with the idiosyncrasies of online support environments varying widely between forums, and it will also be shown in this thesis, with the accepted forms of support differing greatly between the two studied forums. Peterson (2009) in her study of an HIV/AIDS forum for gay men found that members were required to have a positive outlook, and discuss the positive aspects of life in order to access the support provided by the group. Similarly, Bar-Lev (2008), through narrative analysis of an HIV/AIDS support group, found that members had to display a positive attitude when accessing the group. Members also had to present themselves as having sound morals and be willing to seek help or change their behaviour. Moreover, Mundry and Strong (2012) found that there were six

discourses present on a recovery forum for problem gamblers that had implications for site use and the support given on the site. Interestingly, authors looking at self-harm forums have found that the discourses present on sites do not necessarily complement one another, and members have to find a balance between conflicting discourses in order to be considered eligible for support (Franzen and Gottzen, 2011). These studies illustrate that support in online settings is not always immediately forthcoming, but is conditional on members taking up differing presentations or conforming to specific site discourses, which is also a key observation in my own research.

As shown above, a selection of the literature on online support examines the typologies and content of support in online forums, usually those which provide support for a particular physical or mental health condition. While my own research does draw upon typologies of support, with support on ANA and REC appearing at times as esteem, emotional and informational support, it is the form of support that is pertinent. The form of support differs from the typologies outlined above as it does not focus on the *content* of support, but rather on how members of these two communities support one another. Looking at how members of ANA and REC support one another involves analysing the forum and interview data for process, that is, the action/interaction/emotion born out of the context in which they happen (Corbin and Strauss, 2008). And so, looking at form in these two online environments highlights the conditions in which support is created, and illustrates the various ways in which support is expressed. This focus on form and not on content or typologies marks a significant departure from the literature and is one of the unique features of this research. Further to this, the above literature on online support was shown to discuss and explore the impact of participation in online support environments on members/individuals, demonstrating that online support has both positive and negative consequences. My own research does not look to establish the impact of using ANA and REC on members, rather, it is concerned with gaining an understanding of the experience of using an online anorexia forum for support. By emphasising the experience, and not the impact of these support environments, my research seeks to listen to and give voice to individuals with eating disorders.

My research is firmly situated in the literature that looks at online support from the perspective of community or seeks to establish how online support environments are

created through interaction between members. However, my research differs due to the content of sites (specifically ANA, as it does not conform to the standard perception of a support group, as members are not required to work on recovery), and so is akin to research on suicide and self-harm forums (Adler and Adler, 2013; Franzen and Gottzen, 2011; Horne and Wiggins; 2009; Smithson et al., 2011). Like previous research (Mundry and Strong, 2013; Peterson, 2009; Bar-Lev, 2008), my own study looks at site discourses, and illustrates the way in which these constrain how support is understood and what support is deemed acceptable. My research then goes on to show how these discourses shape the different *forms* of support on ANA and REC, which marks it as different from the preceding literature. Further to this, as this thesis centres on support, and not the eating disordered content of the forums studied, the concepts and findings can be applied to other support contexts and are not limited to online anorexia forums.

#### Literature on online anorexia forums

As a body of literature the work on online anorexia forums is typified by breadth. Online anorexia forums have been discussed from many vantage points, including studies that review content (Norris et al., 2006; Borzekowski et al., 2010), studies that seek to highlight the supportive nature of these forums (Dias, 2003), studies that seek to determine the impact such sites have on viewers (Bardone-cone and Cass, 2006; Harper et al., 2008; Wilson et al., 2006; Csipke and Horne, 2007), studies that discuss the role of the body in a disembodied space (Burke, 2012; Boero and Pascoe, 2012; Ferreday, 2003; Ward, 2007), studies that centre on identity construction (Riley et al., 2009; Giles, 2006) and the role of gender (Whitehead, 2010; Day and Keys, 2008). The aim of this section is to give an overview of the pertinent themes in the literature on online anorexia forums, highlighting gaps and placing my own study within this academic context. While I have referred to this body of literature as work on online anorexia forums, it must be acknowledged from the outset that there is limited work looking at pro-recovery websites/communities, with the majority of studies focussing on pro-anorexia. Prorecovery has been studied in comparison with pro-anorexia sites to determine the impact of viewing of such sites (Wilson et al., 2006; Harper et al., 2008) and to establish differences and similarities in language use (Lyons et al., 2006). Riley et al. (2009) conducted discourse analysis of a pro-anorexia and pro-recovery forum, and looked

specifically at constructions of the body in these spaces. They found that members of both communities conform to the culturally prescribed thin ideal and use constructions of the body to present themselves as legitimate and worthy of group membership (Riley et al., 2009). Walstrom (1999; 2000) used a micro-level discourse analysis to study a prorecovery forum, and found that members moved through five stages of recovery identity on the site, from having an indeterminate eating disorder identity to a fully-fledged recovery identity. My own research contributes to the limited literature on recovery by centring on the support that is provided on a pro-recovery site, highlighting the ways in which members make themselves eligible for support and the forms that support takes on such sites.

Perhaps the most enduring theme in the literature on pro-anorexia is the distinction that is made between anorexia as a lifestyle choice and anorexia as a mental health condition. This can be seen throughout the literature, as regardless of the focus of study, discussions of this distinction take place. The lifestyle model of anorexia is evident on sites that do not treat anorexia as an illness, but an admirable lifestyle, to be adopted by those who have the strength to live up to the demands of what is portrayed as a glamourous yet demanding lifestyle (Strife and Rickard, 2011; Bardone-Cone and Cass, 2006). Sites that conform to the medical model of anorexia do not present the condition as a lifestyle, but as a serious mental health condition, which members may or may not want to recover from. However, members of pro-ana sites do not take up the medical model uncritically, there is an ambivalence surrounding the use of medical terminology and diagnostic criteria, with sites rejecting the medicalization of their condition while simultaneously believing themselves to be ill (Hardin, 2003). In looking at the mission statements of 14 pro-anorexia sites, Strife and Rickard (2011) found that there were clear distinctions in the kind of language used on sites conforming to the medical model or lifestyle model of anorexia. Sites adopting the medical model were passive in their portrayal of the illness, and appeared self-defeated. This contrasted heavily with the mission statements of sites conforming to the lifestyle model, which sought to empower viewers, using language imbued with a sense of agency and control. Despite the distinction that exists between the lifestyle model and the medical model, content is consistent regardless of the orientation of the site (Borzekowski et al., 2010). While there is no 'typical' pro-anorexia

site, there are some consistent features but their content will change dependent on the type of site (blog, forum, homepage etc), the orientation of the site (medical model, lifestyle model), their stance on pro-ana (some sites disassociate from this label, instead calling themselves pro-support/pro-acceptance/pro-anorectic). These features include: 'thinspiration' (pictures, motivational phrases, poems and songs that trigger members to continue their weightloss goals), tips and tricks (advice for members on weightloss, restrictions, hiding eating disorder behaviour from others), interactive areas (forums, guestbook etc), poetry or creative writing relating to anorexia, information about eating disorders, information about food/nutrition (Norris et al., 2006; Borzekowski et al., 2010). While the lifestyle and medical models of anorexia are often presented as in opposition to one another, Dyke (2013, p.147) purports they are a "productive paradox" suggesting that they co-construct a sense of resistance to previous portrayals of anorexia. Like Dyke (2013), my own understanding of online anorexia forums, which has been informed by the literature, talking to members of online anorexia forums and extensive time spent immersed in this online culture, is more fluid and less dichotomous. As will be shown in the methods chapter of this thesis, I consider pro-anorexia sites to exist on a spectrum and as is illustrated in the first analytical chapter the role of choice in online anorexia forums is more substantial than creating a distinction between sites that conform to the lifestyle or medical models of anorexia.

The construction of differing identities on pro-anorexia sites has received considerable attention in the literature, with many scholars asserting that members have to present themselves as legitimately/authentically eating disordered in order to access the group. Giles (2006) suggests that these authentic identities serve two purposes, illustrating threats to the community and providing validation to members who conform to them. The way in which members can conform to an eating disorder identity is very much dependent on the site, as there is variance in what 'correct' presenting looks like. Bond (2012) speaks of members performing for a pro-ana audience, which can be successfully achieved through conforming to gendered social constructs (Whitehead, 2010), presenting one's condition as abnormal (Gavin et al., 2008), conforming to the constructions of anorexia on the site (McCabe, 2009; Williams and Riley, 2013) and presenting the body as disordered (Boreo and Pascoe, 2012; Riley et al., 2009). If a

member of a site cannot conform to the specific authenticating eating disorder identity, then they will be marked as an outsider and be ostracised by the community. While there are various groups with outsider status on pro-anorexia sites, including dieters, haters and creeps, it is the 'wannarexics' that are seen as problematic by community members and that have received the most attention in the literature. Wannarexics are individuals who use the site but are perceived as 'inauthentic' in their claims of being eating disordered, and so are seen as trying to imitate anorexic behaviour without having the associated mental health issues, causing other members to be hostile (Whitehead, 2010). Wannarexics are blamed for the closure of sites, ridiculed for the perceived naïve questions they ask about eating disorders, and communities are instructed to be vigilant of their presence (Giles, 2006; Boero and Pascoe, 2012; Whitehead, 2010). Wannarexics are thought to be reviled because they 'blur the boundaries between 'ana' as state of purity and discipline and as helplessly biological/medical 'condition' (Giles, 2006, p.474). Therefore, eating disordered identities are integral in the creation of boundaries on proanorexia sites, where members must conform to the ideals of the site (in whatever form they take) or face being rejected by the community. Rather than discussing authentic eating disordered identities, my own research considers how members of the two observed forums, ANA and REC, create authentic support identities and make themselves appear eligible for support. This is achieved through illustrating the normative nature of support on the two sites, and how members are expected to orientate to particular site ethoses in order to access support.

Online anorexia forums are frequently demonised in the media, but within the academic literature they are often positioned as sites of resistance. Pollack (2003) positions proanorexia sites as a protest, an act of resistance against not only the medical and psychological models of anorexia but also against feminist approaches to eating disorders. While other scholars reiterate this standpoint (Days and Key, 2008; Knapton, 2013), with sites being considered anti-medical establishment and anti-recovery, proanorexia has increasingly been seen as an exaggeration or resignification of views held by the wider society. Bell (2009), in her Foucauldian analysis of pro-anorexia, suggests that these sites are intertwined with the medical discourse on anorexia; unable to escape it, pro-anorexia sites appropriate the markers of medical gaze and subvert their meaning.

Further to appropriating the medical discourse on anorexia, pro-anorexia sites have also been discussed as a symptom of wider cultural issues, namely, the internalisation and extreme enactment of western beauty ideals (Burke, 2009). Days and Key (2008) illustrate this by showing how members of pro-anorexia sites re-work the desire to be thin in western culture as two contradictory discourses that had regulatory functions on the sites. Knapton (2013) also found that the discourses present on pro-anorexia sites were not removed from western thin ideals, but were merely taken to an extreme. The two types of discourse she discusses are anorexia as a skill and anorexia as a religion, which she shows to be rooted in western culture- with dieting/weight management seen as something to be constantly worked at and food/eating frequently discussed in religious terms, such as 'sinful', 'heavenly', etc. Putting pro-anorexia sites in this cultural context has the effect of making them not a product of individual 'dysfunction' but a marker of deep rooted cultural issues.

Finally, a prominent theme in the literature on online anorexia forums is support. Despite pro-anorexia sites being described as "the antithesis of self-help" (Balter-Reitz and Keller, 2005, p.79), support has been shown to be central to online anorexia forums, presented as a reason for members initially accessing sites and the main function that sites, particularly online forums, offer to users (Brotsky and Giles, 2007; Mulveen and Hepworth, 2006: Dias, 2003). Support on pro-anorexia sites has been shown to conform to the previously discussed typologies, with members offering one another a variety of types of support, including emotional, informational and esteem support (Eichhorn, 2008; Winzelberg, 1997). The informational support offered on online anorexia forums has been problematized, with scholars suggesting that members are potentially providing inaccurate information to one another (Juarascio et al., 2010; Borzekowski et al., 2010; Haas et al., 2011). The support offered on pro-anorexia sites is thought to be appealing because members lack support offline (Brotsky and Giles, 2007; Smith et al., 2013; Dias, 2003), therefore pro-anorexia sites become a safe space, or sanctuary, for them to express their eating disordered thoughts, feelings and experiences without judgement from non-disordered friends or family (Dias, 2003). The support offered online is thought to give members of pro-anorexia communities a sense of identity, as although they may self-identify as eating disordered, having a community of similar others bolsters their

association with the disorder (Smith et al., 2013; Mulveen and Hepworth, 2006). However, while this helps to form bonds within the community, it also results in individuals being less likely to be able to separate themselves from their disorder, keeping them entrenched in illness (Tierney, 2006, 2008). Perhaps the most critical study of support comes from Haas et al. (2011), who describe online anorexia forums as 'negative enabling', as they allow members to continue to enact potentially harmful behaviour. Haas et al. (2011) highlight some examples of how support is negatively expressed on sites, these are: the normalisation of eating disordered behaviour that occurs on sites, the self-depreciation that is almost expected of members, and the construction of 'bad' behaviour as positive. My own research contributes to the literature on online anorexia forums as supportive environments by illustrating that support is central to these communities, and that support on these sites takes varied forms and is conditional.

My own research draws on and contributes to the literature on online anorexia forums outline above by: providing an in-depth study of pro-recovery; comparing two different types of online anorexia forum; and expanding the way the role of choice is used to understand the workings of online anorexia forums. As has been shown above, only a limited amount of research has been conducted on pro-recovery communities, through providing an in-depth analysis of the support given on a pro-recovery site, this study advances understandings of these under researched online environments. Further to this, this study provides a comparison between two different types of online anorexia forum, as one is pro-anorexic in orientation and one is pro-recovery. While comparisons have previously been made between pro-anorexia and pro-recovery communities (Wilson et al., 2006; Harper et al., 2008; Lyons et al., 2006; Riley et al., 2008), my own research centres this comparison on support, and through doing so reveals the similarities and differences that exist on these sites in terms of dominant site discourses, normative concepts and expressing support through dialogic and monologic language. Finally, my research contributes to the literature on online anorexia forums through showing that choice is more than a marker of site orientation, or compliance with the lifestyle model of anorexia. In this thesis, community understandings of the role of choice will be shown to be a key element in determining the type of support that is provided on the site, through

the creation of dominant site discourses or ethoses, which influence the varied forms support takes on these two sites. These contributions further advance academic knowledge of the support that is given on online anorexia forums.

In sum, this thesis contributes to the reviewed literature in the following six clear ways: it moves beyond support typologies; prioritises experience of online support over impact; illustrates how site discourses shape the form of support; provides an in-depth study of pro-recovery; offers a comparison between the support on pro-anorexia and pro-recovery sites; and finally expands knowledge about the influence of choice in online settings. Each of these literature contributions reinforce the previously outlined overall contributions of the thesis, which are:

- (1) Providing an in-depth comparison of the support given on two different types of online anorexia forum. This comparison is evident throughout the analytical chapters of this thesis, and is complemented by the grounded theory analysis used, as one of the main tenets of this is method is constant comparison of data (Corbin and Strauss, 2008).
- (2) Illustrating that there is no one form of support given in an online support environment. Again this is shown throughout the thesis, and is reinforced by the comparison of ANA and REC, which allows the variance of support to be noted and in turn analysed. This overall contribution is also illustrated through the focus on *form* of support, instead of on typologies and the content of support.
- (3) Showing support in online environments to be conditional and regulated. This is particularly evident in the first analytical chapter, which illustrates that members of ANA and REC have to conform to differing site discourses, which are shaped by the communities' understandings of the role of choice in their eating disorder.
- (4) Highlighting the impact of existing discourses on anorexia and mental health on the support provided in online anorexia forums. Again, this is shown in the first analytical chapter, where the DSM criteria for anorexia is critiqued and members understanding of the role of choice in eating disorders, determines how support is perceived on the two sites.

#### Outline of the thesis

Chapter two details and discusses the ethical considerations when gaining access to online anorexia forums. The research sites of this study are presented as places of interest for researchers, but as requiring specific ethical reflection due to the blurred distinction between public and private in an online context, which impacts on how/if informed consent is sought and from whom. Further to this as the participants in this study self-define as eating disordered there are issues of power that need to be considered. The disembodied nature of the internet compounds these issues, making the procedures that are applied to similar offline research sites inappropriate for this study. In reviewing the literature on online research ethics and detailing my own experience of gaining access to these online communities, I show that an adaptive and participant centred approach was best suited to this particular study.

Chapter three presents and discusses the methodological approach of this study. Using a grounded theory approach to data collection and analysis, this study sought to gain indepth data on the experience of using online anorexia forums as support environments. This was achieved through non-participant observation and online interviews with members. Two active online anorexia forums were chosen to participate. The first, a prorecovery site, referred to as REC throughout the thesis, focussed on encouraging members into recovery and maintaining their recovery from anorexia and other eating disorders. And the other, what I term a moderate pro-anorexia site, referred to as ANA throughout the thesis. ANA is moderate in that 'tips and tricks' were banned, but were still given. The site had an active thinspiration section, but did not take an anti-recovery stance, nor did it glamourise or promote anorexia or other eating disorders. These two sites were observed for approximately one year, with data taking the form of conversations (known as threads) posted to the forums saved as PDFs and analysed using Nvivo 9. As observation continued and data analysis became more detailed, interviews were conducted with members of both forums. Interviews were conducted online, via the following formats: email, instant messenger, audio chat and video chat. Twentyseven interviews were conducted in total, thirteen with members of REC and fourteen with members of ANA.

Chapter four is the first analytical chapter and discusses how the members of the two sites define anorexia. Despite the differing orientations of the sites, members hold similar views, privileging the emotional and mental difficulties faced by one another over physical symptoms such as low Body Mass Index (BMI). The focus on the emotional elements of an eating disorder and rejection of the physical characteristics stands in opposition to the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000), which members of both communities openly critique. However, the two communities differ from each other in terms of how they view 'choice' in eating disorders. Members of REC believe that they can choose to recover from their eating disorder, and this is expressed through the 'recovery spirit', which requires members to show their commitment to recovery to be considered eligible for support. On ANA members see themselves as having no choice in being eating disordered, and this is expressed through the 'sickness mentality', which allows members to be consumed by their illness. These two site cultures underpin the way support is given on the two sites, as they determine what is considered acceptable behaviour, in terms of expressing eating disordered sentiments and community interaction, on the sites.

Much of the literature on online support is concerned with the content shared on online support communities and whether this conforms to the traditional expressions of support (emotional, instrumental, tangible aid). Chapter five explores the often overlooked *form* of supportive interaction on the two sites. On REC support is expressed through 'challenging', which refers to members' open critique of each other's eating disordered thoughts and behaviours. For example, a member not wanting to stick to their meal plan would be met with calls for critical thinking about why, rather than empathetic support. Through 'challenging' a member's commitment to recovery is tested; they are made responsible for their actions and the choices they make in maintaining their recovery. The techniques used by members when challenging one another are reminiscent of narrative therapy, and the calls for accountability in recovery are akin to those found in Alcoholics Anonymous. On ANA support is characterised by the tenet that members must be non-judgemental. Members offer support in a non-judgemental manner because they seek to support all members, regardless of how they are affected by their eating disorder and where they are in their eating disorder journey. For example, members posting on

different topics such as, entering recovery or finally reaching their goal weight will be offered the same level of empathetic support. Non-judgemental support creates a fluid and inclusive support environment, which can be adapted to serve the differing needs of members. However, as inclusive as non-judgemental support may appear, there are limits to it, with members who express a traditional 'pro'-anorexic identity or discuss dangerous behaviour finding themselves at the margins of the community.

Chapter six is uses the work of Bakhtin (1994) to provide further understanding of how support is communicated on ANA and REC. The analysis looks at the interaction of members on the two sites and the expression of members' voices. This illustrates another form of the support offered on the two communities, showing the constraints of previously discussed concepts on language and how support is expressed through interaction. Using the Bakhtinian notions of dialogue and monologue as sensitising concepts, each community is shown to be simultaneously dialogic and monologic. REC is shown to be dialogic in that members are encouraged to engage with one another, so, members respond to each other's comments, ask one another further questions and quote one another's words. This creates an interaction-orientated support environment. However, this dialogue occurs within the boundaries of the 'recovery spirit' and 'challenging' and is dominated by authoritative discourse, making it monologic. ANA can be seen as monologic, as there is a sense of inertia within the posts of members, with members seemingly not interacting with one another but offering high levels of selfdisclosure, with little interaction between posts. This creates a self-focussed support environment, where having the space to share one's experience is potentially more important than the responses received. ANA is then shown to be dialogic despite its static appearance, as it creates a multivocal community, one in which diverse sentiments can be expressed, allowing conversation to be fluid and move in any direction-reinforcing and facilitating the community tenet of non-judgemental support.

Chapter seven summarises the findings of this study and identifies the ways in which it has filled gaps in, as well as built upon existing knowledge. I will also highlight the limitations of this study, and consider the possibilities for future research. Overall, this thesis explores the forms that support takes in the specific setting of online anorexia forums through analysis of forum data and interviews with members of ANA and REC.

Through this analysis the conditions that precede and contribute to the communities' understandings of support are made apparent, as are the various forms that support takes on the two sites, which in turn illustrate that support in these online settings is conditional, normative and multifaceted.

#### Overview of data collection and study sites

In this section I will briefly give an overview of how the data were collected and the form it takes. I will also provide some details about the study sites in order to give the reader some context for the subsequent ethics chapter, which discusses how I gained access to the study sites and the ethical implications of the study.

#### Data collection

Data were collected from two online anorexia forums, one was pro-anorexic in its orientation and the other had a pro-recovery focus. Both forums were observed for a period of 12 months, during this time I became immersed in these sites, and the cultures that they are part of. Data collection during observation took the form of saving threads (strings of posts on the site, which act as an online conversation) as PDFs and importing them to Nvivo for analysis. In total I collected 621 threads across the two sites.

After a period of observation interviews were conducted with members of the two sites. A total of 27 interviews were conducted, 13 with members of the pro-recovery site and 14 with members of the pro-anorexia site. Interviews were all conducted online and across four different formats, which were, video chat (Skype), audio chat (Skype), instant messenger (AIM, MSN messenger, Yahoo! Messenger, Skype), and email. Participants self-selected to be interviewed and chose their preferred interview format. Video, audio and instant messenger interviews varied in length, the shortest interview was 30 minutes (video), while the longest was 4 hours (instant messenger). Email interviews were conducted over longer periods of time, ranging from 2 days to 3 months. The variation in interview length is due to the format interviews took, a video interview requires both parties to be present and there is an onus on immediate responses in a fixed time period. While an email interview does not place these kinds of restrictions, the conversation is free to stop and start as the medium affords asynchronous communication.

#### ANA- The pro-anorexia study site

The pro-anorexia study site will be referred to as ANA throughout this thesis in order to provide anonymity to the community. ANA can be considered a moderate pro-anorexia site, as it self-defines as pro-anorexic on its homepage, and contains 'typical' pro-anorexic content, such as 'thinspiration' (pictures, motivational phrases, poems and songs that trigger members to continue their weightloss goals). However, members of ANA oppose the glamourisation of anorexia and 'tips and tricks' (information to help an individual exacerbate or maintain an eating disordered state) are banned on the site. ANA was a popular site, with membership peaking at around 50,000 members in 2011 (the year of observation), however due to site changes implemented by the site owner the popularity of ANA declined and the site became defunct in 2013. Before its demise, the site was highly active, with members posting hundreds of messages (approximately 500) to the forums in any 24 hour period.

ANA was easily accessible through search engines such as Yahoo!, Google and Bing. Membership to the site required registration with an email address and the creation of a username and password. The site was studied covertly, the ethical considerations of this and the use of 'private' online communities is discussed at length in chapter 2. Members of ANA have access to all public information that can be found on the homepage, the forum section of the site, a chatroom, and the ability to create a profile on the site on which they can provide some information about themselves, receive comments from others, add members as friends and post pictures. And so, ANA offered members the opportunity to communicate synchronously and asynchronously, and harnessed some of the features of social networking sites like Facebook and Myspace.

ANA was maintained by a site owner, and a small team of moderators. The site owner, an individual who maintained the site in their spare time, was responsible for the overall maintenance of the site, ensuring the site had enough server space to remain online, fixing bugs and glitches that appeared on the site (which were numerous) and updating all content on the homepage. Although there were thousands of members on ANA, the forums and chatrooms were overseen by a relatively small team of eight moderators. The moderators' role was in essence to keep the community safe, this included deleting

spam, blocking outsiders who were intent on causing trouble (usually referred to as haters), ensuring that members were complying with the community's rules (spoken and unspoken) and assisting members with functionality issues (not being able to upload pictures etc). While members did not have to pay to access ANA, they were able to donate to the site to ensure its continued presence online. Later in the site's evolution advertisements which appeared in the side bar of all forums, and on the homepage, helped fund the site.

#### REC- The pro-recovery study site

The pro-recovery study site is referred to as REC throughout the thesis to preserve the anonymity of the community, this site was observed overtly, the implications of which are discussed in chapter 2. REC is a peer-led recovery site, meaning it was created and is maintained by individuals with eating disorders for the benefit of others living with eating disorders. This differs from clinic or charity recovery sites, which are usually maintained by paid staff. REC is easily accessed via popular search engines, and at its peak had 4,000 members, the site has public and private content, registration of an email address and the creation of a username and password is required to access a substantial amount of the site's content. Without registration the homepage and several forums can be accessed, although these forums are read only, as posting requires registration, the content of these forums ranges from support to carers, links to external support sites to information on body acceptance. Registration to REC provides access (and the ability to post) to the majority of forums, and new members are encouraged to start an introductory thread to tell the community a bit about themselves. The more a member posts the more they can access on the forums, there are picture and journal forums that are only accessible after a member has posted a set number of times.

REC is a technologically sophisticated and well maintained peer-led forum. REC has a site owner who founded the site in the mid 2000s, during observation their presence on the site was intermittent and the running and maintenance of the site fell onto a team of approximately twenty moderators. Moderators occupy a position of authority and responsibility on the site, they are required to lead by example, as well as undertake typical moderator duties like, removing spam, blocking outsiders intent on causing

trouble, welcoming new members, moderating posts to ensure they comply with the community rules (spoken and unspoken) and assisting members with functionality issues (being unable to upload an avatar etc). REC can be considered a very stable site, with a core membership and consistent influxes of new members. However, towards the end of the observation period (winter 2011) some members became dissatisfied with the community; this resulted in the creation of a splinter site. Some members went on to be members of both REC and the splinter site, while others no longer used REC at all. Despite this REC remains a popular and active pro-recovery site.

#### **Chapter two**

#### Ethical considerations: gaining access to sites of study

#### <u>Introduction</u>

As a researcher of the internet I do not have to go far to be immersed in the field, sitting in my office I am able to access the communities that were involved in this study and the online cultures to which they belong. However, issues of access in this context are far more complex than logging onto a forum, the ethics of this project cannot be divorced from the methods. Beginning data collection required not only consideration of methods, and the practicalities of research but a thorough and adaptive deliberation of the ethics involved with collecting data in an online context and from communities that can feasibly be considered sensitive and marginalised. Some of the initial questions that needed attention were; do I register to seemingly 'private' sites? What constitutes a 'private' site? How would ethical practice be different if I were to access a 'public' site? Who in these settings is able to give informed consent? How is this effectively broached? Finding the answers to these questions was not a straightforward, linear process and I do not believe I found the 'right answers', but that they were right for this specific research context. And so, a discussion of the ethical considerations that led to gaining access to the two sites of study is pertinent. In this chapter I will outline my own experience of gaining access to two online anorexia communities, reflecting upon the ethical decisions that were made as the relationships with these communities developed. This will be achieved through first discussing questions of power and vulnerability in this specific research context. I will then go on to detail how I went about gaining access to the communities and will look specifically at the role of discourses of public and private in shaping this ethical protocol, issues that arose when gaining informed consent, how I protected participants' and the communities' anonymity and the ethical use of data.

Before moving on to my own experience of gaining access to online forums it is necessary to consider the existing literature on online ethical practice, which is marked by a relative lack of consensus, with no definitive ethical framework being established. This is in part due to the changing nature of the field (Sveningsson et al., 2009), more than one ethical argument being viable in the same setting (Ess and Jones, 2004) and ethics committees

and subject associations offering little guidance to online researchers (Anderson and Kanuka, 2003; Flicker et al., 2004; Sharkey et al., 2011. Also see BSA (2002) statement of ethical practice). Further to these factors reports that have been produced to provide researchers with clear guidance (such as Ess and AoIR 2002 & Markham, Buchanan and AoIR, 2012 and Frankel and Siang (1999) for the AAAS) have been accused of being out of date and for treating online environments as monolithic, offering advice that is too structured to be effectively applied to the myriad of online environments researchers study (Trevisan and Reilly, 2014; Walther, 2002).

Another feature of online research that impacts on ethical practice is whether to adopt a human subjects approach or treat data collected as texts (Ess and Jones, 2004), as the ethical implications are strikingly different for each. A human subject model approach to online research would seek to protect participants from harm through gaining informed consent from participants, protecting their anonymity and taking special measures when dealing with 'vulnerable' individuals (Kozinets, 2010). A text based ethical practice focusses on the legality of using specific texts in research, looking at copyright and protection of intellectual property (Bassett and O'Riordan, 2004). Bassett and O'Riordan (2004) are critical of the mass adoption of the human subjects model of ethics to online environments, as it impedes researchers who want to investigate sensitive, marginalised or 'vulnerable' online communities due to the emphasis in the human subjects model on informed consent. Rather than taking a human subjects or textual approach to ethical practice, it has been suggested that researchers should look at applying core ethical values, such as harm reduction, anonymity, privacy and confidentiality, to online environments, despite the disembodied nature of the setting (Stern, 2002). This has the potential to encourage good ethical decision making without the need to rigidly comply with a potentially out of date or inappropriate ethical framework (Sveningsson et al., 2009; Bond et al., 2013). This focus on core values would allow researchers to adapt the ethical protocol of their study to the community or online environment they are studying, which should ensure a high level of good ethical practice as the approach is tailored rather than prescriptive (Gatson, 2011; Trevisan and Reilly, 2014).

Initially, I had a fixed idea of how gaining access to the communities would occur, expecting the ideal process of co-constructing an ethical framework with each

community to be as desirable to them as it was to me. However, in reality this was a naïve assumption, one which was not appropriate for both of the communities and required me to make some difficult ethical decisions. And so, this study went from having a prescriptive human subjects approach to one which is more fluid and resembles Allen's (1996) vision of a dialogic and negotiated process, one that focusses on causing no harm to participants and keeps their well-being at the centre of all ethical decision making. This results in what I consider to be a well thought out, considered ethical practice. This ethical practice will be discussed through the core ethical principles of; 'vulnerability', informed consent, anonymity and fair use of data. The distinction between public and private spaces online will also be discussed as it is fundamental to ethical decision making in an online context.

## Questions of power and 'vulnerability'

In order to ethically research online anorexia forums, it is necessary to accept that participants are vulnerable and the data sensitive in content, but to also recognise the strength participants have (in terms of pro-anorexia sites they are acting against dominant discourses on eating disorders) and the way in which they protect themselves online. Therefore members of ANA and REC can be seen as empowered and disempowered which ensures that they are not reduced to the label 'vulnerable', but are considered more holistically. The idea that members of online anorexia forums are both disempowered and empowered can be seen in the literature. Members of pro-anorexia sites are frequently described as marginalised (Knapton, 2013; Bond, 2012; Gavin et al., 2008; Haas et al., 2011), while communicating on the internet in such a contested way is also positioned as an act of resistance (Pollock, 2003; Day and Keys, 2008; Ward, 2007), but members are also seen as exposing 'vulnerable' others to eating disordered thoughts and behaviours (Yeshua-Katz and Martins, 2012; Borzekowski et al., 2010), illustrating the contention that exists surrounding notions of dis/empowerment and pro-anorexia. The idea that pro-anorexia has influence over others not actively involved in the movement leads Bell (2009) to suggest that pro-anorexia is not only seen as dangerous but infectious. I would argue that to see members of online anorexia forums as inherently empowered or disempowered is reductive, as it denies the complex reality of these sites

and the wider context in which these discourses exist (See Knapton, 2013 for a critical discussion of the public reaction to pro-anorexia).

In any research setting the researcher is in a privileged position as they set the agenda for the study, and are in control of how participants are represented (Gatson, 2011). This is particularly important to consider when studying online anorexia forums, due to the way in which individuals with eating disorders have been portrayed, as vain, weak, or overly pathologised (Lavis, 2011). As a result of this portrayal and the dominant discourses that surround eating disorders, the voices' of individuals' with eating disorders become marked by 'disorder' and so are not listened or are thought to be mere expressions of the disorder itself (Saukko, 2000). Research, such as my own, can be seen as an opportunity to listen to eating disordered individuals, to give them a voice. However, this idea of researchers giving a voice to eating disordered individuals is not unproblematic, as it in some sense reinforces the idea of eating disorder individuals as victims, something which individuals may contest. Saukko (2008) discusses this in terms of her own interview participants, who rejected the idea that their eating disorder had made them a victim, wanting to show anorexics as capable of being strong. In terms of my own interview participants not one of them self-identified as a victim or 'vulnerable'. They did, however, project this label onto other members of the community, usually through expressing the need to protect other members, for example:

"All the older members are protective of the younger ones, we fear for them because not only are ED's dangerous and often deadly, but they're so young, they don't always understand the consequences to their actions."

(Dana, email interview, ANA)<sup>2</sup>

However, members showed themselves to be aware of the dangers of being so open in an online environment, they spoke of the personal measures they go to in order to protect their offline identities from the communities they are part of. This is noted in the literature, with Livingstone (2008) illustrating that youth engage in privacy management

<sup>&</sup>lt;sup>2</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Email interview indicates that an interview was conducted via email.

online and Shade (2003) highlighting the juxtaposition of female bloggers as vulnerable when in reality they are capable of dealing with the issues online interaction creates. Therefore, there is contention as to how eating disordered individuals are presented on the two sites, they are at once powerless and powerful, with the former depiction being reinforced by dominant discourses surrounding disordered eating. Like Trevisan and Reilly (2014) in their study of disability activists online, I wanted to avoid stereotypical depictions of 'vulnerability', be they from dominant discourse or forum members own perceptions. My own thoughts on representation and ethical stance towards members of both ANA and REC are centred on being aware of the power that I hold as a researcher of a marginalised group, and, to understand and question the dominant discourses that surround individuals with eating disorders.

While I have discussed how members of ANA and REC may or may not be seen as vulnerable, I have yet to detail the provisions for ethically negotiating this. This is because there is no one procedure in this ethical protocol that caters to members' 'vulnerability'. All the procedures that will be detailed below work towards ensuring this study is centred on good ethical practice by ensuring that the basic tenet of 'do no harm' is at the heart of all ethical decisions. This stance and my own understanding of how members are 'vulnerable' (but also my willingness to see individuals as more than vulnerable attributes) should ensure that ethically sound decisions are made.

# Approaching the communities

As previously stated, from the outset of this project I wanted to adopt the same informal, open approach to both of the communities that would be contributing to the research. In order to achieve this I wanted to speak to site owners and moderators about their thoughts on the communities' potential involvement in the study and then with their approval post on the forums in order to gain consent from the community. While this approach was appropriate for REC, it was not for ANA, which resulted in difficult ethical decisions being made.

The process of gaining access to REC was relatively straightforward. I had signed up to the site and had been observing the community for approximately two weeks in order to ascertain if it was suitable for study. In this time I began to get a sense of the community,

functionality of the site and who the popular/influential members were. I contacted the site owner in the first instance, to see if they would be interested in participating in the study. They did not reply for over a week and from my time spent on the forum I understood that their presence on the site was intermittent. I sent an informal but detailed messaged to a British moderator of the site to see if she thought the community would be interested in taking part in the study. She replied positively, but wanted to talk to the other moderators of the site before giving a definitive answer. As a group the moderators decided it was not in their capacity to give me consent to observe the forum, stating that REC is a safe space for members, some of whom have no other outlet of their eating disordered thoughts, and so they suggested I seek community approval to observe by starting a thread on the general discussion forum. The thread I started gave the community information about the study and me as a PhD researcher, it received 400 views and 37 comments:

"I would like to introduce myself to the group, my name is Sarah Lewis and I'm a PhD student at Loughborough University in the UK. For my PhD research I'm looking into pro-anorexia and pro-recovery forums, I'm particularly interested in how support functions in these two settings and how adolescence as a concept impacts on support. Essentially I'd like to ask you as a community if you'd be willing to take part in my research. The good news is this would take minimum effort on your part, all I want to do is observe posts and potentially at a much later date conduct a few interviews about your community via skype or gmail chat."

Most of the comments left on the thread were initially cautious but positive:

"im sure you can understand that we feel protective of our members, so ill say that i think it is a good proposal and i am interested in helping how i can but that obviously we will need to see how members respond also."

(PalmBreeze, forum data)<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> Pseudonyms are used throughout this thesis for forum and interview data. They do not retain the 'spirit' of the original name or username, but are randomly assigned by Sarah Lewis. Pseudonyms for forum data are not replicated, therefore the same member may appear in the thesis under a number of different pseudonyms, this is to provide a higher level of anonymity.

And:

"I take it interviews are anonymous? As I'm not sure what the deal is with you interviewing under-18's without parental permission otherwise."

(KL215, forum data)

As I answered members' questions about their involvement in the study comments became welcoming and members wished me luck with the study, "Welcome to our (big) little community:)", "Anyway [Welcome to REC emoticon] thanks for letting us know what you're all about" and "PM me if I can be of any help". As part of the dialogic and negotiated ethics process (Allen, 1996) I then developed an ethical framework. This is a document which clearly sets out the ethical terms of the study, it is adaptable throughout the research process and is a collaboration between researcher and participants. When drafting the document (the final copy of which can be viewed in Appendix A) I used the comments from members as a starting point and tried to address the issues that seemed pertinent to them, then posted the drafted ethical framework on a new thread in the general discussion section of the site. I hoped members would critique this and have a role in negotiating the ethics of the study, however the comments received were affirmative and stated that they felt comfortable with the research going ahead. The Loughborough University Ethics Committee gave approval for the research to be conducted overtly and for recruitment for interviews to be conducted through the forum.

After having such a positive experience gaining access to REC, I approached the site owner of ANA, aware that their response may be negative, as pro-anorexia sites can be cautious and sometimes hostile to outsiders. Again I felt it was appropriate to speak to the site owner and so emailed them via Facebook (as they encourage all members to do) adopting an informal but informative style. The site owner responded positively to the community taking part in the study, I then suggested talking to moderators of the site and then starting a thread, as I had done on REC. The site owner advised against this, stating:

"I don't think that they would react well. People have tried this in the past and it was shot down quickly. One person even came to me for permission and then wrote that she had permission and it turned out pretty bad.

The issue is that no one wants to be researched. People tend to feel like lab rats and that's not why they are on ANA" (ANA site owner, Facebook correspondence)

This left me unsure as to how to proceed. I wanted to have an open and honest relationship with the communities involved in the study, but the site owner of ANA was recommending researching covertly. We discussed the practicalities of covertly observing the site and the site owner agreed to act as gatekeeper for the later interview stage of data collection. Conducting research covertly had not been something I had considered, but it was quickly becoming apparent that is was the only practical way of including ANA in the study. Interestingly, the Loughborough University Ethical Advisory Committee suggested that it would be preferable to study ANA covertly, but ultimately left the decision of how to proceed with me. The committee's main concern was that my overt presence on the site might impede members' use of the site, and therefore negatively impact on the support they receive. The argument for covert observation on ANA was convincing, not only was it a practical decision, but, on consulting the literature on online ethics and discussing the situation with my supervision team, it could also be an ethically sound one.

The way in which I approached the two communities and the process of making the observation ethically sound bring up four key issues that will be addressed in turn, they are: public/private; informed consent, anonymity and use of data. While these issues will be discussed under different headings it should be clear that the concepts are heavily interlinked and have substantial impact on one another.

# Public spaces or private settings?

Whether an online environment is public or private is often seen a pivotal in how to proceed ethically, as it determines what a researcher is 'obligated' to do (Ess and Jones, 2004). Even in early literature on online ethics, public and private has been seen as a problematic dichotomy, with King (1996) suggesting that what is an online public space may feel private because of where the user is writing from, and therefore gives the impression of a more private online space. Previously scholars have attempted to provide a more definitive answer of what is public and private in online settings with

Eysenbach and Till (2001) suggesting there are four clear markers of private space, which are; subscription, registration, number of users and perception of privacy. Researchers can use this as a guide to determine if a space is public or private. Further to this it is important to consider the intentions of an author of a message in an online environment, as this may have been intended for a specific audience (Sveningsson et al., 2009; Walther, 2002). Therefore, something that was written in a public space can still be deemed as private by the author if they believed the content would only be viewed by certain people. Using these criteria for ANA and REC both sites would be considered private spaces, as they require registration, are perceived as private by members despite both having thousands of members. In the pro-anorexia literature, the distinction between public and private is often over simplified, with some scholars presenting public proanorexia sites as the only ethically viable site of study (Gavin et al., 2008; Castro and Osorio, 2012; Dyke, 2013, Dias, 2003; Smith et al., 2013; Maloney, 2013). A limited number of studies have used 'private' pro-anorexia sites (Fox et al., 2005; Brotsky and Giles, 2007), with Fox et al. (2005) taking an overt approach and Brotsky and Giles (2007) taking a covert approach. Both studies present the overt/covert methods used to be ethically sound. Fox et al. (2005) suggest that because of the sensitive nature of the forum they were studying announcing the researcher's presence in this 'private' space was considered good practice. Brotsky and Giles (2007), however, used covert methods and deception, as the lead author posed as a pro-ana member, and suggested the gains of the study justified the methods used. My own research builds upon the work of Fox et al. (2005) and Brotsky and Giles (2007) through the study of two seemingly 'private' online anorexia forums, encompassing elements of covert and overt observation.

Eysenbach and Till's (2001) criteria for determining public/private status of a site is useful and highly influential, they suggest that there is a false dichotomy of public/private online content and that sites can fall between these categories. Sveningsson et al. (2009) further dispel the public/private dichotomy by presenting public and private online spaces as existing on a continuum, which arguably gives a more nuanced and realistic view of how users and researchers see online space. The continuum is made up of four types of sites, private, semi-private, semi-public and public. Private sites are those that users need an invitation to join, and the content is restricted to the creator and their invited guests.

Semi-private sites are less restricted but require membership and something precursory to membership, like belonging to an organisation or club. Semi- public sites are principally available to everyone, they are restricted in the sense that they require registration. Finally, public sites are accessible to all, without any restrictions (Sveningsson et al., 2009). Considering ANA and REC in terms of the continuum, they would be considered 'semi-public', as they are accessible to anyone but require registration.

What are the implications of seeing ANA and REC as 'private' when using Eysenbach and Till's (2001) criteria and 'semi-public' when using Sveningsson et al.s' (2009) continuum? They are still the same sites, the label is the only thing to change, yet there is the perception that the less private a site is the less ethical obligation a researcher has to members. Interestingly, Sveningsson et al. (2009) critique the continuum for not being able to accommodate the full multi-faceted nature of online environments. Just as a space is not entirely public or private, it is not entirely semi-private or semi-public either. This is apparent on both ANA and REC, as the sites encompass elements of both public and private (in a semi-public environment): once registered the majority of the forum is visible to all members, however some areas are restricted until a member has posted a fixed number of messages to the public areas of the forum, and members can log in 'invisibly' so that other members cannot see they are online. So while registration to the sites allows access, this is conditional. Without giving a definitive solution to this issue Sveningsson et al. (2009) suggest that as researchers of online environments we look at our ethical decision making not in terms of whether a space is public/semi-public/semiprivate/private but instead consider if we are doing harm by researching in that space. This is the most important consideration, one which should not be overlooked regardless of the public/private status of the environment under study. For this study using sites which could be considered private or semi-public is ethically viable as the likelihood of harm resulting from data collection through non-participant observation of forums is minimal, due to my silent presence on the sites. However, although my presence is nonobtrusive that does not negate all harm, members of either site could feel disadvantaged by the research (due to feelings of betrayal of trust, misrepresentation etc), despite the efforts taken to minimise the potential for harm.

## <u>Informed consent</u>

Informed consent is "the principle that states that all research subjects should give their knowledgeable consent to being studied" (Sveningsson et al., 2009, p.70). While an honourable tenet to uphold, informed consent does not transition seamlessly into an online context. This is because issues arise over when to seek informed consent, who is able to give informed consent and how to ensure participants fully understand the issues involved with participation in research. For the AoIR (Ess and AoIR, 2002) there are two qualities of an online environment that will affect whether a research is 'obligated' to gain informed consent from members/users, they are; level of privacy and sensitivity of data. If an online environment is deemed to be publically accessible and the data nonsensitive then the requirement to gain informed consent is altogether void. However, as discussed in the previous section the dichotomy of public/private is problematic in its arbitrary definition and does not consider who is defining an environment as public/private or data as sensitive/non-sensitive (Sveningsson, 2004). Instead of taking such a blanket approach to informed consent, I had to consider whether it was appropriate for the communities under study in this research, rather than seeing informed consent as a marker of ethical practice, I sought to make ethical choices at all stages of the research.

As previously stated, I assess the two communities, ANA and REC, as semi-private environments and ones that discuss highly sensitive topics. For some researchers this would make getting informed consent imperative (Flicker et al., 2004). However, gaining informed consent in an online context is not straightforward, it requires a more nuanced approach. In some online research settings gaining informed consent is impeded by the environment, an example of this is chatrooms or forums with a high flow of users, where, in order to gain consent from the community a researcher would effectively have to spam (send a lot of unwanted messages at one time) to forum or chatroom which runs the risk of rejection by members/users and essentially destroys the naturally occurring data that was initially of interest (Williams and Reid, 2007; Markham, 2005; Eysenbach and Till, 2001; Reid, 1996). Also a researcher must assess the impact of announcing their presence to a group, how will this be received? Will it cause undue distress to members? We cannot assume that members will be unaffected by our interest in studying their community, merely the suggestion of researcher or journalist involvement with a site can

cause tension (Sanders, 2005). Further to this announcing your presence to a group, or inviting a community to take part in research does not guarantee the research will go ahead, as the community may reject your proposal for them to be part of your study (King, 1996). This will undeniably have an impact on the community, potentially a negative one; for example, members may feel the researcher's presence was intrusive and make them wary of accessing the site. Therefore announcing your presence as a researcher may appear to be the most ethically sound decision, but it is not without consequence, even if the research does not go ahead.

Further to assessing the practicalities and impact of gaining informed consent, a researcher must assess from whom they wish to gain informed consent. As previously shown for REC I started with the site owner, then contacted the moderators and then on their advice I approached the community. I decided that this was appropriate for this community, it was respectful of the hierarchy that exists on the site but also ensured that I had consent from a variety of members. As Roberts et al. (2004) assert the traditional consent form is almost redundant in an online context, and this is especially for true for REC, which has thousands of members. Instead of requiring members to opt in to the research project by signing a form, I gave members the opportunity to object to the research being conducted through the research thread started in the general discussion area of the site and also through the development of the ethical framework, also posted in the general discussion area. The ethical framework also provides one of my supervisors, Paula Saukko's, email address, so if members had concerns they did not want to discuss with me they had an independent contact. I also contacted moderators of the site to gauge if the positivity and acceptance that was being expressed outwardly on the forum was mirrored in members' comments to moderators. Fortunately, the two moderators contacted said that no members had been in touch with them with concerns or grievances about the research taking place. They also assured me that members of REC were vocal when unhappy or mistrustful of something, as the site encourages members to be honest with one another. King (1996) problematises gaining informed consent from the community as a whole, as I have with REC, suggesting that some members may always feel like they did not fully consent to the research going ahead. This is a valid

criticism of consent by community, as members may feel under pressure by other members to concede to research being conducted.

As previously stated I wanted to use the same process that had been successful on REC when approaching ANA, however, this was not realistic, as the needs of the communities are different. Instead of moving through the different levels of the site and gaining consent to research at each level, I was cautioned by the site owner, who assured me that members would be hostile about the possibility of me conducting research. Instead the site owner consented to the research going ahead, I conceded that in the case of ANA this was the only option available to me as the process of announcing myself as a researcher to the group would have caused distress among members, something which I felt could not be justified. This sentiment was mirrored by the Loughborough University Ethical Approval Committee, who suggested I covertly observe the forum, in order to protect members and ensure that the study did not have a negative impact on the support offer on the site. While I believe treating the site owner of ANA as a knowledgeable insider and using their information to protect the community from harm is the most ethical way to include the community in the study, some scholars suggest that gaining informed consent from site owners, administrators or moderators is not acceptable, as these individuals cannot be considered to represent the entire community (Bond et al., 2013; Eysenbach and Till, 2001; Sveningsson, 2004). Clearly the decision to covertly observe and gain informed consent from one senior member of an online community is not appropriate for all online research. However, through observing ANA I know what a delicate support environment it is. My overt presence could have had a detrimental effect on a community, which could have resulted in members no longer using the site, which for some is their only outlet for their eating disordered thoughts. Much of the literature on pro-anorexia has collected data from 'public' sites, avoiding such complicated ethical decisions (Day and Keys, 2008; Knapton, 2013; Whitehead, 2010; Mulveen and Hepworth, 2006; Maloney, 2012; Haas et al., 2011). However, Brotsky and Giles (2007) studied a password protected site, using deception and without informed consent. The researchers, however, did discuss the potentially ethically problematic nature of their research and concluded that the potential benefits of the research outweighed the deception involved. The authors stated they wanted to expand

"existing research on pro-ana sites [which] had used publicly accessible data" (Brotsky and Giles, 2007, p.95), through exploring a password protected or private site. I echo this sentiment in the ethical choices for my own study, looking at 'public' sites may appear more ethically viable, but it effectively prevents researchers from looking at 'private' sites and could perpetuate a knowledge gap in which only elements of pro-anorexia are understood (Rouleau and von Ranson, 2011).

Gaining informed consent for the interview phase of the study was more straightforward, and mirrors how the process would be conducted in an offline setting. However, due to the covert observation conducted on ANA, there is the added ethical consideration of paying to have an advert placed on the 'Research Studies' section of the website in order to gain access to interview participants. The advert cost \$25 to place, which was said to go towards the administration and upkeep of ANA. This decision may appear dubious, and actually elicited critique via email from a potential participant:

"Also, I don't mean to sound out of line but you donated money to a pro anorexic website?! Isn't that ethically a bit wrong?" (Potential participant, email correspondence)

Her question is valid; donating money to a pro-anorexia site is not unproblematic. It may have impacted on the way members of ANA perceived me as a researcher and the study, the quote above shows that it was a point of contention for that individual (who chose not to take part in the study). It also reveals the presence of a researcher on the site, while the advert was not on the forum, it acts as an indicator of my presence and intent, which may cause some members stress or irritation. However, at the time donating to the site was the only option available. I had been struggling with how to recruit for interviews from ANA for approximately three months, a non-intrusive advert was therefore a viable alternative to using the forums directly, which at that time would have gone against the wishes of the site owner and moderators. Also the site was not in danger of shutting down, nor was it short of funds, my donation was not pivotal for the continuation of the site. Further to this, giving members the opportunity to take part in interviews gives a voice to those who are already marginalised, as they were asking to express what their involvement in the site means to them, and how they are supported

on ANA. Finally, as someone researching online anorexia forums not donating to ANA felt inappropriate, as it would mean that I was responding to the perception of pro-ana sites as places of danger and harm, when, as someone who had been observing the site for months, I knew the site offered important support to its thousands of members. To not donate would be to see ANA as a place of danger, and not a place of support.

Regardless of the site, or whether participants got in touch via forum message or the advertisement on ANA, the process of gaining informed consent was the same. Flicker et al. (2004) highlight the importance of providing potential online participants with all the elements that would be present in an offline recruitment process. I agree that this is important. Just because we do not have face-to-face contact with participants in online research it does not mean that the process of informed consent is any less worthwhile. Potential participants sent an email to my university account, to which I replied thanking them for their interest and attached a participant information sheet (which can be found in Appendix B). Initially on this participant information sheet there was a link to a consent form hosted by *Surveymonkey*, however this appeared to be a barrier to take up of interviews, and so it was agreed with the Loughborough University Ethical Approval Committee that verbal/written consent would be sought at the beginning of the interview. Arguably, members arranging and then taking part in the interview could be seen as informed consent, however while talking through the participant information sheet, advising participants that they had the right to withdraw and could refuse to answer any questions at the beginning of the interview, it was logical to go on to ask if they were happy for the interview to continue. Seeking informed consent through written/verbal means rather than asking participants to sign a form was more informal, it required less of the participants and made the process less overwhelming for them.

In order to comply with the Loughborough University Ethical Approval Committee, initially only individuals aged 16 and over were eligible to take part in the study. However, on conducting interviews it became apparent that younger members of REC (the first site to be invited to interview) felt slightly affronted by their inability to discuss the community that means so much to them with me. I also felt that this was detrimental to the study, how could I claim to be getting a genuine representation of the site if I was disregarding those under 16? Due to this I applied to the Ethics Committee and amended

the ethical protocol to include members from the age of 13 (individuals under the age of 13 are restricted from using the site)<sup>4</sup>. While this has undoubtedly benefited the study, there are special ethical considerations when interviewing minors online. Children are thought to be vulnerable due to their possible difficulty in understanding the meaning and consequences of being involved in research, and so are thought to be unable to give informed consent (Stern, 2002). Furthermore, children are thought to have a limited understanding of the public nature of the internet (Stern, 2002), although this may not always be the case as adolescents do concern themselves with privacy management (Livingstone, 2008; Shade, 2003). Therefore, it is often suggested that when doing online research, participants should comply with offline consent protocols for vulnerable people (Kozinets 2010). Mann and Stewart (2000) also suggest that research involving children should always gain informed consent from the parents. However this is not straightforward when doing online research. Firstly, parents may be unwilling to consent, given fears surrounding the internet (Stern, 2002). Secondly, independent children and adolescents may find this offensive and most youth use the internet with no parental supervision (Stern, 2002; Flicker et al., 2004). Thirdly, gaining parental consent may not be appropriate, as parents may not know about certain aspects of their child's life- e.g., their eating disorder, online memberships or sexual orientation (Valentine et al., 2001). This last point is particularly pertinent for this study, parents may not know that their child is eating disordered, and so be unaware of their use of online anorexia forums. Attempting to gain parental consent could therefore result in harm being caused to the potential participant through the revelation of information they have felt it necessary to not disclose to their parents. It is for these reasons that informed consent from younger participant's parents was not required.

## **Anonymity**

Affording anonymity to research participants is a basic tenet of research ethics, in both online and offline contexts, as with informed consent, translating a standard offline ethical provision into an online context is not without difficulties or considerations. With anonymity the difficulty takes the form of who or what to anonymise, which will differ depending on whether the online space is seen to be public or private. With a researcher

-

<sup>&</sup>lt;sup>4</sup> Of the 27 interview participants, 2 were 16 or under.

being less 'obligated' to afford a participant anonymity if they are deemed to be in a public environment (Ess and Jones, 2004; Bond et al., 2013), however as previously mentioned, just because an individual is posting in a 'public' online environment that does not mean they are seeking publicity and that they would want their posts to be used in research (Sveningsson et al., 2009).

There are three ways to offer participants anonymity in online research, researchers can anonymise the community under study, participants' online persona/pseudonym or any details of offline identity they might disclose. All of these provisions go towards protecting participants from the potential harm of association with the data and when studying online community ensuring that the community is not disturbed by the research (Allen, 1996). With regards to the literature on pro-anorexia authors differ in their rationale for (not) anonymising the communities studied, differences appear to centre around the type of site being studied, the public/private nature of the site, whether the sites studied are still active and the methods used to collect data (Dias, 2003; Whitehead, 2010; Dyke, 2013; Fox et al.., 2005; Gavin et al.., 2008). As anonymity was a key concern of members of REC, in the ethical framework it was agreed that anonymity would be afforded to the community, members' online personas and offline identities. For continuity the same levels of anonymity have been afforded to members of ANA. I also avoid detailing specific information about the communities that would make them identifiable to others who are familiar with online anorexia forums. Instead they are spoken about in generalities, which offers further anonymity and protects the community from exposure.

When interacting online most services (chatrooms, forums, social networking sites, instant messenger services) require the registration of a username by which you can be identified to other users. An individual's username is potentially meaningful to them and if they use it across a variety of online platforms can be considered more than a pseudonym, it is part of their online persona (Lawson, 2004). Usernames, as well as being important to participants, can also be revealing, in that they may be expressions of the individual's personality (eg, ditzy1452), show their interests (eg, ChelseaFan784), physical attributes (eg, \*Brown-eyes\*) or be telling of the online culture the user is interaction within (eg, Skinny\_is\_perfect) (Svenningsson, 2004; Stommel, 2008; Steinmetz, 2012). As

a username can have significance for the member it is important to protect it, as perceived misuse could cause harm to them if their online persona is damaged and no longer seen as credible (Lawson, 2004). It is for this reason that in this study I have changed the usernames of forum members as well as protecting any offline details that may make them identifiable, affording them a greater degree of anonymity.

Further to protecting the community and members by altering names, pseudonyms or personal information, researchers can also try to ensure that quotes taken from their study site are not traceable by search engines (Riley et al., 2009; Mulveen and Hepworth, 2006; Gailey, 2007). This is an important step in protecting the anonymity of a community and its members, as affording anonymity is almost pointless if it is so easily detected. As the two communities under study are password protected they automatically do not appear in the results of online search engines, this is a marker of the 'private' status of the two sites, and is a way for the community to protect its members. This does not negate my role of protecting participants in this way, I frequently check that direct quotes are still untraceable via search engines, as taking this for granted could undermine other forms of data anonymising.

Sveningsson (2004) and Trevisan and Reilly (2014) discuss the way in which data is analysed as a way of protecting the identities of site members. Both suggest that doing analysis that looks at form over content has the effect of separating the individual from their text, thereby affording them another level of anonymity. My own analysis conforms to this, with the form that support takes being given precedence in each of the chapters, as this is what was dominant in the data. Content on an anorexia forum can range widely; what this thesis examines is how support is expressed and regulated in these environments.

### Use of data

The way in which data are used, in publications for example, has been given considerable attention in the literature on online ethics (Ess and Jones, 2004; bond et al., 2013; Markham, 2012; King, 1996; Reid, 1996; Trevisan and Reilly, 2014). This is in part because the possibility for harm is thought to not be limited to the data collection process, but researchers have the capacity to harm participants through the use, replication and

publication of their words (King, 1996; Reid, 1996). King (1996) suggests that the potential for harm is actually greater when the data has been collected through covert means or through deception. Therefore, the use of data in this study has significance as members of ANA were unaware of the observation phase of the research, and may feel harmed if they are to see themselves quoted in subsequent chapters. However, this is not to say that there are no ethical implications for the use of forum data from REC. While the community as a whole consented to the research being conducted, the potential for unintended harm from the use of quotes needs to be acknowledged.

Some of the discussion surrounding the use of data relates to preserving the anonymity of participants and communities through questioning of the necessity of direct quotes (Bond et al., 2013; Markham, 2012). As previously stated, researchers can protect participants through ensuring quotes are not traceable through search engines (Riley et al., 2009; Mulveen and Hepworth, 2006; Gailey, 2007), however, both Markham (2012) and Bond et al. (2013) suggest alternatives to direct quoting. Markham (2012) puts forward the idea of fabrication, which is when a researcher creates fictional accounts in order to illustrate the key themes of data analysis, therefore not using the words of participants, but still representing them. Bond et al. (2013) believe aggregated quoting is an ethical alternative to direct quoting, they describe aggregated quoting as taking many participants' views on a subject and merging them, in ways in which the meaning is retained but participants are not identifiable. However, an issue with both of these alternatives is the amount of power that is afforded to the researcher, there is the ability to distort data or misrepresent participants. Gatson (2011) claims that representation is the most powerful tool at disposal to researchers; ethical research is about readdressing this imbalance, which neither of these alternatives to direct quoting achieves. In terms of my own study, I have chosen to directly quote both interview and forum data from ANA and REC. Any other form of representation of participants could have a disempowering effect, as individuals with eating disorders are often spoken for, or over, as they are deemed unable to coherently represent themselves (Saukko, 2008; Lavis, 2011; Gremillion, 2003).

The steps I have taken towards making participants anonymous, by protecting the communities, changing online pseudonyms and personal information, acts as harm

reduction for the use of direct quotes. Members of ANA are also protected from harm in that no one member's forum posts are quoted extensively, and so the ability to identify them is further reduced. Protecting members of REC is more complicated, informed consent was gained, so the potential for harm is not due to deception but misrepresentation. There is the potential that I may have interpreted a member's post in a way they did not expect. While this could have positive as well as negative consequences (or be inconsequential), it is necessary to consider. Although I have afforded both communities the same level of anonymity, REC is a more technologically sophisticated site and allows for the retrieval of posts from years ago, which would allow members to search quotes and determine who they were authored by, meaning that quotes can become un-anonymised within the community and the original context reviewed. Therefore, participants are protected from identification from sources external to the community but not internally. In terms of members feeling misrepresented there is little I can do to safeguard against this, as a grounded theorist I have been led by the data and have conviction in the concepts and idea that analysis has born. Being a member of a forum, particularly one based on open critique like REC, requires members to understand that their words will be interpreted differently by different people, and my analysis can be seen as an extension of this. If a member does feel misrepresented by analysis I will explain and evidence my reasoning, and consider their intentions when posting, as this can often not be demonstrated in the impact of a message.

#### Conclusion

In giving such a detailed, reflective account of my own ethical decision making I hope to have shown the merit in discussing and being transparent about ethical conduct in online research ethics. As an emergent field it is vital that researchers are honest about their ethical decision making, as it allows others to learn from and expand upon the experiences of others. My own ethical stance has not been prescriptive, I have not attempted to follow a pre-determined 'tick list' of 'correct' ethical practice. Instead, I have adopted an adaptive approach to maintaining ethical conduct in this study. This was achieved through consistent and continued reflection on the issues that emerged as data collection was ongoing, considering my role as a researcher, the views of my participants and the discourses that surround individuals with eating disorders as marginalised

people. While I appreciate that this approach would not work for all online communities or in all online settings, it was the most appropriate way to manage the changing ethical needs of this particular study.

It was essential to discuss the ethical protocol of this study in such depth as it has influenced how data was collected, and so provides a base for the methodology of the study, which will be discussed in the next chapter.

## **Chapter three**

### Researching online anorexia forums

This study uses grounded theory to gain an understanding of how support functions on two online anorexia forums. In order to achieve this aim two complimentary qualitative methods, non-participant observation and online interviewing, are utilised. This chapter first defines the object of this research and online anorexia forums, before moving on to justify the methods used and then detailing how the research was conducted and analysed.

### Research Design

### Defining online anorexia forums

Online anorexia forums take many forms, and encompass a range of forum based websites that discuss anorexia or eating disorders more generally, from pro-recovery sites to pro-anorexia sites. Pro-anorexia forums are perhaps the most notorious type of online anorexia forum, gaining media attention and even being banned in France (Casilli et al., 2013). Pro-anorexia is difficult to define, as it encompasses so many different types of sites and is riddled with contradictions (Giles, 2006). Frequently pro-anorexia has been defined as sites that glamourise anorexia or treat it as a lifestyle choice, rather than a mental health condition (Knapton, 2013; Lyons et al., 2006; Juarascio et al., 2010; Bardone-Cone and Cass, 2007; Harper et al., 2008; Rouleau and von Ranson, 2011). However, this definition is flawed in that it does not correspond with site members' definitions of pro-anorexia<sup>5</sup> and fails to account for sites that do not adopt the lifestyle model but are still pro-anorexic. Csipke and Horne (2007) offer two different approaches to defining pro-anorexia, one is what they term a "liberal interpretation", a more broad understanding of sites, with pro-anorexia being seen as any site that accepts individuals as eating disordered and do not encourage recovery. Their second approach, which is a "narrow definition", gives a more focussed view of pro-anorexia and describes sites that encourage anorexia as a lifestyle choice as pro-anorexic (Csipke and Horne, 2007, p.197).

<sup>-</sup>

<sup>&</sup>lt;sup>5</sup> This is evident in the work of Yeshua-Katz and Martins (2012), who found that 24 out of 30 of the proanorexia bloggers interviewed described anorexia as a mental health condition, and, did not associate with the lifestyle choice model of pro-anorexia.

Using these two approaches as a starting point I would suggest that pro-anorexia is best thought of as a spectrum, with what I would term PRO-anorexia sites (those that glamourise or revere the condition) at one end and pro-acceptance sites on the other (sites that accept members are eating disordered and encourage frank discussion, including recovery). Sites can then fall at any point along the spectrum, as there are many sites that lie in this middle ground, in that they do not glamourise the condition but exist in order to support members through the lived experience of the condition. Pro-recovery sites are more easily defined and can be considered sites that facilitate individuals in their recovery from eating disorders. They take different forms depending on whether they are peer-led, like REC one of the communities studied in this research, or operated by a charity or clinicians. While pro-anorexia sites commonly discuss or encourage recovery (Borzekowski et al., 2010), a pro-recovery site would not be genuine if it endorsed pro-anorexic material.

### Why study online anorexia forums?

Williams and Riley (2013) state that while studies have looked at the content and impact of pro-anorexia sites, more research needs to be conducted to advance understanding of the social processes involved in site use and community functioning. This thesis aims to address this through looking at the social processes involved with support on online anorexia forums. As well as looking at content (Borzekowski et al., 2010; Rouleau and von Ransom, 2011) and impact on users (Csipke and Horne, 2007; Wilson et al., 2006; Bardone-cone and Cass, 2007; Harper et al., 2008), pro-anorexia has been studied from a variety of viewpoints including: constructions of anorexia (Knapton, 2013); identity construction (Haas et al., 2011; Day and Keys, 2008); the role of the body (Burke, 2012; Riley et al., 2009; Ferreday, 2003) and shown to be supportive environments (Dias, 2003; Mulveen and Hepworth, 2006; Brotsky and Giles, 2007). While support can be seen as a uniting theme in this varied body of literature, little has been written on how support is fostered on pro-anorexia sites, with content being privileged over form. Pro-recovery on the other hand is relatively understudied; the few publications that look at recoveryorientated sites have discussed language use (Lyons et al., 2006), constructions of the body (Riley et al., 2009) and the creation of recovery identities (Walstrom, 1999, 2000). Against this background, this study seeks to contribute to academic knowledge of prorecovery forums and to not only show that online anorexia forums *are* supportive environments but *how* this support operates. Therefore the broad aims of this study are;

- 1. To explore support as an element of online anorexia forums.
- 2. To gain an understanding of how support operates on online anorexia forums.
- 3. To gain an understanding of what elements influence the *form* of support given on online anorexia forums.
- 4. To gain insight into how members experience online anorexia forums as supportive.

# Overview of the methods

There are two stages of data collection in this study; the first involves non-participant observation of two forums, the second is online interviews with members of these forums. These methods have been chosen because they are best suited to meet the aims of the study. Forum observation has been a standard method of data collection in previous research on online anorexia forums (Whitehead, 2010; Maloney, 2012; Juarascio et al., 2010; Gailey, 2006; Smith et al., 2013; Walstrom, 2000), as it allows for a deeper understanding of the functioning of the communities. As my study aims to gain an understanding of how members experience online anorexia forums as supportive, a more immersive data collection technique benefits the study. Further to this non-participant observation allows the researcher to see changes over time, which will also illuminate continuities and discontinuities on the sites. Interviews were chosen to compliment the observation stage of data collection. Few studies have conducted interviews with members of pro-anorexia communities (Ward, 2007; Lavis, 2011; Fox et al., 2005; Yeshua-Katz and Martins, 2012) and as of yet no publications have reported that interviews have been conducted with pro-recovery members. Interviews add another dimension to the study and allow the insights I have gained from observation to be substantiated, as topic guides for interviews were based on the emergent categories from the forum data. Interviews are also an opportunity for members of the two sites to express their thoughts on the forums, providing further insight.

# Grounded theory

Grounded theory, while a systematic and comparative method for data collection and analysis, privileges empirical data, which is at the heart of theory generation (Corbin and Strauss, 2008). Grounded theory analysis is based on four fundamental elements, they are; coding, constant comparison, memo writing and the suspension of preconceptions (Holton, 2010). Grounded theory was chosen for this project because it can be applied to various kinds of qualitative data, and so could be used for both the observation and interview data. Further to this the focus on the data and the requirement for researchers to suspend their preconceptions of their field site is particularly relevant to this project. This is because online anorexia communities have been marginalised, and treated as deviant groups. The above tenets of grounded theory ensure that rather than perpetuating this sensationalist idea about online anorexia forums I am focussed on the data.

## Accessing online anorexia forums

Selecting sites for study

As the literature attests there are hundreds of online anorexia sites, taking many forms and being contributed to by thousands of people all over the world. It is far beyond the scope of this research to try to capture that diversity, and it was decided that only two sites, one pro-anorexic and one pro-recovery, would feature in this study. This decision is both practical and methodological. On a practical level, data collection through observation was expected to take 12 months (with data being collected simultaneously on each site); collecting data over this time period from multiple sites would have been time consuming and have resulted in an overwhelming amount of data. And on a methodological level, the aims of the study support the use of two sites as the focus is on the lived experience of using these sites for support. It is more important for the research to be focussed on two sites, in order to collect rich valid data, rather than develop a broad understanding through studying numerous sites. When searching for possible sites of study I did not limit searches to one search engine, instead I used three popular search engines (google, Yahoo! and bing) as different search engines will yield different results, combining the results of all three allows for wider breadth of sites (Norris et al., 2006; Knapton, 2013). In order to search for a pro-anorexia site the following terms were used;

pro-anorexia, pro-anorexic, pro-ED, pro-eating disorder, pro-ana, pro-mia and proacceptance. For pro-recovery the search terms were not as straightforward. Pro-recovery can refer to various conditions that require a recovery mind-set such as; problem gambling, alcoholism, self-harm, depression and drug abuse. Searching 'pro-recovery' yielded relatively few appropriate results and so the following terms were used on each search engine; recovery anorexia, recovery eating disorder, anorexia recovery support, eating disorder support and eating disorder recovery support. These terms resulted in more relevant sites being found. From the search term results lists were created of possible sites to study. Each site was viewed in turn and exclusion criteria applied. Inclusion or exclusion criteria are frequently applied to sites when conducting research online, in order to reduce the overwhelming amount of data searching key terms can produce (Mo and Coulson, 2010; Flynne and Stana, 2012; Sherman and Greenfield, 2013). Sites were deemed unsuitable for inclusion if they did not have a forum, if the forum had not been posted to in two weeks, or had fewer than 500 members (Riley et al., 2009). Sites that required members to sign in were also considered suitable for inclusion, for reasons outlined in the previous chapter on ethics and gaining access.

Applying these exclusion criteria allowed me to refine the lists of sites to ten potential pro-anorexia sites and seven pro-recovery sites (there are significantly less pro-recovery sites compared to the number of pro-anorexia sites). From this point my sampling takes on a similar form to that of Riley et al. (2009) and Gavin et al. (2008) in that it involved a period of monitoring a number of sites to assess if they were appropriate for study. I joined each site (if registration was necessary) and monitored them for a two week period, in order to gain a better understanding of the site, and ascertain if they were truly active enough to be studied, and importantly to gauge if they would be hostile to a researcher. After this period of observation, three pro-ana sites and two pro-recovery stood out as eligible for study. As I did not want to blanket contact all five sites, I contacted the two sites that I particularly wanted to be involved in the study. I did this for fear of appearing aggressive about my research, as while pro-ana is a large collection of individual sites and communities, they are not totally disjointed, to have a negative or hostile response from one community about my research could impact on being accepted or being seen as legitimate in another community. Sanders (2005) warns that previous

unethical conduct or overuse of the community by researchers and journalists may make a community cautious when approached by a researcher. With this in mind I did not want to exacerbate suspicions that already exist in and between online anorexia forums about researchers by contacting too many communities and becoming a known unwanted figure.

One of the key factors in deciding to contact ANA (the pro-anorexia site featured in this study) was the fact that it was so stable and established. At the time of sampling and recruitment it had been active for four years. As I was going to be observing forum interactions for a 12 month period and then recruiting for interviews with members, this was an important consideration. Pro-anorexia sites are often not stable, dying out due to popular members leaving, top down changes from site owners and moderators, and there is always the risk they will be closed by the server for contravening terms of use (Lavis, 2011; Knapton, 2013). Further to the stability ANA seemed to have, it was also an active site, with the forum being a hive of activity, with members posting new topics and replying to one another at high frequency (hundreds of posts a day). Rather than being at risk of dying out, it also had a growing membership, with new members joining on a daily basis.

As pro-recovery sites are not as precarious as pro-anorexia sites, the stability of the site that would be involved in the study was less of an issue. REC, the pro-recovery site involved in this study, is a peer-led support forum. I purposely wanted to focus on a peer-led site, a site run for and by those with eating disorders, rather than a forum run by a charity or a health organisation. The reason for this is that I wanted to understand how members create a sense of support in their community, which could be clouded if I were to study a site that was imposing particular rules, ideas of support, what it is to be a member and eating disorders on to members. For example, the British eating disorder charity b-eat, has a forum for those struggling with eating disorders. From speaking to members of REC and from my own observations I am aware that this space is moderated by charity workers and feels much more clinical than REC, which would give a different (perhaps more regulated) view of the support offered on peer-led online anorexia forums.

## Non-participant observation

#### Observation

In this section I will detail the process of conducting non-participant observation on the two sites. Although the way in which the sites were accessed for study was different (as discussed at length in the previous chapter), the actual process of observation was similar across the two sites. Over the course of observation I spent hundreds of hours on the two sites, immersing myself in their culture but also following the flow of members, moving beyond the boundaries of the sites as they did (Hine, 2000). On both sites I used the general discussion forums as an anchor point, checking posts made in these sections each time I logged on to get a feel of what had been happening in my absence. In order to collect this data, threads of interest were saved and converted into PDFs to allow them to be coded using Nvivo. Initially I was collecting a variety of threads, as a grounded theorist I was not intent on collecting a specific type of thread, but wanted to have a selection of threads to begin open coding to facilitate theoretical sampling as data collection progressed. A total of 621 threads were collected from the two sites and data collection lasted 11 months on REC and 12 months on ANA.

Once observation began I no longer posted to the forum on REC, taking the role of non-participant observer on both sites. A key difference that must be acknowledged from the outset is that members of REC knew I was observing them, while members of ANA did not. While my presence on REC was not overwhelming (only indicated by my username appearing in the 'online now' section at the bottom of any forum page), members were still aware a researcher was using the forum. The impact of my overt observation has both methodological and ethical implications. One of the benefits of online non-participant observation is that it allows a researcher to collect data without disturbing the naturally occurring data that is of interest (Hine et al., 2009). However gaining informed consent dilutes this in a sense, as forum members are now aware of your role as researcher and may react to this by changing their behaviour on the forum. While there was a distinct possibility of this happening on REC, I have not seen any evidence of it, archived posts and posts made after I began researching the site are indistinguishable. I attribute this to the disembodied nature of the internet (I was observing the site but was

not physically present), the size of the site (REC has thousands of members, the majority of whom are lurkers), and the fact that my research was not a priority concern for members or the community as a whole (therefore it can be suggested that did not consume their time spent on the forum). The ethical implication for overt observation is the potentially detrimental impact of having a researcher present on REC. Overt observation has the potential to make members feel uncomfortable and even stop them from accessing REC, which for some members may be their only outlet for their eating disordered thoughts and feelings. This was considered from the outset and one way of helping to counteract this was the ethical framework, which allowed members to contribute to the boundaries of the study. While I consider my participation on both sites to have been negligible, Gatson (2011) states that acting as a non-participant observer in an online forum is still participatory. This is because the majority of online content is read and not directly responded to, however the reader attributes meaning to the content and engages with it, albeit in a more passive manner than someone posting a reply. While this is an interesting stance, which highlights the participation that goes into being a passive member of an online community, my stance that I researched the communities as a nonparticipant observer is unwavering, as my impact on the communities through reading is limited. I, like all lurkers (members of communities that do not post, they only read), in online communities have not made a contribution, and so have not actively helped shape the community. However, Bond (2012) and Haas et al. (2011) discuss the role of the audience in pro-anorexia communities, with the authors suggesting that active members write their posts with a specific audience in mind and perform pro-anorexic identities that conform to audience perceptions. Therefore my presence as researcher could have impacted on how members of REC performed pro-recovery identities, knowing that I was part of the silent audience.

Observation followed the same process on both sites, I would sign in, go to the most trafficked area of the site (general discussion for both sites), and use them as a reference for events, indicators of who was online and what were popular topics of conversation. Given the geographical dispersion of members of ANA and REC I would observe the forums at different times of the day, knowing that certain times of the day would see peaks of posts from members in particular countries. Also different topics of conversation

are more pertinent at different times of the day, for example perhaps unsurprisingly logging on late at night or in the early hours of the morning would result in a lot of topics being started about insomnia or anxieties about starting the new day. This sense of temporal posting is also seen at starts of new weeks and new months, with members of ANA in particular using them to post new goals and seeing it as a fresh start, a chance to improve on the previously week/month. Other than using the general discussion forums as a marker of current events (almost like a newsfeed on Facebook), there was no fixed pattern to how I observed. I tried to make the process as natural as possible, clicking on threads and profiles that I found interesting, for whatever reason that may have been. I was always drawn to threads started by popular members of both sites (as were other site members) and in retrospect threads that were clear examples of what would become fundamental concepts to the study caught and retained my attention. An example of this on REC is 'challenging', members critique one another's eating disordered thoughts and behaviours in order to offer support. I was immediately interested in threads that contained challenging behaviour, as it was so unusual and at times felt aggressive and contradictory to the communities' aims of support.

My use of the forums was fluid, I did not limit myself to specific areas, as I wanted my observation to mimic an ANA or REC members own use of the site. Data collection during observation took the form of saving threads, which are a string of messages posted on one topic of conversation, and converting them to PDFs so they could then be coded using Nvivo. Deciding on which threads to save was again a fluid process and initially was influenced by the content of the thread. I would save threads that had a lot of replies, ones that had zero, threads that contained disagreement, collective understanding, threads that sparked my interest or struck me as mundane. In the beginning I focussed on reflecting the variety of messages that co-exist on the forums. It was when I began coding that data collection took a more focussed form. When collecting online forum data, researchers have been encouraged to consider the role of time, and the archival nature of forums, as a researcher may not be experiencing content at the same time or in the same order as participants (Hine, 2000). While this is true, I may have missed previous threads that inform more recent ones, or threads may have been deleted before I had seen them (which did happen on ANA), there is no one way of observing a forum, for me

as a researcher or for members, each of whom will have a different experience of the forum (Steinmetz, 2012). Furthermore, the aim of this study is not to provide a snapshot of each forum as it was in the year of data collection, but to use the threads and interactions of members to understand how support functions within the site, which transcends time. Interestingly on REC (which is a more technologically sophisticated site and better archived than ANA) looking at posts started in 2007 highlighted the salient aspects of support on the site, as these were consistent and enduring concepts.

When using grounded theory data collection is influenced by data analysis, as the two are conducted simultaneously, ensuring that the researcher is immersed in the data (Corbin and Strauss, 2008). As is mentioned throughout the literature, the process of beginning coding can be daunting for a novice researcher (Corbin and Strauss, 2008; Holton, 2010; Mruck and Mey, 2010). I was no exception and felt overwhelmed by the coding process, unsure if I was doing it 'right'. I began by line-by-line coding, as well as annotating the threads I had collected, looking at each thread on a micro and macro level, but always keeping in mind the specific support environment they had been taken from. As I became more confident with coding I also began the comparison element of analysis, comparing threads (within the communities and between the communities) and codes in order to establish if the emergent codes were substantive and consistently present in the data (Holton, 2010). This then allowed for theoretical sampling to begin taking shape, as the emerging codes from previous threads influenced why subsequent threads would or would not be saved and in turn analysed. As I began to theoretically sample the distinction between data collection and analysis becomes even more blurred, as selection of which threads to save becomes an analytical process. The inclusion of specific threads is based on how they fit with emerging codes, whether they consolidate a code or expose a gap to be further explored. Data collection at this point is entirely driven by data analysis. This process continued until theoretical saturation, that is until the data no longer yields results that expanded the codes and categories that had emerged from the data analysis (Holton, 2010).

It is important to acknowledge that both forums were gendered spaces, with women and teenage girls making up the vast majority of users on ANA, and all of the users of REC.

This is perhaps unsurprising given that 90% of eating disordered individuals are female (NCCMH, 2004). As these forums were so female dominated, this is reflected in interviews, with all participants being women or teenage girls.

#### *Immersion*

I was not only observing the forum and saving threads, but trying to get an understanding of pro-ana and pro-recovery more generally. Culture on the internet is not limited by geography, nor is it contained within one site, but is fluid and multi-sited (Hine, 2000). It has been suggested that effective virtual ethnography does not focus on place, but instead looks at flows, or links, following the culture that is under study without being bounded to one site (Hine, 2000; Hine et al., 2009; Steinmetz, 2012). I wanted to emulate this to an extent in my own work. While ANA and REC were the focal sites, it was necessary to move beyond these boundaries to develop my understanding of the two communities. Therefore, while I only collected data from ANA and REC, I would routinely sign in to other sites that were points of discussion, I would read the books members were talking about, watch the films that were thought to be 'thinspirational', look at proana and pro-recovery on youtube, twitter, tmblr, various blog sites and Instagram. I would research the diets and tricks that members were using, such as 2,4,6,8, the skinny girl diet, ABC (anorexia boot camp) and the salt water cleanse. I would also view members' blogs if they were linked in their signature (a passage that appears at the end of every message posted on the site, like an email signature). These activities allowed me to gain an understanding of ANA and REC and see them in the context of online anorexia forums more broadly. Members did not restrict themselves to the site, and I felt my observation should mimic this as much as possible. Understanding the culture surrounding the two sites, strengthened my understanding of the sites themselves, and gave me a way of being involved without actively participating in the sites. This immersive observation was shown to be advantageous during interviews, as participants did not need to explain certain things to me because I could say I had read the book, watched the film, or viewed the site, so there was an element of commonality and familiarity that eased discussion.

## Leaving the field

Leaving the field once theoretical sampling has reached saturation was not as straightforward as no longer logging into the communities. I had become attached to the communities themselves having spent hundreds of hours on them over the space of a year, I felt invested in them and was also caught up in some members' life stories, I wanted to continue reading their journal entries and blog posts, hoping that things would get better for them. Illingworth (2001) and Kralik et al. (2000) both mention the difficulties they faced leaving the field and ending research. Illingworth (2001) mentioned the guilt associated with leaving the field as soon as data was collected, making her feel like she had exploited participants. This is something I can relate to. As the weeks went on I began logging onto the forums less frequently and stopped following specific members' blogs, my time was spent continuing to analyse the data I had collected, which was time consuming. Driscoll and Gregg (2010) state that virtual ethnography must move beyond scholarly visits to the site and into the everyday life of the researcher. While there may be merits to this approach, it does not assist researchers leaving the field, which all researchers will have to do at some point.

#### **Interviews**

Inviting members of ANA and REC to interviews

In this section I discuss the process of recruiting participants for interviews from both the sites. The recruitment process differed significantly between the two sites, but resulted in a fairly equal number of interviews being conducted; with 13 being conducted with members of REC and 14 with members of ANA. Interviews were all conducted online, and participants chose their preferred format from the following: video, audio, instant messenger, email.

As the theoretical sampling of forum threads began to reach saturation, I started to think about approaching the communities to see if any members would be interested in being interviewed. Interviewing members of both communities simultaneously was not practical, as interviews, transcription and the subsequent analysis are time consuming. I approached members of REC first, as I knew approaching ANA members would be more complicated, given I was reliant on a gatekeeper and the potential for the community to react with hostility to my presence as a researcher.

Inviting members of REC to interview was a straightforward process. As agreed in the ethical framework I started a thread in the general discussion area of the site, in this I simply outlined that if members were interested in taking part in an interview they should email me (via private message on the site or my university email address) and I would send them further information and if they were still interested we could then arrange a time and 'place' and format for the interview. During my time observing REC a number of members had started a new pro-recovery site, the focus which was to support people who were further into recovery and not necessarily as entrenched in their eating disorder. A moderator of REC (one of the co-founders of the new pro-recovery site) suggested that I also post on the new pro-recovery site, as some members who wanted to take part no longer used REC as regularly and may miss my thread. I registered to the site and posted the same thread as I had on REC, but stipulated that members had to have been a member of REC to take part, as the interview was about use of REC, not the new pro-recovery site.

In total 16 members of REC contacted me about potentially taking part in an interview. A self-selection sample was used for interviews with members of both communities, as it is the most ethically viable option when researching online anorexia forums (Lavis, 2011). When members got in touch with me, either via the site or email, I sent them a participant information sheet, which contained details about the interview process and providing them with a link to the consent form, which was hosted on *surveymonkey*. As discussed in chapter two initially participants had to be 16 years old to participate but this was lowered to 13 years old over the course of the research, although none of the REC participants were under 16. Of the 16 members who contacted me, 13 took part in interviews over a three week period. Members were eager to take up the opportunity to be interviewed, but interest in the study quickly died out. Interviews were conducted over three different formats, video chat (Skype), audio chat (Skype) and instant messenger service (Skype, MSN messenger, Yahoo! messenger and AIM).

Inviting members of ANA to interview was always going to be complicated by the fact that the forum had been observed covertly, and so starting a thread on the forum detailing my study was not initially an option. Recruitment of participants in an online setting has been presented as unproblematic when compared to the difficulties

researchers may face offline (Illingworth, 2001), however my own experience of recruiting from ANA does not support this. Recruitment required much negotiation, ethical thought, and brought to the fore the issues of working in a disembodied space and took a total of eight months.

My starting point was to contact the site owner of ANA, who had previously agreed to act as a gatekeeper. Unfortunately, due to personal reasons, this was no longer something that they could commit to and so they suggested I contact the moderators of the site. I contacted an active British moderator, in the hope that they would have heard of Loughborough University and would see my request to research as authentic. I sent them an informal but detailed message about the study, linking to my staff profile hosted by the university in attempt to make myself visible in a disembodied space. She responded positively and we exchanged several messages, and I suggested potential ways of recruiting from the forum (with the moderators' permission) including a snowball sample (starting with her as she had expressed an interest in being interviewed) and starting a thread about the project on the general discussion forum. She advised against this, mirroring the sentiments of the site owner when I contacted them about the observation stage of the study. She felt members would not react kindly, and did not want to cause upset within the community. Despite her cautiously positive tone she ceased contact, and so I was unable to ascertain her thoughts on snowball sampling (although her lack of correspondence was indicative of discomfort with the situation). I then contacted another active moderator of the site, who was immediately hostile beginning her response with:

"I know you've messaged the other moderators and [site owner] as well."

(Moderator2, correspondence via ANA private message)

She expressed serious concerns with the formats interviews may take, particularly video interviews, as she felt they denied any anonymity to the participant. She was keen to stress that she was protecting members of ANA, some of whom were young teenagers and vulnerable because of their eating disorder and other associated mental health conditions. While I appreciated her stance, I also found myself frustrated, because although the moderator was trying to protect her community I also felt she was denying

them agency, not allowing them to come to their own conclusions about me and my research. McCoyd and Kerson (2006) found in their study of women who had terminated pregnancies due to foetal abnormality, that clinicians acting as gatekeepers at times were controlling of potential participants, which acted to silence those women. While the moderator of ANA felt she was acting in the best interests of members (especially those she considered vulnerable), she was also silencing them. Interestingly, interviewees often mentioned how vulnerable the community was, usually in reference to young members. No interviewees self-defined as vulnerable, and would have potentially been offended had I labelled them so. After a brief exchange of messages the moderator made it clear she wanted me to go back to the site owner, and for them to decide what was acceptable for the community.

The site owner was accommodating when I contacted them again, suggesting that I could advertise the project on a dedicated section of the homepage they had created to satisfy the growing number of researchers looking to recruit from ANA. Placing the advertisement (which can be view at http://homepages.lboro.ac.uk/~ssscl/) required me to make a donation of \$25, the ethical considerations of which have been discussed in chapter two. Once the advertisement had been placed members began to contact me about the project, however after approximately three months I was no longer receiving any messages. I went to the site to see that it had undergone a server change, and all previous content (including my advertisement) had been removed. I contacted the site owner to no avail, logging on to the forum I could see that they had not been present on the site for some time, much to the confusion and frustration of members. I contacted the moderator that had previously been hostile to me, asking if they knew where I could contact the site owner as I had not heard from them in weeks. She responded immediately saying they too had had no contact from the site owner, and they were unaware of the site owner's whereabouts. She suggested that I start a thread on the general discussion forum, as it was public (since the server change) and was the most highly trafficked area of the site, but recommended that I prepare myself for hostility.

I posted a short message on the forum under the title 'PhD research' which gave members a few details about the study and the link to my webpage. The first response on this thread was from the original British moderator I contacted, she left this message:

"Just to add that this has been OK'd to be posted here as Sarah has already donated money to ANA when this was on the old site and has made the transition over to the new site as did we "

(Moderator1, forum data, ANA)

The voluntary offer to post on the forum, and the above message that endorses my study and my presence on the site marks a significant change in the moderators' perception of me. They had gone from treating me as an outsider, and a potential threat to their community to legitimating my research and presenting me as a feature of the site, as I "made the transition over to the new site as [they] did". I am not sure what in particular caused this shift in attitude, in part I think it was the absence of the site owner (who had fallen out of favour with the site), my continued presence on the site (showing me as authentic and a stable presence), my unassuming message (I did not ask to post to the forum, merely if they knew how to contact the site owner) and finally the kind forum posts members made about taking part in interviews and how they found them to be interesting. All of these factors contributed to the moderators seeing me as authentic, and no longer someone to be suspicious of; I had proved myself to be trustworthy. In the weeks following this post I had increased interest from potential participants. In total I received 34 emails from members of ANA interested in being interviewed. This translated to 15 interviews being started, however, one member signed off during an IM interview and did not respond to any follow up emails, 14 interviews were completed over two different formats (instant messenger and email). Of the 14 respondents two were under 16 years old.

# Rationale and process of online interviews

Online interviewing, particularly email interviewing, is becoming an increasingly popular form of data collection, due, in part, to the cost and time benefits they offer (Deakin and Wakefield, 2013). For this study moving from the internet to conduct face-to-face interviews would have been problematic for practical, ethical and methodological reasons, and so semi-structured interviews were conducted via a variety of online formats. Baym (2006) makes a strong case for conducting interviews with individuals about their internet use, stating that without listening to those with lived experience, we,

as researchers, cannot make claims of understanding the intricacies of online phenomena. One of the aims of this study was to gain a greater insight into the experience of accessing support through an online anorexia forum. Online interviews were a key way of meeting this aim, as they moved beyond observation and required members of ANA and REC to express themselves in their own terms. Online interviews were also an opportunity to add depth to the observation data already collected and analysed, as members of ANA and REC gave their thoughts on what were emerging core categories, adding details that could not have been observed and pushing the research forward.

When potential participants contacted me they were sent a participant information sheet, which contained information about the study and, initially a link to an online consent form. There were only two requirements for taking part in the study: participants had to be members of ANA or REC and had to be 13 years of age or older. The online consent form was replaced with gaining written or verbal consent at the beginning of the interview, as it was seen as a barrier to some participants. Once the participant information sheet has been read, potential participants would message me to confirm they were still interested (if they did not do this I would send follow up messages after a week) and an interview would be arranged in their preferred format and using the service provider of their choosing. I invited participants to select the format of interview from the following; video chat, audio chat, instant messenger and email. This ensured that they were able to communicate via a medium that best suited their needs and they felt most comfortable with.

Regardless of the format the interview took they started in the same way, with greetings and thanks for their interest in the study and brief small talk (while it may seem unnecessary it allowed participants to adjust to the research setting, participants would state they were nervous regardless of the interview format). I would then go through what I called 'admin', asking if they had read the participant information sheet, explaining it if necessary and fielding any questions interviewees may have. I would then seek confirmation that the interviewee was still happy for the interview to go ahead. I would then start with my first question, which in all interviews was 'what was your reason for joining ANA/REC?'. I had a topic guide (see Appendices C and D), which contained

questions around topics that were emergent from the observation data. The purpose of these questions was to add depth to the existing core categories, develop them further by highlighting gaps and seeing if members believed them to reflect the user experience of ANA and REC. Deriving interview questions from the in-depth analysis of observation data ensures there are less of my own presumptions and judgements, as the questions emerge from the forum data. This and the revision of the interview schedule between interviews allowed the data collected to be more focussed, retaining relevance to the project and allowing pertinent topics to be further explored. Interviews were informal, and schedules were not stuck to rigidly, but I adapted questions to the flow of conversation, making them fit in with what was being discussed.

### Interview formats

Face-to-face (FTF) interviews have long been considered the 'gold standard' of interviewing in qualitative methods (Deakin and Wakefield, 2013), however this privileging of one method denies the heterogeneity of participants, not all of whom will be able to express themselves fully in this setting and may prefer the disembodiment and perceived anonymity offered by online interviews (Seymour, 2001; Cook, 2012; McElhinney et al., 2013). There were four interview formats available to interviewees. Of the 27 interviews conducted, 4 used video chat, 2 used audio chat, 18 used instant messenger and 3 used email. As is clear, participants preferred the more disembodied formats, rather than the formats more akin to face-to-face interviewing. This may be because of an increased sense of anonymity, but may also be because, as members of an online forum, they are used to expressing themselves through text mediums and may feel more confident using this format (Ayling and Mewse, 2009). As well as being convenient and potentially more user friendly (Cook, 2012), online interviewing has the ability to reduce the power imbalance that is inherent to FTF interviewing. This is because the anonymity they afford allows social cues like gender, age, ethnic origin or class to be easily established (Jowett et al., 2011). However, in making ourselves visible as researchers, in order to be seen as authentic, we may actually re-establish these power imbalances, as we are no longer anonymous and our social cues are there to be read (James and Busher, 2006).

Sanders (2005) asserts that different interview settings will have an impact on the type of information that an interviewee discloses. She was referring to conducting interviews in online and offline settings with sex workers, but this could have implications for the different online interview formats used in my own study. Whatever the format of an online interview it is imperative that the interviewer has appropriate knowledge of the medium, as well as the culture under investigation (Illingworth, 2001), as limited knowledge about Skype for example, will impact heavily on an interview conducted via this service. I appreciate that different interview formats may produce different outcomes, due to the researcher not being able to maintain a distraction free interview setting (Jowett, 2011; Deakin and Wakefield, 2013). Some online interview formats (audio and typed) may lack non-verbal cues which is at times presented as an issue (Davies et al., 2004; Bjerke, 2010), but this can also be beneficial as interviewees cannot be reliant on non-verbal cues, and must verbalise everything (as must the researcher) ensuring a greater level of clarity in the interview (Hinchcliffe and Gavin, 2009). The online space an interview occurs in will facilitate varying levels of anonymity, which may make individuals more inclined to self-disclose personal information (Cook, 2012; Hunt and McHale, 2007). However, medium is not the only factor to consider, and in my own research I think that the community a member came from is more telling of the type of interview that will result, which will be discussed in more detail below.

### Interviews as presentation of self and community

While the formats interviews took will have had an impact on *how* things were said, I think that the need to present oneself and the community the interviewee was representing in a particular fashion was a larger factor in determining the type of information members would relay. Seale et al. (2010) in their comparison of interview and forum data suggest that interviews provoke a specific type of presentation style, one that is positive, consistent, coherent and accountable. The authors' talk of this in terms of the individual, while I suggest that this extends to the community a member is a part of. When interviewing members of ANA and REC it was clear that they were attempting to display the community in a positive and constructive light. This was seen on REC by members stating that the community was not pro-ana, mentioning the importance of having the support of a medical term and the role of moderators in keeping the

community safe. On ANA this was also important, members would describe how the site would never encourage anorexic behaviour, that members are protective of younger members and that anorexia is an illness, not a lifestyle choice. In interviews members constructed a sense of what the communities were, within the boundaries of the community norms. Members also presented themselves within the limits of the communities. One clear example of this was Harriet (a member of ANA) who repeatedly described herself as a "volatile nutcase", strongly emulating the 'sickness mentality' that acts as a site ethos (see chapter four). That is not to say that members were just projecting a sense of community or selves on to me. As I had been so immersed in both ANA and REC, and because the questions I was asking had emerged from the data, the way in which they were presenting themselves and the community resonated with me and was also facilitated by our mutual understanding of the two online environments (Bjerke, 2010).

One of the key differences in the two communities is that when it came to interview, REC members knew I had been observing the forum and ANA members did not. Jowett et al. (2011, p.363) describe having 'insider status' when conducting online interviews with gay men, as the interviewer also openly identified as gay. I do not consider myself to have had 'insider status' on either site. While members of REC knew I had been observing the forum, and so would ask if I had seen particular posts or knew of specific members, they were always talking to me about *their* community, something I was observing but not an active part of. The same was true of ANA, members constructed me as a curious outsider, someone that was interested in *their* community. My position of 'outsider' on both sites and the influence of community constructs on interviews, suggests that in this study, the format the interview took and my role as overt/covert observer were of reduced significance.

# Authenticity in online research

Some of the literature on online research methods encourages researchers to assess the authenticity of their chosen study sites and participants. In part this stems from a mistrust of what cannot be seen, and so cannot be verified (Mann and Stewart, 2000; Hunt and McHale, 2007; Cook, 2012). Hine (2000) problematizes the concept of

authenticity, stating that it is reliant on identity being fixed, rather than fluid and based on context. She states that "standards of authenticity should not be seen as absolute but are situationally negotiated" (Hine, 2000, p.49), suggesting that as researchers we focus less on how 'authentic' participants appear and more on how they interpret what is and is not authentic online. As a grounded theorist, my perception of what is or is not authentic on both ANA and REC should be influenced not by the literature, but by how the two communities respond to authenticity, or accusations of inauthenticity. Having extensively observed the forums and then spoken to individuals about forum life, there is an implied level of trust on both sites, with members taking one another at face value. Like Lavis (2011) I think that it is important to follow the example set by the communities which are participating in the study, and place trust in them, that they are representing themselves and the community in a way that is fitting. Another point to note is that I was unquestioning of members' diagnostic status, like Boero and Pascoe (2012) I was not looking for 'genuinely' eating disordered individuals. For this study the fact that they take part in an online anorexia forum makes their contribution genuine.

Throughout the data collection process I felt the need to present myself as authentic, much more acutely than the need to question participants' authenticity. Not once did I feel the need to verify a members' story, be that on the forum or in interviews. I did, however, go to lengths to make myself appear as an authentic researcher. From the outset of the project I was aware of the need to present myself as credible to participants, as determining if an individual is authentic online is complicated by the disembodied nature of the internet. There were two things I could do as a researcher to present myself as genuine to participants, they were: to be honest and to maintain an online presence. Further to these my status as authentic researcher was validated by influential members of the forum and members who took part in the research.

While honesty and openness is always a valuable trait in qualitative research, it is perhaps more pertinent in online research, particularly interviewing, as the researcher is not visible to participants (Jowett et al., 2011). In all correspondence with site owners, moderators and forum members I was as open and honest about the research as possible. This included admitting when I did not have the answer to a question, and responding to critique without being defensive. This approach was also a large part of my

ethical framework, being honest allowed me to put participants and the communities first in the project, rather than privileging the research itself. While a very simple thing to do, it had impact, members of both communities commented on how they liked the honest approach I had taken to the research, which apparently made them feel like it was a project they wanted to be part of.

As it was the only way members of ANA and REC could assess if I was credible, my online presence was an important factor in creating a sense of authenticity. As I am a PhD researcher my online presence is limited, which can cause issues in creating a credible identity. Sanders (2005) warns that offering small token gestures may not be enough to create a credible identity. Her recruitment of sex workers for interview from the forum PunterNet was jeopardised by her not providing enough evidence of her legitimacy, as she only supplied a university email address and mobile phone number, causing members to be suspicious of her motives. Like Sanders (2005) I was attempting to recruit from a stigmatised population, and so will have been treated with suspicion until I was able to prove myself to be trustworthy. In order to counter this I maintained my staff profile page hosted by the Social Sciences Department at Loughborough University. I could include links to this when introducing myself to site owners, moderators and the communities (when starting threads about research or interviews). This gave members the opportunity to find out more about me, the profile includes my academic qualifications, research interests, teaching responsibilities and a photo. Ensuring that members had a way of verifying who I was online is both respectful and another way of creating an honest relationship with participants (McElhinney et al., 2013). As well as my staff profile I also designed a webpage (which can be viewed at http://homepages.lboro.ac.uk/~ssscl/) to advertise the interview stage of the research to members of ANA. This was another exercise in making myself visible and credible as a researcher. The webpage contains information about the study, advises interested members to contact me via email for more information and again contains a photo. Including a photo of myself on both my staff profile and the advertisement for ANA felt important, as I was making myself visible when I could have remained unknown. It also adds a more personal element, which may result in a more informal relationship being established (Kralik et al., 2000). The advertisement for ANA was an opportunity to not

only present myself as genuine, but also show the project to be non-judgemental, and assure members that I was not going to be demonising or presenting a stereotypical view of pro-anorexia. While the information I presented to members of ANA and REC about myself and the project will have aided my need to create an authentic online presence, the affiliation I had with Loughborough University will have also been valuable. Madge and O'Connor (2004) highlight the benefits of being associated with an institution when conducting online research, suggesting it creates a sense of trustworthiness. My affiliation to Loughborough University is shown through my email address, staff profile on the department webpages of the Loughborough University website, and the advert, hosted by the university. This has the potential to strengthen my sense of authenticity.

While there were steps I could take to appear more authentic to members of ANA and REC, my credibility as a researcher was undeniably aided and in some ways verified by members throughout the research process. When posting on threads I had created about the research on both sites the positive responses of moderators will have set the tone for other member's responses and their influence should not be underestimated (Madge and O'Connor, 2004). When this happened on ANA it marked a significant shift in how moderators perceived me, going from being openly suspicious of me and my agenda, to endorsing my research on the general discussion forum of the site. It was not just moderators that helped to verify my authenticity to the rest of the community, on both sites members publically responded to the invitation to interviews, commenting on the thread that they were interested in taking part or that they had taken part. Again, this kind of endorsement was invaluable, as it simultaneously showed me to be an authentic researcher and encouraged other members to take part in the study. The influence forum members have over the study highlights that as virtual ethnographers we are able to see how our research is being responded to, which in turn, has the power to shape the research study (Sanders, 2005). Research is not abstract in these environments, but is lived. The lived nature of my own study is evident when participants commented on threads saying they had been interviewed on ANA, when members discussed the merits and drawbacks of being interviewed on REC and when moderators made comments like the one above. I was privy to all of these discussions due to my role as observer and was able to see how they impacted on the study.

### **Analysis**

Using grounded theory: Coding, constant comparison, memos

Coding, constant comparison and memo writing are the three fundamental elements to analysing data using grounded theory. Coding takes many forms, which adapt and change over the course of the analysis and can be focussed on micro details in data or used to give more a broad macro level view (Corbin and Strauss, 2008). Coding began with line-by-line coding, as an open form of coding is best used at the beginning of a project because it helps a researcher break into a data set (Corbin and Strauss, 2008). Coding line-by-line allowed me to look beyond what was actually being said, and deconstruct the meaning attributed to data by questioning the data and my own interpretations. Through line-by-line coding core categories emerged from the data, some of which for REC included 'inspirational', 'mother', 'struggle', these were codes that were present a lot in the data, or linked to other codes.

At this point to start making sense of the hundreds of developing codes I began to develop coding trees, to get an overview of what codes were present in the data and how they linked. I did this on and off the computer, using functions in Nvivo and also drawing basic mind maps and making colourful lists to make sense of what I had in front of me. At this time codes were being compared, within and between the two communities, as well as the raw data itself going through a process of constant comparison. I would, for example, compare similar threads that occurred on the same community but might have a different subject matter, threads on the same subject matter between the two communities to see how differently communication was constructed on the sites. All the while through coding and comparing data I would also be memo writing, which is thought to be the bridge that links data and theory in grounded theory (Lempert, 2010). Memo writing at first took the form of reflection, what was I coding, why, critically thinking about the codes that were being generated. As coding progressed and I was more familiar with the data, memo writing was more a process of thought development, a way of linking codes together, of exploring possible reasons for forms of interaction, a way of questioning what I was seeing emerge.

As core categories were corroborated (or shown to be limited in scope) I began to move into selective coding, which is when a researcher codes based on the categories and codes that have already emerged from the data, as open coding provided lines of enquiry to follow (Holton, 2010). This felt like a natural process rather than a conscious decision to move away from open coding, and allowed for appropriate topics for interviews to be established. Once interviews were completed and transcribed if necessary, they were selectively coded using the codes that had emerged during analysis of the forum data, expanding these categories, exposing gaps and further lines of inquiry to be explored in subsequent interviews. Having saturated core categories, I was able to theoretically code, which is establishing relationships between codes are considered in more depth, again I was aided by the use of diagrams in this stage of data analysis, spending time drawing out the links that occur between codes. From this analysis a theory of how support functions on these two sites was established. While I cannot claim it is a complete theory, it is substantiated with the themes and categories weaving together, reinforcing one another, and creating an in-depth understanding of these two different support environments.

The sensitising concepts that are used throughout this thesis are the 'recovery spirit', the 'sickness mentality', 'challenging', 'non-judgemental support', dialogic and monologic communication. Each of these concepts is grounded in the data, and focusses on the *form* of support given on the sites rather than *content*. Form is an integral concept in this thesis, and refers to *how* support is performed, interacted or communicated, in the context of the studied support environments. The focus on form has been a result of the grounded theory approach of this study, as analysing the data for concepts, context and process (Corbin and Strauss, 2008) has led to an emphasis on interaction and how members of ANA and REC act out community. Corbin and Strauss (2008) describe conducting data analysis for concepts, which are 'words that stand for ideas contained in data' (Corbin and Strauss, 2008, p.159); context, which are the conditions in which 'action/interactions/emotions' (Corbin and Strauss, 2008, p.299) take place and; Process, which are the responses, which can take the form of 'action/interaction/emotions' that individuals (or communities) have to situations that arise out of context. While the analysis detailed in this thesis incorporates all three elements of concept, context and

process, I would argue that I have focussed on process and this in turn has led to the exploration of the different forms of support on ANA and REC. In describing process, Corbin and Strauss (2008) use an example of an airport restaurant, suggesting that the work done, the emotions elicited, interactions between customers and staff all demonstrate the process of that particular setting, as they reveal the flow of ongoing interaction in that setting. Process can be analysed in various types of interaction, from the mundane, to the chaotic, to the micro, to the macro. As Corbin and Strauss (2008) suggest, I have used routine interaction "to identify the patterns of inter/action/emotional response that make it possible to establish or maintain social and personal stability" (Corbin and Strauss, 2008, p.100) on ANA and REC. Rather than conceptualising this as a routine or process of support, I have described it as the *form* of support, as I believe this encompasses the routine nature of what has been observed, it does not suggest a linear progression as process does and suggests that support can take many forms, dependent upon the angle from which it is approached.

Taking each in turn I will now briefly describe how each of the above sensitising concepts emerged from the data and was developed through the process of data analysis. Turning first to the 'recovery spirit', which is a site ethos used on REC to unite the community through the empowering potential of choice and the pursuit of recovery. This concept emerged through noticing when members were reprimanded or congratulated, why this happened, and how other members responded to such messages. From the outset of data collection and analysis it was evident that members of REC were conforming to 'something', as the community lacked a strong countervoice or out-group, and members appeared keen to show themselves as compliant and willing to recover; the 'recovery spirit' emerged as that 'something'. The 'sickness mentality', which is the site ethos on ANA, is typified by members' belief that they have no choice in their eating disordered thoughts and behaviours, creates an environment in which members can be consumed by sickness, vent issues and also creates a contentious attitude to the community's main out-group, the 'wannarexics'. This 'sickness mentality' is a concept that is testament to the benefits of constant comparison, as it was the stark juxtaposition between the two communities that really saw this concept take shape. As well as this when collecting and analysing data I was interested in site purpose, why did members keep returning to ANA? What was the appeal of the site? Questions such as these and member's defence of their eating disordered behaviour that contributed to the emergence of the 'sickness' mentality' as a core concept. 'Challenging', the open critique of members' eating disordered thoughts and behaviours, is a concept that already existed on REC and so analysis did not bring it to light but explored what it meant to the community. I initially found 'challenging' jarring and rude, and I was unable to understand the appeal of this very critical form of support. Through analysing 'challenges', as well as responses to 'challenges' and seeing members talk positively about 'challenges' I was able to see the purpose of 'challenging' and see the place it held in this support environment. 'Nonjudgemental' support, the tenet to which support on ANA must conform, took many forms over the course of analysis, initially being thought of as 'the ideal user' and then 'the responsible user'. I was struck by how members of ANA positioned their use of the forum as unproblematic compared to other pro-anorexia sites, or other ANA members. Through continued analysis, and looking beyond member's understandings of what was acceptable behaviour, I began to see that this was part of a bigger, more complex understanding of what constituted support on ANA. From the outset of data collection it was clear that the way in which members of ANA and REC communicated on the forums was different, but both acceptable in their specific support contexts. Members of REC could be seen engaging in high levels of interaction, with members appearing attentive to one another, forming strategies that convey committed membership and advance the support given on the site. While members of ANA appeared to be talking into the ether, with members not required to respond to posts in any specific manner, with communication being typified by self-disclosure rather than fostering a sense of support. Through exploration of these different communication forms the final two sensitising concepts, dialogue and monologue, became pertinent lines of inquiry and as analysis developed were shown to be fundamental to the support that is given on each site. While they are grounded in the data, dialogue and monologue are concepts that have their roots in Bakhtin's (1994) writings, and so a Bakhtinian framework has been applied to further understanding of dialogue and monologue. Through the use of Bakhtin's (1994) dialogue and monologue, the subtleties of these forms of communication were explored and the communication on ANA and REC was found to be simultaneously dialogic and monologic.

Through briefly describing the way in which the sensitising concepts of this thesis were seeded or developed, the focus on form becomes more apparent. The concepts outlined illustrate not just the context or content of support on ANA and REC, but go beyond this and explore the flow of support on the sites, highlighting the constraints that enable support to operate effectively on both sites and thereby illustrating the varied *forms* of support.

### Point of departure

This chapter gave a detailed account of how the data featured in this study was collected and how the subsequent analysis was generated. The following chapters use both data sources (forum data and online interviews) to illustrate the key categories and emergent theory. Chapter four looks at how the culture of a site determines the way in which support is perceived, through the development of two site ethoses, the 'recovery spirit' and the 'sickness mentality'. Site culture is shown to be fundamental in shaping support on ANA and REC. Chapter five looks at the main ways in which support is expressed on the two sites, through analysis of the normative concepts of 'challenging' and 'non-judgemental support' and how this regulates the members using the site. Chapter six looks at how support is communicated on the two sites, and is shown to be simultaneously dialogic and monologic on both communities. The final chapter of this thesis offers a summary of the findings, as well as reflections on the limitations and contributions of this study.

### **Chapter four**

Defining anorexia: the role of diagnosis and choice in the creation of site ethoses

#### Introduction

In this chapter I aim to illustrate that support on both ANA and REC is shaped by the distinct cultures that exist on these forums. These site cultures are specific to these sites, and are influenced by both online and offline phenomena. In order to highlight how they implicate support, I will focus on the communities' understandings of eating disorders, through discussing how they interpret the diagnostic criteria for anorexia and the notion of choice in eating disorders. While observing ANA and REC I was surprised by how openly critical members of both communities were about the diagnostic criteria for eating disorders, particularly the criteria for anorexia, with members frequently critiquing the criteria and reassuring one another that their inability to meet the criteria does not diminish their suffering. The diagnostic criteria members of both communities discussed, and critiqued, was the Diagnostic and Statistical Manual of Mental Disorders (hereafter DSM) (APA, 2000). Published by the American Psychiatric Association the DSM is essentially a catalogue of mental disorders, which provides clinicians with a systematic check list of symptoms and behaviours associated with all recognised mental disorders. One of the key uses of the DSM in the United States is to determine if individuals are eligible for treatment, with the cost being covered by insurance companies; failure to conform to a DSM diagnosis may bar access to insurance and therefore treatment (Kirk and Hutchins, 1996).

Much of the critique that members of ANA and REC level at the DSM criteria stems from the criteria's perceived overemphasis on weight for diagnosing someone with anorexia. This is contrasted with how members discuss eating disorders on the forums, as they focus not on an individual's physical manifestations of anorexia but the lived experience of being eating disordered. Members of both communities discuss the reality of being anorexic in terms of emotional and mental suffering and the way in which their lives are ruled by the condition. By focussing on the lived reality of eating disorders, members of REC are encouraged to see themselves as more than their diagnostic label, further cementing the community's rejection of the DSM. On ANA focussing on the lived

experience of anorexia actually leads to a defence of the DSM by some members, who reaffirm the importance of different diagnostic labels and the role of physical symptoms in anorexia. This does not create conflict on the site, but does produce tension, with members uncertain how to position themselves in order to appear authentically eating disordered.

While the way in which members interpret the DSM criteria highlights the similarities between the communities, through looking at how they interpret the notion of choice the differences become stark. It is through the notion of choice that the impact of site cultures on support become clear, as the way in which choice is interpreted and understood on the sites creates two site ethoses, which constrain the support that is given on these forums. On REC members embrace the idea that they have a choice in recovering from their eating disorder, creating the site ethos of the 'recovery spirit', which empowers members, creates a sense of unity on the site and also marks the boundaries of acceptability. While on ANA members reject the notion that they have a choice to recover or in having an eating disorder, creating what I have termed the 'sickness mentality'. This site ethos allows members to express suffering, deny culpability for their eating disordered thoughts and behaviours; sets a tone on the site and also marks out the largest out-group on the site the wannarexics. The 'recovery spirit' and 'sickness mentality' are not forms of support, but are the means through which members can access support. They can also be seen as the foundation on which the forms of support that exist on the two sites are built upon. In illustrating the way in which the support given in an online environment can be shaped by implicit regulating constructs, this chapter contributes to the literature on online anorexia forums and support forums more generally.

### Wider literature on the DSM

Before examining how the two forums use the DSM criteria for anorexia to create their own understanding of eating disorders, it is useful to review how anorexia is clinically diagnosed using the DSM. The DSM is undergoing a constant process of revision, and during the course of this research a new revised edition has been published, the DSM-V was released in May 2013. Rather than using the revised edition of the DSM, this chapter

will refer to the fourth edition (DSM-IV) throughout, as this is the edition members of both communities engaged with and critiqued. According to the DSM-IV an individual has to meet the follow criteria to be officially diagnosed as anorexic:

- A. 'Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
- B. Intense fear of gaining weight or becoming fat, even though underweight.
- C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
- D. In postmenarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration).

### Specify type:

Restricting Type: during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

Binge-Eating/Purging Type: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)'

(APA, 2000, p.539)

I have chosen to focus specifically here on the criteria for anorexia, rather than looking at other eating disorders, because it is the diagnosis most discussed on the two sites that I have been studying. Also it is well documented that a diagnosis of anorexia carries a sense of credibility and superiority over other eating disorder diagnoses, both online and offline (Dias, 2003; Giles, 2006; Warin, 2006; Allen, 2008; Burns, 2004).

Diagnostic categories often become naturalised, rather than being anchored in a specific social, historical and cultural context in which they are written (Kendler, 2009). The social, historical and cultural context of the DSM exposes the subjective nature of this document and highlights the power imbalances that are embedded in its use. The DSM, first

published in 1952 (Pilgrim, 2007), has been through five revisions over the past five decades (Harper, 2013), with the DSM-I and DSM-II being based on psychoanalysis, which at the time was the dominant paradigm through which mental illness was understood (Lafrance and McKenzie-Mohr, 2013). The first two editions of the DSM were thought to be ambiguous, with the categories for mental illness being vague and resulting in a lack of consistency in diagnosing patients (Lafrance and McKenzie-Mohr, 2013). This resulted in what Mayes and Horwitz (2005, p.249) call the "crisis of legitimacy" in psychiatry, as the discipline was being challenged from a variety of viewpoints, the DSM-III, published in 1980, is seen as an attempt to reinstate a sense of legitimacy to the discipline, and marks a revolutionary shift from a theoretical understanding and categorisation of mental illness to one based on biomedical symptoms (Lafrance and McKenzie-Mohr, 2013; Mayes and Horwitz, 2005; Kirk and Hutchins, 1996). This shift from theory to biomedical understandings of mental illness can be seen as having been successful, as despite critique from a variety of disciplines (Pilgrim, 2007), the DSM persists and continues to be highly influential (Harper, 2013). It is important to note that while the DSM is published by the American Psychiatric Association, it is designed to be compatible with the World Health Organisation's own medical classification system, The International Classification of Diseases, and so has an impact far beyond the US (Cosgrove et al., 2008).

One of the main criticisms levelled at the DSM is the claim that the criteria, and the manual itself are objective and unbiased, when in reality it is "a means through which those in power decide what is socially acceptable" (Lafrance and McKenzie-Mohr, 2013, p.122) through the ability to deem certain behaviour a sign of mental illness. This claim has led to the DSM being described as a "political manifesto" for psychiatry (Pilgrim, 2007, p.538), and, as "institutionally embedded" (Harper, 2013, p.79), as it is necessary for insurance companies to release funding so individuals can access treatment, and in publically funded healthcare systems a diagnosis is frequently required for administrative purposes (Harper, 2013). This has the impact of solidifying the role of diagnosis in medical practice, as it is a gateway to treatment for millions of individuals. In light of this false claim of objectivity Cosgrove et al. (2008) call for clinicians and clients alike to engage with and critique the production of psychiatric knowledge. Claims to objectivity are

further undermined by the increasing involvement of the pharmaceutical industry in the production of the DSM (Cosgrove et al., 2008; Lafrance and McKenzie-Mohr, 2013).

Beyond the claims of objectivity, the DSM is also considered flawed as it reinforces the idea that mental illness is an intrapersonal issue, which results in social inequality and marginalisation being overlooked as influential factors to an individual developing mental health problems (Harper, 2013; Cosgrove et al., 2008). Further to this the dominance of the DSM, and the biomedical perspective of psychiatry it endorses, only enables individuals diagnoses with mental health issues to understand their condition in these terms, they are confined to one discourse and must express themselves using its language (Guilfoyle, 2013). Looking at diagnosis from the perspective of patients, Pitt et al. (2009) in their study of the impact of a diagnosis of psychosis found that individuals reported both positive and negative effects of being diagnosed. The positive impacts were: allowed access to treatment; giving the problem a name; and enabling individuals to work towards social inclusion. The negative impacts were: disempowerment; labelling; and the diagnosis as a reason for social exclusion. Lafrance (2007) also found that diagnosis was contentious for the individual, while it provided them with a sense of validation, and a label for their distress, the focus on the biomedical and the fact that condition is not a somatic illness lead to further feelings of illegitimacy and stigma. Therefore, diagnostic criteria, like the DSM, have the capacity to produce positive change for those subjected to its discourse, while it also has the impact of further marginalising those who are already marginalised in society. This leads to another criticism of the DSM, as it only classifies mental health conditions, and does not offer any treatment recommendations (Kirk and Hutchins, 1996; Pilgrim, 2007).

This chapter builds on the literature that critiques the DSM, through illustrating the ambivalent interpretation of the DSM-IV criteria for anorexia in two online anorexia forums. This will be shown to create an understanding of eating disorders on the two sites, which is framed within a biomedical understanding of eating disorders, but highlights members' lived experience, something which is lacking in the DSM-IV criteria. Giles and Newbold (2013) highlight the importance of studying online community interpretations of diagnostic criteria, and how these in turn shape community constructions of what is it to have a specific mental health condition. Starting by

examining the construction of eating disorders on ANA and REC, the following analysis shows that interpretation or critique alone are not enough to create a boundaried community or a tangible sense of support on the sites. And so, this chapter moves on to discuss the way in which members interpret the role of choice in the construction of eating disorders, which is shown to influence the communities and the provision of support.

#### Diagnosis and choice in literature on online forums

Through the analysis of forum and interview data, it became apparent that the concepts of diagnosis and choice were entwined on both ANA and REC, creating a distinct foundation for support on each site. Both of these concepts, diagnosis and choice, have been discussed in the literature on online anorexia forums and health forums more generally. Turning first to the literature on diagnosis, the role of which on an online forum has been said to be a "blue print for social identity" (Giles, 2014, p.180), as members aspire to and place great value on having a diagnosis (Giles and Newbold, 2011; 2013). This has been shown to be the case on online anorexia forums, where having an official diagnosis can be seen as creating a sense of legitimate membership, with new members stating their diagnostic status in introductory posts to justify their use of the site (Stommel and Meijman, 2011). However, in some communities, having a diagnosis is not enough, members need to have the right diagnosis, in pro-anorexia communities this equates to having a diagnosis of anorexia and not bulimia or EDNOS (Eating Disorder Not Otherwise Specified) (Giles, 2006; Dias, 2003; Bond, 2012). As Giles (2006, p.470) states, there is "something intrinsically authentic about the nature of anorexia" for members of online anorexia forums, giving prestige to a diagnosis of anorexia and exposing the hierarchy of eating disorders that exists. This is true not only of pro-anorexia sites but is visible offline, with anorexia having long been considered the archetypical eating disorder (Allen, 2008; Warin, 2006). Burns (2004), in her feminist poststructuralist analysis of the construction of eating disorders, describes bulimics as 'othered' due to the binary that exists in cultural understandings of eating disorders. With anorexia and bulimia seen as oppositional, anorexia being associated with control, strength and success, and bulimia being associated with greed, failure and weakness, creating a "double pathologisation" of bulimics (Burns, 2004, p.290) and hierarchy of eating disorders, these constructions

persist and are acted out on online settings. Diagnosis in online anorexia communities is usually presented as giving members a sense of authenticity and is affirmative, in that it is something members strive for. For example, Lavis (2011) in her study of the 'good' anorexic (in pro-anorexia communities and in the clinic), describes diagnosis as something which individuals not only strive towards but mould themselves to, making themselves fit or compliant to the diagnostic label. This gave individuals, both in the clinic and online in pro-anorexia communities, a way in which to express their eating disorder. Similarly, Boero and Pascoe (2012) highlight the authenticity having a diagnosis creates on pro-anorexia sites, as members are required to make the body discursively visible online, however, like having the right diagnosis, members had to make the right body visible, that is a diagnostically anorexic body. This allowed forum members to fend off accusations of wannarexia, a term widely used on pro-anorexia sites to describe individuals who are not 'genuine' in their eating disorder (what constitutes 'genuine' is variable dependent on the site), and retain a sense of authenticity, while also making a diagnosis a desirable characteristic for others (Boero and Pascoe, 2012). Interestingly, Bell (2009) in her Foucaldian analysis of pro-anorexia as a movement describes diagnosis not as a marker of authenticity like other scholars, but as a threat to an individual's 'ana' identity. She suggests that the dissemination of diagnostic information on pro-anorexia sites and forums acts as a means for members to pre-empt diagnosis, to evade detection through using knowledge of the diagnostic criteria to present a 'normal' body ensuring their 'ana' identity is undisturbed.

Beyond authenticity, the way in which diagnosis is used on online forums highlights the ambivalence toward the medical establishment that exists on sites. Giles (2006) discusses this in terms of online anorexia forums, suggesting that it is ironic that diagnosis holds such prestige and credibility on online anorexia forums, given that sites actively resist medicalization in other forms and debate whether anorexia is indeed a medical condition or a lifestyle choice. This ambivalence is not necessarily unique to online anorexia forums, with Giles and Newbold (2011) illustrating in their study of user-led mental health forums, that while health professionals were often spoken of in a derogatory manner, their authority to give an official diagnosis was respected. Despite this respect for the authority of official diagnoses (and those that can provide them), community members

also offered one another informal diagnoses, with the authors suggesting that discussing diagnosis in these terms allows members to create a sense of solidarity and validation as behaviour goes from 'odd' to recognisable as something diagnostically significant (Giles and Newbold, 2011).

While diagnosis has been presented as a positive, there are occasions when it can have a detrimental impact on individual's use of online community. Stommel and Meijman (2011, p.25) suggest that the status and authenticity that is associated with having an official diagnosis in online anorexia forums could lead to a sense of members having to be "ill enough" to use sites, causing them to get sicker in order to feel like site use is legitimate. Further to this Charland (2004) warns of putting too much emphasis on diagnostic criteria in shaping online health communities, as the diagnosis criteria are not necessarily consistent and changes in wording or symptoms could result in members no longer fitting the diagnostic criteria. Charland (2004, p.335) claims that the result of this inconsistency is a "madness of identity", which causes members of online health forums to cling to an identity (or diagnosis) that no longer represents them. This is interesting in terms of pro-anorexia, as members strive to fit a particular diagnosis (anorexia). In this instance perhaps the madness of identity does not surround official changes to diagnostic criteria but the need to fit the criteria, as an inability to do so causes the individual to question their identity and place within the community.

Choice has long been discussed in the literature on online anorexia forums, as many proanorexia sites are thought to advocate what is termed the lifestyle model of anorexia,
which depicts the condition not as an issue of mental health but a choice that is actively
made by members and a lifestyle to live by. In many studies the lifestyle model is
definitive of pro-anorexia (Balter-Reitz and Keller, 2005; Bell, 2009; Bond, 2012; Rouleau
and van Ranson, 2011; Gavin et al., 2008). Although the lifestyle model has been widely
discussed in the literature on pro-anorexia, Borzekowski et al. (2010) found that fewer
than 20% of the 180 sites featured in their systematic content analysis actually employed
this discourse. This suggests that the medical model of anorexia, which sees anorexia as a
mental health condition, is the dominant discourse on the majority of pro-anorexia sites
and the role of lifestyle model is overstated. Moreover, Csipke and Horne (2007)
problematize the idea that the lifestyle model is purely an assertion of choice in being

eating disordered, suggesting instead that the lifestyle model may refer to the inclusion of eating disorder behaviour into all aspects of one's life. Regardless of the debatable proliferation and meaning of the lifestyle model, it has been shown to shape online anorexia forums in a variety of ways.

Firstly, Day and Keys (2008), in their discourse analysis of 13 pro-eating disorder websites, found that there were two contradictory discourses present on sites, one was the thin ideal and the other is termed rebellious femininity. The authors highlight the role of "active choice" in creating what they term "rebellious resistance" (Days and Keys, 2008, p.P11) to the thin ideal that permeates western patriarchal society, which allows site members to construct a sense of ownership over their condition and experience it as positive, which contrasts heavily with traditional depictions of anorexia (Burns, 2004). As well as creating sites of resistance, the role of choice in pro-anorexia communities is also thought to establish different metaphors of the condition, which members use to express their experience of anorexia (Gailey, 2009; Knapton, 2013). For Knapton (2013), the advocation of anorexia as a lifestyle choice leads to the belief that anorexia is beneficial to one's health, an argument also seen in other pro-anorexia sites adopting the lifestyle model (Ward, 2007; Fox et al, 2005). The belief that anorexia is in fact a healthy choice, leads to the metaphors of 'anorexia as a skill' and 'anorexia as a religion' being constructed in sites as a means through which members can express their experiences of anorexia (Knapton, 2013). Further to this, sites that employ the lifestyle model of anorexia have also been shown to use more empowering language, which reaffirms the notion that members choose to act out their eating behaviours and are in control of the condition (Strife and Rickard, 2011), therefore the discourse of choice can be said to rationalise anorexia (Gailey, 2009). These studies present the lifestyle model, and the choice that individuals make to become or maintain their anorexic or eating disordered behaviour, as creating a sense of empowerment on sites, as it allows members to reposition their condition as a healthy or productive lifestyle instead of a dangerous mental health condition. Not only does the belief that anorexia is a choice have the potential to empower site members, but it also has an impact on the site structure. Mulveen and Hepworth (2006) conducted Interpretive Phenomenological Analysis (IPA) of a pro-anorexia forum and found that two conflicting constructions of anorexia existed

on the site. The first was 'anorexia nervosa', which conformed to biomedical understandings of the condition, the second was 'ana' which represents anorexia as a lifestyle choice. 'Ana' was seen as choice by some members of the site as it was self-empowering, and importantly was not associated with poor mental health, it was representative of free will and illustrated control. Interestingly, the way in which members used the sites and the support they received differed as to whether they were 'ana' or 'anorexia nervosa', with the former using the site to get tips, and the latter as a means to avoid recovery and manage their low weight (Mulveen and Hepworth, 2006). In this instance the role of choice is pivotal in order to understand site dynamics, and illustrates that members' understandings of choice have far reaching implications for site use and the support given.

This thesis contributes to the existing literature on diagnosis on pro-anorexia sites by illustrating that understandings and interpretations of diagnosis are not always affirmative. Previously, the literature has shown that diagnosis is something to strive towards as it gives members a sense of authenticity, my own analysis challenges this by showing that members of ANA and REC reject the diagnostic criteria. Further to this, diagnosis has been largely discussed in terms of impact on the individual, the following analysis moves beyond the individual and looks at how interpretations of diagnosis by the community influence the communities' shared understanding of eating disorders. This chapter contributes to the literature on choice and online anorexia forums by illustrating that members of both ANA and REC use the notion of choice as a way of creating regulatory site ethoses, that provide a foundation for the way in which support is understood and in turn given on the two sites. This departs from the previous literature on choice, which has focussed on the division between sites that see anorexia as a lifestyle choice and those that see anorexia as a mental health condition. The following analysis will show that choice has a more significant role on sites than classification, and can underpin the support that is acceptable on sites. Choice has also been presented as having a largely empowering impact on sites, the analysis of ANA illustrates the impact on a community when choice is rejected, and members conform to the belief that they are confined by their eating disorder.

The analysis that follows is in two sections, the first titled 'two communities, one understanding of eating disorders', will highlight the similarities between the two communities despite their differing orientations. It will also show that members of ANA and REC are critical of the DSM-IV criteria for anorexia, and despite conforming to the biomedical model of anorexia, both sites construct an understanding of eating disorders based on lived experiences, pain and suffering, not diagnostic criteria. The second section of analysis, titled 'The role of choice in creating site ethoses', will show that through the rejection of the DSM the sites construct different ideas about the role of choice in eating disorders, with REC embracing choice and ANA rejecting choice. This creates two site ethoses, the 'recovery spirit' on REC and the 'sickness mentality' on ANA. These ethoses have regulatory functions, and shape the way in which support is understood on the site, impacting on what is and is not acceptable on the sites and creating out groups.

#### Two communities, one understanding of eating disorders

In this section I will show how members of ANA and REC critique the DSM-IV criteria for anorexia, and how this shapes members' understanding of what it is to be eating disordered. Hardin (2003) similarly found that members of a pro-anorexia site rejected the DSM-IV criteria, while still conforming to a psychological construction of anorexia. This produces an inclusive online environment, as members are not required to display the diagnostic criteria to access the community, but also reinforces dominant discourses of psychology as members actively take on and present a disordered identity in order to be seen as authentic (Hardin, 2003). What Hardin (2003) describes is replicated on ANA and REC, with both communities on the one hand rejecting the DSM and on the other complying to dominant biomedical and psychological understandings of eating disorders, as will be shown in the subsequent analysis. There are four key criticisms of the DSM-IV that appear on the two sites, with two of these criticisms being visible on both ANA and REC and one being unique to ANA and one being unique to REC. On ANA, the idea that the DSM-IV criteria actually motivate individuals to lose more weight is a criticism unique to the site. On both sites the diagnostic criteria are opposed because members assert that eating disorders occur at any weight and that the criteria undermine the psychological impact of having an eating disorder. On REC members also question the

diagnostic tools of the criteria. Although there are differences in the way criticism is expressed on the two sites, the diagnostic criteria are consistently critiqued and challenged on both sites, showing members to be knowledgeable about the DSM and active in their construction of what it means to be eating disordered on these two sites.

Turning first to the critique that is unique to ANA, which is the belief that adherence to diagnostic criteria motivates people to lose more weight:

"I honestly think the weight thing should be taken off! All it really does is encourage girls to become sicker and smaller before they reach out for help."  $(KiKu, forum data, ANA)^6$ .

And:

"yeah its stupid to put weight with anorexia, because then the girls that are anorexic but not underweight just feel even more fat, and get even more sick. goodness:P"

(Blithe, forum data, ANA).

On ANA, the idea that the diagnostic criteria fuels an individual's eating disorder was a key criticism of what both communities believe to be the biggest flaw of the DSM-IV: the over reliance on weight. Rather than being a mere symptom of anorexia, the weight classification set by the DSM-IV as "refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected)" (APA, 2000, p.539), creates a sense of unease for members to the extent that not meeting this particular criterion has the potential to spur them to further weight loss, reinforcing this particular discourse of anorexia (Hardin, 2003). Lavis (2011, p.239) describes how a diagnosis of anorexia is not only affirmative, but also allows an individual the "tools"

\_

<sup>&</sup>lt;sup>6</sup> Pseudonyms are used throughout this thesis for forum and interview data. They do not retain the 'spirit' of the original name or username, but are randomly assigned by Sarah Lewis. Pseudonyms for forum data are not replicated, therefore the same member may appear in the thesis under a number of different pseudonyms, this is to provide a higher level of anonymity.

against which to measure herself", the wide availability of the DSM diagnostic criteria ensures that those without a diagnosis have access to this 'tool' and are able to make their body compliant. Discussing the role of the DSM-IV in creating a spectacularisation of the anorexic, Allen (2008), describes the manual as impacting on those with and aspiring to anorexia as it can be viewed as a minimum standard that must be met in order to be considered anorexic. Thereby, the DSM shapes (and arguably limits) understandings of what it is to be anorexic while giving individuals a formula to follow to embody this particular construction of anorexia (Allen, 2008).

A criticism of the DSM-IV that is apparent on both sites is the belief that an eating disorder can occur at any weight:

"You can be eating disordered at any weight (does it matter which version, really?). An eating disorder at any weight is deadly." (Shanie, forum data, REC)

And:

"What I'm trying, and failing, to say is that by medical definition I'm not an anorexic but don't tell me I'm not mentally ill just because I'm fatter"

(Tulip, forum data, ANA).

From the above quotes we can see that members of both ANA and REC reaffirm that weight is only one element of being eating disordered, and that an individual's weight does not determine how severe their eating disorder is, "an eating disorder at any weight is deadly". This acts as both a critique and a contradiction of the DSM-IV criteria, which are tied to weight and an individual's perception of their weight. For these communities the firm belief that you can be eating disordered at any weight results in discussions and the acceptance of 'overweight anorexia' as a concept, which is where an individual exhibits anorexic behaviours and has anorexic thoughts but maintains a high weight (this was also observed by Hardin, 2003). This critique and the acceptance of eating disorders occurring at any weight has the potential to create inclusive and fluid support environments, were members are not judged on their ability to fit specific weight

criterion in order to receive support. As will be shown, this is the case on both sites, to an extent, but membership is still conditional, as members must conform to the site ethoses that are informed by the communities' rejection of the DSM-IV and role of choice in eating disorders. Linked to the idea that members can be eating disordered at any weight, is the critique that the over emphasis on weight in the diagnostic criteria leads to the psychological elements of an eating disorder being undermined or treated as secondary:

"More importantly, i wish people understood that a specific weight is not what defines an eating disordered person, but that it's the unhealthy thoughts that are the underlying issue. Healthy weight does not equal healthy mind, or healthy body for that matter either. There are countless of examples of serious health complications sufferers experience, even if they are not emaciated"

(Rita, forum data, REC).

And:

"And weight has nothing to do with how sick you are. That's why this is a psychological illness, not a physical one."

(Rolo, forum data, ANA)

By asserting sentiments such as "weight has nothing to do with how sick you are" and "it's the unhealthy thoughts that are the underlying issue", members of ANA and REC again work to discredit the DSM-IV criteria, by focussing on the psychological suffering that members go through to determine if they are eating disordered, rather than placing any emphasis on weight. Undeniably the DSM-IV criteria do mention psychological manifestations of anorexia, namely, fear of gaining weight and disturbance in how body weight/shape is perceived (APA, 2000). However, these are again tied to an individual's physicality and are not the same as the lived reality and emotional pain that members of both communities feel reflect having an eating disorder. Finally, a criticism found on REC, but not on ANA, is members challenging of the tools of the DSM criteria:

"And there's the whole issue of that ED diagnoses are just flawed. There are very few people with eating disorders who fit these categories neatly, if at all. (If you were wondering, studies indicate that with the current ED diagnoses about 65% of patients fall into ED-NOS. Only a third of people with ED at the clinical level actually fit the diagnostic criteria as they stand)."

(Custardxox, forum data, REC)

And:

"I don't think BMI's should be posted, purely because people get so hung up on them, and it is a really, really unaccurate measure that doesn't take so many things into account." (Timber, forum data, REC).

Giles (2014) and Brownlow and O'Dell (2006), in their studies of online communities for people with autism, found that members also critiqued the DSM for being unscientific and inaccurate. Members gave more credibility to the lived experience of autism and individual's capabilities of knowing they are autistic (Brownlow and O'Dell, 2006) and critiquing the validity of psy-disciplines more generally, with members favouring the "hard sciences" (Giles, 2014, p.188). A similar rationale can be seen on REC, where the DSM is positioned as fundamentally flawed, and so as has been shown above, members further critique it on the grounds that it does not reflect the lived experience of being eating disordered, as it prioritises weight, and not the psychological and emotional difficulties individuals experience. Although Custardxox and Timber make these criticisms they are not elaborated, they do not go on to detail why BMI is a "really, really unaccurate measure" or provide further evidence of which studies suggest that "only a third of people with ED at the clinical level actually fit the diagnostic criteria as they stand". This may be in part because it is unnecessary on REC, a community where the 'psychologists bible' (Kirk and Hutching, 1996) is not held in high esteem, and any critique may be deemed valid. And so, critique of the diagnostic tools levelled at the DSM further contributes to an atmosphere on REC where the diagnostic criteria are challenged and never passively accepted.

In sum, the diagnostic criteria for anorexia are critiqued by members of both ANA and REC, while these criticisms appear to take on different forms, they are essentially all variations of the same issue with the DSM-IV; the belief that too much emphasis is placed

on the weight of an individual. Despite the communities' differing orientations their critique of the DSM is markedly similar. While this critical stance cannot be seen as typical to all online anorexia forums, it does illustrate a disparity between the diagnostic criteria and how eating disorders are understood by these two support communities. While the communities' criticisms of the DSM have been detailed, the following section of analysis which discussed the role of choice, will reveal the way in which these criticisms impact the communities and their understanding of eating disorders. Specifically, I will illustrate both the communities' understandings of eating disordered being based on lived experience, how members of REC are encouraged to see themselves as more than the label they assigned through diagnostic criteria and how a sub-group of ANA members act in defence of the DSM.

Instead of revering the DSM-IV criteria for anorexia, both communities actively critique it, giving way to an understanding of eating disorders that is based on lived experience and is measured not by an individual's weight, but the amount of emotional energy expended on acting out behaviours and the suffering it causes (as Hardin, 2003 also found). Warin (2006) in her ethnographic study of relatedness in anorexia discusses how individuals construct anorexia as a way of belonging to a particular identity. The implications of this are interesting when applied to an online community setting. Members of ANA and REC can be said, through prioritizing the lived experience of anorexia, to be fostering a sense of belonging amongst members, not only in the sense of belonging to the community but also facilitating a construction of belonging to anorexia, which is not contingent on embodying the DSM-IV construction of the condition. This was made evident in interviews, when I asked members of both communities when someone could be defined as having an eating disorder:

"Once it has become a controlling factor in their life. I don't think someone needs to be underweight to have an ED, but if it's stopping them from doing things they normally would and causing an unhealthy relationship with food that is
jeopardizing their health."

(Alice, IM interview, ANA)<sup>7</sup>

And:

"When they start using food as a coping mechanism either by depriving themselves of it or by eating to much to avoid facing what's really an issue. I don't agree that a person needs to fit the criteria to receive treatment, I think everyone deserves to be helped if preocupation with food, looks and weight takes a toll on them."

(Sian, IM interview, REC).

Again, what is apparent is how similar these two understandings of eating disorders are, despite being from members of a pro-anorexia forum and a pro-recovery forum. Being described as a "controlling factor", "coping mechanism" and "preoccupation", highlights what is important to members of both communities is not how an eating disorder is expressed or acted out on the body, but how it is *felt*. Both Alice and Sian also position their understanding of eating disorders as oppositional to the diagnostic criteria, "I don't think someone needs to be underweight to have an ED" and "I don't agree that a person needs to fit the criteria", further illustrating the disparity that exists for members of ANA and REC between the diagnostic criteria for eating disorders and what they experience as individuals with eating disorders. This leads to a prioritisation of the lived experience of members, and a discrediting of the seemingly inaccurate DSM-IV, which has also been noted on other online support communities (Brownlow and O'Dell, 2006; Armstrong et al., 2012). For members of a diabetes support forum (purpose made for the research study) expressing a view or experience that countered medical knowledge was a way in which members could develop a sense of authority on the site (Armstrong et al., 2012). Championing the lived experience, and expressing the realities of an eating disorder, can be seen as having a similar impact, as it allows members to speak with authority and legitimacy about eating disorders, without necessarily having to conform to the diagnostic criteria.

<sup>&</sup>lt;sup>7</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. IM interview indicates that an interview was conducted via an instant messenger service.

Looking specifically at REC, the prioritisation of the lived experience, coupled with the rejection of the diagnostic criteria on the basis that it has on overly physical focus, leads to members being encouraged to see themselves as more than a diagnostic label:

"Everyone there has an eating disorder. Most of people on there try to get you to realize your not a label or a diagnosis. Fact is you have ED but you can still live life and you can still be a person and make change" (Victoria, IM interview, REC)

And:

"Without this psychiatric diagnosis clinging to you your possibility is infinite...even if you find out you aren't who you'd like to be right now, recovery will give you the freedom to pursue what ever it is you actually decide you want..."

(Wallflower, forum data, REC).

And:

"You are not a disorder"

(Urban Twilight, forum data, REC).

This discourse is interesting because it at once illustrates the community's rejection of the DSM and diagnostic labels, but also highlights the compliance with biomedical understandings of recovery on the site. As can be seen in the above quotes, an important element of the understanding of eating disorders on REC is to establish that individuals are more than their eating disorder. Rather than being reduced to their diagnostic label, members are seen holistically. According to Guilfoyle (2013, p.91) "DSM labelling practices limit people's access to alternative stories about themselves...It constructs the person as nothing more than a dead thing: nothing more than an object of its own discourse". Through encouraging one another to see themselves as more than labels of the DSM, members of REC are resisting this discourse, by allowing one another to express themselves beyond the confines of the DSM discourse. This, in turn, strengthens the rejection of the DSM, as members are exposed to a variety of different experiences of being eating disordered which may not conform to the DSM diagnostic criteria, and are not required to conform to the criteria in order to be considered eligible for support from

the REC community. In their study of the creation of identity on pro-anorexia and pro-recovery communities, Riley et al. (2009, p.354) argue that the "medical and psychological discourse are compatible with the overt aims and ideology of recovery", and so members were able to utilise these discourses in creating a credible recovery identity. This can also be seen on REC, as although members are encouraged to see themselves as more than a disorder, their understanding of recovery is firmly situated within the medical and psychological discourse of eating disorders and recovery. This is not problematised by members, in the way the DSM criteria are, and as will be shown in subsequent analysis in this chapter as members of REC are expected to conform strongly to the (biomedical) idea of recovery in order to be considered eligible for support on the site.

While on REC the rejection of the DSM and embracing of individuals' lived experiences of eating disorders leads to members being encouraged to see themselves as more than diagnostic labels, on ANA it leads to some members of the community acting in defence of the DSM:

"I don't agree with the people saying that there should not be a weight criteria for anorexia. I know you don't suddenly wake up one day with AN, but the criteria are there for a reason; to define each disorder more precisely. One of the main features of AN is (as said somewhere on this thread); refusing to maintain a healthy weight. If this goes out of the window then you change a big part of the definition of what the illness is."

(Alexa, forum data, ANA).

And:

"Not meaning to offend anyone, but you can't just diagnose yourself with a mental disorder. "Oh look I'm so anorexic....I don't really meet the criteria, but I REALLY want to lose weight". Like, I'm sorry, but there's quite a lot of the population who do really want to lose weight."

(Kayla, Forum data, ANA).

This defensive stance towards the DSM criteria illustrates the ambivalence that exists on the site towards the medical establishment; it is at once rejected and defended by members of the community, leading to a lack of coherence on the site. On ANA this ambivalence stems from what should be considered the markers of anorexia, the physical body (which to comply with the DSM would need to be emaciated) or the lived experience, characterised by emotional suffering. While this ambivalence does not completely undermine members' rejection of the DSM, it does make it uncertain, and hints to the divisions that exist between members who are officially diagnosed and those who are not. Further to highlighting ambivalence on ANA, this defence of the DSM can also be seen as a remnant of the authority of the DSM-IV's construction of anorexia. The physical focus of the diagnostic criteria ensures that the 'legitimate' construction of anorexia is centred on an emaciated body, and so, in order to be convincingly anorexic this is the depiction members should conform to (Allen, 2008). Importantly, members of ANA who do not meet the medical criteria for anorexia are not considered fakers, as they have been shown to be in other studies (Boero and Pascoe, 2012), and are still considered eligible for support from the community:

"If you can't eat normally and its been going on for a couple of months you probably have some sort of distorded thinking about food, or an eating disorder. Even if its not long term, were all still here to support you."

(Ella, Forum data, ANA).

Through the above analysis, I have shown that the DSM is critiqued on both ANA and REC and that the foundation of this critique is the over reliance on weight to determine if an individual is eating disordered. Members of ANA claim that the diagnostic criteria actually act as a motivator for further weightloss, while members of REC question the diagnostic tools of the DSM-IV. Members of both communities critique the criteria on the grounds that eating disorders can occur (and have devastating consequences) at any weight, and that the overly physical focus of the DSM-IV undermines the psychological impact of eating disorders. These challenges levelled at the DSM-IV allow both communities to create a different construction of anorexia, one that is not divorced from psychological

discourse on the condition, but at the same time prioritises the lived experience of having an eating disorder. It is this understanding that members orientate towards when accessing the sites, and on REC leads to members being encouraged to see themselves as more than eating disordered. On ANA while members do understand eating disorders in terms of the lived experience, there are also members who act in defence of the DSM, stating that diagnosis is purposeful and the physical attributes of anorexia are important in correctly diagnosing the condition. Whilst the two communities largely agree on what is problematic about the DSM criteria for anorexia, they do not go on to approach support in the same manner. In the next part of this chapter the notion of choice will be shown to be essential in determining what these two communities believe their role to be in supporting members, and how members can show themselves to be eligible for support on ANA and REC. And so, from similar beginnings, these communities will be shown to develop into very different online support environments.

## The role of choice in creating site ethoses

As was shown in the above analysis, both ANA and REC have similar interpretations of the DSM criteria for anorexia and understandings of eating disorders. Interestingly, this does not lead to similar notions of what should, or can, be done to improve life as an eating disordered individual, and so the communities differ in their belief of how to approach the problem of eating disorders. The notion of choice can be seen as the key in marking this difference between the two communities, as members of REC are encouraged to believe they have a choice to recover from their disorder, while members of ANA orientate to the idea that their choices are diminished due to the biological and "hard wired" nature of eating disorders. Each of these understandings of choice creates a different site ethos, which members must conform to in order to be considered eligible for support on the sites.

Turning first to REC, members' belief that they can choose to recover from their eating disorder is based on an individualistic notion of choice, characterised by a focus on self-reliance that is frequently reaffirmed on the forum by members of the community:

"But only you can make that choice. And it is a choice."

(Daisychain, REC, forum data)

And:

"Recovery is full of all kinds of decisions, difficult ones, no one else can make them for you" (Halfaxa, REC, forum data)

The idea that choice in recovery is individualistic and based on concepts such as self-reliance has been reported elsewhere (Hardin, 2003b; Patching and Lawler, 2009) and can be seen as marking REC as conforming to dominant discourses that surround recovery from eating disorders (Matusek and Knudson, 2009). This individualistic notion of choice that exists on REC is expressed on the forum as the 'recovery spirit', a site ethos that empowers members, creates a sense of unity on the forum and marks the boundaries of acceptability on the site. All members are required to conform to this ethos, which in turn shapes the support that is given on the site.

On ANA choice does not take on this empowering, individualistic form, instead, it is characterised by its absence, as members believe themselves to lack any choice surrounding their eating disordered thoughts and behaviours. Members attribute this lack of choice to the biological and psychological underpinnings of their eating disorder, with members claiming it is "hard wired" and therefore not under control of something they can exert choice over. This is shown in forum posts such as:

"We cannot change the chemical wiring that causes us to think this way"

(Bexi, ANA, forum data)

And:

"I can't change how my brain is wired in it's perception of self. I wish I could"

(Dahlia, ANA, forum data)

This focus on lack of choice due to the biology of their eating disorder creates a sense of resignation on the site and feels defeatist in tone, and facilitates the 'sickness mentality', which is the site ethos that members of ANA comply with in order to be eligible for support. The 'sickness mentality' allows members to be consumed by their illness, deny culpability for their actions, sets a distinct tone for site use and also marks out-groups on the site. Like the 'recovery spirit' on REC, the 'sickness mentality' shapes what constitutes supportive behaviour on ANA.

The following analysis will consider each community in turn, and will show choice to be pivotal to the formation of regulatory site ethoses. These site ethoses, the 'recovery spirit' on REC and the 'sickness mentality' on ANA, have various functions on the sites, but importantly conforming to these ethoses ensures a member is deemed eligible for support and creates a foundation for the support given on each site.

### **REC- The 'recovery spirit'**

During observation of REC, the normative nature of the group was immediately apparent, as an outsider I was aware that members had to comply with 'the rules' or they would not be able to access the site. As the group presented in such a prescriptive manner I anticipated that there were stringent guidelines for site use, but despite searching the site, I could not find any. As observation continued and analysis became more developed it was clear that the dominant 'rules' on the site were derived from and perpetuated by the interaction of members. The 'recovery spirit' is one of the key dominant 'rules' on REC and operates as a site ethos. Simply put, the 'recovery spirit' is the requirement that members be seen to be choosing recovery on the site, but it's influence over and importance to the community should not be understated. As an ethos, the 'recovery spirit' has the impact of empowering members through the privileging of choice in recovery, creating a sense of unity amongst the community, and marking unacceptable behaviour and the boundaries of the group. The 'recovery spirit' is not a form of support, it is a site ethos, as members use the 'recovery spirit' to show themselves as eligible for support and the 'recovery spirit' also lays a foundation for support on the site, as it constrains members expectations of what recovery and support look like in this particular online environment.

The 'recovery spirit' can be seen at site and individual level, as previously mentioned in terms of the site it works as a form of cultural idiom, but for individual members possessing the 'recovery spirit' is a way into and through recovery, it is a mind-set that encourages them to make consistent positive recovery-focussed choices. The 'recovery spirit' is not a concept that can be neatly demonstrated, there is no one statement that encompasses the idea, as it is expressed by members in a myriad of ways. The following extract taken from the forum goes towards illustrating the 'recovery spirit'. This post is a response to another member who expressed their frustration with the site, which they felt was becoming too negative and a place of stagnation:

"We, as a community, will not tolerate unhealthy choices.

We, as a community, will not tolerate self-abuse.

We, as a community, will not tolerate eating disorders running the show.

We, as a community, will not tolerate any form of action or speech that legitimizes self-destruction.

We, as a community, will not tolerate "who's the sickest" competitions.

We, as a community, will not tolerate wallowing in self-pity.

We, as a community, will not tolerate excuses for choosing to engage in eating disordered behaviors." (Dalmatia, forum data, REC)

Framed as a guide to what is not acceptable on the site (no such guide exists on REC), this post underpins the crucial elements of the 'recovery spirit': which are unity ("we, as a community"); the role of choice ("will not tolerate unhealthy choices" and "will not tolerate excuses for choosing") and conformity ("will not tolerate"). These three elements of the 'recovery spirit' will be drawn upon throughout the analysis below, with the 'recovery spirit' being shown to be normative, regulatory and shaping the way support is understood on the site.

### REC-The role of choice

The notion of choice both creates the 'recovery spirit' and is a key theme within the site ethos on REC. In terms of enacting the 'recovery spirit', choice has two clear roles of the

site: empowerment of individuals and illustrating that recovery is more than having a positive attitude. The first role of choice on the site is empowerment of the individual, which can be defined as an individual's ability to perceive themselves as capable of coping with challenges or difficult situations and taking responsibility for their own life (Barak et al., 2008; Wentzer and Bygholm, 2013). The individualistic notion of choice that is evident on REC helps foster a sense of empowerment among members, as in order to access the group they are required to show themselves as capable of making positive, non-eating disordered choices. This is shown on the site through the consistent use of the phrase "choice is powerful", used as a reminder to members that they are making a positive choice and one that will be of consequence. Support groups are thought to empower those who use them because these groups are based on; "reliance on self and peers... voluntary participation and free will... [and finally] helping others and socially identifying with others" (Barak et al., 2008, p. 1869). Each of these attributes are considered to be directly associated to personal empowerment (Barak et al., 2008), and can be seen on REC, some of which are manifest in the 'recovery spirit'. There are said to be a variety of beneficial outcomes of empowerment for an individual through the use of an online support group. The impact of these span both online and offline, and include: the expression of and connection to emotion; the impact of writing; enhancement of decision making; more confidence to liaise with medical professionals; and feeling better informed (Barak et al., 2008; van Uden-Kraan et al., 2009). In their study of empowerment and compliance in online patient support groups, Wentzer and Bygholm (2013) found that although these sites can foster individual empowerment, they do not necessarily create a sense of community empowerment. They suggest that this is because online support groups create an image of an ideal patient, one who is compliant to medical discourses surrounding illness and importantly treatment. In terms of REC and the 'recovery spirit', this finding is interesting, as it suggests that rather than being empowered as a group, they are compliant. The idea of compliancy fits well with REC as a community, as it is a structured and normative online environment. Although the community reject the DSM on the grounds of it having an overly physical focus, as a community they still conform to the dominant medical and psychological discourses of eating disorders and recovery. The 'recovery spirit' as a regulatory ethos also requires compliance from members; as outlined above, conformity to the ethos is essential to be

considered eligible for support. Therefore, members of REC can be thought of as empowered by and compliant to the 'recovery spirit'.

Empowered individual members of REC may experience some of the benefits outlined by Barak et al. (2008) and van Uden-Kraan et al. (2009) but they also serve a purpose for the group, as they illustrate to other members how to correctly embody and present the 'recovery spirit' online. While members of the forum do not talk about one another's recovery stories as 'empowering' they do frequently describe one another, or the site more generally, as 'inspirational'. This can be seen in the following quotes:

"I find it a genuinely inspiring place. A lot of the people here have been to hell and back in various ways yet it is so refreshing to see people still fighting." (Bubbles, forum data, REC)

And:

"I know that I'm really inspired by people posting about how they are feeling good in recovery, and so when I'm feeling like that I post it in the hope that it might inspire other people."

(A\*M\*E, forum data, REC)

Referring to other members as 'inspirational' or in a positive light, may be a common feature on online support, due to the potential for members to view one another as idealised others (Warisse Turner et al., 2001). However, on REC it can also be seen as a way of highlighting members for 'good' behaviour, those that conform to the 'recovery spirit' so efficiently that they serve as a role-model for other members. And so, empowerment at once creates, and reinforces, the 'recovery spirit'.

Further to empowering members, choice is also used to illustrate that recovery is more than just having a positive attitude:

"I also wanted to add, being positive does'nt make you recovered. Helping others and suggesting things THEY can do doesn't make YOU recovered."

(Secondcity, forum data, REC).

Here we can see that a positive attitude is considered a minimum in the pursuit of recovery, and does not constitute having 'recovery spirit', as positivity alone does not lead to change. Members frequently problematize their own and other's recovery efforts, highlighting that more can be done and members must remain active in their recovery. One way this is demonstrated is through members being called upon to 'fight' their eating disorder, for example:

"Being on a recovery website doesn't make you healthy. Going to a group doesn't make you healthy. Fighting makes you healthier." (Bertie, forum data, REC).

And through members stating realisations about their own recoveries:

"this really got me thinking about how I need to start owning my own recovery."

(Gardenia, forum data, REC).

And through member's highlighting the need for continued effort in recovery:

"very true, you could go on a million sites, see multiple doctors and get all the self help books you can find but if you dont give it a 100% every single day b/c you truly want to recover, and for the right reasons, you just arent in recovery. ive done this before a lot."

(Fleur, forum data, REC).

Through the above quotes we can see that what constitutes as having the 'recovery spirit', members are required to show themselves to be making a concerted effort, more than a positive outlook towards recovery, and must show themselves to be active in their recovery. In doing these things members appear honest in their approach to recovery, illustrate that they are committed and are able to take responsibility for their actions, and recovery-orientated choices. Ley (2007) discusses how online and offline elements can shape a member's commitment to a support forum. Looking specifically at a pregnancy and mothering forum, she found that contemporary understandings of pregnancy and the architecture of the site, such as, guidelines for site use and membership policies, impacted on how committed members were to the site and also shaped the tone of the

site. This is important to consider in the case of REC, as through stating that members have to move beyond positivity the 'recovery spirit' requires a level of commitment from members, to the site and to their own recovery. This commitment in turn ensures further conformity to the 'recovery spirit'. Similarities can be seen on REC, where the impact of contemporary understandings (or lack of understanding) of eating disorders and eating disorder recovery could increase a member's commitment to the group, as lack of understanding has previously been shown to influence access to online anorexia forums (Brotsky and Giles, 2007: Dias, 2003; Bond, 2012; Yeshua-Katz and Martins, 2013; Tierney, 2008). So too could the normative and almost exclusive atmosphere created by the 'recovery spirit', which keeps membership select, as only those who meet and subscribe to the ideals of the 'recovery spirit' will be able to maintain membership. Therefore, through stating that members should be beyond positive in their recovery, the 'recovery spirit' creates a space that is active, recovery-orientated and requires commitment (and conformity) from members.

The 'recovery spirit' is not a form of support, it is a means to access support, through enacting the 'recovery spirit' members make themselves eligible for support from REC. Members unable to conform to the ideal are not welcome in the community, as will be shown below. Further to this it is also a foundation for support on the site, as it is essential to the type of support environment REC is trying to forge. It creates a mentality that members have to buy into in order to be a part of the community. This is not a unique feature of REC or online support, but can also be seen in offline support groups. Alcoholics Anonymous in particular require members to "learn how to apply a group perspective to [their] recovery" (Denzin, 1987, p. 33) in order to be accepted members.

### REC- Unity in recovery

The 'recovery spirit' also creates a sense of unity on REC, members of which come from all over the world, and are diagnosed with a variety of eating disorders (REC does not only cater for those with anorexia, but also supports those with bulimia, eating disorder not otherwise specified, binge eating disorder and compulsive over eating). As previously discussed there is a hierarchy of eating disorders that exists on online anorexia forums.

REC, through rejecting the DSM criteria for anorexia, attempts to make the differences that exist between eating disorders less of an issue. However, that alone does not unite the members of REC; their pursuit of recovery through the 'recovery spirit' does. That is not to say that all members will feel that there is no hierarchy on the site, but that efforts have been made to limit the expression of such a hierarchy. This was evident in interviews, as noted above some members spoke specifically about the hierarchal nature of eating disorders, others highlighted that REC was for 'anyone who wants to recover' and stated there was 'no competitive atmosphere' on the site:

"It's for anyone who wants to recover from their EDs, pure and simple, and doesn't want to live life as an eating disordered individual anymore."

(Rachel, IM interview).

And:

"Erm, just because there's no competitive atmosphere there's no sort of like, 'oh well you're not ill enough to be here, you can't say that'. There's just, sort of, respect for each person having trouble" (Caitlin, video interview)8.

As can be seen Rachel and Caitlin do not present REC as a segregated support environment, but one that is unified as members respect that one another are "having trouble" and crucially expect that members want to recover from their eating disorder. Creating a unified and cohesive support environment is made more difficult if members feel they are unable to identify with one another (Jones and Meier, 2011), the 'recovery spirit' provides something for all members to identify with, ensuring that regardless of their differences they are united in their pursuit of recovery.

Wanting to recover is not enough on REC, members must also show themselves to be conforming to the 'recovery spirit', to be committed to recovery and active in making recovery-focussed choices. The 'recovery spirit' can be seen to have a binding or unifying role on the site, as it ensures that members are all in pursuit of recovery. However, being in 'recovery' is not enough, members are all conforming to one type of recovery, the REC

<sup>&</sup>lt;sup>8</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Video interview indicates that an interview was conducted via video chat on Skype.

ideal form of recovery, exemplified through the 'recovery spirit', and open to the specific forms of support that this encompasses. In an interview Erica touches upon the idea of the 'recovery spirit' (although she did not refer to it as the 'recovery spirit') as uniting the varied members of REC:

"it's hard because there's so many different people coming together, but yeah there's a certain like parameter of like 'do you fit this? This is recovery, ok you can hang around', you know."

(Erica, video interview).

Erica's assertion of "this is recovery" and the idea that this is something a member must comply with "do you fit this?", illustrates that this particular notion of recovery is what binds the group. Sophia also mentioned this idea of there being an overarching sense of recovery on REC, again, she did not refer to it as the 'recovery spirit', but as an 'ethos':

"You know, I think everyone's buying into the ethos, it's quite a specific feeling on REC." (Sophia, video interview).

When I asked further about the ethos of the site, Sophia went on to say:

"there's the emphasis on recovery and saying you can make that choice"

(Sophia, video interview).

Again, this illustrates the close link that members of REC associate with recovery and choice, with the choice they have made to recover being a unifying force on the site, which members are able to enact and express through the 'recovery spirit'.

### REC-The edge of the 'recovery spirit'

The 'recovery spirit' is also a regulating force for REC, it allows members to assess whether other members are committed to recovery, it is not enough for members to pay lip service to recovery:

"I'm not saying you're not trying, but your behavior up to this post doesn't necessarily show it." (Sazzle, forum data, REC).

The member who the above post was aimed at was allegedly not living up to what was expected of her, she was failing to embrace the 'recovery spirit' and had a consistently negative attitude towards recovery which focussed on sickness, which was displayed by her regularly justifying her eating disorder behaviour and posting comments which focussed on how little she weighed, calories consumed and purging behaviours. As we can see from the above quote this member's comments were not tolerated and her behaviour was held to account.

Again we can see that more is expected of members, they are encouraged to fully embrace the 'recovery spirit', and the choice they have made to recover, otherwise there is no place for them on the site:

"some members in the past have been permanently banned due to their behaviour" (Isobel, IM interview).

"because it wasn't recovery minded?"

(Sarah Lewis)

"yes. continual posting of how low their weight had been, and not being at all recovery orientated" (Isobel, IM interview)

This example, taken from an interview, shows how important the 'recovery spirit' is to the community, as inability to conform to this idea can result in being banned from the site. Koski (2013) in her study of group therapy sessions for eating disordered individuals found that if members felt that recovery was unattainable they would no longer attend the group, which ensured that the group remained recovery focussed. While individual members of REC potentially do choose to leave the forum, they can also be asked to leave, and physically blocked from the site because of their inability to live up to the 'recovery spirit'. Asking members to leave because of their supposed lack of 'recovery spirit' serves three purposes. Firstly, it ensures that the forum remains a recovery-

focussed environment. More specifically it protects support as defined by REC, as those who are unable to conform to REC's prescriptive brand of support are no longer able to access the site. Secondly, it is normalising, it encourages other members to take up the 'recovery spirit' as they are aware there are severe consequences for those unable to conform. Finally, it gives the community an oppositional figure to compare themselves too; members of REC choose recovery, unlike failed members who are unable to move beyond sickness and embrace the 'recovery spirit'. The oppositional figure in particular links back to members of REC encouraging one another to see themselves as more than a diagnosis, to look beyond the eating disorder. This, coupled with the firmly rooted belief amongst the community that members are capable of choosing to recover further, separates individuals from their disorder, creating a sense of responsibility amongst the group. LaFrance and McKenzie-Mohr (2013) suggest that having a diagnosis is validating for individuals, and also allows them to make a distinction between personal flaw and biological flaw, which has the impact of absolving them of blame. On REC this distinction is present, however, due to members' belief that they choose to recover, a main tenet of the 'recovery spirit', members are held always accountable for their eating disordered thoughts and behaviours.

While the 'recovery spirit' demands that members strive towards recovery and present themselves as choosing health, it is important to acknowledge that recovery is not presented as a linear journey on the site.

"struggling is ok and i personally think it is great to utter that here."

(MirrorImage, forum data, REC)

And:

"I am aware that we ALL have our struggling moments...I am not saying that you cannot express when you are having such a moment, or that you have to hide away if you are struggling, but when you are constantly posting things that are triggering, constantly posting those defeated thoughts... maybe this isn't the place for you at the moment."

(JenniferActually, forum data, REC)

It is anticipated that members will have lapses, but they are expected to be unwavering in their belief that they can choose to recover, and therefore remain committed to the 'recovery spirit'.

The 'recovery spirit' has been shown to be a way in which members of REC can access support, through conforming to the ethos they show themselves to be eligible for support from the site. It is also a confining ethos, in that when members conform to the ethos they are conforming to *one* specific understanding of recovery, which revolves around the embracing of choice and members' ability to choose health. The impact of this is unification of the group, which could otherwise be divided due to their differing eating disorders and stages of recovery. However, as all members are expected to conform to the 'recovery spirit' and embrace their choice to recover, the difference between members are less marked. Further to this, the 'recovery spirit' shapes the support that is given on the site, members are indoctrinated into a normative environment, where there are fixed ideas about what constitutes recovery and how a member should show themselves to be recovering online.

# **ANA-The sickness mentality**

Turning now to ANA, which like REC, rejects the DSM criteria on the grounds that the emphasis is on the physical attributes of being eating disordered, and not the lived experience or the emotional impact, which members of ANA deem more telling of the reality of having an eating disorder. However, members of ANA do not embrace the idea of choice like members of REC, instead they reject the idea that they have any choice regarding their eating disorder, believing that they have no control over their thoughts and behaviours. This is a clear distinction between the two communities, which were initially shown to be similar in their understanding of eating disorders in that they were both critiquing and rejecting the DSM-IV. However, the way the two communities interpret choice marks the differences that exist. The community rejection of choice on ANA creates a site ethos, which I have termed the 'sickness mentality', members of the community do not talk about their understanding of eating disorders using this term, this is a label I have attributed to this ethos.

Unlike REC, members of ANA do not see choice as a powerful concept, instead it is positioned as something which members of the community do not possess:

"It's not a choice, this is the results of a mental illness"

(Azealia, forum data, ANA)

And:

"This is a disease, its a mental illness and it isnt a lifestyle choice... No one chooses this."

(Kylie, forum data, ANA)

This is the 'sickness mentality' being enacted; members are outwardly and unequivocally stating that they are without choice, that they are mentally ill. The rejection of the idea that anorexia could be a choice is significant as it deviates from the lifestyle model concept of pro-anorexia, which sees anorexia as a choice and desirable lifestyle to be adopted (Gailey, 2007; Mulveen and Hepworth, 2006; Haas et al., 2011; Whitehead, 2010). Csipke and Horne (2007), in their study of visitors to pro-anorexia sites, found that members not only embraced anorexia as a lifestyle choice but were praised for this decision by other members, as it showed they had the desirable characteristics to become a good or 'successful' anorexic. This contrasts heavily with ANA, where members strongly refute the idea that anorexia is a lifestyle choice, as shown in the above quotes. This rejection of anorexia as a choice creates the 'sickness mentality', as anorexia is seen as a disease with both physical and mental elements. Members are seen as unable to make choices about their eating disorders because for ANA, the biological and psychological elements of their eating disorders negate their ability to make choices.

And so, ANA can be seen as conforming more uniformly to the medical model of anorexia, which is defined as, complying with the biomedical understanding that anorexia is an illness with physical and mental symptoms, in the literature on pro-anorexia (Strife and Rickard, 2011; Mulveen and Hepworth, 2006). However, their compliance with the medical model is not straightforward but is characterised by ambivalence, something which Bell (2009), in her Foucauldian analysis of the pro-anorexia movement addresses, suggesting that while sites may appropriate the tools of the medical establishment, they

are unable to escape or move beyond its gaze, as it is too pervasive and has also been internalised. ANA is an example of this, on one hand rejecting the medical model because it does not speak of their lived experience, and then on another drawing heavily on the discourse in order to refute the idea (or societal misconception) that they have a choice in their eating disorder. However, accepting anorexia as an illness and not a lifestyle choice does not inherently imply that members have no choice surrounding their disorder. REC is key example of this, as like members of ANA, they define anorexia using biomedical understandings of the condition, yet choice is conceptualised differently, and members are implored to believe they do make choices. I would suggest that the difference between the two communities' understandings of the notion of choice may be due to site purpose. REC has a distinct purpose, recovery, which requires a different mind-set than ANA, which has no fixed purpose, with members using the forum for a multitude of reasons.

The 'sickness mentality' not only highlights ANA's ambivalent relationship with the medical establishment and their understanding of anorexia, but like the 'recovery spirit' on REC it has far reaching implications for the support offered on the site. This is because the 'sickness mentality' governs who can access the site and how eating disorders are understood on the site, shaping the way in which support can be given. The following analysis will show how the how the 'sickness mentality' is enacted on ANA, and illustrate the varied roles it has on the site, and how these impact on the community's understanding of eating disorders and in turn shape the way support is given on the site. The roles of the 'sickness mentality' include: expressions of suffering, relieving members of culpability for their actions, setting a tone for the site, and finally creating the community out group, the wannarexic. The wannarexic is not exclusive to ANA, but is a consistent feature of any pro-ana site, with a wannarexic usually described as someone who lacks the control and self-discipline to be seen as genuinely anorexic (Boero and Pascoe, 2012; Giles, 2006). The wannarexic is generally conceptualised as teenage girls that are on fad diets to lose weight before a big event like summer or prom. A wannarexic is usually rejected both by sites that adopt a lifestyle choice and those that use a medical model of anorexia (Whitehead, 2010; Boero and Pascoe, 2012). What is interesting on ANA is that the wannarexic is not rejected on the grounds stated above, but because she

is not seen as genuinely ill, the wannarexic is thought to be emulating anorexic behaviour out of choice and not due to mental illness. This phenomenon has not previously been addressed in academic research on community conceptions of the wannarexic.

### **ANA-Expressions of suffering**

The first role of the 'sickness mentality' is allowing members to express suffering on ANA. Expressions of suffering have their own implications for the community. Below is a quote taken from a thread which contained pictures of severely emaciated women and asked members if they would want to look like them:

"Honest to God, yes, I would like to look like these girls. My messed up reasoning?

I would be closer to death than I am now. I'm miserable and can't remember being happy."

(Charmed, forum data, ANA)

The intention of the thread was not for members to express the difficulties they are having, but this member expressed them anyway. As ANA adopts the 'sickness mentality' this kind of response is accepted and expressing suffering in this way is often worked into threads for example:

"Sorry if I don't make sense. I'm exhausted all the time and just barely hanging on to that last little bit of hope."

(Dumont, forum data, ANA)

And:

"Nothing matters because you don't matter. You'll cry alone. You'll feel guilty for crying, So you'll purge. The first bite sets something off inside you. More. More"

(Garland, forum data, ANA)

Like Franzen and Gotten (2011) found in their study of a self-injury forum, expressing suffering also serves to create a 'genuine' identity for members. On ANA the 'sickness mentality' enables members to present themselves as ill and not choosing to be anorexic or eating disordered. The need to show oneself as ill is not without its issues on ANA:

"It's like so many people on here want everyone else to believe that they're sicker than the next person."

(OITNB, forum data, ANA)

The above quote shows that there is a competitive element to being seen as genuinely ill, with members wanting to assert themselves as 'sicker' than others. Interestingly on ANA 'sicker' is not a pseudonym for thinner, but members seek to create a 'mentally ill' identity. This need to show oneself as 'genuinely' sick has been observed on other mental health forums, with members of suicide forums feeling the need to assert themselves as 'authentically suicidal' over being depressed (Horne and Wiggins, 2009). Previous studies on pro-anorexia communities have strongly linked the idea of suffering, or being 'genuinely sick' with the body, and specifically with members of sites illustrating that they have a thin or slender body to authenticate this suffering (Burke, 2012; Ferreday, 2003; Boero and Pascoe, 2012). For Ferreday (2003, p.285) the thin body is the crux of community, as she states "community itself is rooted in having an anorexic body and in the day-to-day experiences of living with an eating disorder", and so, the experience of being eating disordered is not divorced from the thin body. However, it has been shown that physical ailments are given more prominence and legitimacy within medical models than issues that are regarded as mental health problems (Album and Westin, 2007). Within this context, LaFrance and McKenzie-Mohr (2013) note that individuals with depression frequently anchor their illness on to something physical in order to feel legitimate. It is perhaps unsurprising that previously studied pro-anorexia sites have used the body in order to create a sense of authenticity around their illness and as a marker of tangible distress. ANA, through its rejection of the DSM criteria and belief in overweight anorexia, separates physical and mental suffering, with the former not being considered indicative of the latter. Expressions of mental suffering are the key to accessing the community and the marker of who is or is not genuine in their eating disorder.

# ANA-The denial of culpability

Adler and Adler (2013) in their longitudinal study of self-injury forums, found that members employed the discourse of self-injury as sickness in order to reduce the stigma related to self-harm. In doing this members also denied agency with regard to their self-

injury behaviour, positioning it as beyond their control due to their illness. A similar process can be seen on ANA with members embracing the idea that they are ill and rejecting anorexia as a choice, the key tenets of the 'sickness mentality' and so making them appear to lack control and therefore culpability in their eating disordered thoughts and behaviours. This is shown in the following examples:

"We're depressed. We loathe ourselves. We cannot change the chemical wiring that causes us to think this way." (Sunflower475, forum data, ANA)

And:

"We don't choose to have these disorders. We can't help what happens to us."

(Meadow, forum data, ANA)

In reducing themselves to being disordered, without any choice or hold over their condition, members of ANA absolve themselves of any accountability for their actions, serving two purposes on the site. Firstly, this ensures that moral judgements cannot be made of individual members, as it is the disorder which is at fault, not them (Giles, 2006; Morrow, 2006; LaFrance and McKenzie-Mohr, 2013). Secondly, this allows members to post comments about potentially harmful behaviour without being reprimanded or coerced into considering recovery, as members understand that they are all mentally ill and do not choose to do these things. There is a caveat to this, that is, if members are posting about extreme behaviours like severe laxative abuse, salt water cleanses and eating non-edible items, other members will respond with the intention to inform and prevent this behaviour from happening again:

"No, it's not safe. The fibers of the cotton can rip up your digestive tract severely. It can bulk up and cause you to not shit because your intestines will get blocked."

(DollyMix, forum data, ANA)

The above quote illustrates that there are limits to the 'sickness mentality', while all members ascribe to this ethos, dangerous behaviour is flagged up and addressed in what the community feels is an acceptable manner.

### ANA-Setting a tone for the site

The 'sickness mentality' allows members to see themselves first and foremost as ill, which in turn sets the tone of the site. Members use the site in part to express the trials and tribulations of having an eating disorder. Group ideals creating expectations of site use have been noted on other mental health forums (Antaki and Veyreda 2009; Smithson et al., 2011). ANA members are not expected to have a positive outlook when they use ANA, they are able to dwell on their illness, and the 'sickness mentality' is called into action if this expectation is challenged. Below is a quote from a member in response to another member suggesting ANA could be a more positive place:

"Yeah that's why they're called eating DISORDERS, not 'eating

TOTALLYFINEANDRATIONALS' we are mentally ill, our brains are not working right.

How insensitive." (Becca147, forum data, ANA)

As can be seen above this member cited the 'sickness mentality' in her argument as to why ANA could not be a more positive place, she emphasises that members are mentally ill and implies that they therefore do not have a choice about the matter. This is illustrative of one of the aspects of the ANA environment, it is a place where members can go to vent their frustrations and to a certain extent dwell on their illness:

"Dude. Seriously? The one place we have to vent how we feel about ourselves and you want us to not post when we're feeling shitty?" (Nico, forum data, ANA)

Therefore, the 'sickness mentality' creates an environment in which being consumed by illness, and the venting of negative feelings is acceptable and to some extent expected of members. To suggest that members should not express negativity on the site results in members acting defensively and utilising the 'sickness mentality' as a reason for their inability to have a positive outlook. While the tone of ANA may appear to be entirely negative, it does not feel that way to members, as Harriet stated in an interview:

"yeah, there's no need to fake the smile and control" (Harriet, IM interview)

Furthermore, as one member discusses on the forum:

"I try to be as positive as I can in the real world, but this is where I get to let the real, negative me out"

(BlackOrchid, forum data, ANA)

Johnsen et al. (2002), in their study of interaction on three mental health forums, found that posts that could be regarded as 'negative' or 'destructive', while infrequent, had a detrimental impact on the entire forum. Rather than being seen as detrimental, the negative tone of the site, created by adherence to the 'sickness mentality', is something members crave and is considered a positive attribute of the site, to be protected. This is because it gives members the opportunity to be honest about their thoughts and feelings, they do not need to frame anything in a positive light.

## ANA-The wannarexic: the formation of out-groups

The final role of the 'sickness mentality' and perhaps the most contentious, due to the conflict and uncertainty it causes, is the creation of the out group, the wannarexics. As previously stated the ANA definition of the wannarexic is different to that on other pro-ana sites, as for ANA a wannarexic is someone who is not mentally ill but trying to adopt anorexic behaviour out of choice. This definition of a wannarexic can be seen as being directly related to the 'sickness mentality', as it invokes both choice and illness:

"Personally I think these people are obviously looking for attention, its like teenagers who think its cool to act all depressed etc, its very insulting to those who are sick."

(jojo413, forum data, ANA)

For ANA the relationship members have with the wannarexic is not as straightforward as it appears on other sites, where 'wanna-baiting' and aggression towards wannarexics being common (Boero and Pascoe, 2012). For ANA members calling another member a wannarexic is seen as unacceptable:

"Noooooo, that's a huge no-no" (Dana, IM interview, ANA)

The above quote, taken from an interview, mirrored my experience of observing the group. After a year of observation I had never seen someone be directly called a

wannarexic by another member. What is interesting is that members are more likely to call themselves, rather than others, a wannarexic:

"I know I'm a wannarexic because I want the official diagnosis of anorexia. I don't want to be some damn EDNOS. WTH kind of diagnosis is that? Obviously I'm not sick."

(Teeny, forum data, ANA)

And:

"Because I'm still in a healthy range. It makes me feel like I belong nowhere. Like a complete failure. Because I'm "not skinny enough to have anorexia" but too worried about gaining weight to eat a normal amount of food."

(Bethany<3, forum data, ANA)

Comments like those above and even threads about members feeling like a wannarexic were very common on ANA. As we can see they point to a tension surrounding the notion of illness. Both of the comments above seem to separate the physical and mental aspects of anorexia, with the physical being seen as a more legitimate display of sickness. This may be in part because an official diagnosis is achieved through being physically anorexic. There is clearly anxiety among members to be seen as sick enough to warrant the use of the site, as has been noted on other mental health forums (Horne and Wiggins, 2009; Franzen and Gottzen, 2011). Anorexics on the site are considered eating disordered because they are ill and lack a choice about their illness, as seen in the discussion of overweight anorexia they do not need to be emaciated. However members of ANA often talk about being 'sick enough' to use the site, and the above comments illustrate that members dwell on fitting both the mental and physical elements of anorexia to feel legitimate. Franzen and Gottzen (2011) in their study of a self-injury forum found that there were two contradictory discourses on the site, one that normalised self-injury and one which pathologised it. In order to be considered 'authentic' members of the forum had to strike a balance between these two discourses, while presenting their self-injury as based on 'real' emotional suffering. Members of ANA can be seen as having to find a similar balance in order to avoid being considered a wannarexic. They must reject the

DSM but at the same time position themselves as mentally ill, which is based not on their ability to meet the diagnostic criteria, but through the expression of suffering on the site.

While the wannarexic is certainly an out group on ANA, mocked for their alleged beliefs that anorexia is glamourous and something one can choose, there is also the contested idea on ANA that the wannarexic too is ill:

"I feel as though wanting the disease is the first step in having it. Who WANTS to be anorexic? Someone fucked up in the head." (FrankieJane, forum data, ANA)

Boundary maintenance through the 'outing' of wannarexics is thought to serve the purpose of making the community more exclusive (Whitehead, 2010). However, due to the blurred and confused reaction of the community to wannarexics, it does not have this impact. Instead, the wannarexics occupy a precarious position, where they are not genuine nor are they exposed as 'fakes'. This can be seen as a result of the 'sickness mentality'; members see themselves as ill and also begin to see the wannarexic, who is trying to ascribe to their way of life, as ill also. Therefore the wannarexic occupies a contentious position on ANA, on the one hand they are seen as choosing an anorexic lifestyle trying to emulate anorexic behaviour for the goal of weight loss. On the other they are seen as having an illness themselves, they are not considered eating disordered but are thought of as sick as they desire the eating disorder.

The 'sickness mentality' serves many functions on ANA and can be seen as regulating members' use of the site. The need to show oneself as sick appears as overwhelming, and the idea that members are ill dominates many elements of group functioning. Allowing members to dwell on their sickness creates a particular kind of environment on ANA, which may be viewed as negative by outside observers, but is clearly desirable to members as they continue to use the site and defend the negative tone. The need to show oneself as ill does create tension in the form of competition and the wannarexic. With members feeling the need to show themselves as 'sick enough' and lacking any choice to be considered legitimate members. In terms of support, the 'sickness mentality' is essential as it creates an overarching sense of what it means to be

eating disordered on the site, and shapes who is considered eligible for support and underpins what can be expressed on the site and how it can be expressed.

### **Discussion and Conclusion**

This chapter began by showing that ANA and REC reject the DSM-IV criteria for anorexia, due to a perceived over emphasis of the physical attributes of the condition. The critique that members of ANA and REC level at the diagnostic criteria are not unique to these sites or even anorexia, with similar criticisms evident in the literature on the DSM, anorexia and autism (Lafrance and McKenzie-Mohr, 2013; Guilfoyle, 2013; Hardin, 2003; Giles, 2014; Brownlow and O'Dell, 2006). Like the community in Hardin's (2003) study of discourses of anorexia, members of ANA and REC, through their rejection of the DSM-IV, place emphasis on the lived experience of anorexia, believing the emotional pain and impact on everyday lives to be a more accurate indicator of a struggle with anorexia (or eating disorder more generally) than the ability to conform to a medical checklist. On REC this understanding of anorexia results in members being encouraged to see themselves as more than diagnostic labels, and on ANA sees members acting in defence of the DSM. This rejection of the DSM-IV and the understanding of eating disorders based on the lived experience taken in isolation do not sufficiently explain the way in which support is constructed on the two sites. In order to understand this, the communities' understandings of eating disorders need to be considered in terms of choice.

Looking at how the two communities interpret the role of choice in eating disorders illustrates that although the communities have similar understandings of eating disorders; this does not lead to the formation of similar support environments. As is shown in the above analysis, on REC members embrace choice, as a motivator into and throughout recovery, and in doing so create the 'recovery spirit' which works as a site ethos, and is a way in which members can show themselves to be eligible for support from the community. The 'recovery spirit' acts to create a sense of unity on the forum, as members may have different eating disorders and be at different stages of recovery, they are united in their belief that they have the choice to recover. While on ANA members firmly reject the notion that they have a choice in their eating disorder, creating what I have termed the 'sickness mentality', which allows members to express suffering, deny

culpability for their actions, sets a tone for the site and also marks the wannarexics as an out group. Both site ethoses, the 'recovery spirit' and the 'sickness mentality', are not features of support but should be considered the foundation on which support is based on ANA and REC. Through the use of and conforming to these ethoses members of ANA and REC mark themselves as eligible for support, they demonstrate to other members that they share their understanding of eating disorders, in terms of the rejection of the DSM and the embracing or rejection of choice. Further to this the 'recovery spirit' and the 'sickness mentality' illustrate to members what is and is not acceptable on the two sites, they shape the way members use the site, and in turn shape their expectations of site use.

These site ethoses illustrate the conditionality of support and the influence of site culture on form of support on ANA and REC. Both the 'sickness mentality' and the 'recovery spirit' require conformity, members must comply with these site ethoses in order to be considered eligible for support, illustrating that support is not given freely on either site, it is conditional. Further to this, as site ethoses, the 'recovery spirit' and the 'sickness mentality', influence the form that support takes on the two sites. The 'recovery spirit' lays the foundation for a normative form of support on REC; members are inducted into a specific mind-set, one that emphasises the importance of self-reliance, accountability and responsibility. This creates an interesting support dynamic, as members are at once selfreliant but also have to display their eligibility to the community. Thus, support can be seen as both individualistic, as recovery is the responsibility of individual members, and also as collective, as members are required to illustrate their adherence to community understandings of eating disorders, recovery and support in order to be eligible to use the site. While on ANA, the 'sickness mentality' is less normative, but still shapes the online environment and support given, largely through the requirement that members orientate to the tenet that they lack a choice in their eating disorder. This creates a space in which members can vent, deny culpability for their actions, and express their sickness. On ANA, few expectations are placed on members and so the support offered on the site feels less purposeful compared to that given on REC. As support is less purposeful, what constitutes supportive behaviour is more fluid, and gives way to an adaptive support environment. This can be seen in the above analysis of the wannarexics; rather than

being a clear out-group, their position on the forum is fraught, with some members believing them to be sick in their own way. And so, the 'sickness mentality' is perhaps characterised by fluidity, and a level of inconsistency, which goes on to facilitate the provision of adaptive support on the site. The differences evident in the site ethoses on ANA and REC illustrate one of the overall contributions of this thesis, which is that support does not take on a singular form.

In terms of contributing to the existing literature the data and concepts presented in this chapter have expanded knowledge of online anorexia forums, but also have applications to online support, specifically support communities for those with mental health conditions or stigmatised illnesses. The literature on diagnosis criteria and online anorexia forums has previously shown that particular diagnoses carry more credibility within communities and also act as a way in which members can forge an authentic identity (Giles, 2006; Dias, 2003; Bond, 2012). My own research develops this further by illustrating that diagnosis alone does not shape support on ANA and REC. Through shifting the focus from just the diagnostic criteria and on to how members interpret choice, the above analysis highlights the nuance that exists in members' understandings of eating disorders. It also shows that potential for these understandings to shape the community, and not just provide individuals with a sense of legitimacy. While the 'recovery spirit' and 'sickness mentality' are specific to REC and ANA, what is transferable to other online support forums is the idea that support is governed and shaped by site ethoses. Rather than being an unconditional feature, members must show themselves to be eligible for support, through the adherence to implicit and explicit ideals on sites.

# **Chapter five**

# Challenging and Non-judgemental support: illustrating the form and normative constraints of support

Following from the previous chapter, which detailed the role of site ethos in creating a specific support environment, this chapter seeks to take the analysis of ANA and REC a step further, and look in-depth at the *form* online support takes on these sites. As previously stated, form is derived from process in grounded theory analysis (Corbin and Strauss, 2008), and refers to the exploration of action, interaction and emotion to highlight the constraints that enable support to operate effectively on both sites. By illustrating the constraints within which support is given, the differences between the two sites become more apparent, and support can be seen as taking on various forms rather than being fixed. And so, in this chapter I will describe and analyse two forms of support that exist on the sites, challenging and non-judgemental support. Challenging is the term used on REC for this form of support, while non-judgemental support is the label I have attributed to the prevalent support form on ANA. Both of these forms of support will be shown to act as norms on the sites, however, their roles and purposes are very different, and highlight the nuance that exists in the *form* support takes in online environments.

Challenging, which is a distinct form of support on REC, involves community members questioning and critiquing one another's eating disordered thoughts. Challenging does not conform to traditional models of support, such as emotional, esteem, information or instrumental support (Lin & Bhattacherjee, 2009; Walther and Boyd, 2003; Baym, 2010), but is still considered supportive by members of REC, who actively seek out this critical form of peer support. Challenging is a distinctive form of online support as it is not affirmative; members' eating disordered thoughts and behaviours are critiqued in order for them to advance further in their recovery and attain health. This differs from other previously studied online support communities, where support is largely affirmative, reinforcing members' thoughts rather than countering them (Malik and Coulson, 2008; Malik and Coulson, 2010; Sherman and Greenfield, 2013). Challenging, which is closely related to the 'recovery spirit', will be shown to be a normative concept on the site, as it

regulates the way in which support is given and the behaviour of members. This will be illustrated through the discussion of the following topics: challenging as a means of showing commitment to recovery; the creation of a sense of responsibility and the importance of challenging being peer-led critique/support.

Offering members non-judgemental support is the main tenet of ANA, where all members are deemed worthy of support, regardless of their circumstances or where they are in their eating disorder journey. Due to this form of support not taking on the critical tone that support does on REC, it is also not as fixed, with the support on the site being adaptive to members' needs. The non-judgemental support offered on ANA can be seen as conforming more readily to the traditional models of support, as members offer emotional, esteem and informational support in order to comfort and support one another. Although it must be acknowledged that while these forms of support are present on ANA, they are not used to encourage members to recover from their eating disorder, as would be the case for other support groups (Haas et al., 2011). While proanorexia sites, including ANA, do not necessarily encourage recovery, this does not diminish their potential to offer support, and importantly to be felt as supportive places by members (Dias, 2003; Mulveen and Hepworth, 2006; Brotsky and Giles, 2007). Nonjudgemental support illustrates what is and is not acceptable on the site, in terms of support and members' behaviour. This is explored through the discussion of the following topics: the importance of empathy on the site, the role of 'pro-ana' in shaping support and the limits to non-judgemental support.

Before illustrating challenging and non-judgemental support, this chapter will give an overview of the literature on online support and support in online anorexia forums, with the aim of highlighting trends in the literature and placing my own research in these bodies of work. I will then go on to discuss challenging on REC and then non-judgemental support on ANA, the chapter culminates with a discussion of the findings.

### The wider literature on online support

Online support groups have proliferated since the late 1990s, and now exist for a wide array of issues, online support groups for health conditions are particularly popular (Adler and Adler, 2013) and take various forms from asynchronous to synchronous, moderated,

unmoderated or professionally monitored (Attard and Coulson, 2010; Kaplan et al., 2011). Support is given online through various formats, including email lists, blogs, forums and social media. It is also prevalent in online spaces where the main purpose is not support (Coulson et al., 2007; Wellman and Gulia, 1999). There is no one definition of online support, however, some of the consistent features described by scholars are: the sharing of information, facilitating expression, discussion of feelings and personal experiences, and the development of relationships (Eysenbach et al., 2004; Chung, 2013; Barak et al., 2008; Evans et al., 2012). The lack of a definitive stance on what constitutes online support is also adopted in my own study, as throughout this thesis support will be shown to be fluid, and to take on differing forms depending the online environment in which it is given and the way in which interaction is analysed.

Online support is thought to have many advantages for users, some of which may make it a more appropriate avenue for support than traditional forms of face to face support. The key advantage frequently discussed in the literature is the lack of spatial, geographical and temporal boundaries to online support (Mo and Coulson, 2010; Coulson et al., 2007). Linked to this is how easily accessible online support is, as members can go online 24 hours a day and find support and reassurance (Walther and Boyd, 2003). As members are not restricted by geographical boundaries they have potentially limitless access to a wider audience, which allows for more heterogeneous support (Walther and Boyd, 2003; Wright and Bell, 2003; Coulson et al., 2007). Further to these benefits of online support, anonymity is also considered a major advantage afforded by the internet (Coulson et al., 2007; Mo and Coulson, 2010), making individuals feel at ease, and creating a safe space in which to share personal information (Flynne and Stana, 2012; Mo and Coulson, 2010; Wright and Bell, 2003). Individuals also have the time to write a considered response, which they are able to edit before sending and in some online forums content remains editable once it has been sent. A particular benefit of online support for eating disordered individuals is the inability to see one another's bodies'. Walstrom (2000) discusses this at length in her study of a pro-recovery site, and finds that for some members the lack of visibility on the site is considered a benefit, as they felt less competitive with other members and also that the extent of their illness was not being judged by their bodily appearance.

As well as offering individuals the above benefits, online support does come at a cost. The first concern noted in the literature is that individuals using the internet for support may withdraw from traditional methods of support and from family and friends (Malik and Coulson, 2008; Hinton et al., 2010). Further to this there is a belief that individuals that use online support may come to idolise, or place undue worth on the people they meet in an online support environment, due to the feelings of empathy and shared connection they have. Again this may cause them to move away from traditional forms of support (Warisse Turner et al., 2001; Hinton et al., 2010). Another key concern that is frequently acknowledged in the literature is the transmission of misinformation through online support communities, with Sherman and Greenfield (2013, p.83) describing misinformation as an "uncommon but persistent issue". While the issue of misinformation is a perceived negative of any online community (Malik and Coulson, 2008), it is also an issue frequently cited by pro-ana scholars (Juarascio et al., 2010; Norris et al., 2006; Borzekowski et al., 2010; Rouleau and von Ranson, 2011).

There are many forms of support that are given in an online context, the majority of which mirror the provision of support in an offline context. The most commonly discussed forms of online support are: emotional support, esteem support, informational support, instrumental support and tangible aid. Emotional support describes support that shows caring, empathy and concern for one another (Walther and Boyd, 2003). Esteem support is displayed through the validation and admiration of other peers and their opinions (Lin and Bhattacherjee, 2009). Informational support is the provision of advice or factual information about a specific topic (Walther and Boyd, 2003). Instrumental support is the provision of practical assistance or financial support (Lin and Bhattacherjee, 2009). Emotional and informational support are thought to be the most commonly sought and received forms of support provided in an online context (Sherman and Greenfield, 2013; Coulson et al., 2007), which may be because they are easily expressed via the medium. Tangible aid, which is the provision of physical support, such as driving someone to the hospital, has been discussed inconsistently in the literature. Some scholars claim tangible aid represents the ultimate limit of online support (Walther and Boyd, 2003; Sherman and Greenfield, 2013; Wright and Bell, 2003). Conversely,

other scholars note the presence of tangible aid and describe it as occurring regularly in online support communities (Baym, 2012; Coulson et al., 2007; Bakardjieva, 2003).

As well as the advantages and disadvantages of support and the forms it can take, there are three further topics that appear consistently within the literature. These include; the similar other, lurkers and the superficial nature of online support. The similar other refers to the perception of members that the community is a like-minded space, with members having shared beliefs and in the case of health forums a shared, perhaps stigmatised, health condition. The concept of the similar other facilitates the creation of a support environment, because there is an understanding that there is common ground between all members (Hinton et al., 2010; Malik and Coulson, 2008; Sherman and Greenfield, 2013; Warisse Turner et al., 2001). It is also thought that the idea of the similar other is appealing to those that seek online support, as there is the assumption that other members will offer a level of understanding and empathy that is otherwise unavailable in an offline context (Sherman and Greenfield, 2013; Warisse Turner et al., 2001). However the similar other is linked to some of the disadvantages of online support, with fears about disconnection from family and friends and normalisation of negative behaviours. Scholarly work focussing on lurkers, individuals that read online information but do not contribute to the creation of content, has attempted to establish why they lurk rather than participate in discussions and their perceptions of the support they receive (Flynne and Stana, 2013; Eastin and LaRose, 2005; Mo and Coulson, 2010). It has been shown that lurkers are also susceptible to the negative and positive elements of online support (Bardone-Cone and Cass, 2007; Mo and Coulson, 2010). Therefore being an active member of a community or online support site is not necessary, as those who are passive in the support process can still get the support they seek. Finally the superficial nature of online support, like tangible aid, is a contested idea within the literature. Brotsky and Giles (2007, p.107) claim that "online cyber buddies can be dismissed with the click of a mouse" and Walther and Boyd (2003, p.4) state "it is quite easy to extricate oneself from the support group- one simply quits writing and leaves the business to many others whose messages fill the void". While this may represent some individuals' experience of online support, it can also act as a denial of the relationships that are formed and the strong feelings of membership and connection individuals have to an online community.

Hinton et al. (2010) mention the way members of online communities construct an image of a rich and fulfilling environment, which contrasts heavily with the idea that these communities are easily dismissed for former members. Walstrom (2000) and Dias (2003) both state that it is imperative that researchers take seriously the support individuals receives online; while both of these scholars are referring to online anorexia sites, the sentiment applies to all forms of online support.

The literature on online support groups is frequently detached from the literature on proanorexia and online anorexia forums more generally, despite pro-anorexia sites being
shown to be supportive environments (Dias, 2003; Mulveen and Hepworth, 2006; Brotsky
and Giles, 2007). Through illustrating the *form* support takes on ANA and REC, my own
work contributes to the literature on online support, as it not only shows that these
environments foster a sense of support, but that support is fundamental to the
functioning of these two communities. Further to this my work moves beyond the
typologies of support, and illustrates that the *form* support takes on a site is in part
determined by the purpose of the site, the ethos of the site and the continued interaction
of members. I will now go on to discuss the literature on online anorexia sites and
support, again illustrating trends and locating my own research in this body of work.

### Online anorexia sites and support

The academic literature on online anorexia forums, blogs and websites has enabled greater understanding of the subculture, in particular this body of work has illustrated that support is a key feature of the sites (Brotsky and Giles, 2007; Maloney, 2013; Giles, 2006; Bond, 2012). The support members received on online anorexia forums has led to them being considered places of safety for those that use them, somewhere they can vent their frustrations without the need to censor their eating disordered thoughts and behaviours (Brotsky and Giles, 2007; Flynne and Stana, 2012; Dias, 2003). The act of eating disordered individuals supporting one another via the internet has also been presented as an empowering process for individuals who are severely marginalised (Days and Keys, 2008; Tierney, 2008; Mulveen and Hepworth, 2006). These sites are potentially the only outlet individuals have to express their eating disordered thoughts. Moreover, they are created by eating disordered individuals, for eating disordered individuals;

something that is not replicated offline (Brotsky and Giles, 2007), thus potentially adding to the sense of empowerment. Online anorexia sites have therefore been presented as a useful support tool for those living with an eating disorder, however, the negatives of such sites have also been discussed in the literature.

Some of the disadvantages of online anorexia sites and the support they provide users often mirror the wider disadvantages of online support. A key concern of online anorexia sites is that the support they provide normalises dangerous eating disordered behaviours (Haas et al., 2011; Gavin et al., 2008; Mulveen and Hepworth, 2006; Borzekowski et al., 2010). The issue of normalisation has also been raised in relation to suicide and self-harm forums (Whitlock et al., 2006; Smithson et al., 2011) and the negative influence of infertility forums have also been discussed (Hinton et al., 2010). Finally while sharing information between eating disordered peers is at times presented as empowering, scholars also question the reliability of the information exchanged (Juarascio et al., 2010; Norris et al., 2006; Borzekowski et al., 2010; Rouleau and von Ranson, 2011). All of these concerns are expressed about online support in general, however when they are discussed in relation to online anorexia forums, particularly pro-anorexia, they are given greater prominence because of the perceived impact on users and the demonization of these sites. Online anorexia forums, and the support they provide are frequently problematized. Bell (2009, p. 152) suggests that such sites are seen not only as "dangerous" but "infectious", which leads to members being positioned as uncritically consuming pro-anorexic material. Members of online anorexia forums are often presented as lacking agency, as if to read these sites is to be overpowered by them (Balter-Reitz and Keller, 2005). Knapton (2013, p.473) suggests that this view point perpetuates the image of pro-anorexia sites being run by "powerful message creators" who are manipulating impressionable youth, when in reality, those creating the sites are marginalised as they usually have an eating disorder themselves and pro-anorexia is a movement driven by its members. The role of members in creating and maintaining online anorexia forums is often lost in the literature, with them being portrayed as lacking the ability to counter what is expressed on the sites, lacking agency and control (Haas et al. 2011; Castro and Osorio 2012; Juarez et al. 2012; McCabe 2009). Like the work of Day and Keys (2008) and Mulveen and Hepworth (2006), my own research

illustrates that online anorexia forums are places of support, which are created through interaction between members and can take on a critical form. Members, in the case of REC, are challenged to rethink their eating disordered behaviour and on ANA there are limits to the support given, boundaries are marked and counter-voices are expressed.

A consistently discussed feature in the online anorexia literature is the idea that individuals use these sites because of an offline unmet need. Authors suggest that a lack of understanding, empathy and individuals' perception of lack of support from family, friends and their medical teams cause individuals to seek out support online (Brotsky and Giles, 2007: Dias, 2003; Bond, 2012; Yeshua-Katz and Martins, 2013; Tierney, 2008). Again this is not something unique to online anorexia sites, with scholars of online support showing that individuals with various medical conditions feel a need to access online support in order to make up for unmet needs offline (HIV- Bar-lev, 2008; Peterson, 2009. Huntington's Disease- Coulson et al., 2007. Infertility- Hinton et al., 2010; Malik and Coulson, 2008; Malik and Coulson, 2010). Flynne and Stana (2012), in their study of a men's online anorexia forum, suggest that stigmatised groups such as eating disordered individuals, particularly men, and those living with HIV/AIDS, would benefit from the peer support that is offered online. While this may be true, eating disordered individuals are not afforded this concession as other individuals are, with the merit or safety of peer support for anorexics being questioned (Juarez et al., 2012; Haas et al., 2010), online anorexia sites being demonised in the media, being closed down by webhosts and an individuals' desire to use such sites being pathologised and considered further evidence of their ill health (Ferreday, 2003).

As can be seen, there are similarities between the wider literature on online support and the literature on online anorexia forums. The advantages and disadvantages of the support offered are the same across the literature and key issues like unmet needs, lurkers, superficial support and the similar other are consistently discussed, rather than being unique to online anorexia sites. What is different is the perceived level of danger that is attributed to online anorexia sites, particularly pro-ana sites.

What follows, in the remainder of this chapter, is an analysis of two online anorexia forums, the aim being to illustrate the *form* that support takes on both sites, the norms

that members create and the reasons for members seeking support online. The discussion also aims to bridge the existing gaps in the literature. While support is a central feature of online anorexia forums, it has largely been positioned as more dangerous than the content, as the support and interaction members access on sites furthers their relationship with their eating disorder, making them associate it with a community, the loss of which may make recovery seem unappealing (Tierney, 2006). Through focussing on support, and the varied forms it takes, and not on the content of online anorexia forums, my study explores why and how these online environments are supportive spaces for members. It also aims to demonstrate that members of such sites are actively constructing support environments, giving them agency and control which is lacking in some studies as outlined above. Further to this, support will be shown to be varied. There is no one form of support given on online anorexia forums, support is shaped and expressed differently on each site.

## Challenging support: The construction of support on REC

Challenging, or the questioning of the eating disordered 'voice' is a distinct way members support one another on REC. Challenging is both an expected and a desired element of the forum, with members describing it as 'harsh but kind' and a 'not so gentle wakeup call'. Challenging does not conform to the standard emotional, informational, instrumental and esteem support that is often discussed in relation to both online and offline support (Walther and Boyd, 2002; Lin and Bhattacherjee, 2009; Baym, 2010), but is considered a form of support by members. This analysis will show the purposes challenging serves in the REC community and why members feel the need for this form of peer led support. This will be achieved through considering the form that support takes, rather than considering the content.

### The challenge

When I first started observing REC I found challenging jarring. As an outsider I could not associate it with being supportive; on the surface it appeared to be abrupt and at times rude. I mentioned this to several members of REC during interviews, most of them laughed and simply agreed that from the outside it probably does look aggressive. Over time and with analysis of forum data, I became accustomed to challenging and was able

to see the merits it had for members. During interviews it became apparent how interwoven the concepts of pro-recovery, support, 'recovery spirit' and challenging were for members of REC. Simply put, challenging can be defined as questioning a member's eating disordered thoughts, with the aim of strengthening their recovery. On REC, challenging is a form of peer-led support that shapes their community through illustrating members' responsibilities to themselves and the group and also highlights members' commitment to recovery.

Below is an extract from the REC forum, which illustrates the way members challenge on the site, and the wider implications it has. Here a member seeks advice and her viewpoint is challenged (NB. This is not a complete thread, but a selection of responses):

Thread title: Restricting

Trixie:

"I want to restrict and lose weight again. I'm at my one of my highest weights and it driving me crazy. I'm trying to fight the urge.

I know if you restrict your metabolism slows down, but what about the people with ED's who become emaciated? is that like rare or something?

I just want to know I'm not planning on restricting again becoming underweight, I just have the urge to"

MsFoxglove:

"Do you want to recover?

I'm a little lost as to why you keep asking question after question trying to justify eating disordered behaviours. I understand when people get here they have questions and hey they might need to ask some of these and that's all great... but you keep asking question after question. As soon as we tell you why for instance purging isn't okay or using online calculators etc you find another "reason" to remain eating disordered.

Why do you want to recover?

It's not our job to find a reason for you to want to recover- you have to find that."

# DayGlow:

"If you really want recovery, then I think a lot of these posts are ED driven. Have you ever heard of separating from your ED? That means that you (Trixie) can learn to differentiate between what your ED wants you to do and what you think is right. It's not easy at first but learning to do this was a major positive step for my recover."

(Forum data, REC)

As can be seen, Trixie was not 'supported' in the traditional sense in this exchange; her eating disordered thoughts were questioned, as was her commitment to recovery. While no challenge is 'typical', as the process is influenced by various factors which will be discussed below, the above extract clearly shows the process of challenging. Trixie's mind-set is seen to be eating disordered, her thoughts are considered counterproductive to the recovery process and so other members take it upon themselves to question those thoughts in order to help Trixie regard her thoughts as "ED driven". From this example of challenging we see the type of support that is acceptable and given on REC. Challenging occurs in all the sections of the forums, and any comments made that are thought to normalise eating disordered behaviour or are "ED driven" will be challenged. It is particularly noticeable in the journal section, where members narrate their daily struggles and triumphs. Challenging cannot be placed within the traditional models of online support, as challenging is not emotional, esteem, informational, instrumental or tangible support (Walther and Boyd, 2002; Lin and Bhattacherjee, 2009; Baym, 2010). In these more traditional models of support, support is given through: reaffirmation, validation, advice, empathy and understanding (Baym, 2010; Walther and Boyd, 2002; Malik and Coulson, 2010). While challenging does embody aspects of these traits, it is the form it takes; that is, the consistent and at times single-minded critique of another member's behaviour that sets it apart.

-

<sup>&</sup>lt;sup>9</sup> Pseudonyms are used throughout this thesis for forum and interview data. They do not retain the 'spirit' of the original name or username, but are randomly assigned by Sarah Lewis. Pseudonyms for forum data are not replicated, therefore the same member may appear in the thesis under a number of different pseudonyms, this is to provide a higher level of anonymity.

Walstrom (1999) also found challenging in her study of the recovery community ASED. However, there are key differences in the form challenging takes on ASED compared to REC. As stated challenging on REC is peer-led critique, while on ASED challenging involves validating other members through offering them an alternative positioning through which to see themselves or the situation they find themselves in (Walstrom, 1999). For example, if an ASED member posts about being fearful of a social situation, a likely response would be to position that member as already brave. Challenging in Walstrom's (1999) study is presented as a rather gentle process, one in which members bolster one another's self-esteem while offering an alternative perspective to help fuel their recovery. While the techniques used on REC and ASED have similarities, the way they are performed is different. Rather than imitating other online support environments, challenging on REC is more reminiscent of an AA meeting, were members have to acknowledge that they have done wrong, express their desire to get better and work on the twelve steps towards recovery (Denzin, 1987). In both AA and challenging, accountability can be seen as a key element of the support that is given.

As well as sharing commonalities with AA, challenging on REC is also reminiscent of narrative therapy for eating disorders. Narrative therapy is a therapeutic approach to treating a variety of mental health conditions, such as schizophrenia, borderline personality disorder and eating disorders (Gremillion, 2003). As a therapeutic approach, narrative therapy does not see illnesses, such as anorexia, as fixed to the individual, but as issues with social discourses that illness is situated in and narrated through (Gremillion, 2003). Just as illness is not fixed to the individual, social discourses too are fluid and multiple. There is no one social discourse that is a root cause of anorexic thinking, this is unique to the individuals' specific personal and cultural context (Gremillion, 2003). This understanding of eating disorders leads to a unique understanding of the self in which "the self is seen as continuously transforming as the form and content of interaction around it change" (Saukko, 2008, p.101). In viewing the self in this manner, narrative therapy departs from traditional approaches to treating eating disorders. Traditionally, in the treatment of anorexia, the self is considered unitary, so at the core the self is always the same, regardless of external circumstances (Hoskin and Leseho, 1996), leading the anorexic to be treated as if there is something inherently

wrong with them, with treatment focussing on refeeding, and addressing intrapersonal issues (Saukko, 2008; Gremillion, 2003). While in narrative therapy the "goal of counselling becomes one of strengthening a new story of the self that can 'protest the oppression' of the problem" (Hoskins and Leseho, 1996, p.246). And so, treatment in narrative therapy involves techniques such as externalisation (separating the self from the eating disorder), deconstructive questioning (asking questions that expose the eating disorder as separate from the self) and adopting different language (language that supports an anti-eating disorder mindset) (Maisel et al., 2004).

While members of REC are not consciously engaging in narrative therapy, during my period of observation and interviews narrative therapy was not mentioned, the way in which they challenge, and therefore offer support, appears similar to narrative therapy. Interestingly, each of the above narrative therapy techniques can be seen in the challenging process, with members distinguishing between the person and the eating disorder, questioning the eating disordered thoughts and using a specific type of language to express these challenges. An example of this is DayGlow suggesting that Trixie externalises her eating disorder: "Have you ever heard of separating from your ED? That means that you (Trixie) can learn to differentiate between what your ED wants you to do and what you think is right".

# Challenging as normative

Challenging can be seen as not only a form of support given on REC, but also a group norm. It is enacted by members without them having to think about it (Baym, 2010). Lauren described this during an interview when I asked if challenging was important to the group:

"yeah I think it's [challenging] important to everyone, everyone takes part in it anyway, whether they know they've doing it or not (laughs)"

(Lauren, audio interview)<sup>10</sup>

-

<sup>&</sup>lt;sup>10</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Audio interview indicates that an interview was conducted via the telephone function on Skype.

While challenging may be the consistent response to an "ED driven" post, it is not always a straight forward process and it can take new members some time to get used to the idea of being challenged and challenging others. While interviewees all claimed that challenging was useful, many said that they initially found it difficult. Two interviewees talked about how testing they found being challenged by others, stating:

"at REC they really challenge you, and when you're new it was a bit of a shock to the system, i was used to people sympathising etc not 'telling me off'- in a loving way lol."

(Isobel, IM interview)<sup>11</sup>

And:

"I was just sort of like 'urgh, they're just being nasty to me, fine I'll just go away."

(Lauren, audio interview)

Some interviewees said that they found challenging others problematic, because they were unsure as to how it would be perceived:

"I used to not challenge people a lot before because I was afraid they would take what I had to say the wrong way or they would be offended by what I would suggest. But I think recently I've gotten more confident with challenging others."

(Eliza, IM interview)

So while challenging was accepted practice on the site, it was not without its difficulties and required members to 'buy into' the ethos of the site; if they cannot do this they are unlikely to remain active on the site:

"If they don't like being challenged they leave pretty quick."

(Megan, audio interview)

-

<sup>&</sup>lt;sup>11</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. IM interview indicates that an interview was conducted via an instant messenger service.

Challenging appeared to be a novel way of approaching peer support for eating disorders, as the similarity to narrative therapy techniques seems to distinguish it from traditional forms of support on offer in offline clinical settings. However in highlighting a critique of narrative therapy Saukko (2008) suggests that, despite attempting to see the self as not in opposition to the eating disorder, like unitary conceptions of the self, the narrative approach perpetuates the judgemental dichotomies (good/bad, thought/behaviour, health/illness) that mirror anorexic thinking. This criticism could also be levelled at challenging, as it allows members to be seen and see themselves in the dichotomies of ED driven/non-ED driven, pathological/healthy and bad/good; but it still serves an essential role on REC. while challenging is a normative feature of REC it is important that is not seen as moderator led, while it will be shown as constraining and regulatory it is not a product of those occupying a position of authority on the site, it is a form of support that has been created and maintained through interaction between community members. As the initial implications of challenging have been discussed, I will turn my attention to the wider implications of challenging, which include; commitment to recovery, responsibility and the need for peer-led support.

# Commitment to recovery

Through challenging members are able to display their commitment to recovery. This is in part because challenging is a group norm, implicitly regulating how members behave, and in the case of REC, offer support to one another. Baym (2010, p.78) suggests that breaking a group norm leads to a "critical response" from other members of the forum, which is evident when members of REC 'fail' to react appropriately to a challenge. Below is an example of this, taken from the above thread started by Trixie on urges to restrict food intake. Trixie received a large number of responses and 'failed' (by the community's definition) to react well to them, this led another member (LaRoux) to reprimand Trixie and assert her right to challenge Trixie:

# LaRoux:

"I offered you a way to evaluate your behaviour and improve on something you've admitted you need to work on.

I don't appreciate your passive agressive response. I will not feel guilty for challenging you and offering you a suggestion for something that might help. If you want to play that game I suggest you play it with someone else."

(Forum data, REC)

This fiery response illustrates how important challenging is to the group. LaRoux clearly feels that her challenge was justified and that it is Trixie who is at fault by 'failing' to accept challenges from members. This response, and the others highlighted above, illustrate that responding not according to expectations to a challenge, elicits a strong reaction amongst members and also brings into doubt a member's commitment to recovery. Trixie was asked, "Do you want to recover?" and "Why do you want to recover?" and her recovery was questioned with the statement "If you really want recovery, then I think a lot of these posts are ED driven", showing that other members felt dubious about her 'genuine' commitment to recovery. This is linked to the previously discussed concept of the 'recovery spirit', which is an ethos that has been created on the site, requiring members to see eating disorders as a choice, recovery as a powerful tool and importantly, visibly show their commitment to recovery on the site. The need to show that you are committed to recovery through accepting a challenge was articulated by Eliza:

"Accepting a challenge is a sign that you want recovery and you're willing to do the work. While I have a hard time being challenged sometimes, I always try to rise to the challenge because it shows that I want recovery."

(Eliza, IM interview)

The 'recovery spirit' not only requires that members are committed to recovery on the site, but that they are also actively engaged in recovery orientated behaviour offline. Challenging exposes the difficulty some members have of translating the 'recovery spirit' into their offline life, or as one interviewee, Erica, described it, "tangible" life. However, it is difficult for the community to patrol this, as members are geographically widely dispersed. It is therefore important for members to write their recovery into action, and present themselves as recovery orientated on the site, and also on other social media that they share with members of REC, as inconsistencies will be noticed and judged.

Boero and Pascoe (2012, p.45), when describing group activities such as fasting on proanorexia sites, suggest that undertaking the fast offline is insignificant, members are
"discursively participating" which serves the same purpose for the community. Mundry
and Strong (2012) discuss the importance of 'doing' recovery in an online problem
gambling support forum, stating that members have to present their recovery as
legitimate by conforming to discourses about recovery on the site. However, for REC
members are required to take these site discourses ('recovery spirit' and challenging)
beyond the confines of the site, and apply them to their tangible life, as their discursive
participation (to use Boero and Pascoe's (2012) term) is deemed insufficient. Due to this
expectation, consistent presentation of a member's recovery story is important on REC as
it creates a sense of legitimacy and commitment to recovery. Nina highlighted the feeling
of frustration a member acting inconsistently elicits, speaking angrily about the hypocrisy
of one member who challenged her, but had not consistently presented herself as
recovery orientated:

"[username]came out and started challenging me, and it actually made me really angry because I know how sick they are and how desperately desperately ill they are, like in and out of hospital and look really unwell and that made me angry and I felt like saying 'well who are you? What are you telling me this for? You don't practice what you preach'"

(Nina, video interview)<sup>12</sup>

Therefore the gaze of the group is not limited to REC itself. Sharing information online (via Facebook, Skype, instant messenger), sending items in the post and meeting up, allows the norm of challenging and the expectation to live up to a challenge, to move beyond the boundaries of the group. However not all members will be willing to share further contact details, and so for them, they only need to perform according to the tenets of challenging on REC. As is shown in the above quote by Nina and the community's reaction to Trixie, to act inconsistently, or not appear to show progress online or offline, is unacceptable and will lead other members to question your recovery.

<sup>&</sup>lt;sup>12</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Video interview indicates that an interview was conducted via the video chat service on Skype.

In analysing challenging I was able to go from seeing it as abrupt, to supportive and in some ways restrictive. While it serves an important purpose for members who go to REC to be challenged and pushed further into recovery by their peers, it is so normative that if you are unwilling to be challenged there is no place for you on the site:

"Do you think people generally are quite positive towards challenging?"

(Sarah Lewis)

"Yeah, yeah seem to be, obviously if not they don't stick around (laughs)."

(Nina, video interview)

And:

"I think if people don't like it [challenging] then they'll go, go somewhere else."

(Lauren, audio interview)

Challenging almost seems like a one track support mechanism, and it is the main form of support on offer on REC. In this sense it further perpetuates the dichotomies Saukko (2008) discusses in her critique of temporal narrative therapy, as challenging is positioned as right, and any form of resistance to this is positioned as wrong:

"If you don't ever take the challenge you'll never get better"

(Megan, audio interview)

The above quote illustrates the right/wrong dichotomy, with challenging being seen as a pillar of health, recovery and progress, and with an anti-challenge mentality occupying the other end of the spectrum and representing sickness and stagnation.

#### Responsibility

Challenging also creates a sense of responsibility on the site. This is keenly felt in LaRoux's response to Trixie above, particularly when she says; 'I will not feel guilty for challenging

you and offering you a suggestion for something that might help', LaRoux will not feel guilty for doing the responsible thing and challenging Trixie's eating disordered thoughts. Responsibility is acted out on the site in three ways: members take responsibility for themselves; members have responsibility for one another and; moderators have an overall sense of responsibility.

Through challenging members are expected to take responsibility for their own recovery, Rachel mentioned this as being held accountable for her actions:

"I get a lot out of them "challenging" me, that is, taking things I say and asking why I think that way, or if it's useful to be posting stuff like that, etc. And also knowing that they understand and can relate and will hold me accountable is incredibly useful"

(Rachel, typed interview)

Challenging allows members to post about their struggles and get constructive feedback. As has been mentioned they are required to act on the challenge to display a recovery orientated mindset, making them discursively accountable for their eating disordered thoughts, behaviour and recovery motivated ways of dealing with them. Creating a perceived sense of accountability for site members has also been noted as an important aspect of pro-ana sites and weight loss blogs, with members posting food logs and diet plans to keep them on track (Haas et al., 2010; Juarascio et al., 2010; Leggatt-Cook and Chamberlain, 2012). Posting and accepting challenges can be seen as the recovery orientated equivalent of food logs and diet plans, as it holds members of REC accountable and seeks to keep them recovery-focussed.

Members are not only responsible for themselves; through challenging they are also made to feel a sense of responsibility for one another. This is evident in the following quotes:

"so I do challenge people if I see them doing dangerous things and I don't want to sit by and basically watch another person die." (Nina, video interview) And:

"I want to help others. I want to challenge Eating Disorder thoughts. I want people to know that they are not alone, and that there is hope. I want to post affirmations, recovery cards, and other helpfull posts for someone just on the cusp of recovering. I want to help others not fall into the pit that I did for so long. I want to be compassionate while being honest and challenging."

(Lilycat, forum data, REC)

Here challenging is not only about what the individual can gain from the forum, but it is also about what members can do to help one another. This again brings to mind dichotomous thinking, as challenging is placed in opposition to any other form of support that is available. Arguably moderators have an added pressure to challenge and live up to challenges, as they are there to ensure the community remains recovery centred and set an example for others. Megan mentioned this during an interview:

"it was good for to help other people because it kept me going in the recovery, because I thought you know 'if I don't eat and start going on the eating disorder path again then I'm not going to be a very good moderator or a good inspiration to other people' so it keep me going that way."

(Megan, audio interview)

Moderators are there to set an example in some ways, and this is something that Megan was very aware of and that helped to keep her recovery orientated. In turn this also keeps the wider community recovery focussed, as those in a position of authority are conforming to the same standards as everyone else.

# Peer-led support

"It's all stuff that they'll have heard before in treatment, from their treatment teams and everyone's been through or done worksheets or whatever so it's just kind of reminding people when they're in that moment that there is another way of looking at it"

(Nina, video interview)

Considering this statement from Nina, if members have heard it all before, what makes them want to engage in challenging on REC? For Eliza and Rachel the answer to this question appears to lie in shared experience:

"I would like to think so. No one said recovery is easy and I think it helps if we constantly strive to move forward and if others are around to help us figure out where to go next in our recovery. Like I said before, I don't believe one should ever stop trying to better themselves and by challenging each other, we're helping each other improve."

(Eliza, IM interview)

#### And:

"I think it opens people up to things that they wouldn't necessarily considered having had that feedback, someone telling you things that you can't see when you're stuck inside your own head."

(Rachel, IM interview)

For Eliza challenging is about helping one another through recovery, "we're helping each other improve" and for Rachel it is about getting challenged and being offered a different perspective on her situation by her peers when "you can't see when you're stuck inside your own head". The ability to gain critique and be questioned creates a sense of shared experience in that they are not working on their recovery alone, they have somewhere to go to gain perspective when they are slipping and also to give other people assistance when they are in need. Members also mentioned the sense of empathy and understanding that they feel when they are challenged by other individuals with eating disorders. The need for empathy is frequently discussed in the literature (Hinton et al., 2010; Malik and Coulson, 2008; Malik and Coulson, 2010; Dias, 2003; Gavin et al., 2008; Wright and Bell, 2003; Flynne and Stana, 2012). Isobel explains the appeal of talking to similar others online:

"it's definitely easier, because it's coming from someone who understands what's going on. it doesn't seem as condescending as such than if its coming from someone who may have no real life experience of what you're going through"

For two interviewees it was particularly important that challenges were from their peers and not medical staff:

"Yeah, I think sometimes it helps, they know deep down that they're not quite doing enough but sometimes it helps to have someone else say, on friendly terms, not like a medical person, to say by the way, you need to be doing a bit more."

(Caitlyn, video interview)

And:

"And I used to get it in treatment, you know struggling with eating and drinking and you've got some person telling you something that's like 'eff off you have no idea'"

(Lauren, audio interview)

So while challenging can be difficult for members to get used to, and is not what some people expect from a support site, ("I was used to people sympathising etc not 'telling me off"), the fact that those who are challenging them have similar thoughts, fears and exhibit similar behaviour is a plus point. Knowing that challenging comes from someone with first-hand experience of an eating disorder makes the process an appropriate form of support, as the critique is based on personal experience and not medical knowledge like the guidance received through treatment centres. REC is not the only online support community that appeals to members because of the empathy and understanding that they can experience. Malik and Coulson (2010) state that empathy and understanding from people experiencing the same issues was the main form of support given on an infertility forum, and other scholars have also discussed the importance of understanding in creating bonds on online forums (Dias, 2003; Gavin et al., 2008; Wright and Bell, 2003; Flynne and Stana, 2012). However this type of understanding that appeals to members of online support groups is unsurprising, as members are there for one shared reason, and potentially have similar experiences of marginalisation, health care systems, coping with everyday living, allowing them to display a higher level of empathy than those without

these similar backgrounds (Wright and Bell, 2003). REC is unusual in that this empathy and understanding is displayed through questioning and critique rather than the use of "words of condolence, hope, encouragement reassurance and validation" as noted by Malik and Coulson (2010, p.316). However, challenging is not only about critique. When someone lives up to a challenge they are congratulated and their achievement is celebrated. Below is an example of this, where a member was challenged to throw away some diet pills and laxatives:

Thread title: questions about the dangers of... (mild trigger)

# Cloudyday:

"I binned the carb blockers late last night, and the laxatives are in the car, and will go to the chemist for disposal. Thanks for your encourgement, it was just want I needed."

#### XARA:

"Oooooh, well done!! I know it was a tough decision to make, even harder to put it into action, so seriously.. well done! Your body will thank you ^.^"

# IrisMay:

"That must have been really hard so I'm proud of you This is what this site is about"

# Lindsayxoxo:

"Good job! That's awesome! I'm proud of you!"

(forum data, REC)

This example illustrates how, through challenging, members are given both emotional and esteem support on REC, as members are being bolstered by other members and also having their feelings validated (Baym, 2010; Lin and Bhattacherjee, 2008). However this support is only forthcoming if a member lives up to a challenge, highlighting a limit to the support that is offered on REC. As has been shown above failure to live up to a challenge

results in further challenging and ultimately questioning of that member's commitment to recovery.

Challenging keeps individual members motivated for recovery through peer-led critique, however as the process of challenging itself is an unquestioned group norm, through continuing to challenge one another members are also keeping the community recovery orientated. Interviewees expressed this by suggesting that without challenging, REC would not be a recovery forum:

"I think so because without it [challenging] I think a recovery forum would be a bit lacklustre, a bit useless" (Lauren, audio interview)

#### And:

"what pro-recovery is I feel, is that people can post their struggles because we all do still struggle but expect or accept that they will be challenged in a constructive way, so and that's where it's different I guess to not being pro-recovery, we will challenge them and say 'ok you know, that's what you did in that situation but what's the next right thing you can do, what's the next small step forward you can do' and that's were pro-recovery comes in."

(Nina, video interview)

The above quotes illustrate how essential challenging is to the REC community, it keeps individual members and the community at large recovery focussed. Without challenging, members feel that REC would not be a sufficient recovery site.

In this section I have shown challenging to be a normative form of support on REC. The critical tone of challenging establishes a support environment in which members have to show themselves to be accountable and committed to recovery (through accepting challenges and adherence to the 'recovery spirit'), and are imbued with a sense of responsibility to themselves and others using the forum. As jarring as challenging may seem, it is sought out by members, who crave to share experiences and be encouraged in recovery by similar others. The next section of analysis will look at non-judgemental support on ANA, and will illustrate the normative features of this form of support, which creates a fluid and inclusive support environment.

#### Non-judgemental support: The construction of support on ANA

For the REC community support was critical, with members questioning others' thoughts and actions. On ANA, support acts in an altogether different manner. The following analysis will show that non-judgemental support acts a norm on ANA, but in a less fixed sense than challenging does on REC. The community lacks a definitive stance on what is considered appropriate support and also on what constitutes pro-ana. This leads to a more open community that is united in providing non-judgemental support to members. Non-judgemental support conforms to traditional models of support, in particular informational, esteem and emotional support (Walther and Boyd, 2002; Lin and Bhattacherjee, 2009; Baym, 2010). However, the support given on any pro-ana site, including ANA, is contentious, as it would not be endorsed by medical professionals and has been seen as developing from an opposition to the social/psychological/medical models of anorexia (Pollack, 2003; Day and Keys, 2008; Ward, 2007). While the main tenet of this community is to offer non-judgemental support to all, there are limits to this support, illustrating that the support on ANA is conditional. Members are still required to live up to the norms of the site in order to obtain the support they need. The limits of support can be seen when members are looking for ways to further exacerbate their eating disorder by asking for tips and tricks. This will be explored below.

# Non-judgemental support

On first observation, support on ANA appeared to be a "free for all", "anything goes". All topics were up for discussion and all ideas and thoughts would be lauded and supported. However, with spending more time within the community, through comparative analysis and interviews, it became clear that the support on ANA was normative, but without rigid and prescriptive boundaries, like those seen on REC. The term non-judgemental support is my own and is an interpretation of how members offer support on ANA. Non-judgemental support as I conceive of it is not discussed openly, or, in these terms on the site.

I have termed the support that is given on ANA 'non-judgemental' because that is the characteristic that underpins how support is given on the site. Whitehead (2010), in her study of femininity on pro-anorexia forums, briefly discusses non-judgemental and conditional support as a group consciousness, with members understanding that eating disorders can be dangerous, but also recognising eating disorders serve a purpose for those living with them and that members are in need of support. Rather than being a group consciousness, non-judgemental support on ANA will be shown to be normative, and fundamental to the support given on the site. Members of ANA offer support in a non-judgemental manner because they seek to support all members, regardless of how they are affected by their eating disorder and where they are in their eating disorder journey. All members are considered to deserve the support they need. The lack of understanding and the judgement of medical professionals towards those with eating disorders are frequently cited as reasons for the development of pro-anorexia as a subculture and the contempt with which medical staff are discussed on such sites (Pollack, 2003; Day and Keys, 2008; Dias, 2003). In interviews the non-judgemental support accessible on ANA was contrasted with that offered by family and friends, with Holly and Alice both mentioning that while friends and family try to understand, they are still judging them:

"My friend has been with me throughout five years of my ED, and she is a recovered bulimic. She offers me healthy tips, like ways to help prevent my enamel erosion, and gives me rides to my physician and therapist. But she also pushes recovery and makes her disapproval obvious."

(Holly, IM interview)

# And:

"exactly, and I think part of what ANA has that most of our family/friends [don't] is the non-judgement. I don't feel the need to hide anything because I know I can get the support I need, not feel guilty or ashamed" (Alice, IM interview)

Therefore the non-judgemental support environment created by members of ANA is something that members seem to lack in their offline lives, and so being able to access such support online fulfils an otherwise unmet need.

Non-judgemental support on the site can be observed on a variety of levels, with members calling on one another to provide informational support (the provision of advice or factual information about a specific topic), emotional support (showing caring, empathy and concern for one another) and esteem support (the validation and admiration of one another's worth) (Lin and Bhattacherjee, 2009; Walther and Boyd, 2002; Baym, 2010). All the support given, whether it is informational, emotional or esteem support, conforms to the overall principle that the support is non-judgemental. Non-judgemental support is a standard by which supportive behaviour is measured; illustrating that non-judgemental support is a norm on ANA. This principle regulates what is deemed acceptable on the site and also highlights the limits of support on the site through exposing unacceptable behaviour. However while non-judgemental support operates as a norm, it is not prescriptive, as challenging is on REC. As long as ANA members are conforming to the norm, that is, being non-judgemental, then most behaviour will be supported. I have caveated that statement by indicating that most behaviour will be supported because there are limits to the non-judgemental support given on ANA; in particular it is frowned upon for members to express a traditional proana identity on the site, that is, an identity that glamourises or seeks to exacerbate their anorexic condition.

#### Inclusive and fluid support

Acting as a norm, non-judgemental support facilitates an inclusive and fluid notion of support on ANA. The overriding sense that members must support each other non-judgementally allows members to support one another in a variety of (and at times contradictory) situations. The sense of inclusivity is particularly evident through the breadth of topics that receive supportive comments and advice. Below are two examples of threads, taken from the forum, that illustrate this sense of inclusivity:

Thread title: I'm going inpatient...

Bluebell:

"Hey girls (and guys)-

well i've lost 60lbs in a matter of 3 months and then yoyo'd back and forth about 10 pounds because of binge and purging. but i eat about 400-600 calories a day. and most of that i purge. Wednesday night i was admitted to the ICU for severe dehydration and heart problems. The cardiologist said my heart problems are strictly ed related. They made arrangements for me to go inpatient and the univeristy hospital 2 hours away from my house...:/ they want me to leave like in a week. (theres 3 people on the list in front of me). I want to go. i want help. I'm sick of counting calories. and being obsessed with being thin. My problem is.... my father. he doesn't think i have a problem. in october i attempted suicide and he blew it off. even though i was inpatient for 2 weeks. i told him about binge and purging then. he later told my fiancee he thought i was faking it... My father is making me change my mimd about going... how do i tell him i'm going? My therapist said she could have like a family session and we could tell him then? how do i do this? i'm scared and he's the only reason why i don't want to go... i obviously need to though... help please..."

#### **JANE471:**

"Congratulations on deciding to take the final step towards recovery. I think family therapy would work, he probably knows you have a problem he just doesn't want to confront it. So if you make him confront it in therapy you will have everyone rooting for you to get better. Take care."

(forum data, ANA).

And Sallyanne seeks and receives support for a very different issue:

Thread title: I've lost 17lbs in 10 days, I am so proud of myself!

Sallyanne:

"I am SO happy with myself. I have regained my self control! I am so proud of myself!"

# Fraggle:

"YAY! Just be sure to rehydrate if ya want pretty skin congrats! When I read the topic title literally the first thought in my head was "HOLY CANOLLI!" haha"

(Forum data, ANA)

Despite Bluebell and Sallyanne seeking support for very different reasons, their needs are attended to in the same manner. First, both members are supported, their messages are responded to in a supportive and affirmative way. While that would seem unsurprising for Sallyanne's post, as the content conforms to a stereotypical idea of topics discussed on pro-ana sites, Bluebell's advice-seeking about entering recovery and the positive response seems contradictory to the very notion of pro-ana. However, it has been shown in the literature that recovery orientated content is a consistent feature of some pro-ana sites (Borzekowski et al., 2010; Brotsky and Giles, 2007; Bond, 2012), and this is also the case on ANA. As well as receiving supportive messages, both Sallyanne and Bluebell are given non-judgemental support. JANE471 and Fraggle both conform to the norm by responding with comments that lack judgement, condescension or a specific agenda. Finally, both Sallyanne and Bluebell are given the support they sought. Sallyanne wanted to be congratulated, while Bluebell wanted advice, and both responses attended to their distinct needs, ensuring they received the support they craved, and not a prescriptive form of support. The non-judgemental support offered on the site enables a sense of inclusivity to develop as members are aware that they will receive supportive and, importantly, non-judgemental responses regardless of their needs. This facilitates conversation, as members are potentially less inhibited about posting. Peterson (2009) in her study of an HIV forum, which had a strong norm about positive thinking and expressions of positivity on the site, found that forum members might feel uncertain about expressing thoughts that do not coincide with the community's conception of support. While non-judgemental support is a norm on ANA, like positivity in the HIV

forum, it is not as inflexible and allows for variance within it, as long as the basic tenet is being obeyed. Again this may enhance the feeling of inclusivity, as members of ANA are less likely to feel a comment is inappropriate or non-conformist because the idea of support that exists on the site is adaptive, rather than prescriptive.

As well as creating a sense of inclusivity on the site, the non-judgemental support that is so fundamental to ANA also creates a fluid form of support, which is not static and can be called on by members regardless of their needs. The fluidity of support on ANA can be illustrated in two ways, first through members lacking a fixed definition of support and secondly through the changing support needs of members continuing to be met. During an interview, I asked Evie what she thought support meant to the ANA community, and she responded with the following:

"I think that in ANA everyone tries to support one another in a positive way through commenting on the post or messaging the user. I think that as a community the main idea is to support one another, I don't think there's a particular way that you're meant to do it as long as it's positive."

(Evie, IM interview)

Evie's comment typifies the way support was discussed by interviewees, as many of them could not articulate what support meant to the community. This suggests that the act of being supportive is more important to the community than having one fixed definition of support, as was seen on REC, where for members support meant challenging one another's eating disordered thoughts. For ANA a clear definition of support is not necessary. As long as members are complying with the norm of non-judgemental support, the finer details of the support given are inconsequential. When discussing support with Caroline and Dana, both mentioned the diverse nature of support needs on ANA:

"But ANA is for everyone no matter what they're looking for"

(Caroline, IM interview)

And:

"there are members that seek different forms of support."

(Dana, email interview)<sup>13</sup>

Both of these statements illustrate the fluidity of support on the site. As members have a variety of reasons for seeking support from ANA, there is no one single purpose for using the site and so there is no one fixed notion of support. Mulveen and Hepworth (2006) describe the participation in the pro-anorexia site they studied as 'multipurpose', as the site was pro-ana but did not adhere rigidly to either the lifestyle or medical model of eating disorders and also did not discourage recovery, ensuring members could use the site for a variety of reasons. Participation on ANA is also multipurpose, but this is because there is no one fixed notion of the support, therefore participation can be multipurpose because support is multipurpose. Alexander et al. (2003) in their study of four different online support communities found that each community created its own conception of support dependent on the needs of the members. This is also the case on ANA and REC, as both groups can be seen as developing different forms of support to fulfil their members' needs.

As well as supporting the needs of various members, the fluidity of support on the site also ensures that members can continue to be supported, even if those support needs change. This was particularly evident when talking to Alice, who went from seeking 'traditional' pro-ana support (tips and tricks to maintain her ED) to wanting to be understood. Alice cites her age and different phases of her ED as causing her support needs to change:

"So what you wanted from the site developed as you used it? From initially wanting 'pro-ana' to support?"

(Sarah Lewis)

151

<sup>&</sup>lt;sup>13</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Email interview indicates that an interview was conducted via email.

"Yes, especially as I got older and went through different phases of my ED. AS it got worse I realized I didn't want a 'pro-ana' site where they'd be encouraging me, I just wanted the support of being understood"

(Alice, IM interview)

Alice did not need to leave the community as her needs changed, as they could still be met by the ANA community. Again this shows support to be an adaptive and fluid concept on the site, facilitated by the principle of non-judgemental support, as all members are deemed worthy of support regardless of their situation. Borzekowski et al. (2010, p.1531) found that over a third of pro-ED sites in their study featured recovery orientated content. They describe this as a "duality of purpose". ANA could be said to have a multifaceted approach to support in a similar vein to this. The dynamic and fluid concept of support, which is created by members of ANA through employing the norm of non-judgemental support, marks ANA as different to other online support forums, which studies have shown to provide a more fixed form of support (Peterson, 2009; Bar-Lev, 2008; Horne and Wiggins, 2009; Antaki and Veyreda 2009; Smithson et al., 2011).

#### The importance of empathy

On ANA, support can be seen working at various levels with members relying on one another for informational, esteem, emotional and, at times, even tangible aid (Walther and Boyd, 2002; Baym, 2010; Wright and Bell, 2003). Informational support, the provision of advice or factual information about a specific topic, is sought and given on the site through threads about inpatient treatment, medical issues and dietary needs/intake (Lin and Bhattacherjee, 2009). Scholars studying pro-anorexia have frequently expressed reservations about the reliability of such information on pro-ana forums (Juarascio et al., 2010; Norris et al., 2006; Borzekowski et al., 2010; Rouleau and von Ranson, 2011). Tangible aid, or the provision of physical support, for example lending someone money or driving them to the hospital, is considered the ultimate limit for an online support group (Walther and Boyd, 2003; Sherman and Greenfield, 2013; Wright and Bell, 2003). While conducting interviews it became apparent that some ANA members (like some members on REC) did find a way to offer support in 'real' life. The clearest example of this was an interview with Emma, where she told me about posting suicidal thoughts on the forum,

which led to a member embarking on a two hour train journey to stay with her for the weekend to ensure she did not take her own life. While this is an extraordinary situation, it does illustrate that some members are willing to, and do, move beyond the boundaries of the online community in order to support one another.

Moving on to esteem and emotional support, these are worked into most threads on the site, with members frequently offering esteem support, the validation and admiration of one another's worth, by telling one another "you're beautiful" and "youre truly amazing xxx". Walther and Boyd (2002, p.155) describe emotional support as being "given through expressions of caring, concern, empathy and sympathy". One element of emotional support, empathy, was shown to be particularly important to members of ANA during interviews and is evident on the forum. The empathy that is expressed on the site can be seen as addressing an unmet need for members, and also creating a specific kind of support environment, while conforming to the non-judgemental support norm.

The ideas of non-judgement and understanding or empathy were interlinked for both Zara and Rosie:

"People can be open about anything involving their eating disorders and not be judged because we all understand what it's like to live with it. We support people when they need it."

(Zara, IM interview)

And:

"When I first joined I was looking for people who understood what I was going through. I was looking for a place where I could vent about food and not be judged"

(Rosie, IM interview)

From these comments we can see that Zara and Rosie not only appreciate being able to express themselves and their eating disordered thoughts, but they both want to do this in an empathetic environment, where their words would be met with understanding rather than misinterpretation or, importantly, judgement. Talking to people who 'truly' understand is often cited as a reason for individuals being members of online support communities (Hinton et al., 2010; Malik and Coulson 2008; Flynne and Stana, 2012;

Peterson, 2009; Coulson et al., 2007; Sherman and Greenfield, 2013). Being able to access a support group that offers understanding is thought to be especially important for individuals who live with a stigmatising condition, such as HIV (Peterson, 2009; Bar-Lev, 2008). However, online support groups for mental health conditions, such as eating disorders and also self-harm and suicide, remain contentious issues, despite literature suggesting they too are supportive and understanding environments (Dias, 2003; Giles, 2006; Brotsky and Giles, 2007; Tierney, 2008). The demonization or lack of understanding that surrounding online anorexia forums, has implications for the non-judgemental support on ANA. They are being judged heavily by the outside world for having an eating disorder *and* using the internet for support. Therefore making their community as non-judgemental as possible allows for all members to feel they have an outlet for otherwise unexpressed views.

Wright and Bell (2003) suggest that the focus a community has will affect the level of empathy members receive. As was shown through the fluid definition of support, ANA seems to lack a definitive focus. While there is no fixed definition of support on the site, the norm of non-judgemental support fosters an empathetic support environment, as members are expected to treat each other with a level of 'compassion and understanding'. This was considered important in creating a supportive environment to Holly:

"what do you think makes ANA a supportive environment?" (Sarah Lewis)

"The compassion and understanding we all handle each other with. We do not reprimand each other or judge."

(Holly, IM interview)

Empathy and non-judgement work together to make ANA a supportive environment for Holly. This is important because empathy or understanding do not guarantee an all-encompassing supportive environment. Comparing REC and ANA illustrates how important the norm of non-judgemental support is in creating the specific support environment that is ANA. Both communities offer members understanding and empathy. The sites offer a refuge where behaviours and thoughts that seem so alien to friends and family can be expressed knowing that others have experienced the same thing. However, non-judgement is not a norm on REC, as it is on ANA. Rather, challenging serves a

normative purpose on REC and so while REC members receive empathy, their eating disorder behaviour is also critiqued and held to account. On ANA, it is the norm of non-judgemental support that allows the empathetic support that is so clearly craved by members to thrive. For Alicia, the lack of judgemental attitudes on the site, allowed ANA to become a more open space, with people being more willing to share their experiences:

"it does..everyone is generally kind to everyone else, and that's different from real life. There are hunderds, maybe thousands of ANA members, but it provides so much support and so little judgment that people are comfortable sharing things"

(Alicia, IM interview)

The above quote reinforced the importance of non-judgemental support in creating the all-encompassing form of support on ANA. The lack of judgement fosters a specific support environment, one in which anything can be shared in the knowledge that it will be met with empathy and support.

## The role of 'pro-ana'

Whitehead (2010) suggests that as the pro-ana movement is not aimed towards achieving social change and does not have an opposition to lobby against, they are united in their desire for support and encouragement. This is also the case on ANA. Support, and specifically non-judgemental support, will be shown to be a unifying concept in a community where 'pro-ana' has varied meanings. As well as unifying the community, the normative concept of non-judgemental support also regulates the community by making apparent members' responsibilities on the site. While there are features that appear consistently on pro-ana sites more generally, it is well established in the literature on pro-ana communities that there is a great deal of variety in the cultures on the sites (Brotsky and Giles, 2007; Giles, 2006; Bond, 2012). Commenting on the heterogeneity of pro-ana sites, Maloney (2013, p.116) states that "if culture were identical on all sites, then only one site would be necessary" While there is variance in cultures and ideals between sites, there can also be inconsistencies within sites. Giles (2006) suggests that the only consistent feature of any pro-ana site is contradiction; this rings true for the ANA

community, which not only lacks a fixed definition of what constitutes pro-ana but contradictory definitions co-exist on the site. When speaking to interviewees about whether ANA as a community has a definition of pro-ana, responses tended to suggest that this was a divisive subject on the site. Emma and Dana's responses illustrate this:

"ANA's community is split near enough in two about what pro ana is."

(Emma, email interview)

And:

"Pro-Ana is this mutant word with a million definitions depending on who you ask"

(Dana, email interview)

It is clear from Emma and Dana's comments that a cohesive definition of pro-ana does not exist on ANA, with the community being "split" and the term being described as "mutant". However the community still supports members despite this lack of uniformity, suggesting that there is something that unifies members.

When asking members if they would describe ANA as a pro-ana site, it became evident that acceptance and support were the two concepts that members felt defined ANA as a community, rather than pro-ana. Interviewees described ANA as "pro-support"," pro-acceptance", "pro-reality" and "pro-anorectic". While each of these definitions orientate towards ideas of support, this does not imply that ANA cannot also still be considered pro-ana. This was discussed by Rosie:

"Like its pro-Ana because its supporting. But it's also pro-Ana because it can be enabling(just like anything with a group of people with a common 'problem' can be)."

(Rosie, IM interview)

For Rosie the support that is offered on ANA does not make it less of a pro-ana site, but is actually something that defines it as pro-ana, as for her the support that is given is also "enabling". While support for Rosie marks ANA as a pro-ana site, it is also something that unifies the community. This can be seen above, with members describing the site as 'pro-support' and 'pro-acceptance'. Regardless of their concept of pro-ana, support is the

consistent element in their understanding of what constitutes the ANA community. Thus, support can be seen as the defining and unifying feature of ANA, with members associating this with pro-ana more widely and also using other terms to disassociate from the traditional view of pro-ana. Members' various understandings of support are what unify the group despite the variety of differences that exist.

As members are united by their need to gain support from one another, and again because there is so much variation in how members define support and pro-ana, the principle of non-judgemental support is key in regulating how members view support, and their responsibilities towards one another. Responsibility has been discussed in the literature on pro-ana, but it usually refers to the way members use self-disclosure on the sites to make themselves responsible for their eating behaviour. For example Haas et al. (2011) and Juarascio et al. (2010), in their studies of pro-ana forums and social networking pages, found that members would post food logs in order to keep them on track, as other members would hold them to account for any misdemeanours. While members undeniably do this on ANA, responsibility also has another meaning which is linked to the non-judgemental support that is provided on the site. Interestingly, it is support givers who are held accountable for their behaviour on the site, while those seeking support go largely unmonitored. It is the support givers who are responsible for upholding the norm of non-judgemental support. The following is an extract from the forum in which support givers are gently reprimanded for not providing the normative form of support on the site:

Thread title: Worried about my purge

#### Yarrow:

"So, I just purged and some blood came up. This hasn't happened to me before. Should I be worried?"

# **Grapefruit:**

"I feel like you are looking for reassurance, and unfortunately you won't get any, that is a serious problem. Take care xx"

#### Sorrel101:

"you can send me a message, if you want to discuss this further? also- what shade was the blood? bright/light red may indicate a tear. and dark blood/black-ish lood may be a sign of internal bleeding.

and, if you're gonna purge- maybe you should keep your nails short? (it's risky enough without it)"

## PumpkinPie:

"Dangerous behaviour=damaging repurcussion, that's what happens when you stick your fingers down your throat."

#### Sorrel101:

"ok...he's obviously very scared right now.

I'm sure he knows purging is bad for you."

(Forum data, ANA)

As can be seen from the above thread, Sorrel101 in her final response to the original post does not hold Yarrow accountable for his purging behaviour. Instead, Sorrel101 attempts to rein in Grapefruit and PumpkinPie, both of whom responded to Yarrow with scolding comments, which do not conform to the norm of non-judgemental support. Bar-Lev (2008), in her study of an HIV forum, found that those seeking support had to show themselves as eligible for support by presenting themselves in a positive and moral fashion. This is not true for ANA, with the responsibility of 'correct' presentation falling on the support giver. This observed difference between Bar-Lev's (2008) study, and my own, is potentially due to the different cultures of support that exist on the two sites. Non-judgemental support is so normative on ANA that it creates an environment in which any question can be asked without moderation. It is the response, which must conform to the norm of non-judgemental support, that is monitored.

## The limits of non-judgemental support

While non-judgemental support is a norm on ANA, it is conditional and not without limits, which often appear contradictory to the other conditions of non-judgemental support. The limits of non-judgemental support are, in part, born out of the contested idea of what constitutes pro-ana to ANA members. As previously mentioned the ANA community does not have a fixed definition of pro-ana, rather a multitude of definitions exist, with non-judgemental support being a unifying norm. However, when discussing 'bad' forms of support with interviewees, it was clear that their ideas of what would be considered 'bad' support on ANA was bound up with traditional pro-ana use. Emma and Alice both mentioned "buddies" and "tips or tricks" when discussing the "wrong" way to use the site and what makes a bad forum member:

"The 'Wrong' way would be by being mean or offensive and offering support, advice, encouragement, tips or tricks on bad things." (Emma, email interview)

And Alice described a bad forum member as:

"The ones that cause drama. Who insult other members and are looking for a fight, or are constantly asking for tips or buddies" (Alice, IM interview)

There are features that are considered consistent across pro-ana sites, despite the variation that exists among them. These consistent features include: tips and tricks (information on how to exacerbate your illness and hide it from loved ones); 'thinspiration' (images, songs, films, poems that inspire further weightloss); ana creed (prayers and letters written to and from ana) and the personification of anorexia (Borzekowski et al., 2010; Norris et al., 2006; Mulveen and Hepworth, 2006; Rouleau and von Ranson, 2011 Bardone-Cone and Cass, 2007). For Emma and Alice it was trying to access these features, traditionally associated with pro-ana, that marked someone as a bad forum member, or in need of 'inappropriate' support. This shows that members are more willing to align themselves with the support elements of the community rather than the contested pro-ana elements. It also illustrates the limits of non-judgemental support for the community. Members are unwilling to support someone in using ANA as a 'pro-ana' site. This is frequently expressed on the forum with members stating; "I don't

promote anorexia or any other eating disorder at all", "I refuse to participate in developing an eating disorder" and "I would never try to help someone be this way".

Members' unwillingness to offer non-judgemental support to those expressing a 'pro' identity creates a further contradiction, as members have joined a pro-ana site (the home page of the site describes the site as pro-ana in orientation). However, the community has redefined what that means, making it difficult for members to express what is termed on ANA as a 'pro' identity. While this can be seen as a positive consequence of the limits of non-judgemental support on ANA, arguably individuals become members of ANA in order to express themselves in a way they are unable to offline. The site fulfils an unmet need. 'Pro' behaviour, being outwardly unsupported on the site, makes expressing a 'pro' identity difficult; the site facilitates the provision of support first and foremost, and expressing a 'pro' identity is frowned upon. Bond (2012) discusses users of pro-ana as performing a pro-anorexic identity, for ANA this performance has to move beyond the public areas and into the private sections of the forum, as publicly 'pro' behaviour is not afforded the same non-judgemental support. Dana and Georgina both mentioned this in their interviews:

"yes, the pro behavior is hidden, I believe a good portion of the members are secretly pro" (Dana, email interview)

And:

"People may be pro ana in emails, of corse this I cannot be sure of but I know I'm not myself" (Georgina, IM interview)

Non-judgemental support focusses on offering members support in all circumstances and suspending any preconceptions. However, expressing a 'pro' identity cannot be afforded this level of support, thus shaping the boundaries of support on the site. Members adapt by using the private features -such as chat or private messages- of the site to get the 'pro' support they crave. Rosie spoke about how she, and her friends from ANA, still managed get the 'pro' support they needed by avoiding the public forums and groups:

"I still have friends that we make similar plans and fast together but we don't post in the forums and make a group out of it... Haha there is a loop hole to just about every rule"

(Rosie, IM interview)

This illustrates that members are willing to adapt to the support environment, using all the features of the site to get the support they require, while publicly still conforming to the principle of non-judgemental support.

#### Discussion and conclusion

The above analysis has shown support on both communities to be normative, however, the roles of the two norms, challenging and non-judgemental support, are different on the two sites. As previously stated challenging does not conform to usual forms of support that are expressed online; it is not esteem, emotional, instrumental or informational support, nor is it tangible aid. While these typologies of support are expressed on the site, they do not hold the same position as challenging, which not only acts as a norm but is sought out by members as something lacking in their offline lives: critical peer support. It is the element of critique that also makes challenging stand out as a different form of support. Challenging contrasts with most online support, as regardless of the form support takes online, it is usually affirmative, providing individuals with what they want to hear and reinforcing their previously held beliefs (Malik and Coulson, 2008; Malik and Coulson, 2010; Sherman and Greenfield, 2013).

Walstrom (1999) in her study of ASED, an online eating disorder recovery forum, discusses 'challenging' at length and illustrates that through challenging on the site members go through five stages, from having an uncertain eating disorder identity, to a fully-fledged recovery identity. Walstrom's (1999) work and my own research highlight that similar concepts may be acted out differently on different online anorexia forums. This may be in part due to the ethos of the site, as this influences the way in which anorexia, recovery and support are understood, as was argued in chapter four. A key difference between 'challenging' on the two communities is that on ASED it is not openly critical and does not require ASED members to show themselves to be recovery orientated in order to receive support, as it does on REC. Further to this, challenging on ASED involves offering one another an alternative position, meaning that members will

suggest a different perspective on an issue, rather than 'challenging' through critiquing behaviour as members do on REC. For the ASED community challenging is a form of support, as it is on REC, and it also acts as a way of creating credible identities, as members co-construct authentic eating disordered identities, through sharing and challenging one another. Which is again reminiscent of REC, as through accepting and living up to 'challenges' members affirm their commitment to the 'recovery spirit', creating an authentic recovery identity which is eligible for support. While there may be similarities that exist between challenging on REC and ASED, the differences are clear, and further highlight the distinctive form of support that is offered on REC.

In order to find a support context that mirrors REC and challenging, it is necessary to look at offline support, specifically Alcoholics Anonymous (A.A.). There are many similarities that can be drawn between A.A. and REC, with both groups being strongly governed by norms that clearly mark the context in which support is given. There is a particular element of A.A. that appears to be similar to challenging on REC, that is, 'the pledge'. The pledge is a commitment every member makes to staying sober and also helping others to stay sober (Denzin, 1993). Denzin (1993) claims that the pledge serves various purposes, including: aligning members to the history of A.A., unifying all members to their collective goal of sobriety, and preventing divisions on grounds of social, economic and political differences between group members. While on REC, challenging and accepting challenges is considered a sign that a REC member is actively embracing recovery. As was shown through the above analysis, challenging serves many purposes for the group, including linking a member to their 'recovery spirit' and showing commitment and, unifying the group in a shared goal of peer support. Further to this, the terminology used by both groups, a 'pledge', a 'challenge' imply commitment from members of those groups. The terms are imbued with a sense of responsibility that must be lived up to in order to gain support from these groups. The support on offer in both contexts, A.A. and REC, is conditional on embracing and accepting the 'pledge' or committing to challenging. The support on offer is also highly normative, with A.A meetings taking a rigid format and even being spoken of in a specific manner which Denzin (1993) describes as 'A.A. talk'. Saukko (2008) critiques narrative therapy as it does not prevent dichotomous thinking, individuals are still trapped in a binary of 'right' and 'wrong'. This same critique can be

levelled at challenging on REC and at 'the pledge' in A.A. groups. Both of these normative forms of support instil in individuals that there is a 'right' and 'wrong' way of recovering from anorexia and alcoholism, allowing dichotomous thinking to persist rather than be dispelled. In comparing REC with A.A., it is clear that the support on offer on REC is more similar to that of an offline peer support group, than the affirmative support displayed in online forums.

The non-judgemental support that exists on ANA appears to conform more readily to the literature on online support and pro-anorexia. In terms of the online support literature, non-judgemental support is affirmative and embodies traditional models of support. The literature on online support largely discusses online support as affirmative, validating and reaffirming (Malik and Coulson, 2008; Malik and Coulson, 2010; Sherman and Greenfield, 2013). Non-judgemental support, as a governing principle, encourages members to offer affirmative support, as support givers are expected to suspend their prejudices when responding to fellow members, and support them regardless of their needs. As the onus of responsibility is placed on the support giver, any question can be asked on ANA, and will be responded to by offering esteem, emotional, instrumental and informational support. Arguably ANA stands out from the support literature, as the site would not be endorsed by medics (in the same manner as self-harm and suicide forums would not), as are some sites for other conditions. This is a consistent critique of online anorexia forums. The support they offer is questioned and demonised by medics, the media and, at times, scholars studying pro-ana, as it is suggested this support may cause harm to members (Haas et al., 2011; Gavin et al., 2008; Mulveen and Hepworth, 2006; Borzekowski et al., 2010; Bardone-Cone and Cass, 2007; Wilson et al., 2006). However, reducing pro-ana sites to the negative consequences they may have denies the potential positive impact they have on members and also detracts from the rich and nuanced support environments that the subculture encompasses.

Positioning ANA so closely to the established literature on online support has the potential to make the support given on ANA appear mundane, as affirmative support has been observed before across different online support settings (Malik and Coulson, 2008; Malik and Coulson, 2010; Sherman and Greenfield, 2013). However, it is the non-judgemental element that marks ANA as different. The norm of non-judgemental support

governs how members are supported on the site; it creates a sense of responsibility among members and marks out the boundaries of acceptability. Non-judgement having such a pivotal role for support has not specifically been discussed in the wider literature on online support or pro-anorexia. Generally, non-judgement is rarely discussed in the pro-ana literature, what is more frequently cited is a need for empathy, which it can be argued entails non-judgement. Scholars have repeatedly argued that a lack of empathy or understanding is what drives eating disordered individuals to seek support online (Brotsky and Giles, 2007: Dias, 2003; Bond, 2012; Yeshua-Katz and Martins, 2013; Tierney, 2008). My study, and the finding of non-judgemental support as a norm on ANA, takes this a step further. It suggests that a need for non-judgement not only draws people online to access support, but this need also influences the form that online support takes within the ANA community.

In terms of the pro-anorexia literature, my own findings mirror many of the themes that are prominent within this work. The literature addresses the need for empathy, pro-ana as resistance to existing medical depictions of anorexia, and the use of online support being used to address unmet needs. These three themes are also evident in my own research.

Bond (2012) and Haas et al. (2011) discuss the ideas of performing a pro-ana identity and an 'audience for ana' respectively, which illustrate the community-constructed nature of online anorexia forums, with members presenting or performing a specific pro-ana identity that makes them credible (which will vary dependent on the site). In terms of an 'audience for ana' the implication is that individuals are writing their blogs, forums posts etc. with an intended audience in mind. They will therefore construct an acceptable pro-ana identity to appeal to this audience. Undeniably members of the two communities have to perform an 'authentic' recovery and pro-ana identity, as was discussed in chapter four in the form of the 'sickness mentality' on ANA and 'recovery spirit' on REC. However both communities centre around the idea of providing peer support for members, therefore members of both REC and ANA also perform support identities and appeal to an 'audience for support'. Challenging and non-judgemental support require members of REC and ANA to adopt specific support identities. For REC members this means they must accept challenges and show themselves to be recovery orientated; members of ANA must

respond to posts in a non-judgemental manner. In terms of writing for an intended audience, members of both communities author posts with an awareness of the cultures of support that exist on ANA and REC. For these communities the act of being supportive is more salient than conforming to ideas of authenticity in eating disorders. This has been shown through the above discussion of findings. Support on the two sites is conditional on members conforming to challenging and non-judgemental support, not on issues surrounding their eating disorder.

Looking at ANA and REC in terms of support, rather than the construction of eating disorder identities, places this research within the wider body of literature on online support. Moreover, my analysis differs from much of the literature on pro-ana, which has traditionally given focus to the eating disorder elements of such sites and treated support as a secondary theme. Strong links can be made between my own analysis and the work of Alexander et al. (2003), Peterson (2009), Bar-Lev (2008) and Morrow (2006), in that their studies also illustrate cultures of support being specific to certain support environments and show support to be conditional on members conforming to the norms and cultures of the site. This highlights the similarities between online anorexia forums and other online support forums, rather than marking them out as different purely due to the sometimes controversial content they may contain.

## **Chapter six: Introduction**

#### Communicating Support: monologue and dialogue in online anorexia forums

In this chapter the form communication takes is given emphasis, through the use of Bakhtin's (1994) concepts of monologue and dialogue, which are applied to the supportive communication that occurs on ANA and REC. Monologic communication can be described as communication that is authoritative, thereby representing a dominant discourse, or communication that is inert, and does not encourage further discussion (Bakhtin, 1994). Dialogic communication is communication in which meaning is constructed through interaction, and communication is fluid and not predetermined (Bakhtin, 1994). Rather than presenting one community as monologic and one as dialogic, I will show that the two forms of communication co-exist on both sites, enhancing the support environments that have been shaped through 'recovery spirit', 'sickness mentality', challenging and non-judgemental support. This current section will act as an introduction to both of the subsequent analysis sections, as I will be drawing on the same Bakhtinian concepts and literature in both. In this introduction I will provide an overview of the literature on communication in the context of online support groups, define and make relevant Bakhtin's (1994) concepts of dialogue, monologue and utterance, outline the following sections and provide a rationale for the subsequent analysis.

As previously discussed (see chapter three), form refers to the grounded theory concept of process, which involves analysing data in context for action, interaction and emotion that highlights the constraints that enable support to operate effectively on both sites (Corbin and Strauss, 2008). In chapter five, form was illustrated through the two site norms that are evident on ANA and REC, non-judgemental support and challenging. These norms regulated support, illustrated to members what was and was not deemed acceptable on these sites, and marked the boundaries of the group. In the following two analytical sections form will be further illustrated, however the focus is slightly different, as previously members' interaction was used to demonstrate site norms that constrain support, and in the subsequent analysis the form of communication is analysed and its influence on support in these two communities is made evident. Form of communication

in the following two sections is discussed in terms of interaction and expression of voices. In the first section of analysis, threads are analysed for interaction, that is, the way in which members of both communities respond to one another. With interaction on REC being predominantly dialogic, and interaction on ANA being predominantly monologic. The second section of analysis focusses on the expression of voices on ANA and REC, and how these are silenced or embraced. Both sites are active and have many members expressing differing eating disordered thoughts, feelings and behaviours, but not all voices are equal, which has an impact on the support given on the sites. Although interaction will be shown to be dialogic on REC, members' voices are silenced, and the community can be seen as representing a 'monologic consensus', where despite the presence of multiple voices, one dominant authoritative voice is adhered to and expressed (Jabri et al, 2008). On ANA, monologic interaction gives way to multivocality on the site, where expression is not limited, but all voices are heard and presented as equal (Bakhtin, 1994). The forms of communication are further discussed in terms of implications for support, as they facilitate the creation of differing support environments. On REC, the mix of dialogic interaction and monologic expression of voices leads to an interaction-focussed support environment, whereby members are heard, engaged with and resolutions to issues are sought. While on ANA, the combination of monologic interaction and multivocal expression of voices leads to a self-focussed support environment, as members attend to their own needs over those of others. And so, exploring form through the lens of communication, illustrates that support in online environments is varied, and expressed in different ways, rather than being monolithic.

# A review of the literature on Computer-Mediated Communication, dialogue and monologue

I will now review the literature on Computer-Mediated Communication, specifically literature relating to communication in support contexts. In particular I will discuss Walther's (1996) work on hyperpersonal communication, and the literature on advice giving and self-disclosure. The literature will be reviewed and made relevant to my own research and will also feature in the following analysis sections. I will then expand upon the previously mentioned concepts of dialogue and monologue and introduce the

concept of utterance, giving definitions of each and making illustrating how these Bakhtinian (1994) concepts relate to my own work as these concepts will be used as a framework for the subsequent analysis.

## CMC in the context of online support communities

The literature on computer-mediated communication (hereafter CMC) in online support communities tends to focus on specific types of communication, particularly advice giving and self-disclosure. The distinction between support and communication is often blurred, with authors conflating the two, as is evident in Wright (2000) and Braithwaite et al (1999). This may be due to the perceived merits and shortcomings of online communication, which include: speed of response; ability to edit; anonymity; accessibility and lack of physicality, as they are almost identical to the advantages and disadvantages attributed to online support (For online communication see, Baym, 2010 and for online support see, Coulson et al, 2007).

One of the most influential articles on CMC in online support environments is Walther's (1996) piece on impersonal, interpersonal and hyperpersonal interaction in CMC, where the author attempts to dispel the idea that online communication is inherently impoverished or enhanced and instead highlights the human acts and thought processes that go towards creating online communication and interaction. In refuting the idea that CMC is either a diminished form of communication or inherently social, Walther (1996) posits that CMC is actually hyperpersonal, that is, more desirable than equivalent face-toface communication. CMC may be more desirable due to reduced cues, anonymity, editability, and the perception that it requires less attention of sender and receiver. These perceived desirable characteristics of CMC allow hyperpersonal communication to flourish as the receiver of messages begins to develop an idealised perception of the sender. The sender is able to control their self-presentation so it is favourable, creating an intensification loop, whereby positive presentation and positive perception are reinforced and perpetuated as communication and interaction develop (Walther, 1996). Haas et al (2011) suggest that the intensification loop may cause an escalation of extreme views in online anorexia sites, as members present a favourable pro-anorexic self and become idealised by other members. Considering ANA and REC in terms of hyperpersonal communication it is likely that these support environments are considered more desirable spaces in which to discuss eating disorders. As has been frequently highlighted in the literature, many individuals turn to online anorexia forums due to unmet needs in their tangible lives (Brotsky and Giles, 2007: Dias, 2003; Bond, 2012; Yeshua-Katz and Martins, 2013; Tierney, 2008). Further to this, members are also able to present themselves in a favourable light if they wish (although *how* a member would present themselves as favourable would be very different on each site), and members may develop an idealised perception of one another.

Advice-giving in online support communities is a prominent feature of the literature. It has been problematized by authors who have frequently questioned the accuracy of advice and information given by lay people in an online environment; this is a particular concern with regards to pro-anorexia communities (Juarascio et al, 2010; Norris et al, 2006; Borzekowski et al, 2010; Rouleau and von Ranson, 2011). Asking for advice is not presented in the literature as a straightforward task, but involves careful selfpresentation in order to receive the type of advice desired and in order to be seen as 'authentic' or worthy of advice (Morrow, 2006; Horne and Wiggins, 2009). Advice giving has also been shown to serve almost as an initiation process. Vayreda and Antaki (2009), in their study of a bipolar support site, found that unsolicited advice was given more frequently to newcomers to the site, acting as a form of socialisation to site norms. Advice-giving has also been linked to self-disclosure, with members of forums being seen to give advice to other members through self-disclosing information about themselves, relating the advice seeker's issue to one they themselves have faced (Wright, 2000; Pfeil, 2010). Advice-giving is different on both ANA and REC, due to their different understandings of support, site idiom and site purpose. On REC advice is given in the form of challenging, or open critique of other members' eating disordered thoughts and behaviours. On ANA advice-giving is not often solicited, instead members call on one another to share experiences, and so advice will frequently be given indirectly and through self-disclosure.

Self-disclosure in online support communities is also a frequently discussed in the literature. Self-disclosure can broadly be defined as any information (thoughts, feelings, experiences) an individual reveals about themselves to others (Leung, 2005; Barak and

Gluck-Ofri, 2007). Mesch and Beker (2010) suggest a narrower definition of selfdisclosure by drawing on literature on online privacy and CMC. They define self-disclosure as the telling of personal information previously unknown to others, this information then makes the individual disclosing information more recognisable offline. Selfdisclosure can be seen as a result of the medium, with members of online support communities having to disclose (sometimes deeply personal details) in order to receive support, as other members may not have prior knowledge of their issues and situation (Pfeil, 2010). The medium through which individuals communicate online may also influence their willingness to self-disclose personal information, as Joinson (2001) found that visual anonymity (not being seen by the other person) increased levels of selfdisclosure in participants. Further to this, Suler (2004) suggests that using CMC creates an online disinhibition effect, facilitated by dissociative anonymity, invisibility, asynchronicity, solipsistic introjection, dissociative imagination and minimisation of authority, all of which potentially contribute to individuals self-disclosing more about themselves in an online setting. Self-disclosure, be it expressed online or offline, has been shown to be reciprocal, and so self-disclosure begets self-disclosure (Barak and Gluck-Ofri, 2007; Dietz-Uhler et al, 2005; Tidwell and Walther, 2002). It has been shown that levels of self-disclosure are higher in online settings than in face-to-face interaction and that self-disclosure is one way in which individuals can reduce uncertainty when interacting online (Tidwell and Walther, 2002). Further to this, Barak and Gluck-Ofri (2007) found that self-disclosure was a more prominent feature of online support groups than it was general discussion groups. However, it has been suggested that higher incidence of self-disclosure online does not equate to the quality or depth of information being shared, it merely indicates a higher quantity of potentially superficial information (Joinson, 2001b; Attrill and Jalil, 2011). Through the statistical analysis of asynchronous online chats about mental health stigma, Dietz-Uhler et al (2005) found that reciprocity of self-disclosure could function as a norm in online settings, and that once this norm has been established it was adhered to and reinforced, and posts that did not conform were ignored. My own research will show self-disclosure to be an essential component of the monologic communication (communication that is static, or lacks clear interaction) that exists on ANA. I will show how this form of communication can be seen as supportive by members and how it contributes to the overall support environment of the site.

#### Dialogue, monologue and utterance

I will now review the literature on the concepts of dialogue, monologue and utterance, with the intention of providing definitions of these concepts and illustrating how they relate to my own research. In Bakhtinian theory, dialogue is a unifying concept, bringing a sense of 'wholeness' to his body of work (Baxter, 2004). Dialogue can be considered a state of consciousness, or a perspective (Holquist, 1990; Baxter, 2007); it can be applied to all forms of expression, from literature to everyday speech to performance art. In dialogue, communication, regardless of the form it takes, only has meaning in term of how it relates to another individual (Bakhtin, 1994; Holquist, 1990). Therefore, the statement 'I am anorexic' is void of meaning until read, interpreted and responded to by another individual, meaning is always co-constructed. Meaning and communication from a dialogic perspective is also always on-going, it is not finite, and does not have a predetermined linear progression (Bakhtin, 1994). Dialogue is therefore characterised as productive, co-constructive and active/reactive (Baxter, 2004). While the creation of meaning is an on-going process that is dependent on social actors, meaning in dialogue is not uniform, but is highly dependent on the context, or the conditions in which meaning is being created (Holquist, 1990). This subjectivity of meaning is heteroglossia, the idea that the meaning of any given word is subject to the context in which it exists, and its meaning is generated through an interplay of social, historical, ideological and interactional factors, creating meaning unique to that particular moment (Bakhtin, 1994). Again, taking the statement 'I am anorexic', the meaning of this changes, depending on the context. It means something different in group therapy than it does in the work canteen, and means something different again on the two sites studied in this thesis. The meaning is dependent on so much more than the words themselves, it is derived from the personal experiences of the social actors involved and their relationship, as well as the dominant discourses on anorexia and mental health more generally. The analysis detailed below will show that communication on REC can be seen as dialogic in nature, and also that this dialogue facilitates a specific type of supportive communication on the site, that is influenced by the previously discussed concepts of the 'recovery spirit' and challenging. However, this dialogue will also be shown to have elements of monologue,

as the normative nature of the site results in censorship being commonplace, regulating communication.

Monologue should not be considered the opposite of dialogue, but is comprised of two interrelated elements; authoritative language and static communication (Baxter, 2007). For Bakhtin, all social life is dialogic, as it is comprised of many voices, opinions and discourses, all of which intersect and influence one another (Baxter, 2004). However, the dialogue of life is flecked with elements of monologic communication, communication that is focussed on reproduction of one dominant voice (Bakhtin, 1994). When speaking of monologue Bakhtin (1994) refers to authoritative discourse and internally persuasive discourse, suggesting that monologue can be a result of external dominant forces that constrain language (authoritative) or are internalised by individuals and taken on as their own language (internally persuasive). Monologue in the sense of authoritative discourse cannot be represented in communication, it can only be transmitted, it is self-serving and cannot be "double voiced" (have more than one meaning) creating communication that is fixed and lacking variation (Bakhtin, 1994, p.344).

In describing authoritative discourse, Bakhtin (1994, p. 344) uses the word 'inertia', which is at once descriptive of the discourse and the communication it generates, which lacks the hallmarks of dialogue. This idea of authoritative discourse as inert, is also descriptive of the second element of monologue, which can be seen as communication that is static, or does not generate further conversation or interaction (Baxter, 2007). Monologue, in terms of authoritative communication and static communication, was considered undesirable by Bakhtin, as it does not celebrate the multivocality of language, and is instead focussed on similarity and uniformity (Baxter, 2007). The communication on ANA can be considered monologic, not because it is authoritative, but because it is static. The way in which members' talk does not facilitate further conversation but can appear stilted and individualistic. However, that is not to say this monologic communication does not also act as supportive communication. The need to talk to empathic others and the high levels of self-disclosure by members will be shown to characterise this monologue. Although monologue is present on the site, ANA is not without elements of dialogue, and can be seen as multivocal. Through monologue and self-disclosure all voices are able to

be expressed on ANA, they are afforded an equal level of importance and encourage further expression on the site, keeping the conversation going.

The Bakhtinian concept of utterance is also fundamental when considering communication in these two communities. Utterance refers to the idea that the words we use, intonation and syntax are imbued with meaning (Holquist, 1990). Each word (regardless of how mundane its use seems) is pivotal in terms of meaning construction, it is laced with history, functions socio-ideologically, influenced by local and global requirements of language and embodies the influence of different, at times, conflicting discourses (Bakhtin, 1994; Baxter, 2007; Holquist, 1990). Further to this the meaning created through utterance is not created in isolation, it is an interactional process, dependent on the utterances of another in order for meaning to be generated (Bakhtin, 1994; Jabri et al, 2008). The holistic concept of utterance, which considers a word's history, varied meanings (which may be context or discourse based), socio-ideological function and interactional construction is integral when applied to online anorexia forums, as it gives context to the words used by members. The way members of both ANA and REC communicate is not accidental, the form it takes is a constructed and negotiated process. So too are the words used, they are influenced by online and offline forces, riddled with power imbalance and authoritative (medical, psychological, psychiatric) and lay (anorexia as vanity, anorexia as rich girls' disease) discourse, shaped by the past and the communities themselves. Utterance, therefore, relates to and informs my understanding of language and communication on ANA and REC.

In analysing the communication forms on ANA and REC it became apparent that while members of both communities were communicating support, the form was different. ANA members favour a seemingly self-focussed form of communication, as members disclose personal and, at times, intimate details about their own life in response to another member's call for help or advice. The communicative trademarks of REC, on the other hand, are more interaction-focussed, with members engaging with a poster, requesting further information and picking over their issues to find a solution or offer alternatives to the poster's current situation. As analysis continued, it became more evident that the way in which members communicated on the sites was reminiscent of

Bakhtin's (1994) concepts of dialogue and monologue, which form the framework for this analysis.

It is essential to bear in mind that while dialogue and monologue may appear as oppositional concepts, they should not be considered a dichotomy, but rather interrelated, with communication being able to encompass elements of both dialogue and monologue. Jabri et al (2008), suggest that a multivocal conversation does not inherently imply polyphony, rather, communication can appear dialogic but if there is a core shared meaning, it may be functioning as a monologue. The fluidity of dialogue and monologue is essential when considering communication on ANA and REC, as communication on both sites can be seen as simultaneously dialogic and monologic.

# Chapter structure and rationale for themes

For readability the data analysis that follows is split into two sections, with this first section acting as a joint introduction for the data sections. The first analytical section entitled, Communicating Support: dialogic and monologic interaction on ANA and REC, illustrates that the interaction on the two sites can be seen predominantly as dialogic (in the case of REC) and monologic (in the case of ANA). This is achieved through analysis of communication and interaction on the two forums. On REC the communication themes that emerged were: returning to the thread; further questions and quoting and are shown to be evidence of the dialogic nature of interaction on the site, as each of these tools encourage further interaction and facilitate discussion. On ANA the monologic nature of interaction of members is highlighted through two themes: lack of dialogic interaction and self-disclosure. I then go on to show that this monologic interaction is supportive for members. What is immediately apparent is that the communities' forms of interaction have not been evaluated using the same themes, for example, the theme of returning to the thread has not been applied to ANA, but used exclusively to understand the interaction on REC. This is because I wanted to highlight what was unique about the interaction on the two sites, rather than reducing the communities' forms of interaction to fitting (or not fitting) certain criteria. This gives the analysis more scope to understand the interaction on the two sites and provides more depth, as it allows the unique elements of dialogue or monologue to be fully explored.

The second data analysis section is titled- Communicating Support: 'Monologic Consensus' and Multiple Voices on REC and ANA. This section focusses on the expression of voices on ANA and REC, and illustrates how these too are constrained by monologue and dialogue. On REC interaction is predominantly characterised as dialogic, however, through exploring the way communication is restricted by the two normative concepts that regulate the site ('recovery spirit' and challenging) it can be seen to be monologic. This monologue is shown through discussion of the following themes: authoritative discourse; 'monologic consensus' and direct censorship. ANA will be shown to be interactively monologic, yet there is dialogue within this seemingly static monologue. Dialogue is expressed through the acceptance and respect of the multiple voices that exist on the site, which can be seen as similar to Bakhtin's (1994) concept of polyphony. Multiple voices on ANA are explored through the themes of: lack of final word; equality of voices and interconnect between voices. The simultaneous expressions of monologue and dialogue give added weight to applying different themes to the two communities, as the way in which the two communities act out monologue and dialogue are different, and so in order to capture the reality of the communication forms they must be treated as unique. Below is a visual representation of the variations of monologue and dialogue on the two communities.

Figure 1: A visual display of dialogue and monologue on ANA and REC

# Interaction-REC

Dialogue shown through:

- 1. Returning to the thread.
  - 2. Further questions.
    - 3. Quoting.

# **Expression of voices- REC**

Monologue shown through:

- 1. Authoritative discourse.
- 2. 'monologic consensus'.
  - 3. Physical censorship.

The variations of dialogue-monologue on ANA and REC.

## Interaction- ANA

Monologue shown through:

- 1. Lack of dialogic interaction.
  - 2. Self-disclosure.
  - 3. Monologue as support.

# Expression of voices- ANA

Multivocality shown through:

- 1. Lack of finalising word.
  - 2. Equality of voices.
- 3. Interconnection between voices.

The left hand column shows the form interaction takes and how it is expressed. The right hand column represents the expression of voices, again showing the form it takes and how this form is expressed.

The analysis within sections 2 and 3 of this chapter illustrate that communication does not have to conform to one form but can be simultaneously dialogic and monologic. The simultaneity of dialogue and monologue has implications for the support that is provided on both ANA and REC, as it facilitates the creation of two different support environments. Through dialogic interaction and the muted expression of voices on REC, support becomes interaction-focussed, meaning that members orientate to the individual with a problem, in order to find a resolution to issues. This is reinforced by the previously discussed concepts of 'recovery spirit' and challenging, as these concepts require members to conform to a specific site ethos and form of support, normalising the expressions of dialogue and monologue on the site. On ANA communication is both monologic and multivocal, creating a specific support environment, typified by selffocussed support, where members attend to their own support needs. Again, this selffocussed support is facilitated by the previously discussed concepts of the 'sickness mentality' and non-judgemental support, which show ANA to be a place in which sickness is embraced, and support is adaptive, allowing members to take what they need from the site, regardless of where they are in their eating disorder journey. Therefore, the following analytical sections of chapter six reveal the various iterations of support that exist on ANA and REC, show them to be closely interlinked, and illustrate how they are expressed through communication.

# **Chapter six (section 2): Analysis**

# Communicating support: dialogic and monologic interaction on ANA and REC

The analysis that follows in this section focusses on the form of communication on both ANA and REC, specifically the interaction that is evident on the forums. The interaction on REC will be shown to be dialogic, while ANA is characterised by monologic interaction. This analysis will illustrate the influence these forms of communication exhibit over the support given on the site, as they facilitate the provision of specific forms of support, which are enhanced by the previously discussed concepts of 'recovery spirit', 'sickness mentality', challenging and non-judgemental support. In order to illustrate the dialogic interaction that is present on REC, I will demonstrate the use of three dialogic tools on the site, they are, returning to the thread, asking further questions and quoting. Each of these dialogic tools contributes to creating a sense of dialogue on the site. The monologic interaction that is present on ANA will be illustrated through the lack of dialogic interaction visible on threads, and the high levels of self-disclosure that members contribute to the forum. While these are both traits of monologue, they will be shown to be supportive for members of ANA. Therefore, ANA is both a monologic and supportive environment.

Threads from the forums are presented verbatim, however they have been cropped as it is not practical to show whole threads here.

# REC- interaction as dialogue

"An important part as well is just keeping the conversation going, keeping people talking about eating disorders" (Lauren, audio interview)<sup>14</sup>.

While interviewing Lauren, she made clear the importance of creating a dialogue about eating disorders on REC. Lauren was not referring to the Bakhtinian concept, but to the idea of open and continued discussion about eating disorders. For Lauren, this was the antidote to the secrecy and insularity an eating disorder can create in an individual. "Just keeping the conversation going" is important to REC but how members speak about

<sup>14</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. Audio interview indicates that an interview was conducted via the telephone function on Skype.

eating disorders is also fundamental in creating a recovery-orientated support environment. As discussed in the chapter five, members are expected to critique their own and others' eating disordered thoughts and behaviours through the act of challenging. This process of challenging (which is similar to a narrative therapy approach to eating disorder treatment) can be seen as dialogic, as meaning is not assumed to be fixed, but is subject to constant reappraisal, different discourses and continued questioning. Without dialogue meaning making "degenerates and dies" (Bakhtin, 1984, p.88), and the same could be said for recovery on REC. Without dialogue, members would not be pushed forward in their recovery and would be left to stagnate, leaving eating disordered thoughts unchallenged. Dialogic communication therefore plays an important role on the site, as it is another tool members use to keep the community recovery-focussed and in-line with the two normative concepts that govern support on the site: the 'recovery spirit' and challenging. Challenging, the critique of eating disordered thoughts and behaviour, also acts as a normative concept, illustrating to members what is, and is not, acceptable behaviour and marking the boundaries of the site. The 'recovery spirit' is also normative; it is a dominant discourse on the site that suggests members have a choice to recover from their eating disorder and is regulatory as members need to show their commitment to recovery.

Dialogue is a continuous process, which does not have a fixed pattern or end point. It is emergent in that the twists of interaction and different constructions of meaning will take the conversation in unforeseen directions (Jabri et al., 2008; Baxter, 2004).

Communication on REC can be seen as having these characteristics. While members do conform to the aforementioned constructs (challenging and the 'recovery spirit'), which provide a level of uniformity (arguably an element of monologue within the dialogue) to the communication, threads are not scripted, they are unpredictable and due to the archival nature of online forums can be resurrected and given a new lease of life at any point. Dialogue is characterised by difference, different meaning being attributed to the same utterance, different discourses and different voices being applied to the same setting. Within that there is some unity, as Baxter (2004, p.7) states: "To engage in dialogue, participants must fuse their perspectives to some extent while sustaining the uniqueness of their individual perspectives". This is evident on REC, where members can

be seen as having a fused perspective as members are striving towards recovery, and, they also comply with challenging and the 'recovery spirit'. The element of difference or uniqueness is sustained as each member has a different recovery story, and is at a different stage in recovery.

The examples below will show the communication on REC to be dialogic in nature, the role of challenging and the 'recovery spirit' in this dialogue, and reveal that an interaction-focussed supportive environment is created through the dialogic tools used on the site. Three dialogic tools will be highlighted in the following analysis of REC (1) returning to the thread; (2) further questions and (3) quoting. Returning to the thread refers to members returning to the same thread to offer continued support, this can be seen as dialogic in that it is a practice that keeps conversation alive and moves it forward with each response. Further questions is the practice of members asking an original poster, or even another contributor to the thread, further questions about their situation. Again this acts to facilitate conversation, taking the dialogue in unexpected directions, as members ask more questions based on the answers given. Further questions also links heavily to challenging, which is reminiscent of the anti-eating disorder language recommended by the narrative therapy approach (Maisel et al., 2004). Finally, the dialogic tool of quoting, is when members quote one another in threads, which shows that meaning is not born out of isolation. Interactions on the forum are informed and meaning is constructed through an ongoing process, as is expected in dialogic communication. The following thread, taken from the mental health sub-forum on REC, will illustrate a member using the first dialogic tool of (1) returning to a thread, what this means in terms of creating dialogic communication and the implications for support on the site:

Thread 1 (REC): Title- Anxiety turned agoraphobia 15

#### GreenBlossom:

"Bear with me if this is a bit disorganized, my brain is a bit disorganized ATM.

<sup>&</sup>lt;sup>15</sup> Pseudonyms are used throughout this thesis for forum and interview data. They do not retain the 'spirit' of the original name or username, but are randomly assigned by Sarah Lewis. Pseudonyms for forum data are not replicated, therefore the same member may appear in the thesis under a number of different pseudonyms, this is to provide a higher level of anonymity.

Just to give you some basic history, I've had an ED for 4 years and I got to be very sick, not really the emaciated kind of sick but the "I've been fucking up my body for so long all I can do is sleep and vomit now" kind of sick. I've made so much progress on my disordered thoughts, I want to get better and I am working on doing so as fast as my body will cooperate.

I've always had issues with anxiety, but in the past few months they have gone to extremes.

•••

I guess what I'm wondering, is if anyone has had similar experiences, maybe some solutions, or thinks that this is an ED issue that might get better once I've restored weight and gotten healthy. I know that starving your brain can create personality changes and cause people to isolate. But this isn't me, I may be shy but I'm not a hermit... And everyone is starting to treat me like a mental case for it."

#### White Rabbit:

"If it's really agoraphobia or something related, you should seriously consider doing exposure/confrontation therapy. Because it's usually not a good course of action to keep avoiding things and hope the anxiety goes away. Meds can help, but you shouldn't rely on them exclusively.

•••

Just a question: Is there anything in particular you're afraid of? Do you have panic attacks as well?"

#### **Greenblossom:**

"Thank you for the response:) I have been considering exposure therapy, and trying to take oppurtunites to get out when I have them, I've just been using my girlfriend as a bit of a security blanket when I do.

•••

I've been on meds before and I really hate relying on them for help, I went off of them without doctors permission because of this about a year ago, but before that I was on them for 2 years... The most frustrating part of all of it is that there really isn't a specific cause right now, just any little thing can trigger it to become worse."

# **Poppies:**

"I'm sure your weight and your behaviours contribute to what's going on with you right now, but weight restoration is not necessarily an antidote to anxiety. That's NOT to say don't weight restore, but rather that you might need something further.

•••

Do you see/have a therapist? If so, have you talked to her or your doctor not just about the anxiety, but your living conditions? Sometimes we need help to live: and it sounds like you could use professional intervention at this point."

#### Jefferson:

"The one thing that really struck me about this is the importance of not using your girlfriend as a caretaker. I know how easy is it to fall into that trap, and it's not particularly healthy for either of you... I guess what I'm trying to say is that if you allow yourself access to the proper tools and you work hard to utilize them, anxiety sucks but it can get better."

# **Greenblossom:**

"Thank you all for your honest and supportive responses xx sorry it's taken me a while to respond, I haven't quite known what to say : x

I see a therapist, and I've talked to her about it.... I'm going to start on meditation and similar practices to help ground and calm me, and today I'm taking a big step by not ducking out of my weekly classes. I'm anxious as hell but I'm dressed and I AM going. I know I'll get out of this, it's just a matter of when. I'm tired of it."

## Richie:

"I just want to give you hugs. I had agoraphobia last year and it can be overcome. Exposure therapy is really good, starting gradually with small things such as walking down the street. It does get easier."

#### **Greenblossom:**

"thank you very much for the hug comment, i needed that:)"

This is a typical example of the dialogue that exists on REC. As well as encompassing the returning to the thread element, there are also further questions asked of the original poster. Greenblossom returns to this thread three times after her initial post in which she asks for advice regarding her anxiety and potential agoraphobia. In each subsequent post she discloses more about her situation by responding to the questions asked by other members. In returning to the thread in this manner Greenblossom is propelling the conversation forward, with the potential for it to go in numerous directions. She is also showing her commitment to recovery as she is engaging with the conversation and making further steps towards getting better.

Through returning to the thread, the content remains focussed on Greenblossom, with all members' comments orientating towards her and the advice she is seeking. Jefferson begins her post with "one thing that really struck me about this", which immediately positions her as having heard Greenblossom and suggests what follows is a considered, thoughtful response. Returning to the thread acts as a means of further disclosure for Greenblossom – who offers high levels of self-disclosure to the forum- while the other contributing members do not self-disclose a great deal about their lives. Jefferson and Richie both include self-disclosure in their posts but in both cases is does not eclipse Greenblossom's need for advice, with Jefferson in particular making her self-disclosure relevant to the original poster by summing up her contribution with "I guess what I'm trying to say is that if you allow yourself access to the proper tools and you work hard to utilize them, anxiety sucks but it can get better". Using self-disclosure as a means of offering advice is, as indicated earlier in this chapter, a common practice on online support forums (Wright, 2000; Pfeil, 2010), but here advice is given freely without the need to self-disclose. This lack of self-disclosure goes towards creating an interactionfocussed environment, in which the original poster (in this case Greenblossom) is the focal point of the interaction and all communication is orientated towards addressing their issues.

The 'recovery spirit' may have a role in creating an interaction-focussed environment. As previously stated, the 'recovery spirit' is a normative concept on REC, it shapes the

community's understanding of support and recovery through making anyone eligible for support, regardless of diagnosis. It also requires members to commit to the idea that they can recover from their eating disorder, as they have the choice to get better. The 'recovery spirit' therefore asserts that members have an element of control over their illness, they can choose to languish in it, or they can choose to commit to recovery. Cutrona and Russell (1990) suggest that the amount of control an individual feels they have over a situation will affect what feels more important to them: high levels of control make individuals problem-focussed, whereas low levels of control make an individual emotion-focussed. With regard to REC and the above thread, this may account for the interaction-focussed support that is on offer. Members are believed to have a level of control/choice in their recovery and so calls for help are met with a problem-orientated mind-set rather than an outpouring of empathetic support. This is facilitated by the dialogic communication as members are encouraged to return to the thread, to further self-disclose and engage in conversation that has the potential to show them the level of control they have over their condition as the meaning of their disordered thoughts and behaviours are re-constructed through interaction-focussed conversation.

The following thread, taken from the exercise sub-forum of REC, also shows a member returning to the thread frequently; construction of others as knowledgeable experts; and low levels of self-disclosure; which are all also present in the previous thread. However, the focus here in the analysis is on (2) further questions, which is the second dialogic tool used by members of REC to facilitate conversation, encourage interaction but also challenge members and keep the community recovery-focussed:

Thread 2 (REC): Title- Is this enough?

#### Camellia:

"I do various exercises that involve cardio, strength training, ec for 30-60 minutes a day or 5x a week.

Is this a good amount? when I exercise it's still kind of driven by how many calories I burn and controlling my weight."

# Firefly:

"I think that's the wrong question. Perhaps you should be asking -yourself-, "Am I doing this for the right reasons?"

#### **Shadow:**

"It sounds like exercise is triggering for you. Perhaps it's not the best thing right now. Are you seeing a dietician or psychologist who can help you determine how much, if any exercise would be best for you?"

#### Camellia:

"I don't have a dietician but I do have a therapist I see. And yeah exercising isn't exactly triggering but it's more driven by ED motivated reasons."

#### Lionheart:

"Here's a different question...

Why are you asking? What difference is the answer people give going to make to you?

What are your definitions of enough/too much on this given you've already said you're going it for eating disordered reasons?

...

Since you've identified already you're doing it for eating disordered reasons how can you change this?"

Again, what is striking in this thread is the level of attention that is given to the original poster, Camellia. All posts focus on her and her question, however she does not get what she was potentially looking for in terms of support, as members challenge her to think about the amount of exercise she is doing and why she does it, rather than simply stating yes or no, or telling her what she wants to hear. Unlike Greenblossom in the last thread, Camellia does not present herself as having 'recovery spirit', she is returning to the thread, and answering the questions other members pose, but she is not disclosing a great deal about her situation and her tone feels defeated and non-committal, she repeatedly uses the terms "I don't know", "I guess" and "I'm not sure". Camellia's inability to present herself as having 'recovery spirit' may account for why members have reacted and challenged her in what could appear as an aggressive manner.

Further questions represent an opportunity to enhance the dialogue, they invite further participation from the member they are directed at, and allow the voices of participants be changed through the interaction. This idea of transitioning from one voice to another is discussed in-depth by Walstrom (1999), who suggests that members of the online anorexia forum she studied progressed through five different voices on the forum, from an indeterminate eating disorder identity to a recovering identity. This progression is fuelled by dialogic interaction on the site, and through members offering one another a different outlook on their eating disorder and themselves (Walstrom, 1999). The dialogic tool of further questions on REC can be seen in a similar manner, they encourage members to consider a more recovery-orientated mind-set and question eating disordered thoughts/behaviours, particularly if they also act as a challenge. As well as serving an interactional purpose, further questions are also useful to the group as they can be used to ensure that dialogue remains recovery-orientated. This is achieved through challenging, asking questions that make a member critique their eating disordered thoughts and behaviour. In this sense the communication can also be seen as monologic, as it is fixed on recovery and getting Camellia to think critically about her behaviour, this stilts the conversation slightly, as the same points are being made by different members. Morrow (2006) argues that questions can also be used to indirectly offer advice to other forum members; however on REC this is unnecessary as the norm of 'challenging' encourages direct critique. Therefore on REC questions are not indirect but are focussed on the individual and what they can do to think more critically about their recovery. Tidwell and Walther (2002) suggest that individuals communicating online ask questions more frequently and that questions can act as a method to reduce uncertainty in CMC. While on REC questions facilitate the creation of an interaction-focussed environment by keeping content orientated towards the support-seeker, further questions can also be seen as reducing uncertainty about an individual's commitment to recovery, as they make the support-seeker respond with self-disclosure which has the potential of exposing perceived non-compliance or commitment to the 'recovery spirit'. Moreover, further questions create an interaction-focussed recovery environment, as members are encouraged to write their recovery into action and continue sharing their story as noted by Mundry and Strong (2012). This interaction-focus creates a sense that posters are being listened to and engaged with, other members want to know more

about their situation in order to offer them support (and to determine their commitment to recovery).

Interaction between members on REC is often shown through quoting, which is the third dialogic tool used on the site. Quoting is a common feature on online forums, and in no way unique to the community. What is particularly interesting about REC is the frequency with which members quote one another on the site. Quoting can be defined as simply quoting another member in your post. Members do this to show appreciation for a response, or agreement with a post, to guide the conversation and as a focal point of their disagreement with another member. Baxter (2007) highlights the reproductive function of unity-focussed (monologic) messages, claiming that these are oppositional to dialogue as they are not focussed on construction or creation. As quoting is reproduction of another's words it can be seen as both monologic and dialogic. It is monologic in the sense that it is a reproduction. However it is dialogic as it facilitates further interaction and also illustrates that different meaning can be read into the same expression, highlighting heteroglossia in action. Further to this, meaning is only created in relation to the other; one cannot forge meaning without interaction (Bakhtin, 1994). In reproducing another's words through quoting and adding their own sentiment members of REC are creating dialogue. The following thread is taken from the mental health sub-forum on REC, and is an example of members using the third dialogic tool of (3) quoting to reinforce points, direct conversation and inform dialogue:

# Thread 3 (REC): Title-Blackout and feeling absent

#### Jenga:

"I've often had wierd feelings of being absent, like I'm watching everything around me on tv, and I'm not actually there. I always thought it had something to do with my depression, but this morning I got up just normally, went to the bathroom, and then I can't remember anything til I'm falling down the stairs (probably 30sec later).

...

Has anyone ever experinced anything similar, or have any idea what this could be?"

#### Petal:

"...

It does sounds a bit like dissociation or depersonalization to me, too. And trauma or a history of prolonged stress might be a cause here, so Birdy's question is worth asking yourself.

But another guess from me would be epilepsy..."

# Jenga:

"Thanks everyone

I don't really have any real past trauma, like abuse or anything...

Quotes Petal- But another guess from me would be epilepsy...

I was a bit afraid of this, since my dad has epilepsy. I should probably call him and ask his opinion about this. And on Monday I'll go see the school nurse, and I'll talk about this with my therapist next time I see her."

#### Callico:

"..

Quotes Petal- But another guess from me would be epilepsy...

Quotes Jenga-I was a bit afraid of this, since my dad has epilepsy...

Ahh, yes, please do see a health professional as soon as you can. I'm not a professional, obviously, but the falling down the stairs thing doesn't sound like dissociation."

# Callico:

"Aaaand if you get any symptoms between now and seeing the nurse, go to the hospital ok?"

# Richie:

"Quotes Connie- I dissociate quite a bit, without any real history of trauma...

I could have written this word for word.

Hope you're okay Jenga."

# Jenga:

"Quotes Callico- Aaaand if you get any symptoms between now and seeing the nurse, go to the hospital ok?

Yes, absolutely"

Again, Jenga is returning to the thread in this post, she is also being encouraged to further self-disclose through other members asking her questions about her situation. Also the thread is very much directed at her, another example of interaction-focussed support, as everyone is working towards offering her advice, with self-disclosure among other members being limited.

The dialogic tool of quoting is first used by Jenga in this thread, as she quotes Petal's suggestion that her black out could be epilepsy. The quote serves the purpose of fuelling the dialogue, as Jenga has used it as an indication to further self-disclosure, and mentions her father suffering from epilepsy. Callico on the other hand, appears to use quoting as a way of directing the conversation, making her words that are added to the thread 'fit'. She can be seen as making the conversation appear more linear, charting (through quotes) Petal's suggestion that the blackouts are epilepsy, Jenga's response, and then adding her own comment.

Quoting, as previously mentioned, can be seen as encompassing elements of monologue, as it is reproduction of another's speech (Baxter, 2007). As well as being monologic quoting can also be authoritative, as statements can be quoted and seen as highlighting an example of behaviour that does not conform to the 'recovery spirit'. This can be seen in the exercise thread Camellia starts, with one member quoting her words and then passing judgement:

#### Zawe:

"Quotes Camellia: I don't have a dietician but I do have a therapist I see. And yeah exercising isn't exactly triggering but it's more driven by ED motivated reasons.

Perhaps I was a bit naive about encouraging you there.

If you keep thinking about how much energy you used then it's a crappy reason..."

Zawe describes Camellia's reasoning for exercising as "crappy", directly showing disapproval and questioning the original poster's motives in recovery. In this sense dialogic tools are important to fuel the conversation but also to keep it on the 'right' track, which for REC is to maintain a recovery-orientated focus.

REC can be seen as an interaction-focussed, dialogic support environment. Members are encouraged to talk about their issues and are facilitated in doing so by other members employing the outlined dialogic tools, which in turn, creates the interaction-focussed support. Members are heard, engaged with and resolutions to issues are sought. The low levels of self-disclosure from respondents to original posters that are evident in the dialogic interaction on REC are interesting in light of the literature, which attests to the reciprocal nature of self-disclosure and its ability to reduce uncertainty amongst communicators (Barak and Gluck-Ofri, 2007; Dietz-Uhler et al., 2005; Tidwell and Walther, 2002). On REC the low levels of self-disclosure may serve the purpose of keeping support focussed on the support seeker, and thereby maintaining an interaction focus. While this support is interaction-focussed, it is not tailored to the needs of members, as they must display themselves as eligible for support- show themselves to be in possession of 'recovery spirit'- and accept that much support comes in the form of challenging rather than empathetic support. Also, while communication on REC is dialogic, it is also at times monologic, as members have to conform to the 'recovery spirit' and challenging, which are highly normative. Monologue and dialogue do not occur exclusively; rather often elements of both are present in interactions.

# ANA- interaction as monologue

Turning to ANA, communication is more monologic in form, as it is non-interactive and static, and is characterised by high levels of self-disclosure and a focus on the self. It is essential that ANA and REC are not seen as representing opposite forms of communication. Rather, dialogue and monologue should be considered a spectrum, with each community occupying points on the spectrum at different times, depending on the needs of the community and how support is shaped and therefore communicated. As previously discussed monologue has two component elements, the first being authoritative language, which is language imbued with sovereign power, that is

expressed explicitly through authoritative discourses and implicitly through internally persuasive discourse (Bakhtin, 1994). The second is static communication, which is language that fails to facilitate further communication and interaction, and is characterised by its 'inertia' (Bakhtin, 1994). It is the second element of monologue, static communication, that can clearly be seen on ANA. The site lacks a cohesive or authoritative discourse, although there are group norms that are present (the 'sickness mentality' and non-judgemental support). However, there is no single overarching, imposed discourse that all members subscribe to, rather the communication on ANA is characterised by what can be perceived as a lack of dialogic interaction. By lack of dialogic interaction, I am not referring to posts being left unanswered, but a lack of engagement between posts in the same thread. Three elements of monologue will be analysed here, the first two show the most prominent element of monologic communication on the site. They are: (1) lack of dialogic interaction and (2) Self-disclosure. The final element of monologue that is analysed is (3) monologue as supportive, which will show this monologic, self-focussed communication to be perceived as supportive by members due to the appeal of empathy from similar others and the site norm of non-judgemental support.

When first observing ANA the lack of dialogic interaction on the site made the support on offer seem insincere and, at times, superficial. However, spending more time on the site, and developing my analysis further showed that this form of monologic communication serves an important purpose for this community. The following extract from the mental health sub-forum of ANA illustrates the first element of monologue on the site, which is a (1) lack of dialogic interaction:

Thread 4 (ANA): Title- What meds are you on?

# SilverRose:

"What kind of meds is everyone taking, and why?

I feel f\*\*\*ed now that I'm taking meds, I think I just recently realized how much I was taking.. I am on Zoloft 50mg (getting upped soon) and two 2mg Abilify for anxiety, depression, voices and such.

It just hit me like, how messed up I feel, and how can I not function without them. Even then half the time they seem to not help.."

#### Cassie:

"i'm on prozac and adderall....i'm cheating on weigh ins so he'll let me keep me adderall lol. I can't function w/o it."

#### Frenchie:

"I'm not on anything right now. I used to be on effexor... I think I was taking something like 350mg or 400mg... I know it was really high because when I asked the doc to up them, he said he couldn't without risking giving me a possible OD... Meds are screwed up. I couldn't function without them and I would get debilitating migraines if I forgot to take one daily dose. I felt like a zombie on autopilot. I could function, but I couldn't form coherent thoughts at all. I finally decided I was going to quit my anti-depressants cold-turkey and I do not recommend that to anyone. I was sick in bed for 2 weeks. I had severe withdrawal symptoms... Couldn't hold down food; even water was a challenge. I had diarrhea, achy muscles and joints, a constant headache, the sweats... You name it and I had it. I lost a lot of weight during those two weeks though (that was the only upside)."

#### SilverRose:

"That sounds horrible! I hope you never have to go through that again <3"

# Belle:

"Prozac, 40mg a day. I would be completely mental without them <3"

# Username1:

"Valdoxan 25mg(Gunnaask for an increase Monday, cause even though it's amazing my hard core restrictingnis starting to mess with me again) I've been on Zoloft, Effexor and about ten others, this is the first that has worked. @SilverRose I have been on 200-250mg zoloft(can't remember, the maximum anyway cause she would let me go higher) before so don't panic too much hon!..plus if it works that got to be better than the alternative doesn't it? Seroquel 25-50mg to help me sleep, or calm down if I need it Used to be 100mg but that just messes with me too much the next day!"

#### Callie:

"I'm on Clozapine 450 mg, it makes me so dopey and I have to have a blood test every week and can only pick up my medicine if my blood results are ok. It's for treatment-resistant schizophrenia.

Apart from that I take 150 mg of venlafaxine M/R"

#### Glimmer:

"Prozac 40mg and Ritalin 20mg. Fun stuff."

The first thing to acknowledge about this thread is that while it is used to illustrate the monologic communication on ANA, there is some level of interaction. It is for this reason dialogue and monologue should be seen as existing on a spectrum rather than as dichotomies. While this thread is characterised by its monologic communication, that is not to say dialogue cannot be present. SilverRose and Username1 both respond to other members, interestingly neither of their attempts at dialogue are taken up by the members they were aimed at. Even SilverRose and Username1's attempts at dialogue can be seen as encapsulating a sense of monologue. Focussing on SilverRose in responding to Frenchie's detailed description of her experience with medications and withdrawal symptoms, does not ask any questions, but states "That sounds horrible! I hope you never have to go through that again <3". This can be seen as supportive as it shows recognition of Frenchie's suffering; it also shows that someone heard Frenchie. However, Frenchie is not the centre of the comment, SilverRose is. While it is a recognition, it is not a call for more information or a pragmatic response offering advice. It merely acts as a form of condolence. Or it would if members were not constantly co-constructing the meaning of posts on the site, making sense of what is said through the interplay of context, utterance and socio-ideological constraints. This comment is an example of heteroglossia, the idea that the meaning of any given word is subject to the context in which it exists, and its meaning is generated through an interplay of social, historical, ideological and interactional factors, creating meaning unique to that particular moment (Bakhtin, 1994). At the point in time that the post was written it meant something different to what it means to me now. Different meaning is attributed to it as the social, historical, ideological and interactional factors I bring to the post as a researcher are different from those of members (who would also each bring something different to the communication).

SilverRose's comment also acts to highlight the fluidity of monologue and dialogue, as it embodies both concepts at the same time.

As has been stated, there is limited interaction between members in this thread. Each post seeks to answer the initial question posed by SilverRose. Members are adopting a monologic form of communication, their voices are not being changed by the interaction, as they would be in dialogue. The conversation remains inert, ending with this post:

#### Caleb:

"As of yesterday I'm now on Abilify, Buspar, and Lamictal instead of the first two and Celexa. I'm happy with the change though I don't feel anything yet. I've read good things about Lamictal, so we'll see if it works for me."

The content of this post is much the same as earlier posts. Caleb is not responding to any members specifically, but to the initial question that was posed thirty posts earlier. As all members are orientating their posts to silverRose's initial question, it would appear that all communication is aimed at her, however (s)he does not return to the post other than to validate Frenchie's negative experience with medication. This suggests that the purpose of this communication is not necessarily interaction, but rather acts as an invitation for self-disclosure.

The second element of monologue on ANA, (2) Self-disclosure, is an important part of community and communication on ANA. Self-disclosure can be defined as the telling of previously unknown information and also how identifiable a person is offline from the disclosure of this information (Mesch and Beker, 2010). In terms of ANA and REC, being identifiable offline is potentially of little consequence due to the geographical spread of members and also the large numbers of members on each site. Self-disclosure is also not unique to ANA and REC, but is a consistent feature of online support groups more generally (Barak and Gluck-Ofri, 2007), with members having to display high levels of self-disclosure in order to get support (Pfeil, 2010). Furthermore, disinhibition effects including: anonymity, invisibility and asynchonicity also encourage high levels of online self-disclosure (Joinson, 2001; Suler, 2004). Therefore, the medium, the internet, also

contributes to the monologic communication that is typified by self-disclosure on ANA, which in turn facilitates a self-focussed form of support on the site. The following thread illustrates the second element of monologue on ANA (2) self-disclosure:

Thread 5 (ANA): Title- Bipolar meds and weight gain

Jen:

"Hey,

last year I had to start my bipolar meds again. lithium, depakote, seroquel, and a bunch of others. Of course all cause weight gain and I gained lousy 20kg! ((((

A couple of days ago I was fed up with that and quit all my meds. my shrink doesn't know about that yet since its the holidays.

does anyone know how long it might take to get rid of the weight???"

LavenderBeauty:

"this is the reason i said no to anti-depressants."

in regards to weight gain> i'd assume it'd come off reasonably easy considering the thing that made you gain the weight has now been taken away, hence a return to the state before the pills were started."

Pixie:

"Im in the same position, same meds except im on epilim. I dont eat but cant seem to lose, however I figure if i dont eat at some point the weight must start to come off. Been a hospital weight whilst on weight gaining meds soo. I dont want to get manic again so really trying to stay on meds but it is very frustrating.

Goodluck and take care."

Claire:

"I've just recently stopped taking my bi-polar meds, because I promisedpromised everyone that I was allIII better, and so I'm off that,

and they've put me on this anti-anxiety/ADHD medicine that actually is aparantly supposed to make you LOSE weight, so I'm super happy, and I'm hoping to get back down to how I was before a year and a half of those fucking medications. I weighed 82.30 pounds the summer of 2011, and my current goal is to get down to 95. I'll go from there:) So good luck, and I'm sure you can do it<3"

This thread begins with Jen behaving as Pfeil (2010) describes, by offering a large amount of personal information in order to be able to ask a question and access support from the community. She receives a large number of responses, and a common element of the responses is that they all contain some level of self-disclosure, as is consistent with the literature, which highlights the reciprocal nature of self-disclosure (Barak and Gluck-Ofri, 2007; Dietz-Uhler et al., 2005; Tidwell and Walther, 2002). As previously suggested there is nuance in all of these interactions, as there are levels of self-disclosure and levels of monologue. For example, the first member to respond, LavenderBeauty offers very little personal information and then goes on to make a suggestion about weight loss. This contrasts heavily with Claire, who merely offers self-disclosure on the topic of medications and weight loss and gain. Both levels of self-disclosure are acceptable on the site, and are perceived as legitimate responses to Jen's original post. In this instance it would appear that the self-disclosure has not facilitated discussion, like in the previous thread, members orientate all posts to Jen, the original poster, and there is little attempt at dialogue. Even Jen has not attempted to establish dialogue, she poses a question for the community, however she does not return to the thread.

From an outside perspective, the monologic communication on ANA can appear inward focussed and the supportive benefits members feel are not immediately apparent. As thousands of members use the site, there must be something about this monologic communication and the support it fosters that members crave. It has been suggested that having the space in which to talk about troubling issues can be more comforting for an individual than the responses they receive (Burleson and Goldsmith, 1998). This is potentially the case with ANA, and would go towards explaining the proliferation of monologic communication on the site. Members could be using the space to vent their frustrations, divulge personal information and ask questions that cannot be answered (or

arguably asked) elsewhere. This suggests that the site feels supportive, in part, because it is a space in which members can talk about their eating disorders. As the literature on pro-anorexia communities frequently asserts, members are drawn to the sites through unmet needs (Brotsky and Giles, 2007: Dias, 2003; Bond, 2012; Yeshua-Katz and Martins, 2013; Tierney, 2008), which was spoken about at length in chapter five. Anorexic and eating disordered patients are often positioned as powerless in their situations; at first controlled by the eating disorder (with all behaviour being pathologised) and then by doctors and clinicians if they go into recovery (Saukko, 2008; Gremillion, 2003). The internet, and the pro-anorexia communities, that have formed act as a way of readdressing this division of power, with members of ANA having discursive power in a way they have never experienced before (Mitra, 2004). They are now able to express their illness on their own terms, they are not constrained by medical discourse, or the need to present themselves as recovery orientated, or confined to psychological categories like those found in the DSM. However, all of these offline tensions and discourses will have influence on the content, context and utterance that is expressed and the meaning members attribute to it (Bakhtin, 1994).

The monologic communication on ANA fosters a supportive environment due to the provision of non-judgemental support and members' perception that ANA is a supportive place. Sharing is considered the most basic form of supportive communication (Aakhus and Rumsey, 2010; Burleson and Goldsmith, 1998), something which there is an abundance of on ANA, making the monologic self-disclosure, which is prevalent, a type of supportive communication. Eichhorn (2008) in her study of pro-anorexia forums found that members sought support that is grounded in problem solving. This is not the case for ANA, where members are focussed on self-disclosure and non-judgement. The following thread illustrates (3) monologic communication as supportive:

Thread 6 (ANA): Title- Addictions

Violet:

"I was wondering if anyone else had addictions of any kind? This is a topic where no one should be judged and people should share what they possibly haven't told anyone.

...

Myself, I feel ashamed, but I'm addicted to pain killers. I even shoot them straight into the veins in my arms. I advise **STRONGLY** that no one do that. **It will ruin your life**. It has ruined mine. But I choose to share this with you because we all have problems. That's why were here on this site."

#### Username2:

"Laxatives. Not a physical addiction more psychological I guess. It ruins my life.I am reducing though."

#### Rhian:

"Been there. Painkillers used to be the only way for me to live. Now I'm addicted to exercise and bars."

#### Katie:

"I have an addiction of fantasizing over people I know I can never have a relationship with, it really upsets me. For example, at the moment my feelings for someone who is much older than me and I know nothing can ever happen because they a family (kids and all), are out of control."

#### Violet:

"Im glad I gotta relator with the pain killer things. I hate those MFr's so much... To Katie, I know what youre talking about. I used to be like... crazy obsessed with Jack White. I mean CRAZYYYY obsessed... Thanks for being honest guys! I felt like an ass when I admitted to shooting up drugs... I just wanted to thank you guys for having an open mind!"

## Katie:

"Ah thanks @Violet, that is reassuring . I hope this obsession goes away, it's a bit stronger than all the rest and the worst part is it's not with a celebrity or someone, it's with someone who I see all the time!!... As for your addiction...have they not tried prescribing or giving you something different so there's some variety and you don't get hooked onto one specific type??"

# Minny:

"Atm dulcolax laxatives, i tried not to take it everyday.."

## Violet:

"I dont want to get prescribed anything else unless its stronger. It sucks because 51% i dont want to stop and 49% i want to get better. Even if its a real person, I know how you feel. Youll eventually get over it."

#### Zinnia:

"I used to cut... when I was at my worst it was a daily thing

Also, I'm normally a bit lazy but once I really get into exercise I have to monitor myself rather carefully otherwise I can end up realy overdoing it & hurting myself"

# Katie:

"No that doesn't sound weird to me at all! I often have strong feelings for younger people as well as older. I've started getting feelings for my girl best friend recently too, ah I am so confused! At least we know we have each other to be the same as So it can't be that unfamiliar. Always here if you wanna talk"

•••

# **Username4:**

"i'm a cutter. have been for almost four years. :/ i should say was, though, since i haven't cut for over a month now. it didn't bother me as much in the earlier days, but lately, i've just been obsessing over it.

... oh, and @katie thank god. i thought that was just me.. i spend like half my day thinking up scenarios in which i get celebrities/people i have no chance with, seriously."

#### Vanessa:

"I am a recovering meth addict, but honestly the reason I would do meth wasnt for the high but to be super skinny so I guess its like 2 addictions in one..."

Again this thread is characterised by monologue, with members offering varying levels of self-disclosure in response to Violet's initial question about addictions, with little interaction between members. There is an exception to this in Katie's responses, which can be seen as a continued effort at dialogue on the thread. However, this is not taken up by other members, who with the exception of Violet and username4, continue to selfdisclose rather than take part in the dialogue. Even Katie's attempts at dialogue are focussed on sharing and self-disclosure (and can therefore be considered monologic), which is in response to other members being able to relate to her feelings, rather than members asking for more information from her. Therefore, self-disclosure and the ability to relate to one another creates further self-disclosure. This contrasts heavily with REC, where further self-disclosure on an issue is encouraged by members through the asking of further questions. On ANA the purpose of sharing appears to be sharing itself, members share or self-disclose information because they, and those reading it, take some comfort it in. Violet, Katie and username4 all appear to take comfort in other members' stories and their ability to relate to them; "Im glad I gotta relator with the pain killer things", "Ah thanks @Violet, that is reassuring " and "... oh, and @katie thank god. i thought that was just me".

The need for empathy and people to relate to is a consistent feature of ANA and the monologic communication fosters this, as members are continually self-disclosing information that others are able to relate to. Although self-disclosure is reciprocal (Barak and Gluck-Ofri, 2007; Dietz-Uhler et al., 2005; Tidwell and Walther, 2002), it does not necessarily need to create dialogue, as is the case with ANA, as any response at all can make a member feel that they have been heard and that they are valued in the

community (Morrow, 2006). The idea that there can be a discrepancy between what is said and how it is perceived is important on ANA, as it means that messages can be interpreted as supportive, even if the poster's intention was not to give support but was purely self-expression. Jabri et al. (2008) refer to this as 'living communication' and highlight that there is a difference in intention of poster and impact on the reader and their interpretation. The authors give the specific example of violence in online messages, suggesting that offence may not be intended, but as a post is interpreted and meaning created through another individual's interaction with that post, the post can be read and interpreted as offensive (Jabri et al., 2008). 'Living communication' can be applied to the context of ANA, messages may not be intended to be supportive, but are read as supportive due to the meaning that is created by the reader interacting with the post. This also adds to the sense of supportive communication being self-focussed on the site, as members are not required to make a response relevant to other members in order for it to be considered supportive. Members make each post relevant and supportive to themselves through their own interpretation and the specific meaning that creates.

Sharing and self-disclosure are dependent on something that is of great importance to members of ANA, and that is non-judgement. The need for non-judgemental support actually functions as a norm on the site, as was discussed in chapter five, with what is and is not acceptable on the site being governed by whether it relates to the tenet of non-judgemental support. Violet makes this clear in her original post, stating; "This is a topic where no one should be judged and people should share what they possibly haven't told anyone". Members are able to share information that they would not usually disclose, as the site has a fluid concept of support, which is underlined by members not reacting in a judgemental manner.

As monologic as the forum appears to be, communication does not start and end with the forum. Members use the private messaging function of the site to support one another and also move beyond the boundaries of the site, adding each other on instant messenger services and social networking sites. The forum could then be a monologic gateway to more dialogic communication through other mediums. Morrow (2006) found instances of members requesting and offering continued support on a sub-forum on netdoctor.co.uk, which can also be seen in the above thread, with Katie saying to Violet

"always here if you wanna talk". While the community appears to be monologic, it is an opportunity for members to seek out others with whom they relate and attempt to create a dialogue through different means of communication. A more direct example of this is members' 'advertising' for ana buddies, where members will post to the forum asking to exchange contact details with members in order to maintain motivation for weight-loss.

Communication on ANA is mainly monologic and fosters a self-orientated environment, one in which members gain support from their own ability to post and the coconstruction of messages as supportive. However, this monologue serves a purpose for members, who return to the site regularly and believe it to be a supportive environment.

# Communicating support: dialogic and monologic interaction on ANA and REC- A summary

The two communities have been shown to have different forms of interaction, which enable two differing types of support (interaction-focussed and self-focussed) to be established on the sites. The dialogic communication on REC, illustrated through the dialogic tools of returning to the thread, asking further questions and quoting, encourages members to be open about their eating disorder, to question one another and to keep dialogue and interaction going. This dialogue keeps the community recovery focussed, as it works in combination with the normative constructs ('recovery spirit' and challenging) that govern the site. On ANA a lack of dialogic interaction and high levels of self-disclosure mark the community as monologic. As static as the communication is, it still serves important functions, as it allows members to express almost anything on the site, and to relate to one another. While this monologue may appear superficial to an outsider, it has impact on members, who flock to the site and perceive the interactions they have on the site as supportive.

As has already been highlighted, monologue and dialogue do not necessarily occur exclusively and communication can embody elements of both concepts (Jabri et al., 2008). The following section builds on what has already been stated about communication, encapsulating both monologue and dialogue by showing how the

dialogic communication on REC has monologic elements, and that the static monologue characteristic of ANA has a dialogic nuance.

# **Chapter six (section 3): Analysis**

# Communicating support: 'monologic consensus' and multiple voices on REC and ANA

In this section the analysis focusses on the expression of voices on ANA and REC, threads from the forums are analysed to demonstrate how voices of members are embraced (in the case of ANA) or muted (in the case of REC). Beginning with REC, the expression of voices is characterised by monologue, illustrated through authoritative discourse on the site, 'monologic consensus' (Jabri et al, 2008) and, the direct censorship of posts. And so, this section shows the community to be a 'monologic consensus' (Jabri et al, 2008) as it is dominated by authoritative discourse, which members are called upon to agree with (despite the seemingly open dialogue) and posts are censored or locked. Members are able to and do express their voices on the site, as can be seen in the variety of disordered experiences that are evident on the site. However, the 'monologic consensus' (Jabri et al, 2008) constrains members voices, so that they all conform to the dominant discourses of the site. Turning to ANA, using three characteristics of polyvocality, including, equality, lack of finalising word and, the interconnection of voices, this analysis reveals the multivocality present on the site. Members of ANA are able to express their voices freely on the site, they are not confined by authoritative discourse as members are on REC, this in turn leads to a more fluid understanding of support and how this is expressed on the site. Through this analysis the simultaneity of dialogue and monologue is made clear, and the implications for support on these two sites is expanded upon.

## REC- the monologic expression of voices

While communication on REC can clearly be described as dialogic, it also has elements of monologue, in that members are frequently expressing the same sentiment (albeit through multiple voices) and the communication on REC is characterised by cohesion, rather than diversity of opinion. As previously stated Bakhtin's (1994) monologue can be seen as being comprised of two elements, communication that is authoritative and that which is static. As the previous analysis shows communication on REC is not static, it is a collaborative process in which members co-construct meaning. However, communication on REC does have authoritative traits, as posts are moderated by site administrators and moderators, and members are encouraged to self-censor, making communication

monologic in the sense that it is internally persuasive. Internally persuasive communication refers to authoritative discourse which is internalised by individuals and taken on as their own language (Bakhtin, 1994). The following analysis will illustrate monologic expression of voices on the site in three ways: (1) through authoritative discourse (2) the idea of 'monologic consensus' and (3) the use of direct censorship. Each of these three characteristics of monologue will be shown through the accepted use of censorship on the site.

Before turning to the monologic expression of voices, it is necessary to acknowledge that censorship plays an important role on REC. As a highly normative community, censorship is considered to have an integral role for members. This can be seen through the way members interact on the forum and how dominant ideas about support and acceptable communication go unchallenged on the site. However, in interviews members frequently stated that they liked the site because it was open and uncensored compared to other recovery sites. Rachel and Megan both mentioned censorship on other recovery forums when discussing the perceived openness of REC:

"I glanced at a few others, but they didn't fit well for me. Something Fishy, for example, is pretty censored."

(Rachel, IM interview, REC)<sup>16</sup>

And:

"So I was looking for a good recovery forum and the b-eat you know the charity but I found that my posts were just constantly getting censored"

(Megan, audio interview, REC)

For Rachel and Megan censorship, or the perceived over-censorship of content on other recovery forums was off-putting. This suggests that the way censorship functions on REC is deemed as legitimate among members. On REC censorship can be seen on two levels, there is the regulation of self (internally persuasive discourse) and the regulation of others (authoritative discourse). These two levels are interrelated but can occur in isolation. The regulation of others is the most significant form of censorship observable

1

<sup>&</sup>lt;sup>16</sup> Interviews were conducted via video chat (skype), audio chat (Skype), instant messenger (Skype, AIM, MSN, Yahoo) and email. IM interview indicates that an interview was conducted via an instant messenger service.

on REC, as the regulation of the self arguably takes place before members write a post, as the dominant voice of the site and acceptable communication becomes second nature to members.

The (1) authoritative discourse on REC pertains to the hierarchal structure of the site, with administrators and moderators able to censor members in the most 'direct' manner through editing posts, locking and deleting threads. 'Direct' censorship is rare on REC, and it is not only those in positions of authority on the site that will reprimand or censor others. Active and regular members have invested heavily into the site, they receive support to recover from their eating disorder, but in return for that support much is expected of them. Members are required to conform to the 'recovery spirit'- a site ethos that posits that members have the choice to recover and should make active progress towards recovery- in order to be eligible for support. Members also need to present themselves as active in their recovery through accepting challenges- critique of their eating disordered thoughts and behaviour. As well as meeting these expectations, members give their time and energy to one another, offering support that is lacking elsewhere in members' lives. When considering the commitment an active and regular member of the site displays and the highly normative environment members have fashioned, it is almost unsurprising that non-conformity is reprimanded or at least brought to attention. In terms of Bakhtin (1994), REC is multivocal, in that there are many voices, expressing a great variety of experiences, thoughts and behaviours. However, the normative nature of these discussions, that must fall within the remit of the 'recovery spirit' and challenging, show that communication on REC can be seen as producing and maintaining a consensus (Jabri et al., 2008).

Jabri et al. (2008) discuss at length that multiple voices do not automatically create polyphony. There are situations in which multiple voices can actually be constricted to saying one thing, Jabri et al. (2008) refer to this as 'monologic consensus'. (2) 'Monologic consensus' can be seen on REC, as many members express themselves and their experiences of an eating disorder on the site; however it is constrained by the overarching concepts of 'recovery spirit' and challenging. "In a monologic consensus, the invitation to participate extends no further than the call to agreement with a predetermined outcome...The call to consensus is essentially a monologue" (Jabri et al.,

2008, P. 674). The following thread, taken from the mental health sub-forum, is a clear example of 'monologic consensus' being expressed on REC:

# Thread 7: Title- A few thoughts on medication questions.

# Selks:

"I might be the only person who feels this way, but I am wondering if sometimes the topics on certain medications get out of line.

What I mean by that is...

We are not all in the medical field....

A few things to remember:

- 1. NO ONE here should be telling you how much of a medication you should be taking.
- 2. Even though there are a couple of people here who are in the medical field (as in nursing, doctors, etc.) it does not mean that they can be your doctor for you...
- 3. Just because one person had a certain reaction doesn't mean that you will...

Maybe this post is out of line and rude, but really folks...no one here is just like you..."

# CrystalCastle:

"I agree."

#### Tennessee:

"agree agree !"

# Peach42:

"Agreed. I think medical questions should not be allowed. I am member of the somethingfishy site and on their forums no medical questions are allowed, no

numbers are allowed either. You cannot diagnose nor give advise to someone over the internet, its not right."

#### Lilo:

"I agree."

#### Sarahlouise:

"I completley agree. Sticky this."

# BlueSky:

"I agree. I see No.3 happening a lot, especially if someone says they know someone who gained weight on a certain med...

I was particularly concerned about the suicide post cos that med does actually help many people."

#### Gabrielle:

"I agree. Thanks, Selks. You're fab."

In this thread Selks draws attention to the number of posts on medications, and in doing so she is highlighting acceptable behaviour and attempting to inhibit members from starting similar threads. Given the dialogue that is present on REC, with members actively encouraged to challenge/critique one another's eating disordered thoughts, Selks's post is met with nothing oppositional, only agreement. This post can be seen as expressing 'monologic consensus' in that Selks potentially knew the outcome before it was posted, this is despite the caveat "maybe this post is out of line and rude". As a regular member (and moderator) of the site, she knows that her post conforms to the dominant discourses on the site. In terms of fostering monologic communication, this post plays on both elements of authority, in terms of hierarchy it comes from a well-respected moderator of the site, and in terms of internally persuasive discourse, it counts on members subscribing to the dominant discourses of the site, rather than challenging Selks and that dominant voice. This post also acts as an example of regulation of the self, in the sense that members are being encouraged to consider what content is appropriate

for the forum, posting in line with 'recovery spirit' and challenging rather than posting without forethought.

The concept of 'monologic consensus' (Jabri et al., 2008) is a consistent feature of the censorship that is employed on REC. The following thread is an example of when members attempt to create dialogue within the 'monologic consensus':

# Thread 8: Title- running q&a

# PurpleBegonia:

"I have very limited time on the net this week... but this site is allowed.

so I wanted to start this thread while I could.

Now that I know there are a few of us runners out there... I thought we could help out those wanting to get into running. How to do it in a healthy way...by answering questions."

#### Nashville:

"Well as you know... I have lots of questions..."

# PT215:

"i have a query about interval training..."

# **GreenMeadow:**

"Maybe...

nourish yourself and try walking... then intervals of walking for 5 minutes and jogging for 30-1 and work it up. I did that rehabbing a fractured hip last spring."

#### PT215:

"thanx, GreenMeadow!!

I'm thinking eight minutes warm up, ten two minute intervals with four minutes of jogging in between..."

Saffron:

"I just want to say that I have my concerns about members running if they are not

fueling their body well enough to do so. Running is great for exercise and the

endorphines are great too, but make sure you aren't lying to yourself and going

from one way of harming your body to another...

Make sure if you are running or thinking about running or exercising in another

stenuous way that you are truly being honest with yourself about your intentions.

(Sorry to throw all this on the thread but I needed to say it.)"

PurpleBegonia:

"I am not certain I like the contents of this thread."

Nashville:

"Quotes PurpleBegonia: I'm not sure I like the contents of this thread.

That is definitely fair enough, Jen.

What were your hopes for this thread?

What can we do to change the contents to be more relevant to what you were

aiming for? Glad you chose to speak up so we can attempt to redirect the content

to what you were aiming for in the first place. This is an important point."

Annoymous:

"i love long distance running too. i usually run at least 8-9 km/day without

stopping."

Silence:

"Quotes PurpleBegonia: I'm not sure I like the contents of this thread.

Seconded."

**Tropicalchancer:** 

209

"Annoymous: are you eating enough and resting enough?"

# PurpleBegonia:

"I know I started this thread but after the first few responses I didn't like the direction it was heading... and even said as much on page two. it turned into something it wasn't meant to be... I should have foreseen the huge potential of that"

The key members in this thread are PurpleBegonia and Nashville. PurpleBegonia is trying to censor or at least gain control over the thread, which she feels has gone wayward; whilst Nashville accepts that the thread is not appropriate and complies to the agreement element of the 'monologic consensus', but also tries to open out the discussion and create a dialogue about how the thread could be moved back in line with the recovery orientation of REC. PurpleBegonia's one and only attempt to censor the thread, is exercised when she states "I'm not certain I like the contents of this thread". While this is not direct censorship in the sense that members are asked to stop discussing running, the implication is clear: this content is not appropriate on REC. Again, PurpleBegonia's comment is encouraging members to self-regulate, to internalise the acceptable practices of the site, and communicate within them. Further to this, PurpleBegonia occupies one of the most senior roles on the site, she is an admin, so this statement also comes from a person in authority. Nashville picks up on PurpleBegonia's disapproval, in her reply she both conforms to the 'monologic consensus' by acting in agreement with PurpleBegonia, but then does something unusual, in asking PurpleBegonia what could be changed to make it more appropriate. While this is still conforming, in that it acts as an agreement that the content needs to be changed, it is also an attempt to create dialogue out of a monologic situation. Nashville employs a technique that is typical of the way dialogue is expressed on REC, she asks PurpleBegonia further questions about how the thread can be adapted and what PurpleBegonia wants from the thread. Interestingly, Nashville's attempt at dialogue is not taken up by anyone, even PurpleBegonia, who is directly addressed in the post. When PurpleBegonia does return to the post, it is not to realign the thread so that it falls in line with her expectations, but to reiterate her distaste with the content of the thread "I didn't like the direction it was heading...and even said as

much on page two". In stating this there is the implication that her 'call to agreement' (Jabri et al.,2008, p. 674) has not been reacted to in the desired way, in that she expected members to act in agreement and stop posting what PurpleBegonia considers inappropriate content. The silence that Nashville's attempt at dialogue is met with, and PurpleBegonia's reaffirmations of 'correct' adherence to the 'monologic consensus,' are telling of the normative nature of this community.

Not only does PurpleBegonia reprimand others in this post, she is also critical of her own conduct, "I should have foreseen the huge potential of that", suggesting that her own regulation of self was not sufficient. This is interesting as PurpleBegonia occupies a position of authority on the site, yet she is still not above the norms of the site, and seeks to conform to the dominant discourses. Saffron, another moderator, can also be seen as trying to keep the thread compliant with the recovery orientated talk typical on REC. While her comments on running during recovery are not censorship, they are an expression of the dominant discourses on the site, as they embody challenging and encourage members to think critically about their motivation for running, suggesting it could be eating disordered in its origins. While this thread is monologic in many respects, the content about running uses dialogic elements typical of REC (quoting and further questions). There is an authoritative call to monologue as the content does not comply with the dominant discourses of the site.

In terms of support, the 'monologic consensus' which exists on REC, further creates a normative supportive environment. While support on REC is interaction-focussed, as was detailed previously, the 'monologic consensus' illustrates the limits of this support and acts to regulate the behaviour of members. In his study of SeniorNet, a forum for elderly internet users, Wright (2000) found that members frequently promoted the community support available on the forum in threads, particularly in threads started by new members. The monologic communication on REC, that is shown through censorship and 'monologic consensus', can be seen as having a similar role as promoting community support on SeniorNet, as it illustrates what support is available on the site. On SeniorNet this community support is promoted by highlighting the positive attributes of the site (Wright, 2000). On REC an understanding of support is created through regulation and

seeing what is unacceptable on the site. The constraints of the site create shared meaning and add a sense of coherence (Aakhus and Rumsey, 2010).

The final example of monologic communication, illustrates (3) 'direct' censorship on the site, the nuance that exists even in monologic communication and presents the expression of the 'anorexic voice' as dangerous to the community. The term 'anorexic voice' refers to the separation of anorexia from the individual, this act of separation leads to anorexia being conceptualised as a voice by those with the condition (Highed and Fox, 2010). Maisel et al. (2004) discuss the subjective nature of the 'anorexic voice', it is not a universal construct, but is unique to the individual. The 'anorexic voice' supports anorexia by giving meaning to the thoughts and behaviours, strengthening the grip the condition has on an individual (Maisel et al., 2004). The 'anorexic voice' can have both positive and negative influence on an individual. Participants of one study said appearance of the 'anorexic voice' was calming, as it gave order to their life and provided comfort, as the illness progressed the 'anorexic voice' began to be more dominant and controlling (Tierney and Fox, 2010). On REC the expression of the 'anorexic voice' is to be avoided, it is presented as a danger to the individual and community as a whole. The following thread is what is generally termed a 'suicide post', as it discusses a member's desire to take their own life. Suicide posts also may contain suicide threats or details of a member's suicide plan. Suicide posts are a standard element of both ANA and REC, as they are on online anorexia sites more generally (Castro and Osorio, 2012), where the nature of online support potentially suits the disclosure of suicidal feelings (Gilat et al., 2011). The way in which suicide posts are attended to will depend on many factors, including the cultural idiom of the site, the sites understanding of support, and the illness or condition that is predominantly discussed on the site. As will be shown in the extract below, suicide posts are not tolerated on REC, they are presented as something that has the potential to bring the community into jeopardy. Suicide posts contravene the formal and informal rules of the site and expose members to the 'anorexic voice' in an unregulated form. In the following thread, where Briar-Rose does not state that she is going to kill herself, but that she wants to die, the initial outpouring of support quickly turns to censorship (monologic communication), in order to protect the community:

# Thread 9: Title-I'm ready to die

#### **Briar-Rose:**

"I have a totally exhaused apathy engulfing me. I have spent most of the past three years locked in various psych wards... litterally. I have spent months and months at a time as an involuntary patient. I struggle with depression, aparantly, but I'm beginning to think I just have a realistic view of the world and life and how it all is. This sheer meaninglessness and apathy towards life is driving me back to suicidal thoughts... Now with my Anorexia threatening another hospital stint I am thinking life just isn't right for me. I am just over it! I'm sickof crying and hating myself and trying to make believe I want recovery, because I just want to die right now. I don't know where to turn to now."

#### Silence:

"I hear you, I have been through the same. Overdoses, ICU etc. Wanting to give up. Now I have a new lease on life though, several things have helped me. Is there anyone you are able to open up to professional or otherwise, is there anything you love doing above anything else?

Keep going please. You are so strong to get as far as you have."

# Boggle:

"I don't know how to answer your post but I feel I can't just leave it.

You do sound vvv depressed. There's so many great reasons to be alive, and I wish you could see through your depression and ed to see them. Can you find one teeny weeny thing that's worth living for?

..."

# Marigold:

"Briar-Rose, this is a recovery forum. Comments like these are not fair on other members. We all have our struggles, but we vow to keep fighting them. You are in need of serious help, from professionals. I realise that you don't want recovery

right now, but please don't come on here and proclaim you want death. This is not the place, as we are not equipped to help you.

Accept the help that is being offered to you."

#### **Briar-Rose:**

"I'm sorry. Never mind."

#### Silence:

"Please don't follow what your instincts may be telling you. I am going to PM you my cell number."

# August:

"^Marigold was just trying to point out that suicide threats/posts are inappropriate and upsetting and that when people feel that way they should be contacting people in RL, family, therapists, even the likes of The Samaritans should they feel they have nobody else, rather than posting about it here.

Posting about being suicidal simply worries, upsets, triggers and frustrates people. We cannot help with that, especially when the person is stating they do not want help.

It is always worth remembering this is a forum for support to recover, get well and rebuild your life. Not to journal your dying thoughts.

That is not a criticism or a show of lack of care for your feelings Briar-Rose- I feel for you as I know how it is- it is simply an explanation of what is and isn't ok on the forum at large, there are certain guidelines we have to stay within for this to remain a supportive and positive environment."

### Focussed4recovery:

"I am sorry to hear you are feeling so low Briar-Rose. n the midst of anorexia the world seems nothing but a black. But seriously, thereare ALWAYS people who care about you, believe it or not, and as horrible as things seem now you know there is

something in you that isn't your disorder... Feel free to PM me anytime by the way. x o"

#### Nora:

"Briar-Rose, if you are feeling suicidal, please contact a real life emergency line.

Please be aware that I did once contact police in another province about a young woman who posted a suicide threat on this forum, and the police did go to her house and they did speak with her parents. There is enough information from an IP address for us to do that.

Maggie, thank you. I thought your post was entirely appropriate."

### Cyress:

"I am now locking this thread. It is important that if others find themselves feeling the same way as Briar-Rose, that they see that others suggest things that will TRULY help: crisis lines, and going to the Emergency room."

Li:

"Sorry, but I have to add my two cents... so you can just think on it.

...

You are clearly still trapped in an anorexic mindset. What is it going to take you to let go of it? Why do you write occasional proana tips on here? Why do you post numbers, weights, BMI so much? Why the talk of suicide? Posting these things propagates the mindset you indicated in your introduction you need to step away from... you know? The only way to learn this is to do it. It's not easy. It's scary as hell. But what's the alternative?

None of the things you've posted have embodied the vision of what this place was meant to be, but maybe it's something you haven't been exposed to before or lately and you just don't know how to write in a positive voice yet.

...

What is preventing you from keeping an open mind towards recovery?"

#### Pilgrim:

"Perfectly put, Diane."

# Focussed4recovery:

"I agree Li, thankyou for posting."

# Pilgrim:

"I think everything that needed to be said, has been said. This thread is now locked."

The first thing to acknowledge about this thread is that while it is classed as monologic, there is nuance within it, with members attempting to create dialogue in some instances, with Silence, Boggle, Focussed4recovery and Li all engaging with Briar-Rose on various levels. Silence, Focussed4recovery and Boggle offer empathetic support, assuring Briar-Rose that they understand her suicidal thoughts but urge her to keep going. This is reinforced through their offers of further contact, offered by Silence and Focussed4recovery, who encourage Briar-Rose to PM (private message) them and Silence even publically announces she is giving Briar-Rose her mobile phone number. Li engages with Briar-Rose and does attempt to create dialogue, which can be seen by the number of further questions she asks, however, her post is not as empathetic as those of Silence, Boggle and Focussed4recovery, her questioning is challenging Briar-Rose, critiquing her eating disorder mentality, with the implication that this is not in line with what REC stands for. These four voices and perspectives are present on the thread, but they are not the dominant voice, which is one of condemnation. The consensus on this thread is that Briar-Rose's post is inappropriate, with members (Marigold, August, Nora) directly telling her this, and while others engage with Briar-Rose, no one challenges the idea that the content of her thread is unacceptable. Therefore, despite the nuance, this exchange is overwhelmingly monologic.

The monologic nature of the communication on this thread is not only expressed through what is said, but also the eagerness of moderators (Cyress and Pilgrim) to lock the thread, which would have the effect of stopping the conversation entirely (in the public forum). As previously said, using a 'direct' form of censorship is not common on REC, which illustrates how inappropriate the post was deemed to be by members. The post is directly censored, but before that is even suggested, the strong and disapproving reaction of Marigold is enough to stop Briar-Rose continuing to post her issues, and her one and only return to the thread is to apologise. Therefore, before the direct censorship, or any other members' comments, Briar-Rose has been effectively censored.

Finally, this post is a clear example of why monologic communication is important to REC, as it serves to keep the community safe from the unfiltered 'anorexic voice' of individual members. In this post Briar-Rose is not employing challenging, she has not regulated her content, and so her post is dominated by the 'anorexic voice'. This is something which is frowned upon on REC, the 'anorexic voice' is not to be believed, it is meant to be critiqued and members are expected to take a self-reflective approach to their recovery, all of which is reminiscent of the narrative therapy approach to eating disorders (Maisel et al., 2004; Saukko, 2008).

Briar-Rose's post is positioned as dangerous in two clear ways. First, it is considered dangerous to other members, and secondly to the community as a whole. August and Marigold make clear that Briar-Rose's words have consequences, by reminding her of their impact and that she is not merely talking into the ether when she posts. August states, "Posting about being suicidal simply worries, upsets, triggers and frustrates people", here she is bringing other members into focus, rather than attending to Briar-Rose's suicidal thoughts, which is only done after Briar-Rose has been reprimanded and informed of the impact of her post. Similarly, Marigold stresses "comments like these are not fair on other members", again the concern here is not for Briar-Rose, the member contemplating suicide, but other vulnerable members reading and reacting to this post. Both of these posts position other members to be at risk, made vulnerable through Briar-Rose's lack of censorship and the dominance of the 'anorexic voice' in her suicide post.

Not only are individual members considered at risk from Briar-Rose's post, but also the community as a whole is to be protected. Again, the focus is not on Briar-Rose, but the fact that her post contravenes expectations of site use on REC, with members decrying the content and while calling for Briar-Rose to seek professional help, with the site objective and unspoken norms being used to give credibility to these posts. The community is positioned as at risk in posts by Marigold, August, Nora and Focussed4recovery. Each of these members show Briar-Rose's post to be inappropriate by either calling on the ideals of the community, that are not adhered to. For example August says "There are certain guidelines we have to stay within for this to remain a supportive and positive place". This comment from August is key in understanding why Briar-Rose's post was treated as a danger, and responded to with censorship and 'monologic consensus' about the inappropriateness of the post. REC has developed into a highly normative community. This is no accident, it is felt and clearly upheld by members, as this post illustrates, that boundaries must be maintained in order to support one another in recovery. Without the boundaries members are exposed to potential threats, like the unregulated 'anorexic voice'. As well as illustrating that Briar-Rose's post does not comply with the community mentality, Briar-Rose is encouraged to seek help elsewhere and so is further pushed away from the community. While this is understandable, the community is not able to offer the assistance she needs, it is a peer support community and does not have the resources to deal with suicide. However, this, coupled with the positioning of her post as dangerous, has the effect of silencing Briar-Rose and potentially making her feel isolated in a community that is meant to be providing her with support. Monologic communication on REC represents safety for the community, the boundaries of what can and cannot be said are clearly defined, it contributes to the normative support environment in which members have to show themselves to be eligible for support. In the following section I will consider the expression of voices on ANA. These will be shown to embody some of the key elements of Bakhtin's (1994) concept of polyvocality, enhancing the self-focussed support that was a result of the previously discussed monologic interaction on the site.

# ANA: the multivocal expression of voices

As previously stated, monologue and dialogue should not be considered a dichotomy, as they can (and do) occur simultaneously in interaction (Jabri et al., 2008). The aim of this analysis is to show that dialogue is present in ANA, through the idea that multiple voices co-exist on the site, which appears to be static and monologic, and further illustrate how this impacts on the self-focussed support that is prevalent on the site.

The communication on ANA appears to be monologic, with members engaging in high levels of self-disclosure and limited interaction between members. That is not to say dialogue does not exist on the site, and that this monologic communication cannot facilitate dialogue. What is apparent on ANA is the variety of members on the site; as seen on REC a high volume of people do not necessarily create an open and dialogic space, as multiple voices alone are not enough to create polyphony (Jabri et al., 2008). Polyphony is a Bakhtinian concept, a musical metaphor that refers to the co-existence of different voices that are also interconnected (Bakhtin, 1994). Saukko (2008) uses the idea of polyphony, or many voices, to give credence to a spatial approach to understandings of the anorexic self, specifically in the context of narrative therapy. She suggests that a polyvocal approach allows multiple voices to coexist and creates dialogue between the differing anorexic voices/selves, avoiding the dichotomies that are frequently associated with eating disordered selves (Saukko, 2008). ANA can be seen as a space in which members' voices (and perhaps anorexic selves) are able to coexist as will be shown through the analysis below. Polyphony is inherently dialogic, created through the interaction of individuals (who themselves are also dialogic characters), this is something that ANA lacks as has been previously discussed; the communication on the site is predominantly static and monologic. It is for this reason that the communication on ANA cannot be truly described as polyphonic. However, despite the lack of dialogue, communication on ANA does accept the multiple voices on the site and conform to other characteristics of polyphony. These characteristics are: (1) a lack of finalising word in communication; (2) equality of voices and an (3) interconnection between voices. These characteristics and the multiple voices present on the site will be shown and further explained through the following extract, taken from the mental health sub-forum of ANA:

<u>Thread 10 (ANA): Title- Has anyone here lost a parent (or anyone)?</u>

# Stephanie:

"Last year I lost my father to cancer on Dec. 3rd. I feel kind of weird saying I lost him...it kind of implies that he can be found again. But he's gone. Forever. I won't see him again until after I'm dead. Which to my disappointment, will probably be later than sooner."

### Blink:

"That must've been really hard. My ex-boyfriend lost his mother too when we were together some years ago and since he never knew his dad, he was suddenly an orphan at 15... I lost a big sister as well when we were very little, only a few years old. I'm not sure I actually miss her, as I'm not sure whether I've made up the memories or they were actually there but being an only child I certainly miss having a big sister."

#### Xena:

"I lost my mum three years ago when I was seventeen so I really do understand how you feel and there's nothing that I can do to make it better for you."

### Junior:

"a very close friend died of a brain aneurysm in the last month of high school, right before prom. It was very emotional and i still think of her every day almost 2 years later and how I should've been a better friend and all the things I never said. It's hard."

### Oz:

"I was 12; that makes it nearly 9 years ago. Wow.

..and since then, I've been to many more funerals than weddings.

The one thing I've learnt through all of this is that time will not stop for you. The world keeps on going and you have to keep on going with it."

The above thread is fairly typical of the communication on ANA. There is monologue, with many members engaging in high levels of self-disclosure, which is peppered with dialogue seen when members offer validation and empathy through statements such as: "That must've been really hard" and "I really do understand how you feel". On the surface this communication can appear disengaged, with members being self-focussed and attending to their own needs and experiences over that of the original poster. However, this seemingly monologic communication has significance for members, who return in their thousands to the site to post in what they feel is a supportive environment. The acceptance of multiple voices contributes to this sense of support, as all can be expressed and heard, members need not censor their thoughts and behaviours when using the site. This acceptance of multiple voices is aided by the polyphonic characteristics; a lack of finalising word in communication, equality of voices and an interconnection between voices.

In literature, the polyphonic novel has "no finalising, explanatory word" (Dentith, 1995, p.42), meaning that the dialogue between narrator and characters continues and is always unfinished. Within this there is an unspoken sense of a lacking of authoritative discourse, the polyphonic novel does not conclude with one message or moral to impart to the reader (Vice, 1997; Dentith, 1995). There are strong parallels between this and the communication on ANA, as is exemplified in the above thread which lacks (1) a finalising word. There is no conclusion to the thread Stephanie starts, she is not given advice, pushed in a specific direction or required to rethink her thoughts and feelings. The conversation ends in much the same way it starts, with a member self-disclosing personal information about themselves. As stated in previous chapters, in order to use the site members must conform to two normative constructs, the 'sickness mentality' and nonjudgemental support. The 'sickness mentality' is a shared understanding on the site that eating disorders are mental health conditions, not a lifestyle and members have no choice in being eating disordered. Non-judgemental support simply refers to the shared idea that support on the site needs to cater for all members, and so should be given without judgement, as every member has a different story and background. While these constructs regulate and create conformity in a diverse group, they do not function as an authoritative or oppressive element; as they lack an overarching sense of morality, they

do not require members to prescribe to one mind-set, but encourage them to be mindful of the variety of members that use the site. This lack of a distinctive authoritative voice allows members to behave as they have in the above thread, each offering a contribution which adds to the diversity of voices/experiences on the site.

Linked to the idea of there being no overarching moral or authoritative stance in the multiple voiced communication on ANA, is that voices on the site are also positioned as equal, another characteristic of polyphony. The polyphonic novel is democratic in that the utterances of narrator and characters are given equal importance, with neither being considered the 'right' discourse (Vice, 1997). While this concept refers specifically to the novel, this can be applied to the context of ANA. The role of narrator on ANA can be seen as being held by the 'community' as a whole, the site, as a reified body can be considered as having a voice, which usually takes the form of the 'sickness mentality' and nonjudgemental support. The characters of ANA are the members, who are a heterogeneous group, and bring their varied experiences and voices to the community. This can be seen in the above thread, where there is (2) an equality of voices amongst members who are positioned as equal. No one person's suffering or story is given prominence, instead members are contributing to the thread with their own experiences of loss, potentially aware it will be heard in the same way as the original poster's. Comparing this to REC, the differences are stark, as the recovery-focus of the site ensure that some voices (members/characters) are positioned as 'right' and so are held in higher esteem, as they conform to the dominant discourses on the site. The equality of voices on ANA is reflected in threads and the way the site is moderated. Moderation on the site is limited, with there being eight active moderators on the site, for 55,000 members. As well as being limited in the sense that there are few moderators, the roles they take on the site are akin to members, while they have administration responsibilities (locking/editing threads, detecting spam) they are treated like any other member in threads. In terms of support this sense of equality allows members to freely express themselves, as anything is considered a valid contribution to the forum (this must be caveated in that it must conform to the 'sickness mentality' and non-judgemental support). This creates an open supportive environment, but may also contribute to the self-focussed nature of communication. Members do not have a shared goal or purpose, they are not problemsolving for one another, expression and variety are hallmarks of the community, making it appear self-focussed.

The third and final characteristic of polyphony that is present in the multiple voiced communication on ANA is (3) an interconnection between individual voices. Bakhtin (1994, p.412) describes this interconnection as each voice "begin[ning] to sound differently than it would have sounded on its own". Meaning that each utterance is not in isolation, there is the creation of a sense of collective meaning, in which each voice is heard but also shaped by those of others, making what is said sound different. This characteristic of polyphony is easily confused with heteroglossia, and while the concepts are similar, polyphonic interconnection focusses on voices, while heteroglossia is focussed on languages (Vice, 1997). In terms of the above thread, this interconnection can be seen on ANA. As more members contribute to the thread, their posts impact on one another through the meaning that is created through their collective expression of grief. This is not to suggest a collective voice, as each member is still heard in their own right, but the shared stories of grief are not taken in isolation, and when read together they are intrinsically linked for the reader, shaping the meaning that is created from them as a collective.

Online self-disclosure, the revelation of previously unknown information that makes someone's online identity more identifiable offline (Mesch and Beker, 2010), was used as an example of monologic communication on ANA. Here it will also be shown as having elements of polyphony, and being multi-voiced and facilitating dialogue on the site, despite being static and monologic. Self-disclosure on ANA is monologic, there is little interaction between participants, as was previously noted, and when dialogue is created through self-disclosure it frequently leads to members offering further self-disclosure. However, it can also be seen as encompassing characteristics of polyphony and thereby being an example of the multivocal communication on ANA. Again, through self-disclosure the key characteristics of equality of voices, lack of finalising word in communication and an interconnection between voices are evident. Furthermore, viewing self-disclosure as a representation of multiple voices on ANA also illustrates the supportive benefits of being self-focused in the monologic yet multivocal environment.

The following thread, taken from the mental health sub-forum of ANA shows selfdisclosure as a marker of multiple voices on the site:

Thread 11: Title- Alcohol and ED

marybeth:

"Drinking alcohol and having an eating disorder, how do you feel?

I mostly mean when you havent eaten much and then drink, do you get drunk quicker? I sure do...

I'm kind of hearing or seeing things right now and think its because i'm drunk, I took my meds at 3ish and now its 5:30pm so maybe this is the reason? At least I think so.

I know drinking isnt good for me and I definitely have a problem with it but I just cannot seem to stop, like my ED."

LuLu:

"When I drink and haven't eatten much that day I get drunk really fast and usually over do it and throw up. Be careful mixing your meds with alchohol!(:"

marybeth:

"I will try! maybe ill skip my meds that i take at night just for today"

Sally:

"When I get really caught up In my ed, I drink a lot and I get drunk quite fast and like u I cant seem to stop and I feel like shit but honestly anything is better than feeling like I normally do."

Borgen:

"well, I honestly don't eat much besides coffee...so recently while drinking I have definitely noticed that I got drunk much quicker."

Petunia:

"Yeah, when I haven't eaten much and drink I get drunk way easily. Which is saying something, because I'm a ridiculous lightweight anyway, it doesn't take much at all to get me tipsy. I've learnt my limits though, so I know exactly when to stop."

#### Lashes437:

"I love to drink vodka with Diet Coke & lemon on an empty stomach. The high I get is exhilarating — especially when mixed with my meds.

Of course the labels on everything say "Do not drink" and I guess I'm taking a chance of getting a bad reaction. But it feels so damn good that I can't stop"

Again, this thread is a typical example of self-disclosure and monologic communication on ANA. It is started by marybeth, who self-discloses and poses a question to other members, this initial question does not require members to respond with advice, but is asking for lived experience. This thread also highlights the multiple voices present on ANA. While members are discussing a common experience, no one is positioned as wrong- despite the dangerous behaviour members reveal-and again there is an interconnection between seemingly disconnected voices.

In this thread, as in the last, two of the characteristics of polyphony- (1) a lack of finalising word and (2) equality of voices - are heavily linked and so will be discussed together, as they reinforce one other. Here we see marybeth pose an initial question about members' alcohol consumption, she receives a variety of responses, and this variety highlights the lack of finalising word on the site. There is no set rhetoric members need conform to when answering; they are able to respond as honestly as they want to, as the range of acceptable answers is broad. Compared to REC, which is highly normative and members are required to show themselves as eligible for support through embracing the 'recovery spirit', the expression of variety on ANA is creating a space for possible open dialogue (which is filled with monologic self-disclosure), showing that a lack of finalising word on the site is both a characteristic of multiple voices and also a facilitator for dialogue. In the above thread there are members admitting to a variety of dangerous behaviours, firstly excessive alcohol consumption, starvation and mixing prescription drugs with alcohol.

These confessions are alongside Petunia's comment "I've learnt my limits though, so I know exactly when to stop", which is a single expression of control on the thread. While these comments are oppositional, they do not create conflict, are not perceived as judgmental or untoward by members and neither extreme seems out of place. This also highlights the equality of voices on the site, no member is heard over another, the 'voice of the site' is also not dominant enough to distort the expression of members. Self-disclosure is an expression of multiple voices on ANA, it allows members to create an environment in which all is acceptable, as members can self-disclose anything, other members can see themselves represented in these confessions and feel able to add their own experience to the conversation if they do not relate to the messages already posted. The feeling of freedom this creates also acts to facilitate dialogue on the site, members want to add their own experiences, keeping the conversation alive through monologue.

Another indication that there is no finalising word on the site is the lack of any countervoice, open critique or call to conformity. The only word of caution is offered by LuLu when she says "Be careful mixing your meds with alchohol!(:". However this is not an example of counter-voice or a challenge, as would be seen on REC, it is not intended to make marybeth rethink her behaviour and does not require an action, it is more an expression of concern, which is happily taken up. LuLu's comment is potentially a remnant of the pro-anorexia saying "stay strong" which members across pro-ana forums leave as a parting comment on posts, particularly when members are expressing or admitting to dangerous behaviour, thoughts or low weights. Again, the fact that there is no moral overtone to the posts suggests that self-disclosure can be seen as multivocal, members are able to express themselves as themselves, and not through the filter of dominant site discourse.

Again there is a sense of (3) interconnection of voices in this thread. This interconnection moves beyond shared experience and topic content, but refers to the way in which each post (through the lack of dominant discourse and the equal representation of voices) influences the meaning of the next post and conveys a different overall sense of meaning than the reader would be left with if each post was taken individually. Bakhtin (1994) states that meaning can only be generated through interaction with another, in this case the posts impact on one another, creating a new meaning for the reader. Taking Sally's

post as an example, she states "When I get really caught up In my ed, I drink a lot and I get drunk quite fast and like u I cant seem to stop and I feel like shit but honestly anything is better than feeling like I normally do". Taken in isolation this post feels slightly frantic and like a stream of consciousness. It also seems entirely negative, an expression of sadness and the revelation of attempts to quell this sadness. However, when read in the thread, with the other contributions acting upon it, the meaning of Sally's post is altered. Sally's post no longer feels like an expression of sadness, but now, for me, appears an admission of guilt, she is confessing her drinking behaviour to similar others, whom she knows relate to her experiences.

Multiple voices, and the characteristics of polyphony act to reinforce the self-focussed support that is cultivated on ANA. This is due to there being no overarching message the site is attempting to conform to, members are not required to 'buy into' a particular idea and there is no one common purpose on the site. Therefore, individual members are able to express their lived experiences of eating disorders on their terms, see themselves represented through others' words and take solace in their shared commonality. The variety of voices present on the site enables members to adapt their use of the site to fulfil their own needs, they are able to customise an individual site experience, and contribute to the conversations as they see fit. As members are accessing what they need from the site, and often this is not prescriptive support (as is offered on REC), the focus remains on the individual, which goes towards creating a self-focussed support environment.

In this section of analysis REC has been shown to have a monologic expression of voices, due to members being constrained by authoritative discourse, the 'monologic consensus' and the direct censorship of posts. While ANA displays some of the traits of polyvocality, as there is an equality of the voices on the site, there is no finalising word and voices are interconnected, making the expression of voices on ANA multivocal. On both communities these expressions of voices reinforce the forms of support outlined in the previous section of analysis. For REC, the interaction-focussed support that was born out of dialogic interaction was aided by the monologic expression of voices, as it ensured that the community remained recovery orientated and suppressed the 'anorexic voice'; while on ANA, self-focussed support is enhanced by the multivocality of the site. Members are

able to adapt support to their own needs, as the site is not dominated by authoritative discourse. This section of analysis has illustrated the ramifications of communication for support, demonstrated the deep-seated nature of the discourses that exist on the sites, and further illustrated how monologic communication can be supportive.

#### **Discussion and conclusion**

Over the course of this chapter the interaction and expression of voices on ANA and REC has been shown to be simultaneously dialogic and monologic. Further to this the form that the communication takes on the sites, be it dialogic or monologic, has been shown to contribute to and reinforce the way in which support is given on the two sites.

Turning first to REC, the interplay of dialogue and monologue was shown to foster an interaction-focussed support environment, which reinforced the site construct the 'recovery spirit' and the normative support mechanism known as 'challenging'. REC was shown to be dialogic as members were encouraged to return to threads they had posted on, ensuring that members engaged with one another and pushed the conversation forward. One of the ways in which members did this was through the second expression of dialogue, which was asking further questions. This took the conversation into different directions, while posts remain orientated towards the original poster and are decidedly interaction-focussed, the questions posed by other members add different voices and perspectives to the dialogue. Finally, members of REC express dialogue through quoting one another in posts, this adds new meaning to posts, and again pushes the conversation forward. Monologue on REC is a result of the authoritative discourses that are present on the site: those are the 'recovery spirit' and challenging. Members are encouraged to communicate and support one another within the remit of these two constructs, this was shown through the monologic consensus that exists on the site, while members are encouraged to challenged one another, they are not expected to challenge the dominant discourses on the site but are expected to comply accordingly. While the dialogic and monologic expressions of communication have been presented separately for clarity, the two expressions are intertwined, and rather than being contradictory are complementary and together reinforce the dominant discourses of the site and expose another characteristic of support on REC: interaction-focussed support.

On ANA communication is predominantly monologic but is also typified by a sense of multivocality, which is dialogic. The site construct the 'sickness mentality' and the tenet of non-judgemental support are reinforced and expressed through the monologic and dialogic communication on the site, and reveal another characteristic of support: selffocussed support. Monologue on ANA differs from the monologue expressed on REC, as is characterised not by authoritative discourse, but through the inertia of communication. This was shown through the lack of dialogic interaction in messages, with members not consistently engaging with one another in threads. While members do not necessarily engage with one another, they do exhibit high levels of self-disclosure on the site, with many members choosing to contribute to threads through the telling of their own experience of eating disorders. These two expressions of monologue are shown to create a self-focussed support environment, where members need not engage with one another, but can focus on their own use of the site in order to feel supported. This monologue can be seen as supportive, despite appearing to be detached and selfinterested, because it is what members are seeking in their use of the site and, because meaning is co-constructed, members read support into the posts of others. Within the monologue characteristic of ANA there is also dialogue, which takes the form of multiple voices on the site. Multivocality on the site was shown to be present on the site through the lack of finalising word on the site. Unlike REC, communication on ANA is not constrained by the need to adhere to overarching dominant discourses, there is no one true voice. Further to this there is an equality of voices on the site, no one stance or individual is privileged over others, members are all seen as equally valid contributors to the discussion. There is also an interconnection between the voices on the site, they shape and influence one another and different meaning is created due to this. This multivocality again strengthens the self-focussed support on ANA, as members are able to get what they need from the site and contribute in the way they see fit. As with REC, for clarity, the dialogue and monologue of communication on ANA was presented separately. However, it is the combination of these two expressions of communication that is of importance, as they reinforce one another and the 'sickness mentality' and nonjudgemental support that are so fundamental to creating a fluid and needs-led support environment expressed through the self-focussed support.

Through adopting a Bakhtinian framework for this analysis, the form of communication and interaction has been shown to be different on ANA and REC, there are two key implications for support, which are: support as taking on differing forms and the deep rooted nature of support structures.

This chapter has illustrated that there is no one form of support that exists across these online support forums, or on individual forums, support, is made up of a variety of forms. This has been displayed through the exploration of dialogue and monologue on ANA and REC, which revealed that support is self-focussed and interaction-focussed respectively on these two sites, and so takes on a different form than discussed in chapter five. Further to this the form of support is not the same across the two sites, but is unique to those individual sites. Thus suggests that the while there may be similarities between sites in terms of support, particularly content of support and if it conforms to the much discussed typologies of support (Eichhorn, 2008; Winzelberg, 1997; Coulson et al., 2007; Coulson, 2005), the *form* it takes, that is the way in which it operates (which is shown through, action/interaction/emotion), will differ across sites and is dependent on dominant discourses (forged online and offline), the resultant sites' cultures and the agentic interaction of members.

While this chapter reveals the different forms of communication on the site, and how these contribute towards two differing support focusses, interaction-focussed support on REC and self-focussed support on ANA, it also highlights how deep rooted and intertwined the support structures of each site are. Support on both sites is regulated by site constructs, on REC these take the form of the 'recovery spirit' and challenging and on ANA they are manifest in form of the 'sickness mentality' and non-judgemental support. The analysis in the previous two sections has shown how these are expressed through interaction and the expression of voices, how they influence the further iterations of support on both sites. This illustrates that these concepts are not superficial, but are deep seated in both communities, and integral to the support that is given. The deep rooted nature of these concepts further highlights one of the key contributions of this thesis, which is that support is conditional. This has been a concluding point in each analytical chapter, as the site ethoses as well as the normative forms of support illustrate that support is not necessarily freely given on ANA or REC, but is dependent on a members'

ability to conform to these constructs. This is again reaffirmed through the analysis in chapter six, as although it reveals a different form of support on each site, members are still bound by site tenets whether they are communicating interaction-focussed support on REC or self-focussed support on ANA.

This chapter has revealed the various iterations of support that exist on these two sites, shown them to be closely interlinked and illustrated how they are expressed through communication.

#### Conclusion

The aim of this thesis was to explore online anorexia forums, with a focus on support, specifically;

- 1. To explore support as an element of online anorexia forums.
- 2. To gain an understanding of *how* support operates on online anorexia forums.
- 3. To gain an understanding of what elements influence the *form* of support given on online anorexia forums.
- 4. To gain insight into how members experience online anorexia forums as supportive

In order to meet these aims I used grounded theory analysis of data collected through non-participant observation of two forums, one pro-anorexic and one pro-recovery in orientation, and conducted online interviews with members of the forums. In this chapter I will summarise the findings of this thesis, outline the limitations of the study and highlight the four contributions this thesis makes to academic knowledge of online anorexia forums and online support.

In chapter four, the first empirical chapter of the thesis, I showed that the culture of a site is expressed through its site ethos, which influences the support given to forum members. I first analysed how members' interpretation of the DSM-IV criteria for anorexia shaped both communities' understandings of what it means to have an eating disorder, and how this is enacted online. For members of both ANA and REC fulfilling the DSM criteria was not a requirement in order to be eligible for support. Instead, members focussed on the lived experience of having an eating disorder, and rejected the overly physical focus of the criteria. Critique of the diagnostic criteria can be seen as a consistent feature of patient groups and has previously been noted by scholars (Giles, 2014; Brownlow and O'Dell, 2006; LaFrance and McKenzie-Mohr, 2013). Resistance to the medical establishment has previously been seen on online anorexia forums (Days and Keys, 2008; Bell, 2009; Pollock, 2003), as has members of online anorexia forums rejecting the DSM for being overly physical, and instead favouring the lived experience (Hardin, 2003). ANA and REC therefore display characteristics similar to those observed of

other patient groups and online anorexia forums. The analysis of members' critical interpretations of the DSM criteria showed the communities to be more similar than different, however, it does not explain why these support environments differ so significantly. Therefore, critique of the DSM can be seen as part of the site culture that implicitly contributes to members' understanding of eating disorders and support. Chapter four explores the notion of choice, which distinguishes the different site ethoses on ANA and REC. Choice is understood differently on each site. On REC, choice takes on an individualistic form and facilitates the creation of the 'recovery spirit', a governing ethos on the site which serves the following functions: it creates a sense of empowerment amongst members; acts as a unifying force; and illustrates the boundaries of the group. Alternatively, on ANA members perceive themselves to be lacking choice with regard to their eating disorder, believing their biological and psychological "hard wiring" negates their ability to exhibit any choice or control over their eating disorder. This particular understanding of choice contributes to the formation of the 'sickness mentality', again a governing site ethos, which serves the following purposes: it allows members to express suffering; to deny culpability for their actions; sets a tone for the site; and finally, exposes out-groups. Although these site ethoses are different, the functions they serve on the two communities are the same. Importantly, they are ways in which members can make themselves eligible for support and shape the support given on the site by creating a sense of what constitutes support on these two sites. This ensures that only certain behaviour will be considered supportive in these contexts, and so, these site ethoses are integral in creating the specific support environments that are ANA and REC. In sum, the key findings of chapter four are: understandings of choice creates two distinct site ethoses on ANA and REC; members must conform to site ethoses to be eligible for support; and site ethoses shape members understanding of what is supportive in that particular environment.

In chapter five the analysis focussed on the *form*, which was illustrated through the exploration of two concepts, challenging on REC and non-judgmental support on ANA. Challenging can be defined as open critique of members' eating disordered thoughts and behaviours, with the aim of strengthening their recovery. Challenging, which was shown to act as a norm on REC, and did not conform to the traditional support typologies found

in existing literature (esteem, emotional and informational support). Through the norm of challenging members of REC demonstrated their commitment to recovery, and showed themselves to have 'recovery spirit', further solidifying their continued eligibility for support. Challenging also creates a sense of responsibility amongst members, as they feel that they have to live up to challenges, but also have to challenge one another, as this helps a member through their recovery. As challenging is so normative, and such a prescriptive form of support on REC, it was shown to reproduce the dichotomous thinking Saukko (2008) highlights in her critique of narrative therapy. Non-judgemental support was shown to operate as a norm on ANA. It lacks the rigidity of the norm of challenging on REC, and can be seen as a more inclusive form of support as most behaviour is tolerated on the site, as long as members remain non-judgemental. The norm of nonjudgemental support on ANA creates a fluid notion of support, with members able to use the site for a variety of purposes, making the support on ANA adaptive to the needs of participants (within the norm of non-judgement). The non-judgemental support characteristic of ANA was shown to be born out of a need for empathy, as members found this lacking in other elements of their lives. The norm of non-judgemental support creates an inclusive and adaptive support environment on ANA. However, the norm is not maintained by regulating the original posts on threads. Instead, it is the responses to members' calls for support that are expected to conform to the norm of non-judgemental support, by not pushing a certain agenda and avoiding judgemental overtones. Regulating the norm in this way reinforces the inclusive environment, as its members are able to express themselves freely. Although non-judgemental support appears affirmative, the norm does have limits, and there are topics that are not thought appropriate for discussion on the site. This includes content that is associated with traditional or stereotypical pro-anorexic content, such as: the glorification of anorexia; looking for tips and tricks or posting dangerous behaviour. While this marks the limits of nonjudgemental support, it also illustrates the influence of the 'sickness mentality', as arguably, this behaviour is frowned upon as it undermines the community understanding that anorexia is a disease, and therefore brings the 'sickness mentality' into contention. Chapter five gave a detailed account of how members of ANA and REC support one another through the exploration of the form of support, which was found to be different on each site. The main findings of this chapter were: support can operate as a norm;

support can take on a critical form; support can be adaptive; responsibility is a consistent feature of these support environments, but how it is displayed differs; and, finally, support is not without community constructed and enforced boundaries.

In chapter six, the form of support was further explored, but this time from a different angle, as the communication of support was the main focus. Chapter six first examined communication from the perspective of interaction, and utilised the Bakhtinian (1994) concepts of dialogue and monologue to illustrate how members of ANA and REC interacted and the influence that the type of interaction had on the support given on both sites. Interaction on REC was shown to be dialogic through: members returning to threads that they had posted on; asking further questions of one another and; through quoting one another in responses. This type of interaction was considered dialogic as it is part of a continuous process, and is dependent on the different constructions of meaning that take the conversation in unforeseen directions (Jabri et al, 2008; Baxter, 2004). In terms of support, the dialogic interaction characteristic of REC facilitates the provision of interaction-focussed support, which is support that 'hears' or listens to the issues members have, engages with them and attempts to find a resolution. Interaction on ANA was considered monologic in form, not because it is authoritative, but because it is static, meaning that posts did not explicitly refer to or interact with other posts. This was shown through the lack of dialogic interaction on threads and the high levels of self-disclosure that member's exhibit on the forum. Monologic interaction was shown to be supportive, as it creates a space in which members can express themselves, or vent about a situation. Messages may not even be intended to be supportive, but are read as supportive due to the meaning that is created by the reader interacting with the post, which is referred to as "living communication" (Jabri et al, 2008). This monologic interaction fosters a selffocussed support environment, in which members are not required to problem-solve for one another, but focus on their own posts and read support into the posts of others. These interaction and self-focussed forms of support were further explored in chapter six, through an analysis of the expression of voices on the two forums. The expression of voices on REC was shown to be monologic, despite the dialogic interaction, as there was a strong authoritative discourse present on the site, through the concept 'monologic

consensus' and as members' posts were censored. Rather than undermining the interaction-focussed environment, this monologic expression of voices, characterised by consensus, actually reinforced it, as monologue maintains a recovery orientated environment and illustrates the constraining force of the previously discussed concepts of the 'recovery spirit' and challenging. On ANA, voices are multivocal, meaning that they conform to some of the tenets of Bakhtin's (1994) polyvocality including lacking a finalising word, equality between voices and an interconnection between voices. Due to the preceding monologic interaction, however, the voices on ANA cannot be considered fully polyvocal. The multivocality of voices creates a sense of diversity on the site, as members are able to express their own experiences of eating disorders without having to conform to a dominant discourse due to the lack of shared goals or site purpose. And so, multivocality reinforces self-focussed support, as members are able to take what they need from the site, can take solace and read support into the words of others. On ANA the focus is on the individual, but the support does not have a problem-solving edge to it, instead the focus is on the individual crafting the support they seek. Through looking at interaction and expression of voices on ANA and REC, support was shown to have another form on the sites, namely being self-focussed on ANA, and interaction focussed on REC. These forms of support differ from the forms discussed in chapter five, but are closely intertwined, reinforcing one another and the site ethoses which regulate support on the communities. Therefore, the salient findings of chapter six are: support can take more than one form on a site; monologic environments can be supportive and; site discourses reinforce one another to enhance the support environment.

And so, as previously stated the aim of this thesis was to explore *how* support operated, the *form* it takes, and *experience* of support on two online anorexia forums. This thesis has illustrated that support is central to the functioning of these communities, as it establishes a cohesive sense of what is and is not acceptable, defines the terms of eligibility to access the group and provides a sense of unity. With regard to *how* support operates, through the progression of the three empirical chapters, it is clear that there is no one solitary function of support on ANA and REC, but that it is multi-purpose, and that there is strong continuity between the sites despite their differing orientations.

Specifically, support has been shown to operate through site ethoses (the 'recovery spirit'

and 'sickness mentality'), through normative concepts (challenging and non-judgemental support) and through interaction and the expression of voices on the site (monologue and dialogue). Highlighting how support operates exposed the similarities between the two communities, it is when considering form, that is the process of support expressed through action/interaction/emotion, that the differences become more apparent. Form has been shown to be varied, with no one fixed form being present across the two sites, and individual sites also displaying different forms of support, this was illustrated through the discussion of challenging and non-judgemental support, which were the main ways in which support was provided on the two sites and also operated as norms. Further to this, form was also illustrated through analysing the way in which members of ANA and REC interacted and the expression of voices on the sites, which revealed that the simultaneous dialogic and monologic communication on both sites created interactionfocussed support on REC and self-focussed support on ANA. Rather than the forms of support contradicting one another, they are complimentary and reinforce the overall tenets of these support environments. Experience of these sites as supportive is weaved throughout these chapters, with the voices of interview participants giving credence to the forum data.

# <u>Limitations of this research</u>

While this thesis has made contributions to knowledge of online anorexia forums and online support more broadly, it is not without limitations. Perhaps the most apparent limitation is that only one pro-recovery forum and one pro-anorexia forum have been used in the study, therefore, the findings of this thesis cannot be generalised to *all* online anorexia forums. However, the focus on *form* throughout this thesis has yielded concepts that are transferable to other online anorexia forums and online support environments. Although the site ethoses take the form of the 'recovery spirit' and 'sickness mentality' on REC and ANA, it is feasible that site ethoses that govern support are also evident in other online environments.

One limitation of this study is that interviews were collected at the end of the observation period of forums. This will have influenced who took part in interviews as membership of both communities (in particular of ANA) is transitional, and therefore,

conducting interviews at a different point, or over a longer period, would have resulted in different members being active on the site and taking part in the interview stage of this project. A further limitation of this thesis is that it uses data from forums accessible through search engines, and so does not give an indication of the content or form of support provided on invite-only, unsearchable sites. Future research studying non-searchable pro-anorexia sites would be interesting, as these are usually small, close-knit communities, and may provide different forms of support as members are all known to one another (online or offline).

# Contributions of this thesis

As stated in the introduction of this thesis, and reiterated throughout the analysis, this thesis has made four key contributions to the literature on online anorexia forums and online support. They are: (1) offering an in-depth comparison of two online anorexia forums, which advanced the scholarly analysis of support; (2) highlighting that support does not take one form across online anorexia forums, and that different forms of support co-exist in individual sites; (3) illustrating not only that support is conditional in this online environments but how the conditional elements are expressed on the sites; and (4) displaying the influence of existing discourses on online anorexia forums. These four contributions will now be discussed in turn and their advancement of the literature highlighted.

In-depth comparison of pro-anorexia and pro-recovery communities

This thesis has provided an in-depth comparison of the support provision on two online anorexia forums, one a pro-anorexia site and one a pro-recovery site. This comparison is evident throughout the thesis, and is complemented by the method used, as one of the core tenets of grounded theory analysis is the constant comparison of data. In terms of the literature on online anorexia forums, few comparative studies of this type have been conducted, and of those that have, the focus of analysis has been on issues surrounding language, the body and impact on viewers (Lyons et al., 2006; Riley et al., 2009; Wilson et al., 2006; Harper et al., 2008). And so, my own work sits in this small collective of comparative research on online anorexia forums, and is marked as different due to the focus on support and the data collection methods used. Centring the comparison of ANA

and REC on support reveals the similarities and differences that exist on these sites in terms of dominant site discourses, normative concepts and expressing support through dialogic and monologic language.

No one form of support present on sites

Rather than looking at support from the perspective of typologies, as is common in the literature on online support (Eichhorn, 2008; Winzelberg, 1997; Coulson et al, 2007; Coulson, 2005; Evans et al, 2012; Stewart-Loane and D'Alessandro, 2013), the analysis in this thesis has focussed on form of support. The form of support differs from existing typologies as it does not focus on the content of support, but rather on how members of these two communities support one another. Looking at how members of ANA and REC support one another involves analysing the forum and interview data for process, that is, the action/interaction/emotion born out of the context in which they happen (Corbin and Strauss, 2008). Therefore, while this study can be situated in the literature on online support, it differs in its orientation, and offers an alternative perspective from which to analyse online support. One of the main findings of this thesis is that support does not take one form on online anorexia forums, but is varied. Firstly, support is varied as there is no one form of support that is present across these online anorexia forums. While both sites have site ethoses, and normative concepts which act to regulate support, they are not expressed in the same manner, in part due to the different site cultures that have led to the development of specific understandings of what constitutes support on these sites. Secondly, support does not take on one form on the individual sites, but takes on many forms, which can be seen as operating at different levels of interaction and communication. In the case of ANA and REC, the different forms of support present on each site act in a complementary way, reinforcing one another and the dominant discourses of support that exist on these sites. On ANA the different forms of support were illustrated through non-judgemental support, which operates as a site norm, and self-focussed support which was shown to be the result of the monologic interaction on the site combined with the multivocal expression of voices. These two forms of support co-exist on the site, and create a specific support environment in which support is characterised by high levels of sharing and empathy, a lack of reciprocity, and importantly, non-judgement of others. On REC the two forms of support that were

illustrated in this thesis were challenging, a norm on the site, and interaction-focussed support, which was the result of the dialogic interaction and the monologic expression of voices on the site. Again, these two forms of support reinforce one another, and create a support environment which is based on problem-solving, is highly regulated, critical, and prizes consensus and conformity from members. Through discussing form, and displaying the varied ways it can be manifest in online anorexia forums, this thesis has shown that support is a multifaceted phenomenon.

### Support as conditional

Central to this thesis is the idea that support on ANA and REC is conditional, and this is displayed and discussed in chapters four, five and six. Previous research on online support communities has shown that accessing the community, and also the support given online is dependent on members complying with the dominant site discourses, or creating a credible identity (Bar-Lev, 2008; Peterson, 2009; Mundry and Strong, 2012; Franzen and Gottzen, 2011). Similarly, the literature on online anorexia forums also highlights the need for members to present themselves as authentic, and credible in order to access the community (Boero and Pascoe, 2012; Giles, 2006; Gavin et al, 2008; Williams and Riley, 2013). While being eating disordered is a key element to use of both ANA and REC, my own research differs from previous literature on online anorexia forums, as members of both communities are shown to be aligning to the tenets of support, and not only forging a sense of authenticity. This indicates that the findings of my study are transferable to other online support settings. And so, my own research sits between these bodies of literature, as it illustrates the conditionality of support, but moves beyond the idea of creating authentic identities in order to access the communities. This thesis illustrates that the conditionality of support is not just relevant to new members and is not merely an initiation. The conditions of support are woven into the various forms of support that are evident in these support environments and are established through the formation of site ethoses. All members are required to show themselves to be complying with the conditions of support, however, their displays of eligibility for support must be consistent, otherwise they are undermined and support may be withdrawn. Support has been shown to be conditional, beginning with my analysis in chapter four, which highlighted the presence of the 'recovery spirit' on REC

and the 'sickness mentality' on ANA. Compliance to these site ethoses was shown to be one of the ways in which members of ANA and REC show themselves to be eligible for support, and compliance enabled them to access the sites. While chapter five shows one of the forms of support that members of ANA and REC are expected to conform to, on ANA support takes the form of non-judgemental support, and on REC challenging is the dominant form of support. Both non-judgemental support and challenging were shown to be normative, having regulatory functions that members were expected to comply with. Non-compliance in both cases would lead to members being reprimanded, and on REC consistent non-compliance could result in being banned from the site. Finally, chapter six illustrated the conditions of support through displaying how the site ethoses and normative concepts previously discussed are manifested in the interaction and expression of voices in both communities. This highlights how deep-seated these conditions are, they influence each form of support present on ANA and REC, and members are expected to consistently comply with all conditions of support. This thesis has thus revealed the extent to which support is conditional on ANA and REC, how these conditions operate, and are conformed to by members.

# *Influence of existing discourses*

The final contribution of this thesis is the way in which it illustrates the influence of existing discourses on the support that is given on ANA and REC. Existing discourses are predominantly discussed in chapter four, through the analysis of the critique of the DSM diagnostic criteria for anorexia by members of both communities. This critique was shown to contribute to a community understanding of eating disorders, which contrasted with the physical focus of the DSM by highlighting the mental and emotional reality of living with an eating disorder. Another discourse that was discussed in chapter four was the hierarchy of eating disorders, which positions anorexia as the exemplary eating disorder. This discourse can be seen as having been rejected by REC through the focus on unity in recovery that was a key element of the site ethos, the 'recovery spirit'. Finally, chapter four also illustrated the influence of the notion of choice on the support given, and examined the discourse of anorexia as a lifestyle choice, a discourse rooted in proanorexic websites (Strife and Rickard, 2011). While both communities reject the notion that anorexia is a lifestyle choice, this did not lead to the formation of similar site

ethoses, as members of REC are encouraged to believe they can choose health and members of ANA are able to be consumed by sickness that their alleged lack of choice creates. The critique of the DSM, management of the hierarchy of eating disorders, and the rejection or acceptance of the notion that being eating disordered is a choice, all contribute to the site cultures of ANA and REC, which in turn shape support by influencing the way in which eating disorders, and support itself, is understood on the sites. This facilitates the creation of specific forms of support that are the result of the communities' attempts to make sense of dominant discourses that surround eating disorders. Through highlighting the influence of existing discourses, this thesis illustrates that the support given in online environments is not only forged in those environments, but can have origins outside of the online context.

### References

Aakhus, M., Rumsey, E. (2010) 'Crafting Supportive Communication Online: A Communication Design Analysis of Conflict in an Online Support Group' <u>Journal of Applied Communication Research</u> 38(1) pp.65-84.

Adler, P.A., Adler, P. (2013) 'Self-injury and the internet: Reconfiguring the therapuetic community' Social Science Research on the Internet 1(2) pp.17-46.

Album, D., Westin, S. (2007) 'Do diseases have a prestige hierarchy? A survey among physicians and medical students' <u>Social Sciences & Medicine</u> 66(1) pp182-88.

Alexander, S.C., Peterson, J.L., Hollingshead, A.B. (2003) 'Help at your keyboard: Support groups on the internet' in Frey, L. [ed] <u>Group communication in context: Studies of bona</u> fide groups New Jersey, Lawerence Erlbaum Associates, Publishers.

Allen, C. (1996) 'What's wrong with the golden rule? Conundrums of conducting ethical research in cyberspace ' The Information Society 12(2) 175-88.

Allen, J.T. (2008) 'The Spectacularisation of the Anorexic Subject Position' <u>Current Sociology</u> 56(4) pp.587-603.

American Psychiatric Association. (2000) <u>Diagnostic and statistical manual of mental</u> <u>disorders: DSM-IV-TR</u> Washington D, American Psychiatric Association.

Anderson, T. Kanuka, H. (2003) <u>E-research: Methods, strategies and issues</u> Boston, Pearson Education Inc.

Armstrong, N., Koteyko, N., Powell, J. (2012) "Oh Dear, Should I Really be Saying that on Here?: Issues of Identity and Authority in an Online Diabetes Community' Health: An <a href="Interdisciplinary Journal for the Social Study of Health, Illness and Medicine">Interdisciplinary Journal for the Social Study of Health, Illness and Medicine</a> 16(4) pp.347-365.

Attard, A. Coulson, N.S. (2012) 'A Thematic Analysis of Patient Communication in Parkinson's Disease Online Support Group Discussion Forums' Computers in Human Behavior 28(2) pp.500-506.

Attrill, A., Jalil, R. (2011) 'Revealing Only the Superficial Me: Exploring Categorical Self-Disclosure Online' Computers in Human Behavior 27(5) pp.1634-1642.

Ayling, R., M, A.J. (2009) 'Evaluating Internet Interviews with Gay Men' <u>Qualitative Health</u> Research 19(4) pp.566-576.

Bakhtin, M. (1984) <u>Problems of Dostoevsky's Poetics</u> Manchester, Manchester University Press.

Bakhtin, M. (1994) The Dialogic Imagination: Four Essays Austin, University of Texas Press.

Balter-Reitz, S., Keller, S. (2005) 'Censoring Thinspiration: The Debate Over Pro-anorexic Websites' Free Speech Yearbook 42(1) pp.79-90.

Bar-Lev, S. (2008) '"We Are Here to Give You Emotional Support": Performing Emotions in an Online HIV/AIDS Support Group' Qualitative health research 18(4) pp.509-521.

Bakardijeva, M. (2003) 'Virtual Togetherness: An Everyday-life Perspective' Media, culture & Society 25(3) pp.291-313.

Barak, A., Boniel-Nissim, M., Suler, J. (2008) 'Fostering empowerment in online support groups' Computers in Human Behavior 24(5) pp.1867-1883.

Barak, A., Gluck-Ofri, O. (2007) 'Degree and Reciprocity of Self-Disclosure in Online Forums' <a href="Mailto:CyberPsychology">CyberPsychology</a> & Behavior 10(3) pp.407-416.

Bardone-Cone, A.M., Cass, K.M. (2007) 'What Does Viewing a Pro-Anorexia Website Do? An Experimental Examination of Website Exposure and Moderating Effects 'International Journal of Eating Disorders 40(6) pp.537-548.

Bassett, E.H., O'Riordan, K (2004) 'Ethics of Internet research: Contesting the human subjects research model' Ethics and Information Technology 4(3) pp.233-247.

Baym, N. (2006) 'Finding the quality in quantitative research' in Silver, D., Massanari, A., Jones, S [Eds]. <u>Critical Subculture Studies</u> New York, New York University Press.

Baym, N. (2010) Personal Connections in the Digital Age Cambridge, Polity Press.

Baxter, L. (2004) 'Relationships as dialogues' Personal Relationships 11(1) pp.1-22.

Baxter, L. (2007) 'Problematizing the problem in communication: A Dialogic Perspective' Communication Monographs 74(1) pp. 118-124.

Bell, M. (2009) '@ the Doctor's Office: Pro-anorexia and the Medical Gaze' <u>Surveillance</u> and <u>Society 6(2)</u> pp.151-162.

Bjerke, T.N. (2010) 'When My Eyes Bring Pain to My Soul and Vice Versa: Facing Perceptions in Email and Face-to-Face interviews' Qualitative Health Research 20(12) pp.1717-1724.

Boero, N. and Pascoe, C.J. (2012) 'Pro-anorexia communities and online interaction: Bringing the pro-ana body online', <u>Body and Society</u> 18(2) pp. 27-57.

Bruch, H. (1978) The golden cage: The enigma of anorexia nervosa London, open Books.

Brumberg, J. (1988) <u>Fasting girls: The emergence of anorexia nervosa as a modern disease</u> Cambridge, Harvard University Press.

Bond, C., Ahmed, O.H., Hind, M., Thomas, B., Hewitt-Taylor, J. (2013) 'The conceptual and Practical Ethical Dilemmas of Using Health Discussion Board Posts as Research Data' Journal of Medical Internet Research 15(6) pp.00-00.

Bond, E. (2012) 'Virtually Anorexic- Where's the harm? A research study on the risks of pro-anorexia websites' [Online] Available from <a href="https://www.ucs.ac.uk/virtuallyanorexic">www.ucs.ac.uk/virtuallyanorexic</a> [Accessed 29.11.12]

Bordo, S. (1993) <u>Unbearable Weight: Feminism, Western Culture and the Body</u> Berkley, University of California Press.

Borzekowski, D., Schenk, S., Wilson, J., Peebles, P. (2010) 'E-ana and e-mia: A content analysis of pro-eating disorder websites' <u>American Journal of Public Health</u> 100(8) pp.1526-34.

Braithwaite, D., Waldron, V.R., Finn, J. (1999) 'Communication of Social Support in Computer-Mediated-Communication groups for people with disabilities' <u>Health</u> Communication 11(2) pp.123-51.

British Sociological Association (2002) 'Statement of Ethical Practice for the British Sociological Association' [Accessed 16/02/14]

http://www.britsoc.co.uk/about/equality/statement-of-ethical-practice.aspx

Brotsky and Giles (2007) 'Inside the pro-ana community: A covert online participant observation' <u>Eating disorders.</u> 15(2) pp.93-109.

Brownlow, C., O'Dell, L. (2006) 'Constructing an Autistic Identity: AS Voices Online'

<u>Intellectual and developmental disabilities</u> 44(5) pp.315-321.

Burke, E. (2009) 'Pro-anorexia and the Internet: A Tangled Web of Representation and (Dis)Embodiment' Counselling, Psychotherapy, and Health 5(1), pp. 60-81.

Burke, E. (2012) 'Reflections on the Waif: Images of Slenderness and Distress in Proanorexia Websites' <u>Australian Feminist Studies</u> 27(71) pp. 37-54.

Burleson, B. R., Goldsmith, D.J. (1998) 'How The Comforting Process Works: Alleviating Emotional Distress Through Conversationally Induced Reappraisals' in Andersen, P.A., Guerrero, L.K. [Eds] <u>Handbook of Communication and Emotion: Research, Theory, Applications and Contexts.</u> San Diego, Academic Press.

Burns, M. (2004) 'Eating Like an Ox: Femininity and the Dualistic Constructions of Bulimia and Anorexia' Feminism & Psychology 14(2) pp.269-295.

Campbell, J., Cecez-Kecmanovic, , D. (2011) 'Communicative Practices in an Online Financial Forum During Abnormal Stock Market Behaviour' <u>Information and Management</u> 48(1) pp.37-52.

Casilli, A.A., Pailler, F., Tubaro, P. (2013) 'Online networks of eating-disorder websites: why censoring pro-ana might be a bad idea' <u>Perspectives in Public Health</u> 133(2) pp.94-95.

Castro, T.S., Osorio, A. (2012) 'Online violence: Not beautiful enough... not thin enough. Anorectic testimonials in the web' <a href="https://psych.org/psych.org/">Psych.org/<a href="https://psych.org/">Psych.org/<a href="https://psych.org/">Psych.org

Charland, L.C. (2004) 'A madness of identity; Psychiatric labels, consumer autonomy and the perils of the internet.', <u>Philosophy</u>, <u>Psychiatry & Psychology</u> 11(4) pp. 335-49.

Chernin, K. (1984) <u>Womansize: The Tyranny of Slenderness</u> London, The Women's Press Limited.

Chung, J.E. (2013) 'Social Interaction in Online Support Groups: Preference for Online Social Interaction Over Offline Social Interaction' Computers in Human Behavior 29(4) pp.1408-1414.

Cook, C. (2012) 'Email Interviewing: Generating Data within a Vulnerable Population' Journal of Advanced Nursing 68(6) pp.1330-39.

Corbin, J., Strauss, A. (2008) <u>Basics of Qualitative Research 3e: Techniques and Procedures for Developing Grounded Theory</u> Los Angeles, Sage Publications.

Cosgrove, L., Pearrow, M., Anaya, M. (2008) 'Toward a New Paradigm for Psychiatric Diagnoses and Clinical Research in Sexology' <u>Feminism & Psychology</u> 23(1) pp.457-65.

Coulson, N. (2005) 'Receiving Social Support Online: An Analysis of a Computer-Mediated Support Group for Individuals Living with Irritable Bowel Syndrome' <a href="CyberPsychology&">CyberPsychology & behaviour 8(6)</a> pp.580-584.

Coulson, N.S., Buchanan, H., Aubeeluck, A. (2007) 'Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group' <a href="Patient Education and Counseling">Patient Education and Counseling</a> 68(2) pp.173-178.

Cranwell, J., Seymour-Smith, S. (2012) 'Monitoring and Normalising a Lack of Apetite and Weight Loss. A Discursive Analysis of an Online Support Group for Bariatric Surgery'

<u>Appetite</u> 58(3) pp.873-81.

Csipke, E., Horne, O. (2007) 'Pro-eating disorder websites: Users opinions' <u>European</u> <u>Eating Disorders Review</u> 15(3) pp.196-206.

Cutrona, C.E., Russell. D.W. (1990) 'Type of social support and specific stress: Toward a theory of optimal matching' In Sarason, B. R., Sarason, I. G., Pierce, G.R. [eds] Social support: An interactional view Oxford, John Wiley & Sons.

Cutrona, C.E., Suhr, J. (1992) 'Controllability of Stressful Events and Satisfaction With Spouse Support Behaviors' Communication Research 19(2) pp.154-174.

Davis, M., Bolding, G., Hart, G., Sherr, L., Elford, J. (2004) 'Reflecting on the Experience of Interviewing Online: perspectives From the Internet and HIV Study in London' <u>AIDS Care:</u>

<u>Psychological, and Socio-Medical Aspects of HIV/AIDS 16(8) pp. 944-52.</u>

Day, K., Keys. T. (2008) 'Starving in cyberspace: a discourse analysis of pro eating-disorder websites' <u>Journal of Gender Studies</u> 17(1) pp. 1-15.

Deakin, H., Wakefield, K. (2013) 'Skype Interviewing: Reflections of Two PhD Researchers'

Qualitative Research doi: 10.1177/1468794113488126

Dentith, S. (1995) <u>Bakhtinian Thought: An Introductory Reader</u> London, Routledge.

Denzin, N. (1987) The Alcoholic Self London, Sage Publications.

Denzin, N. (1993) <u>The Alcoholic Society: Addiction and Recovery of the self</u> New Brunswick, Transaction Publishers.

Dias, K. (2003) 'The Ana Sanctury: Women's Pro-Anorexia Narratives in Cyberspace' Journal of International Women's Studies 4(2) pp. 31-45.

Dietz-Uhler, Bishop-Clark, C., Howard, E. (2005) 'Formation of and Adherence to a Self-Disclosure Norm in an Online Chat' <u>Cyberpsychology & Behavior</u> 8(2) pp.114-120.

Driscoll, C., Gregg, M. (2010) 'My Profile: The Ethics of Virtual Ethnography' <u>Emotion</u>, <u>Space and Society</u> 3(1) pp.15-20.

Dyke, S. (2013) 'Utilising a Blended Ethnographic Approach to Explore the Online and Offline Lives of Pro-ana Community Members' Ethnography and Education 8(2) pp.146-161.

Eastin, M.S., LaRose, R. (2005) 'Alt.support: modeling social support online' <u>Computers in Human Behavior</u> 21(6) pp.977-992.

Eichhorn, K.C. (2008) 'Soliciting and Providing Social Support Over the Internet: An Investigation of Online Eating Disorder Support Groups' <u>Journal of Computer-Mediated-Communication 14(1) pp.67-78</u>.

Ess, C., AOIR Ethics working committee (2002) 'Ethical decision making and internet research: Recommendations from the AOIR ethics working committee' [Accessed 12.01.11] <a href="https://www.aoir.org/reports/ethics.pdf">www.aoir.org/reports/ethics.pdf</a>

Ess, C., Jones, S. (2004) 'Ethical Decision-Making and Internet Reseach: Recommendations from the AoIR Ethics Working Committee' In Buchanan, E.A. [Ed] Readings in Virtual Reseach Ethics: Issues and Controversies Hersley, Information Science Publishing.

Evans, M., Donelle, L., Hume-Loveland, L. (2012) 'Social support and online postpartum depression groups: A content analysis' <u>Patient Education and Counselling</u> 87(3) pp.405-10.

Eysenbach, G., Till, J. (2001) 'Ethical issues in qualitative research on internet communities' British Medical Journal 323 pp.1103-05

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., Stern, A. (2004) 'Heath Related Virtual Communities and Electronic Support Groups: Systematic Review of the Effects of Online Peer to Peer Interactions' British Medical Journal 328 pp.1166-72.

Ferreday, D. (2003) 'Unspeakable bodies: Erasure, embodiment and the pro-ana community' Journal of Cultural Studies 6(3) pp. 277-295.

Flicker, S., Haans, D., Skinner, H. (2004) 'Ethical Dilemmas in Research on Internet Communities' Qualitative Health Research 14(1) pp.124-134.

Flynne, M.A., Stana, A. (2012) 'Social support in a men's online eating disorder forum' International Journal of Men's Health 11(2) pp.150-69.

Fox, N., Ward, K., O'Rourke, A. (2005) 'pro anorexia, weight loss drugs and the internet: an anti recovery model of anorexia' <u>Sociology of health and illness.</u> 27(7) pp.988-71.

Frankel, M., Siang, S. (1999) 'Ethical and Legal Aspects of Human Subjects Research on the Internet' [Accessed 13.01.11] <a href="https://www.asss.org/spp/sfrl/projects/intres/main.htm">www.asss.org/spp/sfrl/projects/intres/main.htm</a>

Franzen, A.G., Gottzen, L. (2011) 'The Beauty of Blood? Self-injury and Ambivalence in an Internet Community' Journal of Youth Studies 14(3) pp.279-94.

Gailey, J. (2007) 'Starving is the most fun a girl can have: The pro-ana subculture as edgework' Critical Criminology 17(2) pp.93-108.

Gatson, S.N. (2011) 'The Methods, Politics, and Ethics of Representation in Online Ethnography' in Denzin, N.K., Lincoln, Y.S [Eds] <u>The Sage Handbook of Qualitative Research</u> Los Angeles, Sage Publications.

Gavin, J., Rodham, K., Poyer, H. (2008) 'The presentation of 'pro-ana' in online group interactions' Qualitative Health Research 18(3) pp.325-333.

Giles, D. (2006) 'constructing identities in cyberspace: the case of eating disorders' <u>British</u> <u>Journal of Social Psychology</u>. 45(3) pp463-77.

Giles, D. C. (2014) "DSM-V is Taking Away Our Identity": The Reaction of the Online Community to the Proposed Changes in the Diagnosis of Asperger's Disorder 'Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine 18(2) pp.179-195.

Giles, D. and Newbold, J. (2011) 'Self and other- diagnosis in user led mental health online communities' Qualitative health research 21(3) pp. 419-428.

Giles, D.C., Newbold, J. (2013) "Is this Normal?" The Role of Category Predicates in Constructing Mental Illness Online' <u>Journal of Computer-Mediated-Communication</u> 18(4) pp.476-490.

Gilat, I., Tobin, Y., shahar, G. (2011) 'Offering support to sucical individuals in an online support group' <u>Archives of Suicide Research</u> 15(3) pp. 195-206.

Gremillion, H. (2003) <u>Feeding Anorexia: Gender and power at the treatment centre</u> Durham, Duke University Press.

Guilfoyle, M. (2013) 'Client subversions of DSM knowledge' Feminism & Psychology 23(1) pp.86-92.

Hanna, P. (2012) 'Using Internet Technologies (such as Skype) as a Research Medium: A Research Note' Qualitative Research 12(2) pp. 239-242.

Hardin, P.K. (2003) 'shape-shifting Discourses of Anorexia Nervosa: Reconstituting Psychopathology' <u>Nursing Inquiry</u> 10(4) pp.209-217.

Hardin, P.K. (2003b) 'Social and Cultural Considerations in Recovery from Anorexia Nervosa: A Critical Perspective' <u>Advances in Nursing Science</u> 26(1) pp.6-15.

Harper, D.J. (2013) 'On the Persistence of Psychatric Diagnosis: Moving Beyond a Zombie Classification System' Feminism & Psychology 23(1) pp.78-85.

Harper, k., Sperry, S., Thompson, J.K. (2008) 'Viewership of Pro-eating Disorder Websites: Association with Body Image and Eating Distrubance' <u>International Journal of Eating Disorders</u> 41(1) pp.92-95.

Haas et al (2011) 'Communicating thin: a grounded model of online negative enabling support groups in the pro-anorexia movement' New media and society 13(1) pp.40-57.

Hepworth, J. (1999) <u>The Social Construction of Anorexia Nervosa</u> London, Sage Publications.

Herring, S. (2004) 'Computer-Mediated Discourse Analysis: An approach to researching online behaviour' in Barab, S., kling, R., Gray, J [eds] <u>Designing for Virtual Communities in the Service of Learning New York, Cambridge University Press.</u>

Hinchcliffe, V., Gavin, H. (2009) 'Social and Virtual Networks: Evaluating Synchronous Online Interviewing Using Instant Messenger' <u>The Qualitative Report</u> 14(2) pp.318-340.

Highed, L., Fox, J.R.E (2010) 'Illness Perceptions in Anorexia Nervosa: A Qualitative Investigation' British Journal of Clinical Psychology 49(3) pp.307-325.

Hine, C., Kendall, L., Boyd, D. (2009) 'Can Qualitative Internet Researchers Define the Boundaries of their Project?' in Markham, A., Baym, N. [Eds] <u>Internet Inquiry:</u>
Conversations about method Los Angeles, Sage Publications.

Hine, C. (2000) Virtual Ethnography London, Sage Publications.

Hinton, L., Kurinczuk, J.J., Ziebland, S. (2010) 'Infertility; Isolation and the Internet: A Qualitative Interview Study' <u>Patient Education and Counseling</u> 81(3) pp.436-441.

Holton, J.A. (2010) 'The Coding Process and Its Challenges' in Bryant, A., Charmaz, K. [Eds]

<u>The Sage Handbook of Grounded Theory</u> London, Sage Publications.

Holquist, M. (1990) Dialogism: Bakhtin and his World London, Routledge.

Horne, J., Wiggins, S. (2009) 'Doing being 'one the edge': Managing the dilemma of being authentically suicidal in an online forum' <u>Sociology of health and illness</u> 31(2) pp170-184

Hoskins, M., Leseho, J. (1996) 'Changing metaphors of the self: Implications for counseling.' Journal of Counseling and Development 74(3) pp.243-251.

Hunt, N., McHale, S. (2007) 'A Practical Guide to the Email Interview' Qualitative Health Research 17(10) pp.1415-1421.

Illingworth, N. (2001) 'the Internet Matters: Exploring the Use of the Internet as a Research Tool' Sociological Research Online 6(2) <a href="http://www.socresonline.org.uk/6/2/illingworth.html">http://www.socresonline.org.uk/6/2/illingworth.html</a>

Jabri, M., Adrian, A.D., Boje, D. (2008) 'Reconsidering the role of conversations in change communication: A contribution based on Bakhtin' <u>Journal of Organisational Change</u>

<u>Management</u> 21(6) pp. 667-685.

James, N., Busher, H. (2006) 'Credibility, Authenticity and Voice: Dilemmas in Online Interviewing' Qualitative Research 6(3) pp.403-420.

Johnsen, J.A.K, Rosenvinge, J.H., Gammon, D. (2002) 'Online Group Interaction and Mental Health: An Analysis of Three Online Discussion Forums' Scandinavian Journal of Psychology 43(5) pp.445-449.

Jones, A., Meier, A. (2011) 'Growing <u>www.parentsofsuicide</u>: A case Study of an Online Support Community' <u>Social Work With Groups</u> 34(2) pp.101-120.

Jowett, A., Peel, E., Shaw, R. (2011) 'Online Interviewing in Psychology: Reflections on the Process' Qualitative Research in Psychology 8(4) pp. 354-369.

Kaplan, K., Salzer, M.S., Solomon, P., Brusilobskiy, E., Cousounis, P. (2011) 'Internet Peer Support for Individuals with Psychiatric Disabilities: A Randomised Controlled Trial' <u>Social Science & Medicine</u> 72(1) pp. 54-62.

Kendler, K.S. (2009) 'An Historical Framework for Psychiatric Nosology' <u>Psychological</u> <u>Medicine</u> 39(12) pp.1935-1941.

Koski, J. P. (2013) "I'm Just a Walking Eating Disorder": The Mobilisation and Construction of a Collective Illness Identity in Eating Disorder Support Groups' Sociology of Health and Illness pp.1-16. Doi: 10.1111/1467-9566.12044

Kozinets, R. (2010) <u>Netnography: Doing Ethnographic Research Online</u> London, Sage Publications.

King, S. (1996) 'Researching internet communities: Proposed ethical guidelines for the reporting of results' <u>The Information Society</u> 12(2) 119-127.

Kirk, S. and Hutchins, H. (1996) <u>The selling of DSM: The rhetoric of science in psychiarty</u>, New York: Aldine De Gruyter.

Knapton, O. (2013) 'Pro-anorexia: Extensions of Ingrained Concepts' <u>Discourse and Society</u> 24(4) pp. 461-477.

Kralik, D., Koch, T., Brady, B.M. (2000) 'Pen Pals: Correspondence as a Method for Data Generation in Qualitative Interviews' <u>Journal of Advanced Nursing</u> 31(4) pp.909-917.

Joinson, A. (2001) 'Self-Disclosure in Computer-Mediated Communication: The Role of Self-Awareness and Visual Anonymity' <u>European Journal of Social Psychology</u> 31(2) pp.177-192.

Joinson, A. (2001b) 'Knowing Me, Knowing You: Reciprocal Self-Disclosure in Internet-Based Surveys' <a href="Mailto:Cyberpsychology">Cyberpsychology</a> & Behavior 4(5) pp.587-591.

Juarascio, A., Shoaib, A., Timko, C.A. (2010) 'Pro-eating disorder communities on social networking sites: A content analysis' <u>Eating disorders</u> 18(5) pp.393-407.

Juarez, L., Soto, E., Pritchard, M.E. (2012) 'Drive for Muscularity and Drive for Thinness: The Impact of Pro-Anorexia Websites' <a href="Eating Disorders: The Journal of Treatment & Prevention 20(2) pp.99-112">Eating Disorders: The Journal of Treatment & Prevention 20(2) pp.99-112</a>.

Lafrance, M.N. (2007) 'A Bitter Pill: A Discursive Analysis of Women's Medicalised Accounts of Depression' <u>Journal of Health Psychology</u> 12(1) pp.127-140.

Lafrance, M.N., McKenzie-Mohr, S. (2013) 'The DSM and its lure of legitimacy' <u>Feminism</u> <u>& Psyhcology</u> 23(1) pp.119-140.

Lavis, A. (2011) <u>The Boundaries of a good anorexic: Exploring pro-anorexia on the internet and in the clinic Doctoral thesis, Goldsmiths, University of London. [Thesis]: Goldsmiths Research Online. Available at: http://eprints.gold.ac.uk/6507/</u>

Lawson, D. (2004) 'Blurring the Boundaries: Ethical Considerations for Online Research Using Synchronous CMC Forums' in Buchanan, E. [Ed] Readings in Virtual Research Ethics: Issues and Controversies Hersley, Information Science Publishing.

Leggatt-Cook, C., Chamberlain, K. (2010) 'blogging for weight-loss: personal accountability, writing selves and the weight-loss blogosphere' <u>Sociology of Health and Illness</u> 34(7) pp. 963-977.

Lempert, L.B. (2010) 'Asking Questions of the Data: Memo Writing in the Grounded Theory Tradition' in Bryant, A., Charmaz, K. [Eds] The Sage Handbook of Grounded Theory London, Sage Publications.

Leung, L. (2002) 'Loneliness, Self-Disclosure and ICQ ('I seek you') Use' <u>Cyberpsychology & Behavior</u> 5(3) pp.241-251.

Ley, B. B. (2007) 'Vive les Roses!: The Architecture of Commitment in an Online Pregnancy and Mothering Group ' <u>Journal of Computer-Mediated-Communication</u> 12(4) pp.1388-1408.

Lin, CP., Bhattacherjee, A. (2009) 'Understanding online social support and its antecedents: A social-cognitive model' <u>The social Science Journal</u> 46 (4) pp.724-737.

Livingstone (2008) 'Taking risky opportunities in youthful content creation: teenagers' use if social networking sites for intimacy, privacy and self expression' New Media and Society 10(3) 393-411.

Lyons, E.J., Mehl, M.R, Pennebaker, J.W. (2006) 'Pro-anorexics and Recovering Anorexics Differ in their Linguistic Internet Self-Presentation' <u>Journal of Psychosomatic Research</u> 60 (3) pp.253-56.

MacSween, M. (1993) <u>Anorexic Bodies: A Feminist and Sociological Perspective on Anorexia Nervosa</u> London, Routldge.

Madge, C., O'Connor, H. (2004) 'Online Methods in Geography Education Research'

<u>Journal of Geography in Higher Education</u> 28(1) pp.143-152.

Maisel, R., Epston, D., Borden, A. (2004) <u>Biting the Hand that Starves You: Inspiring</u>

<u>Resistance to Anorexia/Bulimia</u> New York, W.W. Norton and Company.

Malik, S.H., Coulson, N. (2008) 'Computer-mediated infertility support groups: An exploratory study of online experiences' <u>Patient Education and Counseling</u> 73(1) pp.105-113.

Malik, S.H., Coulson, N. (2010) 'Coping with infertility online: An examination of self-help mechanisms in an online infertility support group' <u>Patient Education and Counseling</u> 81(2) pp.315-318.

Maloney, P. (2013) 'Online Networks and Emotional Energy: How Pro-Anorexic Websites

Use Interactional Ritual Chains to (re)Form Identity' <u>Information, Communication and</u>

<u>Society</u> 16(1) pp.105-24

Malson, H. (1998) <u>The Thin Woman: Feminism, Post-Structuralism and the Social</u>
<u>Psychology of Anorexia Nervosa</u> London, Routledge.

Mann, C., Stewart, F. (2000) <u>Internet Communication and Qualitative research: A</u> Handbook for Researching Online London, Sage Publications.

Markham, A. (2005) 'The methods, politics and ethics of representation in online ethnography' in Denzin, N., Lincoln, Y [Eds] The Sage Handbook of Qualitative Research London, Sage Publication.

Markham, A., Buchanan, E., AoIR, (2012) 'Ethical Decision Making and Internet Research' [Accessed 20.02.2014] <a href="http://aoir.org/reports/ethics2.pdf">http://aoir.org/reports/ethics2.pdf</a>

Markham, A. (2012) 'Fabrication as Ethical Practice: Qualitative Inquiry into Ambiguous Internet Context' Information, Communication and Society 15(3) pp.334-353.

Matusek, J. A., Knudson, R. M. (2009) 'Rethinking Recovery from Eating Disorders: Spiritual and Political Dimensions' <u>Qualitative Health Research</u> 19(5) pp.697-707

Mayes, R., Horwitz, A. (2005) 'DSM-III and the Revolution in the Classification of Mental Illness' <u>The Journal of History in the Behavioural Sciences</u> 41(3) pp.249-267.

McCabe, J. (2009) 'Resisting Alienation: The Social Construction of Internet Communication Supporting Eating Disorders' Communication Studies 60(1) pp.1-16.

McCoyd, J.L.M., Kerson, T.S. (2006) 'Conducting Intensive Interviews Using Email: A serendipitous Comparative Opportunity' <u>Qualitative Social Work</u> 5(3) pp.389-406.

McKenna, K.Y.A., Bargh, J.A. (1998) 'Coming Out in the Age of the Internet:Identity 'Demarginalisation' Through Virtual Group Participation' <u>Journal of Personality and Social Psychology</u> 75(3) pp.681-694.

Mesch, G., Beker, G. (2010) 'Are Norms of Disclosure of Online and Offine Information Associated with the Disclosure of Personal Information Online' <u>Human Communication</u>

<u>Research</u> 36(4) pp. 570-92

Miah, A. and Rich, E. (2008) The medicalisation of cyberspace, London: Routledge.

McElhinney, E., Cheater, F.M., Kidd, L. (2013) 'Undertaking Qualitative Health Research in Social virtual Worlds' <u>Journal of Advanced Nursing</u> DOI: 10.1111/jan.12281 [Accessed 30.03.2014]

Mitra, A. (2004) 'Voices of the Marginalised on the Internet: Examples From a Website for Women of South Asia' Journal of Communication 54(3) pp.492-510.

Mo, P.K.H., Coulson, N.S. (2010) 'Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'.' Computers in Human Behavior 26(5) pp.1183-93.

Morrow, P.R. (2006) 'Telling about problems and giving advice in an internet discussion forum: some discourse features' Discourse Studies 8(4) pp.531-48.

Mruck, K., Mey, G. (2010) 'Grounded Theory and Reflectivity' in Bryant, A., Charmaz, K. [Eds] The Sage Handbook of Grounded Theory London, Sage Publications.

Mulveen and Hepworth(2006) 'An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating.' <u>Journal of health psychology</u> 11 (2) pp.283-296.

Mundry, T. E., Strong, T. (2012) 'Doing Recovery Online' <u>Qualitative Research Methods</u> 23(3) pp. 313-325.

National Collaborating Centre for Mental Health (2004) Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders. London, British Psychological Society and Gaskell

Norris, M., Boydell, K., Pinhas, L. and Katzman, D. (2006) 'Ana and the internet: A review of pro-anorexia websites', <u>International Journal of Eating Disorders</u>, 39(6) pp. 443-447.

Orbach, S. (1984) Fat is a Feminist Issue London, Hamlyn Paperbacks

Orbach, S. (1993) <u>Hunger Strike: The Anorectic's Struggle as a Metaphor for Our Age</u>
Harmondsworth, Penguin Books.

Patching, J., Lawler, J. (2009) 'Understanding women's experiences of developing an eating disorder and recovering: a life-history approach' Nursing Inquiry 16(1) pp.10-21.

Peterson, J.L. (2009) ' "You have to be positive": Social Support Processes of an Online Support Group for Men Living with HIV' <u>Communication Studies</u> 60(5) pp.526-541.

Pfeil, U. (2010) 'Online Support Communities' in Zaphins, P., Ang, C.S. [Eds] <u>Social</u> Computing and Virtual Communities Boca Raton, Taylor and Francis Group.

Pilgrim, D. (2007) 'The survival of psychiatric diagnosis' <u>Social Science & Medicine</u> 65(3) pp. 536-547.

Pitt, L., Kilbride, M., Welford, M., Nothard, S., Morrison, A.P. (2009) 'Impact of Diagnosis of Psychosis: User-led Qualitative Study' <u>ThePsychiatric Bulletin</u> 33(11) pp.419-423.

Pollack, D. (2003) 'Pro-Eating Disorder Websites: What Should be the Feminist Response?' Feminism & Psychology 13(2) pp. 246-251. Reid, E. (1996) 'Informed consent in the study of on-line communities: A reflection on the effects of computer mediated social research' <u>The Information Society</u> 12(2) 169-174.

Riley, S., Rodham, K., Gavin, J. (2009) 'Doing Weight: Pro-ana and Recovery Identities in Cyberspace' <u>Journal of Community and Applied Social Psychology</u> 19(5) pp.348-59.

Roberts, L., Smith, L., Pollack, C. (2002) 'Conducting ethical research online: respect for individuals, identities and the ownership of words' in Buchanan, E. [Ed] Readings in Virtual Research Ethics: Issues and Controversies Hersley, Information Science Publishing.

Rodriquez, J. (2013) 'Narrating Dementia: Self and Community in an Online Forum' Qualitative Health Research 23(9) pp.1215-1227.

Strife, S. R., Rickard, K. (2011) 'The conceptualisation of anorexia: The pro-ana perspective.' Affilia 26(2) pp. 213-213.

Rouleau, C.R., von Ranson, K.M. (2011) 'Potential risk of pro-eating disorder websites' <u>Clinical Psychology Review</u> 31(4) pp.525-531.

Sanders, T. (2005) 'Researching the Online Sex Work Community' In Hine, C. [ed] <u>Virtual Methods: Issues in Social Research on the Internet</u> Oxford, Borg.

Saukko, P. (2000) 'Between Voice and Discourse: Quilting Interviews on Anorexia' Qualitative Inquiry 6(3) pp.299-317.

Saukko, P. (2008) <u>The Anorexic Self: A Personal, Political, Analysis of a Diagnostic</u>
<u>Discourse</u> Albany, State University of New York Press.

Saukko, P. (2009) 'A Critical Discussion of Normativity in Discourses on Eating Disorders' in Malson, H., Burns, M. [Eds] <u>Critical Feminist Approaches to eating Dis/Orders</u> London, Routledge.

Seale, C. (2006) 'Gender accommodation in online cancer support groups' <u>Health: An interdisciplinary Journal for the Social Study of Health, Illness and Medicine</u> 10(3) pp.345-60.

Seale, C., Ziebland, S., Charteris-Black, J. (2006) 'Gender, cancer experience and internet use: A comparative keyword analysis of interviews and online cancer support groups'

<u>Social Science and Medicine</u> 62(10) pp.2577-2590.

Seale, C., Charteris-Black, J., MacFarlane, A., McPherson, A. (2010) 'Interviews and Internet Forums: A Comparison of Two Sources of Qualitative Data' <u>Qualitative Health</u> Research 20(5) pp.595-606.

Seymour, W. S. (2001) 'In the Flesh or Online? Exploring Qualitative Research Methodologies' Qualitative Research 1(2) pp. 147-68.

Shade, L. (2003) 'Weborexics: The ethical issues surrounding pro-ana websites' Computers and Society 32(7) pp 2-14.

Sherman, L.E., Greenfield, P.M. (2013) 'Forging friendship, soliciting support: A mixed-method examination of message boards for pregnant teens and teen mothers'

<u>Computers in Human Behavior</u> 29(1) pp75-85.

Sharkey, S., Jones, R., Smithson, J., Hewis, E., Emmens, T., Ford, T., Owens, C. (2011) 'Ethical Practice in Internet Research Involving Vulnerable People: Lessons From a Self-Help Discussion Forum Study (SharpTalk)' <u>Journal of Medical Ethics</u> 37 (12) pp.752-8.

Smith, N., Wickes, R., Underwood, M. (2013) 'Managing a marginalised identity in proanorexia and fat acceptance cybercommunities' <u>Journal of Sociology</u> DOI: 10.1177/1440783313486220 pp.00-18.

Smithson, J., Sharkey, S., Hewis, E., Jones, R., Emmens, T., Ford, T., Owens, C. (2011) 'Problem presentation and responses on an online forum for young people who self harm' <u>Discourse Studies</u> 13 (4) pp.487-501.

Steinmatz, K.F. (2012) 'Message Received: Virtual Ethnogrpahy in Online Message Boards' <u>International Journal of Qualitative Methods</u> 11(1) pp.26-39.

Stern, S. (2002) 'Studying adolescence online: A consideration of ethics' in Buchanan, E. [Ed] Readings in Virtual Research Ethics: Issues and Controversies Hersley, Information Science Publishing.

Stewart, M., Barnfather, A., Magill-Evans, J., Ray, L., Letourneau, N. (2011) 'Brief Report: An online support intervention: Perceptions of adolescents with physical disabilities' <u>Journal of Adolescence</u> 34(4) pp.795-800.

Stewart Loane, S., D'Alessandro, S. (2013) 'Communication that Changes Lives: Social Support Within an Online Health Community for ALS' Communication Quarterly 61(2) pp.236-251.

Stommel, W. (2008) 'Mein nick bin ich! Nicknames in a German forum on eating disorders' <u>Journal of computer mediated communication</u>. 13 (1) pp141-62.

Stommel, W., Meijman, F.J. (2011) 'The Use of Conversation Analysis to Study Social Accessibility in an Online Support Group on Eating Disorders' Global Health Promotion 18(2) pp.18-26.

Suler, J. (2004) 'The Online Disinhibition Effect' <u>Cyberpsychology & Behavior</u> 7(3) pp.321-326.

Sveningsson, M., Buchanan, E.A., Stern, S.R. (2009) 'How do various notions of privacy influence decisions in qualitative internet research?' in Markham, A., Baym, N. [eds]

Internet inquiry: Conversations about method Los Angeles, Sage Publications.

Sveningsson, M. (2004) 'Ethics in internet ethnography' in Buchanan, E. [Ed] <u>Readings in Virtual Research Ethics: Issues and Controversies</u> Hersley, Information Science Publishing.

Thompson, B.W. (1994) A Hunger so Wide and so Deep: A Multiracial View of Women's Eating Problems Minneapolis, University of Minnesota Press.

Tidwell, L.C., Walther, J.B. (2002) 'Computer-Mediated Communication Effects on Disclosure, Impressions and Interpersonal Evaluations' <u>Human Communication Research</u> 28(3) pp.317-348.

Tierney, S., Fox, J.R.E. (2010) 'Living with the 'anorexic voice': A thematic analysis' <u>Pyschology and Psychotherapy: Theory, Research, and Practice</u> 83(3) pp.243-254. Tierney, S. (2006) 'The Dangers and Draw of Online Communication: Pro-Anorexia Websites and

their Implications for Users, Practitioners, and Researchers' <u>Eating Disorders</u> 14(3) pp.181-190.

Tierney, S. (2008) 'Creating communities in cyberspace: pro-anorexia web sites and social capital' Journal of Psychiatric and Mental Health Nursing 15(4) pp.340-343.

Trevisan, F., Reilly, P. (2014) 'Ethical Dilemmas in Researching Sensitive Issues Online:
Lessons From the Study of British Disability Networks' <u>Information, Communication and Society</u> DOI: 10.1080/1369118X.2014.

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2009). 'Participation in online patient support groups endorses patients' empowerment' Patient Education and Counseling 74(1)pp. 61–69.

Valentine, G., Butler, R., Skelton, T. (2001) 'The ethical and methodological complexities of doing research with 'vulnerable' young people' <a href="Ethics, Policy and Environment">Ethics, Policy and Environment</a> 4(2) 119-125.

Vayreda, A., Antaki, C.(2009) 'Social Support and Unsolicited Advice in an Online Bipolar Disorder Forum.' Qualitative Health Research, 19(7) pp. 931-942.

Vice, S. (1997) Introducing Bakhtin Manchester, Manchester University Press.

Walstrom, M.K. (1999) <u>"Starvation...is who I am": From eating disorder to recovering identities through narrative co-construction in an internet support group.</u> Urbana, University of Illinois at Urbana-Champaign.

Walstrom, M.K. (2000) ' "You know, Who's the Thinnest?": Combating Surveillance and Creating Safety in Coping with Eating Disorders Online' <u>CyberPsychology & Behavior</u> 3(5) pp.761-783.

Walther, J.B., Boyd, S. (2002) 'Attraction to computer-mediated social support' in Lin, C.A., Atkin, D. [Eds] <u>Communication Technology and Society: Audience Adoption and Uses.</u> Cresskill, Hampton Press.

Walther, J.B. (1996) 'Computer-Mediated Communication: Impersonal, Interpersonal, and Hyperpersonal Interaction' <u>Communication Research</u> 23(1) pp.3-43.

Walther, J.B. (2002) 'Research ethics in Internet-enabled research: Human subjects issues an methodological myopia' <u>Ethics and Information Technology</u> 4(3) pp.204-216.

Ward, K.J. (2007) "I Love You to the Bones': Constructing the Anorexic Body in 'Pro-Ana' Message Boards' Sociological Research Online 12(2) pp. 00-00.

Warin, M.J. (2006) 'Reconfiguring Related in Anorexia' Anthropology & Medicine 13(1) pp.41-54.

Warisse Turner, J., Grube, J.A., Meyers, J. (2001) 'Developing an optimal match within online communities: An exploration of CMC support communities and traditional support' <u>Journal of Communication</u> 51(2) pp.231-51.

Wellman, B., Gulia, M. (1999) 'Net surfers don't ride alone: Virtual communities as communities' in Kollock, P., Smith, M. [Eds] <u>Communities and cyberspace</u> New York, Routledge.

Wentzer, H.S., Bygholm, A. (2013) 'Narratives of empowerment and compliance: Studies of communication in online patient support groups' <u>Internation Journal of Medical Informatics</u> 82(12) pp.386-394.

Whitehead, K. (2010) 'Hunger hurts but starving works: A case study of gendered practices in the online pro-eating disorder community' Canadian Journal of Sociology 35(4) pp.595-626.

Whitlock, J.L., Powers, J.L., Eckenrode, J. (2006) 'The virtual cutting edge: The internet and adolescent self-injury' <u>Developmental Psychology</u> 42(3) pp.407-417.

Williams, S., Reid, M. (2007) 'A grounded theory approach to the phenomenon of proanorexia' <u>Addiction Research and Theory</u> 15(2) pp.141-52.

Williams, C., Riley, J. (2013) 'Finding Support and Negotiating Identity: An Analysis of the Structure and Content of Newbie Posts and their Elicited Replies on Five Pro-Eating Disorder Websites' Social Science Research on the Internet 1(2) pp.49-72.

Wilson, J., Peebles, R., Hardy, K., Litt, L. (2006) 'Surfing for thinness: A pilot study of proeating disorder website usage in adolescents with eating disorders' <u>Pediatrics</u> 118(6) pp.1635-43.

Winzelberg, A. (1997) 'The Analysis of an Electronic Support Group for Individuals with Eating Disorders' Computers in Human Behavour 13(3) pp.393-407.

Wright, K. (2000) 'The Communication of Social Support Within an On-line Community for Older Adults: A Qualitative Analysis of the SeniorNet Community' Qualitative Research Reports in Communication 1(2) pp.33-43.

Wright, K.B., Bell, S.B. (2003) 'Health-related Support Groups on the Internet: Linking Empirical Findings to Social Support and Computer-mediated Communication Theory' <u>Journal of Health Psychology</u> 8(1) pp.39-54.

Yeshua-Katz, D., Martins, N. (2013) 'Communicating Stigma: The Pro-Ana Paradox' <u>Health</u> Communication 28(5) pp.499-508.

## **Appendices**

## **Appendix A- Ethical framework with REC**

### Ethical framework for REC.

#### Who?

I'm Sarah Lewis, I'm a first year PhD student in the Department of Social Sciences at Loughborough University in the UK. You can see my student profile at <a href="http://www.lboro.ac.uk/departments/socialsciences/staff/phdstudents/lewis-sarah.html">http://www.lboro.ac.uk/departments/socialsciences/staff/phdstudents/lewis-sarah.html</a>
. My PhD is being funded for three years by the UK government's Economic and Social Research Council.

#### What?

I would like the opportunity to observe the REC community through discussion forums. This observation would form the base of my PhD, which is yet to be titled but focussed on pro-anorexic and pro-recovery communities (specifically forums), the role of support and how adolescence as a concept impacts on support.

For the first phase of my research I'd like to observe the community only. Right now I can't say how long I'll be an observer for, I'd estimate a year. I can't give an exact time frame because I'm using a data collection technique called Grounded Theory. This approach is all about allowing the data speak for itself, the research is guided by the data and themes emerge. I would then research these themes further if they fit in with the ideas of community, support and adolescence.

The second phase of my research would involve interviewing community members. Although my research interest is adolescence, you don't have to be a teenager to take part. To study the impact of teens properly I need to ask a variety of age ranges their views on community, support and adolescence. I'd begin conducting interviews with those who agree to participate while I'm still observing the forum, roughly in six- eight months time. Interviews would take place over skype or gmail chat, they could be video interviews or non video interviews, I would leave that completely up to the participant, either is fine for this research. Both skype and gmail chat are free to download so the

participant will not have to pay anything to take part. If someone wanted to take part but their computer would not support either skype or gmail chat, then I would consider doing a telephone interview instead, of course I would pay call costs for this.

Finally once interviews have been completed and I have enough information about your community from observation, the collection aspect of my research is complete. So I would no longer use the REC account I've set up (username-pinkysera) but can be contacted via my email address, s.c.lewis@lboro.ac.uk.

### When?

I would start my research after getting consent from the REC community and ethical approval from Loughborough University. The next Ethics Committee meeting is 14<sup>th</sup> January and researchers are told within two weeks of the meeting if they have gained approval. So research would begin at the end of January.

# Why?

I'm conducting this research as part of my PhD. I'm interested in pro-anorexia and prorecovery as I feel they have been misrepresented in the media and to understand them we have to engage with them. My hope is that my PhD thesis will help to better understand forums devoted to anorexia and how they support their members.

### Consent

Due to the fact that you are a large community, I cannot get each one of you to fill in a consent form to allow me to observe. As you will have seen I've posted a thread in the general discussion section, on which I've encouraged any questions, which has led to a lot of really positive feedback and the creation of this framework. Rather than have everyone say 'yes' to the research, in communities as large as yours it is easier to have people object to the research. If anybody objects to this research being conducted I recommend they leave a post on the research thread, stating the concerns they have. I would then address these concerns in the hope that they can be resolved and the research go ahead.

Consent for interviews would be gained from each individual participant. Again I would start a thread in the general discussion section of the forum, this time with the title 'Interviews', if people were interested in taking part they could reply on the thread, by private message or through my university email at the top of the page. From there I would send them a consent form (See bottom of page), if on reading the consent form they still wanted to participate, we would arrange a suitable time and medium (skype/gmail chat) through which to conduct the interview.

#### Withdrawal

You are free to withdraw from the study at any time and for any reason. If, as a community you decide against this research you just need to contact me via the means already provided. If individuals want to withdraw from interviews (even after they have been conducted) they can do so, again they would just need to contact me and let me know their wishes.

## **Privacy**

I will only be observing the community and not participating, this is important as it allows the community to function as it always has, I don't want to disrupt the community.

The information collected in my study will be kept in confidence, and all posts, interviews and the name of the forum will be anonymised. Anonymity will work on many levels. First the name and web address of the forum will not be revealed, usernames will be changed and any extracts used will be checked up and modified if needed to ensure they don't come up when typed in a search engine. Any quotes that are used in publications will not be traced back to the REC community or specific individuals. Interviews will also be anonymous, participants need only give their age and gender, each interview will then be assigned a pseudonym. Personal details that may be discussed during interviews will be altered to ensure anonymity. For example 'My boyfriend John thinks REC is a really good place for me' would be changed to 'My boyfriend Peter thinks this site is a really good place for me'. The meaning is the same but all personal content is removed.

## Data storage

Data will be collected by me only, no other researchers will be involved with data collection. In order to collect data and preserve what is being said on the forum, interesting threads will be tuned into pdf files. These will then be saved to my memory stick and external hard drive. No one else will have access to these files, my external hard drive is password protected and files on the memory stick will be encrypted using the programme TrueCrypt. Data will be stored for 5 years after the completion of my PhD and then destroyed.

Interviews will be recorded using a computer programme or Dictaphone and then transcribed by me. Again the results of this will be stored on my external hard drive which is password protected. Again data will be stored for 5 years after the completion of my PhD and then destroyed.

#### **Results**

As I've mentioned I'm just starting my PhD, so the results of this may take a number of years to become available. Despite this the results will be made available to you in whatever format they take (book, academic journal, etc). Again I can do this through the forum using my old username (pinkysera) and post a thread in the general discussion section titled 'Results'. Here I could leave the details of how results can be obtained.

#### Contact

I can be contacted in three ways;

- On the forum via the research thread in the general discussion section.
- On the forum via private message, username pinkysera.
- Via my university email, which is, <a href="mailto:s.c.lewis@lboro.ac.uk">s.c.lewis@lboro.ac.uk</a>

However you can also contact my supervisor if you have any concerns about my research that you do not want to discuss with me:

My supervisor is Dr Paula Saukko. Email, p.saukko@lboro.ac.uk

# Appendix B- Participant information sheet sent to members of ANA and REC

# **Participant information**

This information sheet is designed to tell you everything you need to know about my research, if after reading it you still have questions email me (<u>s.c.lewis@lboro.ac.uk</u>).

## Who?

I'm Sarah Lewis, a second year PhD student in the Department of Social Sciences at Loughborough University in the UK. You can see my student profile at (<a href="http://www.lboro.ac.uk/departments/ss/staff/research\_students/lewis.html">http://www.lboro.ac.uk/departments/ss/staff/research\_students/lewis.html</a>) My PhD is being funded for three years by the UK government's Economic and Social Research Council.

#### What?

I am conducting interviews with users of pro-anorexia and pro-recovery forums because my PhD looks at support and adolescence on online anorexia forums. I am interested to see the reality of forum life. Interviews can be conducted via Skype or an instant messenger service of your choice (eg, Gchat, MSN, Yahoo), and can be video, audio or simply typed. The form the interview takes is your decision.

## When?

We can arrange the interview at a time and date convenient for us both.

# Why?

Why should you take part? My study is trying to understand the reality of pro-anorexia, as a member of a pro-ana forum you understand the daily workings and the ways people support one another better than anyone else, the insight you can provide me is invaluable.

Are there any issues in taking part? While the conversation will be focussed on community and support, eating disorders will also be discussed, you may find this difficult.

#### Consent

This sheet is the participant information sheet, which gives you all the info you need to decide if you want to take part. If you are 13 and over you can give consent to take part. You can withdraw from this research at any time even after you have completed the interview, for any reason whatsoever. In such cases the data would be destroyed and it would be like you never took part.

## **Privacy**

Privacy is very important in this study. Anonymity (not being able to be recognised) will be granted by giving each interview a case number and taking minimal personal data, I'd only want to know your age and gender. Any personal details that are discussed during the interview will be altered to ensure participants anonymity.

## Confidentiality

Confidentiality is very important to this project, and everything will be kept confidential.

# **Data Storage**

Interviews will be recorded using a Dictaphone and then transcribed by me. The results of this will be stored on my external hard drive which is password protected. Data will be stored for 5 years after the completion of my PhD and then destroyed.

#### Contact

I can be contacted via my university email, which is, s.c.lewis@lboro.ac.uk

However you can also contact my supervisor if you have any concerns about my research
that you do not want to discuss with me:

• My supervisor is Dr Paula Saukko. Email, p.saukko@lboro.ac.uk

## What now?

If you want to take part then please email me (<a href="mailto:s.c.lewis@lboro.ac.uk">s.c.lewis@lboro.ac.uk</a>) to arrange an interview. In the email if you could state which time zone you live in, what day(s) and time you would be available that would be really useful.

If this information sheet has not answered all your questions then please get in touch via email.

# Appendix C- Initial topic guide used in interview with members of REC

The purpose of these interviews will be to substantiate the themes that have been found during observation, establish if/how adolescence is being expressed on the site and to gain first hand information about the site. The questions below aim to reflect and work towards these aims.

Before starting the interview I will go through the informed consent sheet, ensuring that the participant understands what is written and is still willing to take part.

# Online use

- 1. What do you do online?
- 2. Why did you join REC?
- 3. What has made you stay a member of REC?

# <u>Adolescence</u>

- 4. What do you think about teenagers using REC?
- 5. How do teenagers use the site?

## Recovery

- 1. How would you describe pro-recovery?
- 2. Can you describe what recovery means to you?
- 3. What does recovery mean to REC?

# Support

- 4. What does support mean to you?
- 5. What does support mean to REC?
- 6. Is REC a supportive environment? If yes/no, why?
- 7. How does REC compare to any offline forms of support you may have?

# Challenging

8. What would you say are the important elements that make REC a useful place to visit?

- 9. I've noticed people mention challenging a lot, could you tell me a bit about what challenging is?
- 10. Do you think challenging is important to the group? If yes/no, why?

# Censorship

- 11. Does REC have any rules?
- 12. How would/are rules be enforced?
- 13. Do you think there are subjects that should not be discussed on REC?

# **Definitions**

- 14. What does having an ED mean to you?
- 15. When can someone be described as having an eating disorder?
- 16. Does REC have a 'definition' of an eating disorder?

# **Closing questions**

- 17. What would you describe as the best and worst features of REC?
- 18. Do you have anything else you'd like to add?

# Appendix D- Initial topic guide used when interviewing members of ANA

## ANA Topic Guide

The purpose of these interviews will be to substantiate the themes that have been found during observation, establish if/how adolescence is being expressed on the site and to gain first-hand information about the site. The questions below aim to reflect and work towards these aims.

Before starting the interview I will go through the informed consent sheet, ensuring that the participant understands what is written and is still willing to take part.

#### Online use

- When you joined ANA, what were the reasons that made you join?
   -Follow up question: did you consider joining any other sites, and if so, what did you decide?
- 2. What are the features of ANA that have made you stay a member?
- 3. What would you describe as the best and worst features of ANA?

## Support

- 1. What does support mean to you?
- 2. What does support mean to ANA?
- 3. Do you find that ANA is a supportive environment? If yes/no, why?
- 4. Do you have any support off-line? If so, what/who
- 5. How would you rate the importance of the different forms of support you have which is the most important? Least important?
- 6. How does ANA compare to any offline forms of support you may have?

### Definitions

- 7. What does having an ED mean to you?
- 8. When do you think someone can be described as having an eating disorder?
- 9. In your view, does ANA have a 'definition' of an eating disorder?
- 10. The media claims pro-anorexia sites see EDs as a lifestyle choice, what do you think about this?
- 11. How would you describe pro-anorexia?
- 12. Can you describe what pro-anorexia means to you?
- 13. What does pro-anorexia mean to ANA, in your view?

#### Ideal user

- 14. Do you think there is a 'right' or 'wrong' way to use ANA?
- 15. Are there any rules or codes of conduct on ANA? By rules I don't just mean formal forum ones but ones that are 'unspoken'.
- 16. Can you think of an example of a good forum member on ANA?
- 17. Can you think of an example of a bad forum member on ANA?

# Sharing

- 18. What do you enjoy about talking to other members on ANA?
- 19. Do you share personal or private information with people on ANA?
- 20. Do you think sharing stories is important to the group?

## Wannarexia

- 21. What do you think of the term wannarexia?
- 22. Have you ever been called a wannarexic?

# Adolescence

- 23. Do you have any views about teenagers using ANA?
- 24. Do you think there is a particular way in which teenagers use the site?
  How do teenagers use the site?

# Closing questions

25. Do you have anything else you'd like to add?