

UNDERSTANDING THE EXPERIENCE OF AMBIVALENCE IN ANOREXIA NERVOSA: THE
MAINTAINER'S PERSPECTIVE

Abstract

People with anorexia often feel ambivalent about whether they wish to maintain it or recover from it. One place where individuals can communicate their experiences of wanting to maintain their anorexia is through pro-anorexia websites. This study investigated the experiences and understandings of those who wish to maintain their anorexia and looked at how these understandings may affect their treatment experiences. Data were collected online and analysed using interpretative phenomenological analysis (IPA). Anorexia denoted meanings of a 'tool' an 'entity' and a 'disease'. Participants felt ambivalent about whether their anorexia gave them control or controlled them, whether it played a positive or negative role and whether they wished to maintain their behaviours or recover. Participants also discussed barriers to recovery. Theoretical and treatment implications are discussed.

Keywords

Anorexia nervosa; pro-anorexia; ambivalence; online; qualitative research.

Understanding the Experience of Ambivalence in Anorexia Nervosa: The Maintainer's Perspective

Treatment for anorexia nervosa is often resisted (Cooper, 2005) and has high dropout rates (Cooper, 2005; Eivors, Button, Warner & Turner, 2003). One reason for the resistance in treatment is the fact that many with anorexia deny that their behaviours are problematic or do not perceive it as such due to the egosyntonic and functional nature (Garner & Bemis, 1982; Vitousek, Watson, & Wilson, 1998). Garner and Bemis (1982) describe how anorexia is different from other mental health problems as it is seen positively by those who experience it. Thus, treating anorexia can be difficult as patients are often reluctant to give up the positive aspects they get, which is often thought to be the only way they can achieve happiness.

At the same time as receiving positive, egosyntonic effects from the behaviours those with anorexia may also acknowledge the negative effects, causing strong feelings of ambivalence. Ambivalent feelings will also play an adverse role in treatment resistance. Ambivalence can be defined as the process of having “*conflicting motivations*” or “*feeling two ways about something*” (Miller, 1998, p.123) and can often be “*immobilising*” (ibid) for the individual as they constantly think of the pros and cons of a behaviour and whether to change it. Indeed, Vitousek et al. (1998) describe how the more ambivalent the anorexic is the more they will manipulate aspects of treatment in order to maintain behaviours.

A number of qualitative studies have identified the ambivalence felt by those who experience anorexia (e.g. Colton & Pistrang, 2004; Serpell, Treasure, Teasdale, & Sullivan, 1999; Reid, Burr, Williams & Hammersley, 2008). Serpell et al. (1999) looked at patient's attitudes towards anorexia by asking them to write two letters to their disorder: one as if it was a friend and the other as an enemy. Results illustrated the personal functionality of anorexia: it protected, gave feelings of control and self-confidence, it gave a sense of achievement and allowed the communication of emotions. However, simultaneously, anorexia could have negative effects on the physical health, psychological well-being, and social interaction of the person and on others around them. Similarly, Colton and

Pistrang (2004) found that participants in their study felt ambivalent about both their anorexia and treatment including whether they were ready or wanted to get better and whether anorexia was seen as a friend or an enemy.

Participants in a study conducted by Reid et al. (2008) expressed ambivalence towards the level of control they felt they had. Anorexia began as a way of feeling an element of control but as behaviours became more entrenched, participants began to feel that they had lost control of their restriction and instead they were now being controlled by their behaviours. These feelings of lost control lead to treatment seeking.

Mukai (1989), a self-described recovered anorexic tells how anorexia is seen negatively by healthcare professionals, as a disorder that needs to be treated and cured. She calls for attention to the positive side of the disorder. By neglecting to address the “*egosyntonic nature of thinness and self-control*” healthcare professionals are making a “*fundamental error*” (Vitousek et al., 1998, p.398). Gremillion (2003) also recognises the conflicting views between healthcare professionals who see anorexia as a ‘sickness’ and those experiencing anorexia who do not see it as problematic. It is perhaps unsurprising then that those who enter treatment often feel misunderstood by healthcare professionals and so therefore seek support and comfort from the only other people they feel can understand, others with anorexia (Rich, 2006) and one place they can go to do this is the internet.

The internet offers a popular place for finding support about conditions that are felt to be misunderstood and unrecognised in healthcare settings (Davison, Pennebaker & Dickerson, 2000). For example, a survey study conducted by Berger, Wagner and Baker (2005) found higher levels of internet use with those with a stigmatised illness, than those without, especially when the stigmatized illness was of a psychiatric nature (depression and anxiety). Participants in online forums can obtain mutual support and can discuss their experiences in a frank and open manner (Kral, 2006) in a safe and physically anonymous environment (Walstrom, 2000).

This anonymity allows internet users to express a true self (Bargh, McKenna & Fitzsimmons, 2002) and one that may be “*considered to be unacceptable in real life*” (Adams, Gavin & Rodham 2005, p.1295). Online support groups exist for a host of stigmatised conditions including addictions (King, 1994), self-harm (Adams et al., 2005) and those with anorexia (e.g. Walstrom, 2000). The online, anonymous environment also allows individuals to express views about their disorder that would be judged negatively in offline surroundings. ‘Pro-sites’ for those with positive beliefs about a stigmatised behaviour exist for such behaviours as drug use, self-harm and suicide although the most well known ‘pro-sites’ are pro-anorexia sites.

Pro-anorexia internet forums are considered by users to be the only place that they can obtain support, acceptance and understanding for their beliefs (Dias, 2003; Gavin, Rodham & Poyer, 2007).

The online forums and discussion boards allow users to discuss positive aspects about their behaviours, which they feel would be judged or stigmatised in other settings. Pro-anorexia websites have been recognised as a place for people to go who recognise that they have an eating disorder but do not wish to recover (Dias, 2003; Mulveen & Hepworth, 2006; Uca, 2004; Williams & Reid, 2007). Research into pro-anorexia websites has also recognised the ‘anti-medical’ views of those that use the sites (Fox, Ward & O’Rourke, 2005; Pollack, 2003). For example, Fox et al. (2005) concluded that pro-anorexia opposes other explanatory models (such as medical, psychosocial, sociocultural and feminist perspectives) that see anorexia simply as a disorder that needs to be cured.

The pro-anorexia model developed by Williams and Reid (2007) illustrates how people that use pro-anorexia websites “want” their anorexia because of the positive perception that they have towards it. Anorexia gave individuals desired results and subsequently made them feel better about themselves, giving them positive feelings of empowerment, personal control and personal identity. Thus, individuals hid their anorexic behaviours from others and continued pursuing them despite the knowledge that they could be harmful. The positive values placed on anorexia also meant that individuals did not feel ready for or want recovery. However, sometimes the anorexia could be

considered a problem for the pro-anorexics and it was during these times that the idea of recovery was considered. The authors concluded that further research into sufferers' positive cognitions would aid better understanding of the disorder (Williams & Reid., 2007).

Related to this, cognitive behavioural theories have begun to acknowledge the role of pro-anorexic beliefs in the maintenance of the disorder (Schmidt & Treasure, 2006; Wolff & Serpell, 1998).

However, as Schmidt and Treasure (2006, p.354) reveal, “[f]urther research is needed to establish the role of pro-anorectic beliefs as a maintenance factor”. The current study was of people who use pro-anorexia websites and who wanted to maintain anorexia. The aims were 1) to explore their experiences and understandings and 2) to determine how their positive attitudes to anorexia may affect maintenance, recovery and treatment. Although a small number of qualitative studies have been conducted on the experiences of those who use pro-anorexia websites (Fox et al., 2005; Mulveen & Hepworth, 2006; Williams & Reid, 2007) these studies have focused on the experience of pro-anorexia and not at looking at experiences of living with anorexia and/or receiving treatment.

The study used a phenomenological approach, namely Interpretative Phenomenological Analysis (IPA: Smith, Jarman & Osborn, 1999), as this allowed the researcher to look at the participants' everyday experiences of living with anorexia, therefore enabling an understanding of these experiences to be obtained. As Colton & Pistrang (2004, p.315) state: “*A phenomenological approach has the potential to enrich both our understanding of anorexia and the debate about how best to treat it.*” The study looked at the views held by those who use pro-anorexia websites and so used an online approach for both recruitment and data collection. As Pollack (2003, pp249-250) suggests, it is important for researchers to investigate pro-anorexia beliefs by “*engage(ing) with these women [sic] in their chosen community of cyberspace.*”

Method

Participants

Participants consisted of 13 females and 1 male aged 18-36. This study was an international study with participants located in USA (n=5), Canada (n=2) and one each in Spain, South Africa, Australia, New Zealand, Romania and India. A self-report questionnaire was designed for the current study and looked at participants' demographic information, eating disorder history and other mental health problems, eating disorder related internet use, and attitudes to eating disorders. All participants used pro-anorexia websites with frequencies ranging from around five times a month to 10-15 times a day, whereas use of pro-recovery websites ranged from never to twice a day. All participants believed that they had anorexic behaviours at the time of the study and wished to maintain them, however, and ambivalently, three participants also wished to recover from their eating disorder and five wanted to receive treatment.

The Eating Disorder Examination-Questionnaire (EDE-Q, Fairburn & Beglin, 1994), a self-report instrument measuring frequency and severity of behaviours and psychopathology was also administered. As this study used an online approach, permission was obtained to administer the questionnaire electronically via a word document for participants to fill in and e-mail back to the researcher. The EDE-Q results indicated that all participants had high eating disorder psychopathology and with the exception of two all had a low Body Mass Index (BMI; one was unknown and one was in the normal weight range).

Recruitment Procedure

Participants were recruited through pro-anorexic web pages and forums. The search engine 'Google' was used to find pro-anorexia sites, as at the time of recruitment this was the most popular search engine (Sullivan, 2006). Websites were identified using the search term 'pro-anorexia', which found 348, 000 results (number of results were for the 25th September 2006). One result was a directory of the 23 most popular pro-anorexic sites therefore these sites and links from these sites were used for identifying people that could be contacted for recruitment.

Potential participants were contacted by an initial e-mail giving a few details about the study and asking them to contact the researcher if they would like further information. E-mail addresses were found on the 'contact' pages, site guestbooks and forums and were used under the assumption that these addresses were left for people to be contacted regarding their pro-anorexia. Pages that required registration for the user were not used as this was thought to be unethical. When a person requested further information, a formal information sheet and a consent form were e-mailed out. On receipt of a consent form, a person was then considered a participant and asked to fill in the two self-report questionnaires and arrangements were made to set up an account for them for the online study.

Procedure

Online research

Online methods are increasingly becoming popular in the social sciences (Stewart & Williams, 2005). Whilst potential disadvantages of online methods have been acknowledged, mainly regarding the lack of non-verbal cues (Kenny, 2005; Stewart & Williams, 2005), researchers have identified key advantages that online methods may offer over offline methods. Most importantly, the internet offers participants a completely anonymous environment that can aid communication, as participants feel more comfortable in disclosing information (Adams, et al., 2005; Kenny, 2005; Stewart & Williams, 2005; Turney & Pocknee, 2005). This can be particularly advantageous given the sensitive and personal nature of exploring lived experiences.

Online Focus Groups (OFGs)

An OFG method was chosen to collect data as this emulates online forum situations that those who use pro-anorexia websites are accustomed to. The OFG was hosted on the institution's virtual learning environment, WebCT. Although originally designed as an online educational tool WebCT has been successfully employed to collect research data (Kenny, 2005; Turney & Pocknee, 2005). WebCT is considered easy to use (Kenny, 2005), nonetheless a detailed user guide was e-mailed to participants on the first day of the study and participants could e-mail the researcher should they experience any problems. One key advantage to the use of WebCT is that access is restricted to only those who have

been provided with a password (Kenny, 2005). This ensures participant confidentiality and safety and prevents the event of undesired interaction from non-participants; such was experienced in an online focus group conducted by Adams et al. (2005). The WebCT site consisted of a discussion board, web-links to support websites for eating disorders, details of the ground rules for using the OFG and the contact details of the researcher.

The group was asynchronous (non real time) and lasted five weeks. Participants were asked to pick a username and on the first day, they were e-mailed information about how to log on and were asked to read the ground rules for using the site. Three discussion topics were already set up. The first, a welcome topic, allowed the researcher to welcome participants, remind them about the purpose of the study, of their right to withdraw and introduce them to the features of the WebCT site. The second consisted of a discussion topic where the researcher introduced herself and asked participants to do the same as a way of building rapport amongst participants and with the researcher. The third was the first in the topic schedule asking participants to give a history of their anorexic behaviours. Further discussion topics such as the causes of anorexia, maintaining anorexia and treatment seeking were introduced throughout the next four weeks (see box 1). At the end of the fourth week a summary of the discussions was posted. Participants were then given one more week to make any final contributions to discussions. Questions were designed to explore participants' understandings of anorexia based on their lived experiences and therefore used a semi-structured approach to allow them to discuss aspects of their experience which they felt to be important. As recommended by Smith & Osborn (2003) questions were neutral, jargon-free and open-ended. The topic schedule was informed by the work of other IPA authors (Adams et al., 2005; Smith & Osborn, 2003). For example, Adams et al. (2005) asked their self-harming participants what role their self harm played in their life and it was thought useful to similarly ask participants what role their anorexia played in their life. The topics covered areas considered important for the study aims and stemmed from our previous research (Williams & Reid., 2007) which concluded that further investigation into the positive cognitions of those using pro-anorexia websites was needed.

Participants were asked to log in at least three times a week to keep updated with any new posts. Subsequently, the researcher checked the OFG at least three times a day to moderate posts and ensure participants were following the ground rules, keep updated with the progress of discussions and looking for opportunities to probe or ask further questions. At the end of the OFG, discussions were locked to prevent participants accessing the site after the study period, debrief information was e-mailed out and data from the WebCT discussion boards were downloaded into a word document ready for analysis.

E-mail Interviews

Two participants contacted the researcher once the focus group had begun and as it was too late to join the OFG, they were offered e-mail interviews covering the same topics. Once the two questionnaires had been completed and returned, the researcher began the e-mail interview by asking the first question. The respondent then replied and another question was posed by the researcher. The questions followed the same semi-structured topic schedule used in the online focus group and were asked one at a time rather than all at once to allow unanticipated answers to be explored.

Ethical approval was obtained from the university ethics committee. British Psychological Society (British Psychological Society, 2005) ethical guidelines were followed and ethical guidelines for online research (Ess and the AOIR Ethics Working Committee, 2002) were consulted.

Insert box 1. here

Analysis

The OFG was successful in yielding rich data regarding participants' experiences. In total participants posted 162 posts of varying length. Interestingly, participants in the e-mail interviews gave shorter and less detailed answers. One e-mail participant described a preference for communicating in a group situation, supporting our initial decision to use an OFG approach to researching this sample, as this is

familiar to participants. As with existing online discussion boards some participants contributed more to the discussions than others where some chose to contribute to every topic and others chose those most relevant to their experience. One reported ethical advantage of using an online environment is that participants may feel more comfortable withdrawing or choosing not to answer particular questions (Turney & Pocknee, 2005). The levels of group interaction amongst focus group participants varied. Some participants simply replied to the researcher's questions whilst others communicated with one another and formed their own discussions. Some also quoted each other or replied to other's posts agreeing with a statement and then providing further elaboration based on their own experiences. However, because of the idiographic nature of the data analysis (Smith, 2004) the differences in group interaction were not seen as a problem. The idiographic approach also meant that the focus group data and e-mail interview data could be incorporated into the same study.

Data were analysed using Interpretative Phenomenological Analysis (IPA: Smith et al., 1999). The principle focus of IPA is concerned with understanding a person's experience from their own perspective; it uses a double hermeneutic approach (Smith, 2004) as the researcher is making sense of the individual making sense of their experience. The idiographic nature of IPA allows the researcher to identify participants' distinct meanings and experiences of a phenomenon but also allows for the identification of the areas where these meanings and experiences are shared. Because of the strong idiographic nature, IPA is recommended for, and more commonly used with interview data. However, Millward (2006, p.295) acknowledges that in some cases, focus group methods are more suited and as such individual accounts "*need to be parsed out from the group discussion*".

Adams, Rodham & Gavin (2005) refer to Smith et al. (1999) for their IPA analysis of data collected from online focus groups and e-mail interviews and these same guidelines were employed for this study. The full focus group transcript was read through a number of times to determine the context of the discussions and initial notes were made regarding preliminary themes. Posts were numbered in the order they occurred in the focus group discussions and then individual responses were 'parsed out' into separate transcripts so that the participants' idiographic accounts could be explored. The

numbering meant that the researcher could consult the full focus group transcript if the context of a discussion needed to be checked. As recommended by Smith et al. (1999) initial themes were generated from the participants' own accounts of their experiences and then these were used to formulate more interpretative themes based on psychological concepts before collecting together to form clusters of related themes. This process occurred for each transcript before comparisons were made between them. Interpretative themes were checked with the second author for validity.

Results

The analysis yielded two overarching themes 'ambivalence and conflict about anorexia' and 'barriers to recovery'. As will be seen, both themes contribute to participants' maintenance of anorexia.

Theme 1: Ambivalence and conflict about anorexia

As in previous studies (Colton & Pistrang, 2004; Reid et al., 2008), participants' experiences of anorexia were fraught with ambivalence. Underlying this ambivalence was a conflict between the belief that anorexia provided a sense of control yet also, at the same time, was in control of them. This ambivalence about control is expressed by Emma when she explains the positive and negative roles of anorexia, both of which encompass control:

The main way I can really think of in which anorexia is positive is that it helps me survive with my day to day life with a slight sense of control... I guess in a way it helps me live. It is negative in the fact that it controls my thoughts and behavior.

This conflict led to further ambivalence about whether anorexia was a functional, controllable tool and therefore something to maintain, or whether it was a disease or enemy that was out of their control and should be ceased. For example, Emily distinguishes between a disorder that can be controlled (managed) and a disease that controls when she says, "Anorexia can be both a disease and be a manageable disorder." Whilst Gabriella and Charlene express their ambivalence regarding whether or not to maintain or recover: "Sometimes, I hate it so much I just wish I could end it... Then others, I can't imagine myself without it"(Gabriella) and "Your emotions are in a whirlwind...one day

you cant see life without Ana, the next day, you just want to be normal, or whatever that is!"

(Charlene)

The remainder of this theme will focus on these opposing experiences by further exploring anorexia 'as a functional and controllable tool', as a 'friend or foe' and 'anorexia as an uncontrollable disease'.

Anorexia as a functional and controllable tool

Participants iterated the results of previous studies that saw anorexia as playing a functional and egosyntonic role (Garner & Bemis, 1982; Serpell et al., 1999; Williams & Reid, 2007; Vitousek et al., 1998). Participants expressed how their anorexia could be used as a multi-functional tool as a way of feeling in control, achieving something and as a form of coping. Anorexia was also used as a way of feeling safe, a way of expressing emotion, as an escape or a focus to avoid negative situations and emotions, a way to disappear, to feel strong and successful, to feel happiness, a way of fighting puberty, and a way of punishing themselves or others. Furthermore, for participants in this study this tool was used to fix the individual's life problems, for example Hailey believes "*thinness will fix everything*". These responses echo earlier suggestions that eating disorders are not problematic for the individual but a solution (Bruch, 1978), table 1 illustrates how, when looking at the contributing factors to the onset or maintenance of anorexia, and then looking at the perceived positive effects, it can be seen as a tool for fixing their problems.

****Insert Table 1 here****

When anorexia was given the meaning of a tool that they could use when needed, participants felt in control of the disorder and felt it was egosyntonic. Furthermore, participants expressed how the sense of control that came with restriction led to increased positive emotions. This was expressed in relation to eating and not eating, where not eating led to positive feelings of control and being good and eating led to feeling bad, fat, out of control and feelings of self-hatred: "*If I don't eat, I'm*

good...If I eat, I'm a fat, out of control eejit, and I hate myself." (Maria) and "Yes that is so true cause when I'm starving I feel control and when I eat I feel bad" (Hayley).

The egosyntonic nature meant that respondents perceived their anorexia to play a significant role in their life therefore affecting the maintenance of the disorder: "At the moment, anorexia plays a massive role in my life. Everything I do or think, I relate it to anorexia in some way." (Maria); "they [anorexic behaviours] are everything to me, almost my entire life." (Anita). Jack's anorexia is also highly important as for him it has become his identity: "My anorexia is my life. It is who I am."

Anorexia nervosa: Friend or foe?

When participants felt in control of their anorexia, they ascribed the meaning of a friend that they could depend on, subsequently when they did not feel in control it was seen as an enemy. They therefore described an ambivalent relationship with anorexia: "Its become my friend! And yet not! Ana is something that is there for you when no one else is!" (Charlene) and "Ana is my friend, my foe, I love, yet hate her" (Hailey).

Some participants personified their anorexia using the pro-anorexic term 'ana' or by referring to it as 'her', however as the next three extracts illustrate, this personification and description goes beyond a simple pro-anorexic convention and expresses participants' beliefs about anorexia as something capable of performing actions and having emotions of its own. Here, anorexia is seen as something that is able to take control of the individual and to enforce behaviours upon them.

Anita experiences her anorexia as "the voice in my head". It is a negative entity that controls all of her actions and makes her feel depressed; it has "expectations" that she needs to meet through her behaviours, she no longer makes her own decisions, and instead she makes her decisions to "satisfy" her anorexic voice:

It makes me depressed and suicidal because i am never good enough to meet my expectations or rather the expectations of the voice in my head. (...) i wouldnt be able to

make any decisions because i forgot a long time ago what i wanted... now all my decisions are made to satisfy the voice in my head.

For Grace and Jack anorexia is both a positive and negative influence. For Grace, anorexia plays a triple role of her best friend, a teacher and a murderer. As a friend and teacher it is capable of “telling” her what she needs to know to pursue her behaviours, although she uses the inanimate pronoun ‘it’ she describes how it “holds” her hand and “sleeps” next to her, actions that an inanimate object is unable to do. This extract, exemplifies the ‘guardian’ theme suggested by Serpell et al. (1999) where for many individuals anorexia plays a role of a friend that is always there for them and can always be depended upon for protection:

My anorexia plays the role of my best friend. it is always there for me. it makes me happy and always tells me the truth...that i am fat, and underserving and that food is not what's going to make me happy. it teaches me what i need to know...how to lose weight, how to lie to people, how to avoid feeling by not eating. it holds my hand when i need to feel safe. it sleeps next to me every night. it makes me feel safe and secure.

However, later on Grace describes the role of anorexia as a deadly disease yet at the same time it is also implied that it has a motivation of “trying to kill”.

It's just like cancer in that one moment your fine and then something else is inside you, something you have no control over and it is trying to kill you.

Jack also describes his anorexia as a friend. His friend plays the ‘guardian’ role of being something to depend on “no matter what” but his friend is controlling and causes many negative consequences: it “causes” his grade to drop, “isolates” him from those around him and “forces” him into a “stressful” relationship:

It is the friend that is there no matter what through thick and thin, I always have my anorexia to turn too (...) It causes my grades to drop in school. You cant pass out in class and maintain high grades. It isolates me from my parents and sisters, it takes my

friends. It forces me into a relationship between just it and I which as one can imagine is pretty stressful at times.

Anorexia as an uncontrollable disease

Authors such as Pollack (2003) and Fox et al. (2005) describe how the pro-anorexia movement is anti-medical and oppose explanatory models that see anorexia as a disease that needs to be treated, however, the beliefs expressed by participants in this study suggests otherwise. Despite their involvement in pro-anorexic websites, participants in this study described their anorexia as a “disease”, “disorder” or “illness” and recognised the negative effects on health a disease causes. For example, *“It’s a disease no different from cancer, or multiple personality disorder.”* (Grace) *“Anorexia is a potentially fatal disease. It’s like cancer. You don’t treat it you’re gonna die of it”* (Anita). Furthermore, Jack describes how despite being an *“active member”* on pro-anorexic sites he still sees anorexia as a *“serious”* disease that requires treatment and can lead to death. Interestingly, Jack’s use of the word “consumes” effectively illustrates the lack of control he has over the disease. This description is also far removed from his earlier accounts of anorexia as a tool for control and a friend.

I do believe that anorexia is a disease, however, I am a very active member on a couple of (pro?) anorexia forums [...] I would feel that anorexia is a serious but treatable condition. Without treatment it completely consumes the life of its host and eventually leads them to death.

Similarly, Hailey also uses the term ‘consumed’, for her this feeling of being consumed (or controlled) by anorexia leads to her not wanting it: *“I do wish to not have this poison that consumed my mind”* (Hailey). However, this lack of control also means that stopping behaviours is not easy to do as Taylor describes, *“I find myself talking to myself in my head begging myself to stop things and I cannot.”*

Pro-anorexia is said to be promoting a lifestyle choice for the individual, however, Taylor does not agree with this concept: “Anorexia is NOT A “LIFESTYLE CHOICE”¹ It’s a disease.” Although some participants did describe anorexia as a lifestyle or a way of life, this lifestyle had not been deliberately chosen by the individual. Rather, this way of life is due to being entrenched in the disorder for a long length of time, which causes many to believe that recovery is not possible. For example, Cristina describes how anorexia has become a way of life and therefore she feels unable to give it up: “I think i got used so much to this way of living, that i wouldn't be able to live in another way.” Similarly, Grace explains how the length of time she has had anorexia is a contributing factor for continuing to maintain her behaviours, for her giving up anorexia is akin to losing all of her important possessions. She would feel “lost” without the behaviours that have been such a large part of her life:

Part of it is also the length of time I've been anorexic. It's pretty much all I know...I can't imagine waking up one day without it...it'd be like losing my car, my cell phone and my puppy all at once...I'd be lost.

Related to this, Maria says to the other users of the focus group, “I would say to you girls, if you can help it, don't fall into this illness at all, because then you're in too deep, and it can kill you.” Here she describes a number of stages of anorexia, one where to begin with the person can have some control over, or choice to stop anorexia (“if you can help it”) and another where the individual can become “in too deep” where they do not have control over or a choice to stop. Maria also expresses the importance of anorexia as an illness that “can kill you”, and it is this fear that may also lead to a wish to recover. Later, she says,

I don't want to die, but I don't want to recover, though-not yet...mostly because of fear, and a small bit of me wants to get better sometimes, but I wouldn't know how.

This extract further exemplifies the feeling of ambivalence about recovery where in the exact same sentence she talks about both wanting and not wanting to recover. Maria also describes how she “wouldn't know how” and in this next extract we can see that she believes that there is lack of

¹ It is important to note here that capital letters in online communication represents shouting.

services available to her where she lives, however, if the option was there then she would choose to get treated. We can therefore see that although she is contemplating recovery and treatment there are barriers for her to do so:

If I lived in a city that offered proper treatment and I thought my life was going to be in danger, I would probably have to think a bit about it, but in the end, I'd choose to get treated...

Theme 2: Barriers to recovery

Theme 1 has already highlighted how feelings of ambivalence act as a barrier to recovery. Two other barriers were also expressed by participants: low self-efficacy and perceived treatment limitations.

Low Self-efficacy

Theme 1 identified how anorexia could become a way of life for people due to feelings of entrenchment, causing low levels of self-efficacy about changing behaviours. Another theme surrounding low self-efficacy for change was participants' fears of recovery. DSM-IV criteria for anorexia nervosa requires an anorexic to have an *"Intense fear of gaining weight or becoming fat, even though underweight"* (APA, 2000 p.544) and this was expressed by participants in this study. Respondents also described a fear of losing control which was associated with ceasing restraint and gaining weight. *"Gaining weight is a big fear for me."* (Emily) *"I guess I can't stop now because I'm scared of "letting myself go" mentally and physically."* (Abigail); *"I'm terrified of losing control and becoming massive or something."* (Maria)

Understandably, individuals were afraid to recover, as this would inevitably lead to weight gain and a sense of lost control. Emily describes how individuals with anorexia (herself included) all want to *"get better"* but they are too scared to do so:

But I do NOT discourage recovery, because ultimately that is what we are all seeking: to get better. But we are all scared of getting better, because we are all messed up.

Perceived limitations of treatment

Participants described numerous negative attitudes towards treatment. For some these attitudes had come from their own past experiences of trying to recover or seek treatment whereas others' attitudes seemed to be based only on perception, perhaps from researching on the Internet and listening to others experiences in the pro-anorexic forums, either way, having these attitudes were barriers to seeking or attempting recovery.

Taylor did not seek treatment because she did not feel it was needed. She had had past negative experiences and expressed a lack of confidence in the treatment centres available to her: *"The reason I do not seek treatment at the moment is because i a) think treatment centers are a load of crap b) dont think i need it yet."* Later she describes how treatment focused too heavily on weight gain and not on the psychological problems or what was happening *"inside"*: *"IP treatment facilities really only serve to fatten you up so that they can collect their exorbitant fees based on you "looking healthier" while inside youre still a mess."* This supports views expressed by participants in previous studies and indicates the importance of targeting psychological problems (Bell, 2003; Colton & Pistrang, 2004). Charlene, who has never had treatment for her eating disorder, does not even contemplate treatment because it will not focus on her psychological problems: *"I don't want to go into treatment. Because I feel, it doesn't get to the root."*

It has also been suggested that an empathetic and understanding relationship during treatment is imperative for it to be effective (Bell, 2003) yet from participants' experiences this was not always received. For example, Jack, who was currently in the process of treatment at the time of the study, felt that the knowledge held by healthcare professionals was limited and that more research needed to be conducted about *"proper treatment"*:

There really doesn't seem to be a lot of knowledge among medical professionals about proper treatment, and I think that this is another area that could use a lot more research.

However, participants also acknowledged that anorexia was a difficult disorder to understand. For example, Anita describes how she finds it difficult to understand her disorder so can therefore see how

difficult it is for someone who hasn't even experienced it: *"I can hardly understand why i wanna weigh 75 lbs, i can imagine how difficult it must be for someone on the outside to really understand."*

Hailey and Grace questioned the motivations of the staff involved in their treatment and from their past experiences it seemed that staff only worked for wages and did not care about the patient:

"Doctors don't really care they just fake it for money." (Hailey); *"The counselors did not give a fuck about you and were only there for a paycheck."* (Grace). For Grace, her negative experiences only acted to exacerbate her behaviours; making her more determined to maintain them and not let anybody else find out about them:

It was the most wretched experience i have ever had and i vowed to never ever let anyone find out about my ED ever again, so instead of getting better, i just found better ways to cover it up, and more reasons to have it because of the way they treated me.

The extracts above therefore illustrate the roles of unhelpful treatment experiences and negative relationships with staff in the maintenance of anorexia suggesting that interpersonal as well as intrapersonal factors are involved.

Discussion

Participants experienced ambivalence and a 'battle' of conflicting emotions and experiences regarding their anorexia. On the one hand, anorexia is seen as a controllable tool, a way for achieving desired results and fixing the underlying problems in their life, for some it is also seen as a reliable friend that can be constantly depended upon. On the other hand, anorexia is seen as in control; it is a disease, which negatively affects the health and life of the person and an entity capable of controlling their thoughts and behaviours. Anorexia can be both positive and negative, a friend and an enemy, a tool for achieving control and an entity or disease that controls them, it can be some or all of these things at different times or at the same time. The positive emotions reinforce feelings of wanting to pursue and maintain anorexia, whilst the negative emotions cause many to contemplate recovery. Again, at the same time, individuals can want to do both: recover and maintain.

These feelings can be interpreted as a 'double approach-avoidance conflict' (see Miller & Rollnick, 2002) as they feel both positive and negative emotions about both recovery and anorexia. Both options, continuing anorexia or attempting recovery have strong positive and negative aspects, causing conflicting emotions and therefore ambivalence. Ambivalence is considered a "*natural phase in the process of change*" (Miller & Rollnick, 2002, p.14) however, if an individual get stuck in ambivalence this can become problematic affecting a person's motivation to change. Participants varied in the level of ambivalence that they had regarding anorexia and treatment and one limitation to the study was that participants were not asked about how long they had had their eating disorder.

It is clear that these levels of ambivalence need to be targeted in therapy in a collaborative manner. Motivational interviewing (Miller & Rollnick, 2002, p.25) is described as: "*a client-centred, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence.*" This approach has been recommended for and adapted for use with those with eating disorders (Treasure & Schmidt, 2001). Increasing motivation for recovery has implications for reducing treatment resistance. Enhancing motivation for change will increase feelings of self-efficacy as by exploring the pros and cons of change, clients' fears of weight gain and loss of control can also be identified and dealt with. Furthermore, focusing on motivation can help clients feel more ready and willing to change their eating disorder behaviours.

This study supports much of what is already in the literature regarding the functional and egosyntonic role and ambivalent attitudes about anorexia and treatment. In particular, many of the themes found by Serpell et al. (1999) were reiterated by the participants in this study. Participants in the study used their anorexia as a tool to fix their underlying psychological and life problems. This illustrates the need for healthcare professionals to recognise that unlike other physical and mental health problems, anorexia, like substance dependence disorders (e.g. drug and alcohol addiction) plays a functional role for the individual (Vitousek et al., 1998). Treatment needs to target alternative 'tools' for obtaining

the positive results gained through anorexia, also, treatment needs to focus on the underlying problems that caused the individual to seek these tools in the first instance.

Previous IPA work in the field of eating disorders has looked at the experiences of using pro-anorexia websites (Mulveen & Hepworth, 2006), adolescent's experiences of inpatient care (Colton & Pistrang, 2004) and healthcare professionals' experiences of treating adolescent patients (Jarman, Smith & Walsh, 1997). To our knowledge, this is the first phenomenological study to look at the experiences those wishing to maintain anorexia have of anorexia and treatment. As with previous studies, (Colton & Pistrang, 2004; Reid et al., 2008) ambivalence was expressed over the amount of control participants felt they had. Participants used their anorexia as a tool for control but also felt that the anorexia was in control. Control has long been recognised in relation to the onset and maintenance of anorexia but the ambivalent feelings felt by those experiencing anorexia needs further attention.

This study used an online approach to engage users of pro-anorexic communities in their chosen environment of the internet (Pollack, 2003). One potential limitation of the research is that the sample was biased to those who had access to and already used the Internet. However, one could argue that this participant group may have felt more uncomfortable and less likely to disclose details of their pro-beliefs if they were in an offline environment. Thus, the anonymity of the online approach could be seen as advantageous. Furthermore, it may have proved difficult to advertise for recruitment for this population in an offline sample. Participants were recruited through their participation in existing online resources so already had an interest in communicating about their positive beliefs about anorexia. This may have affected the results obtained, although the strong theme of ambivalence illustrates that participants were not biased to a positive view and the concurrence with results found in offline studies (e.g. Reid et al., 2008; Serpell et al., 1998) suggests similar beliefs between online and offline samples.

Conclusion

People wish to maintain their anorexia because of the positive effects that they get from using it as a tool, the positive feelings they get from restriction and their relationship with their disorder as a constant and reliable friend or ‘guardian’ (Serpell et al., 1999). However, at the same time anorexia plays a role of an enemy and a disease, both of which cause negative implications on the individual’s health, life and significant others and causes feelings of lost control. Individuals are therefore caught in ambivalence about whether their anorexia plays a positive or negative role and whether they wish to continue with their behaviours or recover. Participants felt fearful of seeking recovery, had low self-efficacy in their ability to recover due to being entrenched in the disorder and had negative attitudes and perceived limitations of treatment. If anorexia plays both a positive and a negative role but there are perceived barriers for remedying the negative effects then it makes sense to continue the behaviours so at least the positive effects are still experienced. This research may aid understanding as to why people with anorexia use pro-anorexic websites and why many who undergo treatment relapse or drop-out.

References

- Adams, J., Rodham, K., and Gavin, J. (2005) Investigating the “Self” in Deliberate Self-Harm. *Qualitative Health Research*, 15 (10), 1293-1309.
- American Psychiatric Association (2000) *Diagnostic and Statistical Manual of Mental Disorders*. Revised, 4th Edn (DSM-R). Washington, DC: APA.
- Bargh, J.A., McKenna, K.Y. A., & Fitzsimmons, G.M. (2002) Can you see the real me? Activation and expression of the “true self” on the internet. *Journal of Social Issues*, 58(1), 33-48.
- Bell, L. (2003). What can we learn from consumer studies and qualitative research in treatment of eating disorders. *Eating and Weight Disorders*, 8, 181-7.

Berger, M., Wagner, T.H., & Baker, L.C. (2005) Internet use and stigmatized illness. *Social Science and Medicine*, 61, 1821-1827.

British Psychological Society (2005) *Code of Conduct, Ethical Principles & Guidelines*. The British Psychological Society: Leicester.

Bruch, H. (1978) *The Golden Cage The enigma of Anorexia Nervosa*. London: Harvard University Press.

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, 12, 307-316.

Cooper, M.J. (2005) Cognitive theory in anorexia nervosa and bulimia nervosa: Progress, development and future directions. *Clinical Psychology Review*, 25, 511-531.

Davison, K.P., Pennebaker, J.W., & Dickerson, S. S. (2000) Who Talks? The social psychology of illness support groups. *American Psychologist*, 55(2), 205-217.

Dias, K. (2003) The Ana Sanctuary: Women's Pro-Anorexia Narratives in Cyberspace. *Journal of International Women's Studies*, 4(2) 31-45.

Eivors, A., Button, E., Warner, S., & Turner, K. (2003) Understanding the Experience of Drop-out from Treatment for Anorexia Nervosa. *European Eating Disorders Review*, 11 (2) 90-107.

Ess, C. and the aoir ethics working committee (Approved by AOIR, November 27, 2002) Ethical decision-making and Internet research: Recommendations from the aoir ethics working committee. Available online: www.aoir.org/reports/ethics.pdf

- Fairburn C.G., and Beglin S. J. (1994). The assessment of eating disorders: Interview or self-report questionnaire? *International Journal of Eating disorders*. 16, 363-370.
- Fox, N., Ward, K., & O'Rourke, A. (2005) Pro-anorexia, weight-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia. *Sociology of Health & Illness*, 27(7), 944-971.
- Garner, D.M. & Bemis, K. M. (1982) A cognitive-behavioral approach to anorexia nervosa. *Cognitive Therapy and Research*, 6(2), 123-150.
- Gavin, J., Rodham, K., & Poyer, H. (2008). The presentation of 'pro-anorexia' in online group interactions. *Qualitative Health Research*, 18, 325-333
- Gremillion, H. (2003) *Feeding anorexia: Gender and power at a treatment center*. Durham: Duke University Press
- Jarman, M., Smith, J.A., & Walsh, S. (1997) The psychological battle for control: A qualitative study of health-care professionals' understandings of the treatment of anorexia nervosa. *Journal of Community & Applied Social Psychology*, 7, 137-152.
- King, S. (1994) Analysis of electronic support groups for recovering addicts. *Interpersonal Computing and Technology*, 2(3), 47-56.
- Kral, G. (2006) Online communities for mutual help: Fears, fiction and facts. In M. Muero & R.E. Rice (Eds) *The Internet and Health Care: Theory Research & Practice*. London: Lawrence Erlbaum Associates, Publishers. Pp215-232.

Miller, W. R. (1998) Enhancing Motivation for Change. In W.R. Miller & N. Heather (eds) *Treating Addictive Behaviors* (2nd Ed.) pp.121- 132.

Miller, W. R. & Rollnick, S. (2002) *Motivational Interviewing: Preparing people for change* (2nd edition). The Guildford Press: London.

Millward, L.J. (2006) Focus Groups. In G.M. Breakwell, S. Hammond, C. Fife-Schaw and J.A. Smith (eds), *Research Methods in Psychology* (3rd Edition). Chapter 14. Pp276-299.

Mukai, T. (1989) A call for our language: Anorexia from within. *Women's Studies International Forum*, 12(6), 613-638.

Mulveen, R. & Hepworth, J. (2006) An Interpretative Phenomenological Analysis of Participation in a Pro-anorexia Internet Site and Its Relationship with Disordered Eating. *Journal of Health Psychology*, 11(2), 283-296.

Pollack, D. (2003) Pro-eating Disorder Websites: What Should be the Feminist Response? *Feiminism & Psychology*, 13(2), 246-251.

Reid, M., Burr, J., Williams, S., & Hammersley, R. (2008) Eating disorders patients' views on their disorders and on an outpatients service: A qualitative study. *Journal of Health Psychology*, 13(7), 956-960. .

Rich, E. (2006) Anorexic dis(connection): managing anorexia as an illness and an identity. *Sociology of Health & Illness*, 28(3), 284-305.

Schmidt, U. & Treasure, J. (2006) Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, 45, 343-366.

Serpell, L., Treasure, J., Teasdale, J., & Sullivan, V. (1999) Anorexia nervosa: friend or foe? *International Journal of Eating Disorders*, 25, 177-186.

Smith, J. A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.

Smith, J., Jarman, M., & Osborn, M. (1999) Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (eds) *Qualitative Health Psychology: Theories & Methods* pp218-240. London: Sage

Smith, J. A. & Osborn, M. (2003) Interpretative Phenomenological Analysis. In J. A. Smith (Ed) *Qualitative Psychology: A practical Guide to Research Methods*. London: Sage.

Stewart, K. & Williams, M. (2005) Researching Online Populations: the use of online focus groups for social research. *Qualitative Research*, 5(4), 395-416.

Sullivan, D. (2006) Hitwise Search Engine Ratings, Search Engine Watch. Retrieved 25th September 2006 from the World Wide Web <http://searchenginewatch.com/showPage.html?page=3099931>

Treasure, J. & Schmidt, U., (2001) Ready, willing and able to change: Motivational aspects of the assessment and treatment of eating disorders. *European Eating Disorders Review*, 9, 4-18.

Turney, L. and Pocknee, C. (2005) Virtual focus Groups: New Frontiers in Research. *International Journal of Qualitative Methods*, 4(2), 1-10.

Uca, E.R. (2004) *Ana's Girls The Essential Guide to the Underground Community Online*.

Authorhouse: USA.

Vitousek, K., Watson, S., & Wilson, G.T. (1998) Enhancing motivation for change in treatment resistant eating disorders. *Clinical Psychology Review*, 18(4), 391-420.

Walstrom, M.K. (2000) "You know, who's the thinnest?": Combating surveillance and creating safety in coping with eating disorders online. *Cyberpsychology & Behavior*, 3(5), 761-983.

Williams, S. & Reid, M. (2007) A grounded Theory Approach to the Phenomenon of Pro-anorexia, *Addiction, Research & Theory*. 15(2) 141-152.

Wolff, G. & Serpell, L. (1998) A cognitive model and treatment strategies for anorexia nervosa. In Hoek, H., Treasure, J. & Katzman, M. (eds) *Neurobiology in the treatment of eating disorders*. Chichester: Wiley.

Box 1. Topic guide

Box 1: Topic guide

Experiences of Anorexia

Q: Please could you give me a brief history of your anorexic behaviours from the beginning to the present day?

Causes of Anorexia

Q: From your understandings and experiences what factors do you think contributed to the onset of your anorexic behaviours?

Defining Anorexia

Q: What is your definition of anorexia?

The Role of Anorexia

Q: What role does anorexia play in your life? Is this a positive or negative role? Please explain.

Follow up: What do your anorexic behaviours mean to you?

Maintaining Anorexia

Q: What type of factors have influenced your decisions to maintain your anorexic behaviours?

Decisions for treatment

Q: What type of factors have influenced your decision to seek treatment? If you have never sought treatment, why not?

Diagnosing Anorexia

Q: What are your opinions on the diagnostic criteria for anorexia?

Treatment Experiences

Q: Please can you describe any experiences of treatment you have received for your anorexic behaviours?

Follow up: Which of these aspects did you find most helpful or unhelpful?

Follow up: In your opinion, what do you think treatment should consist of to ensure it is beneficial for those with anorexic behaviours?

Healthcare Professionals and Anorexia

Q: What are your opinions about the healthcare professionals who have been involved in your treatment?

Table 1: Anorexia as a Functional Tool

Contributing Factor to onset	Functional aspect of anorexia	Examples from the data
A need for control	Restraint as control	“I dont think I have ever felt in control of my own life... And this disease gives me the control over my life to do with it as I so desire.” (Jack)
A desire for perfection	Thin body as perfection	“The desire to be perfect: I’m a perfectionist, and that’s a reason why I want to be thin.” (Maria)
Self-hatred/ negativity about self	Achievement	“I want to be as perfect as possible on the outside, so that maybe I wont always be rejected, and il be more loved. I am such a disappointment, I just want to be good at one thing!” (Charlene)
	Self-punishment	“I was too stubborn and afraid to ever let anyone SEE my weakness so i just took punishment out on myself and my own body.” (Taylor)
Stressful situations/ difficult emotions	Coping mechanism	“Its how I cope and get through!” (Charlene)
	Avoidance	- “To me my ed is the one thing in my life I use to suppress all my feelings. There are just some things I still can't deal with. My ed protects me from certain feelings.” (Hailey)
Inability to express true emotions	Communication	“It's my way of talking to the world. it tells everyone what i can't. it allows me to show them how much i am hurting, how scared i am, how much i feel i am without.” (Grace)
Unhappiness	Happiness	“My behaviours are the way i can achieve happiness, so they are very important for me.” (Cristina)

<p>Changes during puberty</p>	<p>“Fight(ing) puberty”</p>	<p>“In the face of the possibility of puberty, I had this fear that if I started showing signs of 'growing up' it might make my parents feel "old" I did not want my parents to feel old or like they were losing me so I sought to 'fight puberty' by not eating.” (Taylor)</p>
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