INSIDE THE EXPERIENCE OF RECOVERING FROM ANOREXIA NERVOSA: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF BLOGS

Melanie Bradley
Dr. Susan Simpson

University of South Australia

Word count: 7474

Correspondence: Psychology Clinic, University of South Australia, Magill Campus, GPO Box 2471, Adelaide, SA, 5001.
Tel: 08 83024875
Fax: 08 8302 4894
Email: bramk003@mymail.unisa.edu.au

Abstract

This study explored which aspects of recovery from Anorexia Nervosa (AN) are perceived by sufferers as the most and least helpful, identifying turning points for change. Data were collected from 5 women using internet blog sources and analysed using Interpretative Phenomenological Analysis (IPA). Five superordinate themes were identified: factors linked to recovery, reclaiming identity, turning points, barriers to recovery, and lived experience of anorexia. The results highlight the importance of interpersonal connections in facilitating recovery, while a lack of appropriate treatment services for this client group was identified as a barrier. Accepting the paradox that one can recover in spite of high levels of discomfort and frustration during the recovery process was a major turning point identified by several sufferers. These findings contribute new evidence to further understand the individual's perspective of recovery from AN. Future research should aim to replicate these findings by using larger samples and alternative qualitative designs.

Keywords: anorexia; recovery; perspective; blogs; IPA; qualitative
Inside the Experience of Recovering from Anorexia Nervosa: An Interpretative Phenomenological Analysis of Blogs

While Anorexia Nervosa (AN) has a low prevalence rate of 0.2-0.5% in women (Beumont et al., 2004), only approximately 47% of AN patients fully recover (Steinhausen, 2002). This suggests that there is a cause for concern in regard to the effectiveness and acceptability of current treatment options for this diagnostic group.

Research on recovery from AN is currently dominated by quantitative studies, which have so far remained inconclusive about the effectiveness of currently available treatment models (Jenkins & Ogden, 2012). Even treatments with the best outcomes, such as Enhanced Cognitive Behaviour Therapy (CBT-E), show limited success, especially for anorexic disorders. In a Randomised Control Trial (RCT) using CBT-E, AN had the lowest recovery rate for full remission (17.6%) compared with Bulimia Nervosa (BN; 32.5%) and Eating Disorder Not Otherwise Specified (EDNOS; 41.2%; Byrne, Fursland, Allen, & Watson, 2011). Studies have also found AN to have high rates of treatment drop out. In a study comparing rates of client early treatment termination among different eating disorders, drop out was highest for AN (58.8%), compared with BN (32.9%) and EDNOS (49.4%; Carter et al., 2012). This is consistent with Byrne et al. (2011), where AN had the highest rate of drop out (50%) compared to BN (35%) and EDNOS (37.3%). These low recovery and high dropout rates indicate that there is considerable scope to develop our understanding of what factors drive recovery in this diagnostic group, with a view to improving treatments and treatment outcomes.

Qualitative research lends itself to addressing the issue of investigating the factors linked to recovery in AN, through its ability to tap into the lived experience of the disorder. Qualitative studies have shown women to describe important aspects of their recovery as; the therapeutic relationship (Ross & Green, 2011); achieving the “finding me” turning point, separating themselves from their eating disorder (Weaver, Wuest, & Ciliska, 2005); and social networking (Nilsson & Hägglöf, 2006).

Espíndola and Blay (2009) analysed 16 studies in a metasynthesis of the qualitative literature available for the treatment of AN. Findings of particular relevance within this study are two of the thematic categories identified; “factors which favour recovery”, encompassing subthemes such as “satisfactory affective relationships”, and “factors which limit recovery”, encompassing subthemes such as “lack of social support” (Espíndola & Blay, 2009).

The predominant method of data collection in qualitative studies to date has been based on face-to-face interviews. In order to increase the potential scope and perspectives of qualitative studies it would be beneficial to explore whether these findings are replicated in studies that collect data from alternative sources, such as blogs. These naturalistic data sources are cost effective, easily accessible and available in the public domain (Hookway, 2008). Additionally, blogs provide the benefit of individuals being able to more freely express their experiences, given the anonymous nature of online blog entries and detachment from researcher bias (Hookway, 2008).

Another gap in the qualitative literature is the limited research on ‘turning points’ for recovery. These are defined as experiences which trigger a change in the
individual's perspective that the anorexic disorder is ego-syntonic (i.e., believing the AN is consistent with who they are), to becoming ego-dystonic (i.e., being able to separate themselves from the AN; Fox, Larkin, & Leung, 2011). Nilsson and Hägglöf (2006) conducted a study to explore the perspective of individuals through their recovery of AN. Each participant successfully identified a turning point, which was often accompanied by the realisation that their behaviour could have led to further harm or even death. Turning points are particularly important due to the fact that denial and motivational resistance to recover are prevalent in the AN population. A significant challenge is presented in finding ways to assist clients in reaching a point where they can make the decision to change. However, a preliminary literature search for turning points in AN recovery raised limited results of less than ten studies. There needs to be further research into what lived experiences function as turning points, to inform the development of more effective treatment options for AN (Halvorsen & Heyerdahl, 2007). Furthermore, suggested research for this area should place an emphasis on identifying the language used by participants to conceptualise their AN. Further studies are needed to investigate the way in which sufferers experience and describe their eating disorder, as a means of increasing our understanding about the relationship that the sufferer has with their AN and to aid in developing more effective treatments (Federici & Kaplan, 2008).

It is important to consider patients' satisfaction and viewpoints on treatment approaches to direct the development of future research (National Institute for Clinical Excellence [NICE], 2004, p. 72). The lived experiences of treatment and recovery for those with AN should more frequently be taken into account in the
planning of treatment programs, as it has been suggested that the rich understanding of concepts through using in-depth qualitative approaches may make the decision making processes linked to recovery more accessible than quantitative methods (Federici & Kaplan, 2008). This qualitative literature has the potential to then direct and provide focus for future research in both qualitative and quantitative studies aimed towards treating AN.

This study aimed to investigate and interpret the treatment and recovery experiences in AN from the perspectives of recovering individuals. It addresses the importance of sourcing additional means of learning about the lived experience of AN, rather than limiting the field to interview-based studies, by sourcing naturalistic data from blogs. The study also addresses the limited research on turning points in the recovery of AN, using an Interpretative Phenomenological Analysis (IPA) approach to understand and interpret the participants' view of their experience, while also focusing on the language they have used to conceptualise their AN. The study attempted to answer the following research questions: (i) What do sufferers describe as the most and least helpful aspects of recovery in AN? (ii) What language do sufferers use to conceptualise their AN? (iii) What are the types of events or experiences described by sufferers as the turning points in their recovery of AN?
Method

Design

Data were sourced through publicly accessible blogs via the internet, which were then qualitatively analysed using Interpretative Phenomenological Analysis (IPA; Smith & Osborne, 2003).

Sample

Data were sourced from internet blogs as pre-existing, textual accounts of individuals' experiences. As they were available within the public domain, these data were treated as documentary evidence (Sixsmith & Murray, 2001), rather viewing the individual bloggers as participants, and as such did not require informed consent. Ethical issues concerning data sourcing in this study were discussed with the Chair of the University of South Australia Human Research Ethics Committee (HREC). It was advised that ethics approval was not required as the material being sourced was within the public domain, on the condition that names were not identified. The researcher remained vigilant in removing identifiable information by using pseudonyms to ensure anonymity and maintain confidentiality.

Small sample sizes are appropriate when using IPA, given the idiographic nature of this research (Shaw, 2010). Smith (2004) suggests a sample size between five and ten, while Smith and Osborne (2003) have stated five or six is a reasonable sample size for student projects. As guided by the recommendations in this literature, the current study used a sample of five blogs. When referring to a “blog”, the study classifies this as one unit of documentary evidence, which is considered to represent
several blog entries on the same website from one person. The five women who wrote the blogs were between 27 and 45 years of age, with a mean of 35 years of age.

Blogs that were used in the analysis met the following inclusion criteria: (i) the individual writing the blog has identified as being diagnosed with AN, (ii) the individual is currently recovering from AN, (iii) the individual is female, (iv) the blog is written textually, in the English language, (v) the blog is available in the public domain, and (vi) the blog is written from an adult perspective. The current study defines an individual “recovering from AN” as one who acknowledges the AN, identifies that the AN is harmful, has made the conscious decision to recover, and takes actions against the AN. As such, the study has included blogs from women who have experienced relapse, but are still considered on the path to recovery. The grounds for exclusion criteria consisted of: (i) blogs apparently written by an individual under 16 years old, (ii) blogs designed to promote anorexic behaviours, and which do not relate to the treatment and recovery of AN, (iii) blogs written over 10 years ago, (iv) blogs which require an account and password for access, (v) blogs which use forms of communication other than text (e.g., photos and videos), (vi) blog entries and comments on the same site from persons other than the AN sufferer, and (vii) blogs written by persons about the AN sufferer, rather than the sufferer themselves.

**Procedure**

Data collection took place during the month of July in 2013. The procedure for this study is illustrated in Figure 1.

**Data Analysis**

Data were analysed using IPA (Smith & Osborne, 2003). Shaw (2010) explains this research method as having epistemological underpinnings in both phenomenology and hermeneutics. As both these epistemological stances encompass the methodology for this study, IPA was appropriate to use. The goal of IPA is to explore the lived human experience through emotional states and events. This is achieved through the research analyst interpreting the meaning which the individual is making of their own experience (Smith & Osborne, 2003).

The first researcher read each transcript to familiarise herself with the data, keeping an open mind about what was being expressed. An additional reading followed, where initial thoughts about the data were recorded. Each transcript was thematically coded individually from this point. During the third reading, the left hand margin was used to write notes which summarised passages of long text and draw out interesting or significant pieces of information. In the fourth reading, the right hand margin was used to make initial interpretations by generating themes which captured the essence of the varying codes. The researcher created a list of common themes which were referred to during later analyses, to ensure the use of consistent language throughout the process. As an overestimated number of themes (2,239) were generated by the end of the thematic coding phase, each theme was given a reference code to keep track of the specific case within the transcript. Themes were clustered together and initially labelled based on connections between them, then grouped together to begin forming the basis for superordinate themes. The first researcher completed this stage for one transcript and discussed the evolving structure with a
second researcher to gain insight on the placement of the themes. This collaborative process was repeated several times during analysis. Here, further superordinate and subordinate themes were created, often by collapsing others together, and each theme listed under a superordinate and subordinate category was checked to ensure they were accurately represented. The resulting thematic structures from the meetings between researchers were then applied to the other transcripts. A master structure of superordinate and subordinate themes was created, then used to select rich quotes from the transcript.

Figure 1. Research report procedure flowchart
As recommended by Shaw (2010), a reflective diary was kept for the duration of the study, as a part of an audit trail. The diary was particularly useful to record the researcher's initial ideas about the data through to the final thematic structure. Consistent with IPA, the researcher was an integrative part of how the data were analysed. It is therefore relevant to mention the researcher was a 21 year old Caucasian female, undertaking the study as a component of her Honours year in Psychology from the University of South Australia, with no preferred theoretical or therapeutic orientation.

**Results**

Five superordinate themes were generated, each with associated subordinate themes (see Table 1). Each subordinate theme discussed has been supported by extracted quotes from the transcript, which capture its essence. The main findings of each subordinate theme will be discussed in further detail below.

**Factors Linked To Recovery**

**Practical aspects of recovery.** Chloe described how writing her thoughts down on paper helped her to see how quickly they were spinning ‘out of control’ and enabled her to analyse them more objectively, reminding her of how she would rather act. Allowing food cravings which embodied the experience of recovery was seen as important by Fiona, as she describes:

I told myself that I didn’t really like food, that it all tasted bland and I didn’t crave anything. The joke was on me. Once I started eating, I started craving

...some weird things. Like Pop-Tarts. And chocolate... with each bite, the fear lessened.

Some of the women found that challenging the AN voice within their heads repeatedly helped them overcome their desire to listen to it. Lisa describes ‘The more often you can challenge those knee-jerk cognitive responses, the weaker they'll become, till most of them do die out entirely.’

**Interpersonal connection.** Several women described the key role of having loyal friends who supported them tirelessly and urged them determinedly to choose recovery. Without having this support during her initial decision making, Lisa ‘couldn't have managed it ...not in the same way.’ This social support continued throughout her recovery, strengthening Lisa's healthy authentic voice and her desire for recovery along with it:

He made me feel less alone, and less deadly serious, in my endeavour. And that allowed the other element that went along with the fear - the longing - to whisper a little louder than it would otherwise have done.

Although support was recognised as an essential ingredient for change, several women described difficulty in asking for the support they needed due to their fear of becoming a burden to others. Chloe developed a healthy system to ease her fears about becoming a burden:

I try to add a new person to my growing list of supports every week... I hate the thought of being a burden to anyone... the more supports I have, the less likely I will feel like I am constantly boring just a handful of friends with my problems.
Pro-recovery attitudes. Recognising the value of one's own efforts in working toward change, as opposed to judging oneself in black-and-white terms, was seen as a critical step in recovery by several women. ‘The rough patches don't mean you're failing. They mean you're trying’ (Amy). Fiona described herself waking up in the morning, and not wanting to get out of bed for fear of reality, but then told herself ‘I can either let this defeat me, or I can fight back and have the life that is waiting for me.’ Fiona has acknowledged that attaining this would incur letting go of the AN from which she once thought was the only way to live out her life. She recognises that there is an element of choice and persistence to achieve full recovery and that she would need to ‘grasp recovery with both hands, hold on, and never let go.’

Table 1
Summary of Superordinate and Subordinate Themes

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factors linked to recovery</td>
<td>Practical aspects of recovery</td>
</tr>
<tr>
<td></td>
<td>Interpersonal connection</td>
</tr>
<tr>
<td></td>
<td>Pro-recovery attitudes</td>
</tr>
<tr>
<td></td>
<td>Tackling problems</td>
</tr>
<tr>
<td></td>
<td>Treatment factors</td>
</tr>
<tr>
<td>Reclaiming identity</td>
<td>Conceptualisation and externalisation of AN</td>
</tr>
<tr>
<td></td>
<td>Accepting imperfections</td>
</tr>
<tr>
<td></td>
<td>Separate healthy authentic self from AN</td>
</tr>
<tr>
<td>Turning points</td>
<td>Recognising the costs of AN</td>
</tr>
<tr>
<td></td>
<td>Individuals' specific turning points</td>
</tr>
<tr>
<td></td>
<td>Recognising the investment needed in recovery</td>
</tr>
<tr>
<td>Barriers to recovery</td>
<td>External barriers</td>
</tr>
<tr>
<td></td>
<td>Factors linked to failure to engage and relapse</td>
</tr>
<tr>
<td></td>
<td>Costs of giving up AN</td>
</tr>
<tr>
<td></td>
<td>Unhelpful aspects of treatment</td>
</tr>
<tr>
<td></td>
<td>Heightened emotion</td>
</tr>
<tr>
<td>Lived experience of</td>
<td>Underlying emotional vulnerability and distress</td>
</tr>
<tr>
<td>anorexia</td>
<td>Functions and maintaining mechanisms of AN</td>
</tr>
</tbody>
</table>

**Tackling problems.** ‘If recovery were a road, then these issues would be my roadblocks’ (Julie). The women described feeling increasingly well equipped to deal with threats to their recovery ‘by addressing these issues head-on.’ Lisa discovered the compulsion to compare herself to other women was a dangerous habit, but difficult to resist. She expresses:

> The sting can be taken out of them [comparisons] if you try to widen the scope of those comparisons by choosing a part of the body of the other person that isn't weight-related - their hair, or their feet, or something.

Similarly to Julie, Fiona also found she would not allow her triggers for relapse to ‘derail’ her journey to recovery and would instead advise herself to ‘take each trigger and exam [sic] it. See what it might have to teach you about society's unrealistic expectations and turn it around into a way of accepting yourself.’

**Treatment factors.** Julie described particular aspects of Dialectical Behaviour Therapy (DBT) to be important during her treatment, particularly the distress tolerance module, as she was able to create a list of ‘alternative behaviours’ to engage in as a substitute for AN behaviours. Julie also describes her relation to the DBT term, “radical acceptance”, stating:

> Sometimes, recovery sucks. It sucks much less than anorexia does, but it still sucks. I've found the only way to get through these tough times is to accept that this will suck. And that it's okay. The suckiness will eventually pass. Giving myself permission to utterly hate this part has actually been somewhat liberating.

Only once she had found a ‘helpful therapist and dietitian who could see through the ED bulls**t’ could Julie finally receive the most appropriate plan of action for her recovery. Similarly, the therapeutic rapport between Fiona and her eating disorder psychiatrist was a particularly vital treatment factor:

Although I often prayed that I would die from anorexia... a tiny flame of hope flickered within my heart after I met my current eating disorders psychiatrist... I trusted him the minute I met him and we have built a very strong therapeutic relationship that has been invaluable in my recovery process.

Reclaiming Identity

**Conceptualisation and externalisation of AN.** Fiona conceptualised her AN as serving a clear purpose and function in her life: ‘Being thin is the outward manifestation of the inner turmoil and anxiety that I feel daily... Take away my thinness and how do I show you that I still have these feelings?’ She began to envisage her AN voice as ‘Nazi Brunhilde’, ‘evil’, and as a thief:

Anorexia is a thief that has stolen my self-confidence... my dreams of a full, rich, joyful and normal life. I want back what anorexia has stolen... Like any thief, anorexia isn't going to just give me back the traits it has stolen from me...

I have to take back my stolen life.

Similarly, Lisa began to conceptualise both the AN and associated rituals almost as if they were “foreign beings”. This allowed her to get in touch with negative feelings of resentment and anger toward the disorder: ‘I'd come to think of the obsessive-compulsive habits that haunted me as “sl*ts”, because I despised them so much, even while I was seduced by them.’ As she began to externalise the AN during her
transition to recovery, Lisa remembered the feeling as ‘coming from the darkness into the light. I cried at the memory ...my body responded to that warm pastry like a sign of forgiveness.’

Accepting imperfections. ‘Have a little grace’ (Amy). The women described that being able to accept their perceived flaws was a significant step to reclaiming their identity. It enabled them to discover how they could function within society without AN:

Recovery means accepting the full catastrophe of life. It means juggling many different roles and tasks, and it also means that you won't be everything to everyone. It means dealing with people rather than calorie counting manuals. It means–and this is a big one for me–accepting uncertainty and imperfection. (Julie)

The feeling passes. I know it does. And I know that I haven't done anything wrong. I need to remind myself of this positive fact ...I'm not stupid and incompetent. If I have made a mistake, it's just a mistake. I can face it and deal with it, but it's not the end of the world. I am not to blame for everything ...This feeling will pass. (Chloe)

Separate healthy authentic self from AN. Learning how to “strip away” the AN and reclaim their identity was described by the women as an important aspect in the recovery process. For Fiona, her identity was ‘wrapped up in being thin and sick’ and her small clothes were ‘symbols’ of that identity. To shed away this anorexic identity and reveal who she is underneath, Fiona's first step was to rid herself of the anorexic clothes:
These clothes were the barometer of my identity. If I could fit into them, I was me. If I could not, I had to strive to... recovery means jettisoning anorexia and embracing life... discovering a new identity, the person hidden behind the layers of starving and self-harm and self-hatred. I'm getting there.

Being able to differentiate between their healthy authentic self and the AN voice was also important in reclaiming their identity. Chloe describes her first experience of noticing the AN voice as harmful:

...almost like someone else was having the conversation and I was just listening-in thinking “that is such a stupid idea”... It was no longer *my* conversation - it no longer belonged to me... I've started to become able to separate my thoughts from my actions. My mind is still yelling abuse and telling me what to do (and the consequences if I don't), but my body is on auto-pilot.
Turning Points

Recognising the costs of AN. As they began to focus on recovery, many of the women began to recognise the downsides to AN, as Fiona found, ‘anorexia created more problems than it ever solved.’ Lisa expressed her regret at forfeiting ‘the chance to excel at something... in exchange for the empty talents of memorising calorie counts.’ Acknowledging that AN had left physical damage to their bodies was also an important realisation for the women.

Before the AN struck, my appetite was just fine ...I know that all of these years of having this eating disorder have probably messed that nice little system up. Maybe it will come back, maybe it won't. It's certainly not a reason to throw in the towel and give up. I need to work with my body, as it is right now. (Julie)

Individuals' specific turning points. ‘I would receive treatment for just long enough to pull me back from death's door, and then be turned loose’. This realisation that treatment and health services would not provide her with a lasting solution was described by Julie as her first turning point. She continues to explain her day-patient experience at this time:

Insurance had kicked me out, told me that I was no longer in need of health services. It was this horrific feeling, that I had been living in this bizarre limbo between deathly ill and truly healthy for years... no one was going to pull me out. Ultimately, it was up to me... I made a U-Turn. Said whatever happens can't be worse than this half-life.

Lisa described her reasons for choosing recovery differently to Julie, as having no ‘magic moment’ for wanting to resume eating, rather, she said that ‘reasons for
changing accumulate gradually, until they become more or less incontrovertible.’ A major turning point described by the women during the recovery process, was the acknowledgement and acceptance that they did not have to enjoy eating again, but they did have to do it.

I don't have to like the entrees. I do have to eat it. (Julie).

It's time to embrace my change. I'm not promising I'm going to like it. But change happens regardless of how hard we try to stop it – and this is my chance to direct and drive that change... my time to me is worth saving (Chloe).

**Recognising the investment needed in recovery.** ‘You will be a real person again, not just a starving creature. It can be done ...one mouthful at a time’ (Lisa).

Being able to take one step at a time and accept that recovery is a long process was an important realisation for the women. As Chloe states, ‘if there's one constant in recovery, it's that everything takes time. Nothing is a quick fix.’ Fiona recognised that before any work can be done on recovering, the first step will always be ‘accepting that you do have an illness that deserves and needs treatment.’ Chloe further acknowledged the importance of tangible aspects of recovery and change, especially nutritional restoration, ‘change will not happen without nutrition. No amount of introspection will compensate for starvation.’
Barriers to Recovery

External barriers. The women noticed that significant others have a tendency to make incorrect face value assumptions about the status of their recovery, and as Lisa explains ‘seeing shouldn't be believing.’

Fiona recognised the influential role of media and society, in maintaining and exacerbating AN:

I do not believe that eating disorders, and in particular, anorexia, are caused by the media and society's continued worship of those teetering between too-thin and skeletal ... However, the media and society do not make things any better, and can make things worse for some people [who] struggle with eating disorders.

Perhaps one of the largest barriers for actually receiving treatment was described by Amy, who describes the irony of insurance companies refusing financial support to AN sufferers on the grounds that they are not sufficiently unwell to warrant treatment:

It's bad enough that for 99.9% of us, our eating disorders tell us that we aren't “sick enough” to need or deserve treatment. Then to have our insurance deny claims because, essentially, we're not “sick enough”? Do you understand how that can mess with our brains?

**Factors linked to failure to engage and relapse.** Some of the women felt overwhelmed by the task ahead of them. The sheer process of increasing their eating sufficiently to gain weight was difficult for them to conceptualise in manageable steps, and hindered their ability to engage in treatment:

However negligible those kilos in some respects are, they couldn't be put on with an extra banana a day: the amount of food that had to be eaten was also dauntingly huge, it felt impossibly unfeasibly unlike anything even the greediest glutton could ever eat in a single day. (Lisa)

Alternatively, Fiona referred to external or environmental factors affecting her appetite, perpetuating her avoidance of food. She explains, ‘The heat causes me to lose my appetite, and I cut back. At first it is not intentional. I’m simply too hot to eat. But as I well know, it is a slippery slope.’

**Costs of giving up AN.** When first contemplating a life without AN, Julie acknowledged that this would mean giving up her ‘virtual valium’, her ‘go-to anxiety coping skill’, which left her to question: ‘what the heck am I going to do without my trump card?’ When faced with the removal AN as a coping mechanism, there was a very real sense of loss, even after acknowledging the destructive role of AN. For Lisa, who restricted during the daytime so that she could eat just before she went to bed, it was particularly hard to let go of this nightly eating ritual that she had held for over 10 years:
I can't give up this end-of-day pinnacle... I couldn't conceive of a life where there was no nightly ascension to this peak of physical ecstasy in eating, but instead just the dull punctuation of mealtimes, little hills along the flat as opposed to my high mountain peak.

**Unhelpful aspects of treatment.** Several women identified that information given to them by clinicians during treatment was ‘contradictory’ to the reality of recovering from AN. ‘I focused on “issues” in therapy even as what remained of my health went down the toilet. Literally ...you can practically feel yourself dying a little more each day’ (Julie). For Lisa, bringing clients with AN together in an unstructured setting was seen as a ‘hindrance’:

Anorexia is in most people a competitive illness... where many anorexics are brought together, deceptive tricks to avoid eating and avoid being accurately weighed can be shared instead of instructive reflections on illness and recovery. This can kill motivation as effectively as anything in the world.

The importance of feeling that one's therapist has taken time to understand and form a personal bond with the client was highlighted by Fiona's negative experience as an inpatient, ‘I felt she was cold and did not care if I lived or died, that I was just another eating disorder patient and that she was tired of us all.’
Heightened emotion. The predominant emotion expressed by the women as a barrier to reaching recovery was guilt. Fiona described feeling guilty in response to a sense of “fullness” whilst eating with a friend, and the thought of eating something when she was not hungry made Julie feel ‘absurdly guilty.’ Lisa explains how even her taste for food during recovery became a source of guilt: ‘The taste of that familiar cereal bar was a taste corrupted: normally it was a well-earned afternoon indulgence, but now it represented only a surrender to morning obligation, guiltier than the other despite being imposed from without.’

Lived Experience of Anorexia

While these two subordinate themes could also be classified under “Barriers to Recovery”, the researcher separated them in order to better reflect the context of the blogs in which they appeared. They have been included to provide some insight into the development of individuals’ recovery journeys.

Underlying emotional vulnerability and distress. Some women disclosed underlying vulnerabilities and fears which may have acted as a predisposing factor in the development of AN, including the need for control:

It is not the pursuit of beauty or the ideal body shape... it is a control issue. My world was spinning out of control, so I could control one thing—my weight.

And by God, I was going to do it even it ended up killing me. (Fiona)

Functions and maintaining mechanisms of AN. It was clear that AN played a highly functional role in the lives of sufferers, often compensating for aforementioned underlying vulnerabilities and fears. A frequently mentioned function which AN served was to keep anxiety ‘under control’ (Chloe). Julie found ease in the
familiarity of the AN and its perceived predictability: ‘I knew what to say and do. I had my day planned out down to the minute. It was comfortable and familiar.’ In several women, the simplicity of AN was seen to help them escape from their life problems: ‘I was lonely and miserable and not eating was a way of dulling the pain, stopping me feeling anything much’ (Lisa). Once functioning within them, the AN began to maintain itself using ingraining mechanisms. Amy identified this, explaining that ‘eating disorders thrive on secrets.’ Fiona found the energy required to hide the AN was too great, and it was instead easier to ‘stay home’ and ‘disconnect’ from her friends.

Discussion

The current study aimed to explore the experience of AN recovery from the perspective of the sufferer. Interpersonal connections were seen as one of the most helpful aspects in recovery, whereas external barriers such as insurance companies and the media were seen as damaging to the process of recovery. Permitting one's self to dislike the uncomfortable and challenging aspects of recovery while carrying on with the process was identified as a major turning point. It was also found that many sufferers began to de-identify with the AN as they recognised its consequences, learning to separate the AN from their healthy authentic selves.

Having interpersonal connections was regarded as one of the most helpful aspects in recovery. This factor includes relationships through partnerships, friendships, within families, as well as a strong therapeutic rapport with their clinician. In many cases, these relationships were identified as important for fostering
trust and strength among the women; where others would assist the sufferer in initial
decision making, attend food shopping, help them prepare meals and accompany them
to appointments. This facilitated a belief that they could attain a full recovery, as
reflected in previous findings (Federici & Kaplan, 2008; Jenkins & Ogden, 2012;
Nilsson & Hägglöf, 2006; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003; Wright &
Hacking, 2012). External barriers are perhaps the least helpful factors to recovery as
the individual has very little influence over the ability to challenge them. Both
insufficient insurance coverage and the misrepresentation of AN in the media, which
consequently fuels stigma within society, were found to contribute to the impediment
of treatment. This is consistent with existing research (Crisafulli, Von Holle, & Bulik,
2008; O’Hara & Smith, 2007), but is scarcely documented within the literature. The
research which does address the public’s attitudes towards eating disorders frequently
reports that sufferers are seen to have the ability to control their AN, and are
consequently blamed for its presence and maintenance within the individual
(Crisafulli et al., 2008). This is an extremely radical view that can have detrimental
repercussions for the sufferer, as it categorises AN as being completely underpinned
by sociocultural factors and ignores systemic (e.g., family, peers), psychogenic,
genetic or biological influences in its onset (Crisafulli et al., 2008). The current study
found one of the most damaging consequences of these varying opinions has been the
lack of acknowledgement from insurance companies as to what the most appropriate
requirements are for treating AN, placing a higher value on physical health (which
was identified as important) but disregarding the need for further psychological
treatment once physical health had been restored. The constant back and forth

---

reinforcement, between the media; in perpetuating these myths, and the insurance companies; in accepting them as fact, were both perceived to contribute to an immense barrier in the recovery of AN for those who were suffering and desperate for treatment.

The process of recovery was likely to be more successful in the aftermath of a turning point. Turning points were discussed differently among the women, where receiving treatment for just long enough to avoid death was seen as a defining moment for one woman, whereas another described it as the accumulation of reasons to recover until the scale tipped. One of the biggest turning points described by the women was the acceptance that they did not have to like recovery in order to carry out the behavioural changes required to make it happen. Acknowledging this point was often a huge step, as the women were ultimately exposing their vulnerabilities and facing life problems without the maladaptive coping mechanisms which AN provided. While tolerating exposure without AN has been documented elsewhere as a central factor in the recovery process and reclaiming identity (Federici & Kaplan, 2008; Lamoureux & Bottorff, 2005), accepting the need to engage in recovery whilst recognising that it will require an ability to tolerate feeling intensely uncomfortable (i.e., “not liking it”) is a new finding contributing to the existing body of literature on turning points (Nilsson & Hägglöf, 2006; Weaver et al., 2005).

Accepting that recovery would be hard work and time consuming was seen as liberating and helpful, assisting the women in rediscovering themselves without the harmful presence of the AN (i.e., “reclaiming identity”). This ability to accept uncertainty and to tolerate frustrations is echoed in previous research (Lamoureux &

Bottorff, 2005). Another factor associated with the women reclaiming their identity was beginning to de-identify with the AN, by recognising its negative consequences and learning to view it as separate or external to their healthy authentic selves. By associating the AN with negative conceptions, the women were reminded of its harmful effects which helped reduce the temptation of becoming entrapped within the AN again. These findings highlight the importance of this de-identification process and the role of sustaining a clear view of the negative consequences of the illness throughout the recovery process.

Using blogs as the data source within this study was seen to be a major strength, as they provide advantages over other qualitative methods. In blogs, individuals will more likely express what they are really thinking and feeling without the influence of researcher bias (Hookway, 2008). Additionally, bloggers gain the advantage of being able to edit their writings before posting them, to accurately express a vivid portrayal of their thoughts; whereas during an interview, the participant may sometimes struggle to accurately express what they are feeling in a concise manner, especially if they are feeling self-conscious. There are also limitations present within this study, which need to be considered. Firstly, although the researcher adhered to the recommended sample size appropriate for IPA, the sample size is too small to generalise findings. Secondly, while the researcher judged each potential blog strictly according to the inclusion and exclusion criteria during data reduction, the end sample was selected by the researcher, and could be considered a convenient sample. Finally, this sample is made up of adult females, which limits the generalisability of these findings to males, children and adolescents.
As is common with qualitative research, the limitations of this study are largely the result of its subjective nature. However, this research does provide new insight into the factors associated with recovery from the perspective of the sufferer, which should be taken into consideration in the construction of future quantitative research in this area.

Future research should investigate the impact which insufficient insurance coverage, the media and attitudes held by society, have on treatment success for AN, in the hopes that increased awareness of AN pathology will reduce stigma and promote positive change within insurance policies. Many countries impose restrictions on the number of sessions which are offered to patients with AN through publicly funded or private health insurance. As AN is a potentially life-threatening disorder, there needs to be recognition that the current evidence points to a requirement for a minimum of 40 sessions to provide adequate treatment (Murphy, Straebler, Cooper, & Fairburn, 2010). Further studies should be aimed at specifically investigating turning points in AN recovery. This would construct a more detailed view of these experiences, to confirm whether they support existing findings in the area, as well as expand on this body of knowledge. Finally, further qualitative research into understanding the way sufferers conceptualise their AN should be conducted to further understand the actual relationship between the sufferer and their eating disorder, and the role of externalisation and de-identification in the recovery process.
Conclusion
This qualitative study has aimed to explore the experience of AN recovery through the perspective of the sufferer. Blogs provided rich content, and were used as the data source for the analysis. The findings suggest that interpersonal connections can be one of the most helpful aspects of recovery, while some of the least helpful aspects are external barriers such as insurance companies and the media. This study also provides preliminary findings, suggesting that allowing one's self to dislike the uncomfortable and challenging aspects of AN recovery while carrying on with the process is a major turning point. The study also found that as the sufferers started to recognise the consequences of AN, they began to de-identify with it and separate the AN from their healthy authentic selves. The generalisability of these findings is limited due to the qualitative nature of the research. It has been suggested that future research be carried out to investigate the extent to which insufficient insurance coverage, the media and attitudes held by society, have on treatment success for AN.

References


