

**A thesis submitted to the University of Birmingham in partial fulfilment of the  
regulation for the degree of**

**DOCTOR OF CLINICAL PSYCHOLOGY (DClinPsy)**

**VOLUME I**

**Research Component**

**Recovery from Anorexia Nervosa: A Systematic Qualitative Review**

**&**

**Chronic Anorexia Nervosa: The Personal Meaning of Symptoms and Treatment**

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## Overview

This thesis presented comprises two volumes. Volume I is the research component and is made up of three papers consisting of a literature review, empirical paper & Public Domain Briefing Paper. Volume II is the clinical component and is a collection of five Clinical Practice Reports (CPR) completed whilst on placement over the course of clinical training.

### Volume I

The first paper is a systematic review and meta-synthesis of qualitative studies which have investigated service users' experiences of recovery from Anorexia Nervosa (AN). In total, eleven studies were selected for review. The methodological quality of the studies were critically appraised. Themes identified the process of recovery is a complex psychological process, which involves women to reclaim an identity and sense of value and worth separate from AN. The experience of acceptance through meaningful relationships, and then the experience of acceptance of the self are the most important factors in determining long-term outcome.

The second paper is an empirical study which aimed to investigate the experiences of clients with chronic AN. In total, 6 women with recurring difficulties of AN for over a decade were interviewed regarding their experience of their eating disorder and of their treatment. Interpretative Phenomenological Analysis (IPA) was utilised as a framework for data analysis. Results identified the functional role of AN to resolve complex underlying psychological difficulties, and the role of unhelpful treatment experiences and negative relationships with staff in the maintenance and chronicity of AN.

Both of these papers were written with the aim of publication in the International Journal of Eating Disorders.

The third paper is a Public Domain Briefing Paper, this summarises both papers in language which is accessible to the general public.

## Volume II

The second volume is the clinical component. It consists of five CPR's, each completed whilst on placements over my clinical training.

CPR1 (Child and Adolescent Mental Health Service, year 1). The first CPR presents a 9 year old girl with behavioural problems. This report details the assessment process, and formulates her difficulties from two psychological perspectives; cognitive behavioural and systemic.

CPR2 (Child and Adolescent Mental Health Service, year 1). The second CPR was an evaluation of staff and service user experiences of using an outcome measure within a child and adolescent mental health service. The findings are incorporated into a set of recommendations for the team to inform discussions with regard to the implementation of these measures within the service.

CPR3 (Child Learning Disability Team, year 2). The third CPR employed a single case experimental design to evaluate the effectiveness of a psychodynamic and behavioural intervention for an 18 month old girl with physical health difficulties and global developmental delay, presenting with sleep difficulties. A sleep diary recorded by parents enabled the use of an A-B design to measure change.

CPR4 (Older Adult, year 2). The fourth CPR was a case study of a 75-year-old woman presenting with long standing depression and previous suicide attempts. A formulation based on a cognitive behavioural model was initially used to guide the intervention; however a reformulation was undertaken using a Psychodynamic perspective to meet the client's needs.

CPR5 (Adult Eating Disorders, year 3). Finally the fifth CPR was an oral presentation of my work with a 17 year old woman referred to the Eating Disorder Service with Anorexia Nervosa.

Systemic and psychodynamic models were used to assess and formulate her difficulties. As CPR5 was an oral presentation, only the abstract is presented.

## **Acknowledgements**

Firstly, I wish to thank all the participants who took part in the study. Thank you for sharing your stories with me. I have been moved and touched by the experiences you shared. I hope this study reflects your experiences and benefits you and others who are in a similar position.

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## **Recovery from Anorexia Nervosa: A Systematic Qualitative Review**

## Abstract

**Background:** Anorexia Nervosa (AN) is a complex and challenging condition and recovery is often a slow and difficult process.

**Aims:** This paper aims to systematically review qualitative studies which have investigated service users' experiences of recovering from AN and carry out a meta-synthesis of the themes they identified.

**Methods:** Meta-ethnography was used to select and synthesise the studies. Articles published between 2002-2014 were searched in PsycInfo, EMBASE, CINAHL and Medline. Studies were included if they explored recovery from AN using a qualitative design. The methodological quality of the studies was critically appraised.

**Results:** 11 studies were selected for inclusion. Themes identified the process of recovery from AN as a fragmented sense of self, to a turning point where insight and commitment to recovery is developed, and, in recovery, a reclamation of self through meaningful relationships, rebuilding identity and self-acceptance.

**Conclusions:** Recovery from AN is a complex psychological process with many contributing factors. Findings highlight the need to reconsider clinical practice & treatment provision to incorporate the psychological components of self-identity into recovery programmes.

**Key words:** Qualitative systematic review, meta-synthesis, lived experience, Anorexia Nervosa, recovery

## Introduction

### 1.1 Anorexia Nervosa

Anorexia Nervosa (AN) is a serious mental health condition with numerous physical, psychological and social difficulties. AN is characterised by significant reduction in food intake, resulting in severe weight loss in relation to age and height. Weight gain is feared and avoided and perceptions of body weight and shape are disturbed (DSM-IV; APA 2000). There is no known etiology for AN and it appears that the pathway is influenced by a number of risk factors such as a genetic predisposition, familial difficulties, low self-esteem and high anxiety (Steinhausen, 2002). The course of AN can have severe adverse effects on the individual, indeed AN has the highest mortality rate of any mental health problem and outcome studies suggest that less than half of sufferers are recovered at follow up (follow up ranged from 1-29 years; Steinhausen, 2002; Harbottle et al, 2008). Despite research on treatment effectiveness and ongoing development in therapies, recovery rates have not improved and successful intervention remains limited with up to one-fifth of sufferers developing a chronic condition where they do not recover from their anorectic symptoms (Steinhausen, 2002; Strober, Freeman & Morrell, 1997).

There are a number of accepted treatment methods for AN (e.g. Family Therapy, Cognitive Analytic Therapy (CAT), Interpersonal psychotherapy) and the settings for these vary from outpatient care to intensive inpatient care (e.g. NICE, 2004). However, treatment evidence remains limited as reflected in the NICE guidelines (2004), where recommendations are based on weak evidence. Indeed, there are no Grade A recommendations for AN. Several problems have been highlighted with research into treatment effectiveness for AN which include high attrition rates, small sample sizes, insufficient rigour in design and analysis, and a lack of standardised definitions (Agras et al, 2004). Consequently, there is a lack of evidence to determine how services can support the process of recovery and uncertainty about the factors that lead to successful recovery and it is thus not possible to reliably predict which patients will recover and which will develop chronic AN (Strober, 2004).

AN imposes a heavy financial burden on health care services as patients often suffer multiple long term medical complications as a result of the condition, and have repeated episodes of hospitalisation. Those in recovery tend to present with poor weight maintenance after treatment and there is increased risk of relapse and readmission for those treated as inpatients (Vandereycken, 2003). The length of time that an individual has been free of symptoms post treatment has varied between studies (follow up period of 1-29 years; Steinhausen, 2002) and in some cases only brief time periods (Strober, Freeman & Morrell, 1997). Most researchers have only investigated only short term physical recovery and in order to determine whether full recovery has been achieved, a more comprehensive and long-term approach, including the measurement of psychological, behavioural and social functioning, is needed (Bardone-Cone et al, 2010).

## 1.2 Recovery

Recovery from AN is a complex process that rarely occurs quickly (Strober, 2010). The length of time to recovery has been reported to be on average 6 years (e.g. Treasure, Schmidt & Hugo, 2005 cited in Tierney & Fox, 2009). There are significant methodological issues in relation to the definition and measurement of recovery from AN with criteria varying vastly between studies and no consensus on definition. The majority of the research on recovery from eating disorders has used quantitative outcomes from a medical model perspective; which defines recovery from AN as failing to meet diagnostic criteria (due to weight gain and return of menses) (DSM-IV; APA, 2000) and/or improvement on eating disorder self-report questionnaires (e.g. EDE-Q Eating Disorder Examination Questionnaire). However, these indicators do not necessarily represent a return to normal functioning and full physical and/or psychological wellbeing. Whilst patients may have regained weight, they may still be experiencing significant psychological distress (Lowe et al., 2001). Indeed, researchers have recently identified the need for a resolution of physical, behavioural and psychological symptoms. However to date such an approach has not been consistently or widely used

(Bardone-Cone et al., 2010). Furthermore, recovery from AN may require the development of more adaptive coping strategies.

### 1.3 Qualitative Research

Recently there has been an interest in exploring individuals' lived experience of recovery (e.g. Granek, 2007; Weaver, Wuest & Ciliska, 2004). A number of researchers have used qualitative methods in an attempt to explore the experience of having an eating disorder (ED), perceptions of treatment and the identification of recovery factors (e.g. Malson, 1999; Colton & Pistang, 2004; Tierney, 2008). The results of these studies reveal that recovery from AN goes beyond conventional treatment factors, and has identified peer relationships, support from family, the individual's concept of recovery, engagement in activities, experiences that improve self-esteem and the therapeutic relationship as fundamental to recovery (Federici & Kaplan, 2008; Lamoureux & Botorff, 2005; Nilsson & Hagglof, 2006; Tozzi et al, 2003). However, our understanding of AN recovery remains limited whilst there is a growing need to support the recovery process and prevent chronicity.

### 1.4 Previous Reviews

Espindola and Blay (2009) conducted a systematic review and meta-synthesis of qualitative studies published from 1990 to 2005 on patients' understanding of treatment for AN. This identified several second order themes across articles, which included the 'process of change' and the 'perception of treatment modalities'. From this, a third order interpretation yielded a meta-category of 'self-reconciliation'. However, this review did not look exclusively at AN and focussed on all forms of eating disorders (ED). Indeed 5 included studies included mixed ED samples. Despite the suggestion of the trans-diagnostic nature of EDs (Fairburn, Cooper & Shafran, 2003) distinct differences exist between how symptoms are perceived across EDs and there are also differences in treatment requirements (e.g. inpatient care, nasogastric feeding are more specifically linked to AN; Fox, Larkin & Leung, 2011; NICE 2004). Additionally, Espindola and Blay (2009) did not report in detail their critical appraisal of the methodological quality of the studies included.

A review of 23 studies by Bell (2003) on patients experiences of treatment suggests that support, understanding and empathic relationships (professional or non-professional) are essential factors for facilitating successful treatment and that interventions that address psychological and physical outcomes are essential for recovery. However, in this review only 11 out of 23 papers were qualitative studies of patients' with AN, while the remaining studies focussed on patients' with bulimia nervosa (BN), mixed eating disorder populations or families and carers.

Considering the above findings there is a need to summarise the existing qualitative research on recovery from AN in a succinct body of evidence.

### 1.5 Meta-synthesis

The term meta-synthesis is commonly used to describe a number of methods that involve thorough examination and interpretation of the findings of qualitative research. The themes and quotations from qualitative studies are synthesized and as the methods are interpretative in nature, the aim is to further develop understanding and explanations of phenomena, generating more substantial and new insights and understanding (Walsh & Downe, 2005).

The current paper expands on the previous reviews by systematically reviewing the most recent qualitative research on the experience of recovering from AN, whilst providing in-depth methodological appraisal of the qualitative studies in a meta-synthesis.

### 1.6 Research Questions

How is the journey to recovery experienced by women diagnosed with AN? What do service users consider to be important factors determining long-term outcome?



## Method

### 2.1 Search Strategy

A systematic search of the literature was conducted using Medline, PsycINFO, Embase, and CINAHL (2002-2014). The initial search was carried out in September 2012 and an updated search was conducted in January 2014 to incorporate any recently published studies. The following exploded search terms were used:

“Anorexia” OR “Anorexia Nervosa” AND “Recovery” AND “Qualitative” OR “Narrative”  
OR “Thematic analysis” OR “Phenomenolog\*” Or “Grounded”

Additional studies were located from manual searches of previous reviews and article reference lists.

### 2.2 Inclusion and Exclusion Criteria

Studies identified were evaluated and selected if they met the following inclusion and exclusion criteria:

#### *Inclusion criteria*

- Published in the English language
- Published in a peer reviewed journal
- Included individuals with who had met DSM-IV criteria for diagnosis of AN
- Reporting qualitative research on experience of recovery from AN
- Included adolescents and/or adults only

#### *Exclusion criteria*

- Primarily quantitative in research design, including only parts of qualitative methodology
- Unpublished, case study or book chapter
- Review articles
- AN was not the primary problem or included a mixed ED sample

## Results

The systematic search yielded 158 papers, these were screened according to relevance from title and abstract. From these 20 required further scrutiny to determine whether they met the review criteria. Finally, 11 were reviewed. Studies were excluded because they included a mixed eating disorder sample (N=6); did not focus on the experience of recovery (N=2); and a case study (N=1).

A summary of the characteristics of all the studies reviewed and strengths and limitations is presented in Table 1.

### 3.1 Assessment of Quality

Assessing the quality of qualitative research has been debated for many years. There have been a number of suggestions as to what constitutes quality in qualitative studies with no consensus as to which criteria should be used. (Critical Appraisal Skills Programme (CASP) 2002; Mays & Pope, 2000; Walsh & Downe, 2005). The quality of studies included in the current review were assessed using a quality appraisal checklist incorporating ten evaluative criteria from existing qualitative quality frameworks (CASP, 2002; Mays & Pope, 2000). This method was chosen as it represents the criteria accepted as important by most researchers.

Study quality was appraised using the following criteria: (1) presence of a clear aim contextualised by existing literature; (2) the methodological design is appropriate; (3) methodological procedures presented and discussed; (4) evidence of purposeful sampling and definition of sample characteristics; (5) systematic account of data collection methods; (6) reflexivity demonstrated; (7) demonstration of sensitivity to ethical concerns; (8) systematic account of data analysis and clear audit trail; (9) results presented and evidence of credibility checks and (10) level of contribution to existing knowledge and limitations discussed.

Using the outcome ratings of Cesario, Morin & Santa-Donato (2001) each criterion was assessed and given a score of 3 points if well addressed, 2 points if adequately addressed, 1

point if poorly addressed and 0 points if not applicable or not reported to determine a profile of strengths and weaknesses. A total quality score was given as the sum of each criterion out of a possible 30. Studies that met 75%-100% of the maximum total score (22.5-30) were given a grade of “++”. These studies were considered to have high transferability. Studies that met 50%-74% of the maximum total score (15-22.4) were given a grade of “+”. These studies were defined as having a moderate transferability. Studies that met less than 50% (<15) of the maximum total score were given a grade “-“and were said to have low transferability.

The quality ratings for the studies are presented in Table 2.

Ratings ranged from 13 (Nilsson & Hagloff, 2006; Darcy et al, 2010) to 27 (Jenkins & Odgen, 2012) out of a possible 30. Six studies had a total score of 75% or more and were assessed to have high transferability (Weaver et al, 2004; Lamoureux & Bottorff, 2005; Jenkins & Odgen, 2012; Espindola & Blay, 2013; Hay & Cho, 2013; Dawson et al, in press). Three studies had a total of 50-74% and were assessed to have a ‘moderate’ transferability (Tozzi et al, 2003; Granek, 2007; Fedrici & Kaplan, 2008). Two studies had a total of <50% and were assessed to have ‘low’ transferability (Nilsson & Hagloff, 2006; Darcy et al, 2010)

Table 1. Selected research studies in chronological order and quality ratings

Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
1. Tozzi, Sullivan, Fear, Bulik (2003)  New Zealand	Interview	Thematic analysis?	69 women (average age 32.3 years)  42% restrictive AN 58% binge / purge subtype of AN  10.1% were not recovered and still met diagnosable criteria for AN	Maturation Supportive relationship Supportive friendship Support from other patients Therapy Medications' Leaving home Religion Children/pregnancy "Waking up" Increased self-esteem Willpower "Good loss" Job	Appropriate methodology and clear aim. Data collection procedure described adequately. Recovery defined as absence of symptoms.	Data analysis not explicit. No reference to saturation. Included participants who were not recovered. Reflexivity not addressed.	+
2. Weaver, Wuest & Ciliska (2004)  Canada	Interview	Feminist Grounded Theory	12 women – "recovered or recovering" Aged 14-63  Recovery defined as what the women said it was rather than by professional diagnosis.	<b>"Not knowing myself"</b> * Struggle with not knowing identity and place in society, uneasy well-being <b>"Losing myself to AN obsession"</b> Succumbing to the lure, establishing AN identity, obscuring consequences <b>"Finding me"</b> Turning point <b>Informed self-care</b> letting others in, self-development, self-awareness – acknowledging feelings <b>"Celebrating Myself"</b> moving on, restructuring relationships	Participant involvement to refine and confirm explanation of theory. Theoretical sampling to broaden age of onset and time between onset and recovery. Sample well described with reference to saturation.	No objective measure of recovery. Reflexivity not addressed. Not all participants had an official diagnosis of AN but met diagnostic criteria for AN.	++

Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
3. Lamoureux & Bottorff (2005)  Canada	In-depth open-ended interview	Grounded Theory	9 women with a previous diagnosis of AN (8 restrictive AN 1 binge-purge AN) Self-report of "recovered" Age 19-48 years	Becoming the real me. Seeing the dangers Inching out of AN Tolerating a sense of vulnerability Gaining Perspective by changing the AN mind-set Rediscovering and reclaiming self as "good enough" and accepting self.	Appropriate methodology and clear aim. Sample well described. Ongoing verification of themes with participants.	No reference to ethical approval although informed consent documented. No objective measure of recovery. Limitations and future directions not outlined.	++
4. Nilsson & Hagglof (2006)  Sweden	Interview	Content analysis	58 women – recovered from AN	<b>Turning point:</b> Fear of death/physical harm, tired of illness <b>Important people:</b> family members, friends, boyfriends & professionals <b>Willpower/Inner strength</b> <b>New activities</b>	Clear aim. More than one researcher involved in analysis.	Sample not clearly described. Method not clearly outlined. Results not supported by participant excerpts. Limited reference to credibility checks. Limitations not discussed and no suggestion of further directions.	-
5. Granek (2007)  Canada/ United States	Open-ended Interview	Grounded Theory	5 women Out of treatment for 1 year, self-identified as recovered from AN (age 25-30 years)	Relational AN – impact of peers. Self-Worth: Anorexia and the Quest for Love. Finding alternative sources of self-worth. Positive male influence. Unconditional acceptance Relationships with others	Appropriate methodology and clear aim. Reflexivity well addressed. Excerpts provided. Implications and	Sample not officially diagnosed with AN but described symptoms of AN. No objective measure of recovery.	+

Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
					future directions well documented.		
6. Federici & Kaplan (2008)  Canada	Semi-structured interview, EDE, SCID	Thematic analysis? Qualitative research software NVIVO	15 women  7 “Recovered” BMI > 19 kg/m <sup>2</sup>  8 “Relapsed” BMI<17.5 kg/m <sup>2</sup>	Internal motivation to change Recovery as a work in progress The value of specific treatments Developing supportive relationships Awareness and tolerance of negative emotion Self Validation	Clear aim, appropriate methodology and context explicit. Clear data collection and analysis. Objective measures of recovery. Excerpts provided.	Sampling bias. Limited reference to credibility checks. No respondent validation. Reflexivity not addressed.	+
7. Darcy, Katz, Fitzpatrick, Forsberg, Utzinger & Lock (2010)  United States	Mixed methods. Focus groups and semi- structured Interviews. EDE- Q, ANSOCQ, EDQOL	Thematic analysis?	20 women 19-52 years Mean age 29.35 years SD 12.11 Childhood or adolescent onset AN	<b>Symptom specific recovery</b> – eating comfortably, no distorted thinking, restoration of weight and menses, resolution of body image/self-esteem deficits, general overall healthy functioning. <b>No such thing as recovery.</b> <b>Ambivalent</b> – recovery ongoing, AN easier than recovery <b>Social/Interpersonal</b> – social/relationships, confidence/assertive	Clear aim, reference to triangulation and credibility checks. Excerpts provided.	Ill defined sample and recruitment. Data analysis not explicitly stated. Included participants who had not recovered. No reference to reflexivity.	-
8. Jenkins & Ogden (2012)	Semi-structured telephone	Interpretive Phenomenolog	15 women – 'recovered or	<b>Being anorexic</b> (Anorexic behaviour, anorexic cognitions,	Reference to reflexivity. Details	No reference to saturation of data.	++

Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
UK	Interviews	Qualitative Analysis	'in recovery' from AN 19-49 years	the anorexic voice and anorexia as a form of communication) <b>Process of change</b> (difficult journey, limitations of therapy, using therapy and relationships, managing emotions, acknowledging consequences of AN and controlling the AN voice) <b>Being recovered</b> (Ambivalence about recovery, benefits of recovery, managing AN identity and descriptions of full recovery) Dichotomies – mind & body, rational & irrational side	of sample provided. Focus on personal experience of recovery. Excerpts provided.	No objective measure of recovery.	
9. Espindola & Blay (2013)  Brazil	Semi-structured Interviews	Grounded Theory	15 women (aged 22-32). AN in remission for at least 5 years	<b>Motivation to change/stimuli</b> (Desire to change/determination, Affective relationships of support, Pregnancy, Physical complications/imminence of death) <b>Empowerment/autonomy</b> (Autonomy in relation to family environment, Self-acceptance, Spirituality) <b>Media related factors</b> (Diaries, journals, magazines, Internet, Information about AN from the media, Conferences) <b>Treatment factors</b> (Multidisciplinary, Hospital, Drug, Nutritional, Psychotherapeutic & Alternative treatments)	Clear aims and appropriate methodology. Reference to data saturation. Sample clearly defined. Remission defined as absence of symptoms confirmed by self-report, doctor & family member. Excerpts provided.	Sampling bias. No details provided of the number of participants recruited via doctor or snowball technique. No reference to reflexivity. No objective measure of remission.	++

Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
10. Hay & Cho (2013)  Australia	Written published autobiographical accounts that described recovery.	Thematic analysis QSR-NVivo software	English Autobiographical accounts that described recovery. 29 Female narratives. (N=19 mean age 34 years)	<b>Desire for recovery</b> Increased self-regard Hope Mental and physical pain against AN <b>Professional help</b> Qualities of the therapist Specific techniques <b>Hobbies - Life outside work or study</b> <b>Positive experiences within relationships</b> Other individuals with an eating disorder Responsibility towards family (Husband, Children) Supportive friends Spiritual Relationships with pets	Clear aim with focus on recovery factors. Excerpts provided. Saturation of main themes reached. Two researchers reviewed data.	Full details of sample not available from autobiographies. Limited generalizability. No objective measure of recovery	++
11. Dawson, Rhodes Touyz. In Press.  Australia	In-depth face to face interviews	Narrative Inquiry QSR-NVivo 90	8 women assessed as fully recovered (31-64 years) AN for 9-44 years (mean 15.5 years) Self-reported years of recovery 5-30 years (mean 13 years)	<b>Unable/Unready to change</b> (Maintaining energy for AN, External locus of control, AN internalised, Treatment perceived as unhelpful, Misunderstood by others, Unaware of cause/function of AN) <b>Tipping point</b> (worn out by AN, Understood by others, Increase in insight, AN externalised, Internal locus of control motivates change) <b>Active pursuit of recovery</b>	Purposive sampling. Objective recovery criteria used. Audit trail to ensure analytic transparency. Excerpts provided.	Reflexivity not addressed. Sampling bias.	++



Study (Year) Country	Data collection	Data Analysis	Participants	Themes	Strengths	Limitations	Study Quality
				(recovery orientated skills – self-awareness, mindfulness, goal setting, treatment, persistence & self-discipline) <b>Reflection and Rehabilitation</b> (Self-discovery, self-acceptance, feeling understood & accepted, rebuilding lost identity, insight into cause/function of AN, recovery end point or ongoing process?, belief recovery is possible, support from others)			

**List of table abbreviations.** ANSOCQ: Anorexia Nervosa Stages of Change Questionnaire; BMI; Body Mass Index; EDE-Q: Eating Disorder Examination Questionnaire; EDE: Eating Disorders Examinations; EDQOL: Eating Disorder Quality of Life Instrument; SCID Structured Clinical Interview for DSM Disorders.

\* Super-themes are in bold, all other themes are in normal text.

Table 2. Quality appraisal of included studies

	Quality Criteria										Total Score	Overall Rating
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)		
Studies												
1. Tozzi, Sullivan, Fear & Bulik (2003)	2	2	2	2	2	0	2	1	1	2	16	+
2. Weaver, Wuest & Ciliska (2004)	3	3	2	3	3	0	2	2	2	3	23	++
3. Lamoureux & Bottorff (2005)	3	3	3	3	2	0	1	3	3	2	23	++
4. Nilsson & Hagloff (2007)	3	1	1	1	2	0	2	1	1	1	13	-
5. Granek (2007)	2	2	2	2	2	3	1	2	2	3	21	+
6. Federici & Kaplan (2008)	3	3	3	2	2	0	3	2	2	2	22	+
7. Darcy et al (2010)	2	1	1	1	1	0	2	1	2	2	13	-
8. Jenkins & Ogden (2012)	3	3	3	3	2	2	2	3	3	3	27	++
9. Espindola & Blay (2013)	3	3	3	3	2	0	2	3	2	3	24	++
10. Hay & Cho (2013)	3	3	3	2	3	0	0	3	3	3	23	++
11. Dawson, Rhodes & Touyz (In Press)	3	3	3	3	2	0	2	3	3	3	25	++
Total Scores for Each Criterion	30	27	27	25	23	5	19	24	24	27		

- (1) Clear statement of aims/objectives contextualised by existing literature.  
 (2) Research design is clear and appropriate for the research aims.  
 (3) Methodological procedures presented and discussed  
 (4) Sample selection was purposeful and participant characteristics clearly described.  
 (5) Data collection is clear including specific instrumentation used and saturation discussed.  
 (6) Reflexivity demonstrated (relationship between researcher and participants considered, critical examination of researchers own role, personal biases etc.).  
 (7) Ethical considerations (approval sought, informed consent, confidentiality, effects of the study on participants)  
 (8) Data analysis clearly described and referred to a clear data audit trail.  
 (9) Results were clearly supported by the data (Use of quotes). Credibility of findings discussed e.g. triangulation, respondent validation, others involved in analysis.  
 (10) Contribution and implications to existing knowledge of the research, while outlining its limitations and future directions.
- 3 = Well addressed      2 = Adequately addressed      1 = Poorly addressed      0 = Not reported/not applicable

### 3.2 Critical Appraisal

The following section will critically appraise the studies.

All eleven studies reviewed were contextualised by describing existing literature, with all researchers making a clear statement of their rationale and research aim.

Most studies appeared to have a good match between research aims and chosen methodology. Of the eleven studies reviewed, eight used interviews, one used telephone interviews, one used a mix of focus groups and interviews and one used published autobiographical accounts of recovery. A range of qualitative approaches were utilised with four of the reviewed studies using grounded theory, one using interpretative phenomenological analysis, one using content analysis, one using narrative enquiry, one using thematic analysis and three studies did not specify the approach utilised. Three studies used QSR-NVivo software to aid analysis.

The sample size ranged from 5-69 (median 15) and included 247 participants in total (aged 14-64). Most studies included details of recruitment procedure and participants characteristics. All of the studies presented only female participants. The majority of the studies did not report additional demographic information such as ethnicity or socio-economic background. Indeed, only three studies reported on the ethnicity of participants (Lamoureux & Bottorff, 2005; Weaver et al 2004; Darcy et al, 2010). A strength of Espindola & Blay (2013) and Weaver, Wuest & Ciliska (2004) was the detail included of SES, marital status, religious beliefs and educational level of participants.

Recruitment varied across the eleven studies, with studies recruiting participants who had used hospital services (Tozzi et al, 2003; Fedrici & Kaplan, 2008; Espindola & Blay, 2013), child and adolescent psychiatry clinics (Nilsson & Hagglof, 2006), through posters, flyers & newspaper advertisements (Weaver, Wuest & Ciliska, 2004; Lamoureux & Bottorff 2005; Granek, 2007; Dawson et al, in press) broadcast on radio and television (Dawson et al, in press), "snowball technique" (Weaver, Wuest & Ciliska, 2004; Espindola & Blay, 2013; Granek,

2007), flyers circulated to self-help organisations (Lamoureux & Botorff 2005), community sources and internet postings (Darcy et al, 2010), and a research database from a registered charity for those with an ED and an advert on their website (Jenkins & Ogden, 2012). In studies that utilised different methods of recruitment the number of participants recruited by each method was not reported, this may have influenced the sample and pose a sampling bias.

The definition of recovery varied across studies. Five studies used absence of symptoms (Tozzi et al, 2003; Nilsson & Hagglof, 2006; Federici & Kaplan, 2008; Espindola & Blay, 2013; Dawson et al, in press). Espindola & Blay (2013) had absence of symptoms confirmed by self-report, doctor and a family member. A strength of Dawson et al (In press) study were the use of objective recovery criteria (BMI taken at time of interview, absence of behavioural features of an ED, and scoring with one SD of community norms on all subscales of the Eating Disorder Questionnaire EDE; Fairburn & Cooper, 1993). Self-reported recovery was used by Lamoureux & Botorff (2005), Granek (2007), Jenkins & Odgen (2012), Weaver, Wuest & Ciliska (2004). Hay & Cho (2013) chose autobiographical accounts that described recovery as either weight gain, or physical and psychological improvement. Darcy et al (2010) recruited participants still in the process of recovery, defined by scores on EDE-Q.

Credibility of findings was most frequently done by having more than one researcher involved in the analysis (Federici & Kaplan, 2008; Hay & Cho, 2013; Espindola & Blay, 2013; Nilsson & Hagglof, 2006; Tozzi et al, 2003; Dawson et al, in press). Jenkins & Odgen (2012) had discussion between authors but transcripts were not independently coded. Darcy et al (2010) had 20% of sample interview coded by another researcher. Only Espindola & Blay (2013), Hay & Cho (2013) & Weaver, Wuest & Ciliska (2004) discussed having reached a point of data saturation. Dawson et al (In Press) provided the most thorough attempt at ensuring credibility by keeping an audit trail to ensure transparency, coding by two researchers, memo writing and verifying the analysis with participants. Lamoureux & Botorff (2005) & Weaver, Wuest & Ciliska (2004) also involved participants in verifying and refining their analysis. All studies except Nilsson & Hagglof (2006) used quotes to support their interpretations. The

majority of the studies did not explicitly demonstrate reflexivity, (by considering the relationship between researcher and participants, or a critical examination of the researcher's assumptions, background and biases). The exceptions were Granek (2007) who provided a thorough report and reflection on her assumptions and biases and her specific view point, and Jenkins & Odgen (2012) who utilised a qualitative support group to encourage reflexivity.

Reference to ethical considerations varied across studies. Nine studies stated that they had sought ethical approval or gained participants consent. Hay & Cho (2013) due to the use of autobiographical qualitative data in the public domain did not seek approval as it was deemed not necessary. Granek (2007) only made reference to confidentiality and anonymity.

Finally, evidence of contribution and implications to existing knowledge of the research were provided by all studies. Acknowledgement of study limitations was generally provided, with the exception of Nilsson & Hagglof (2006), Lamoureux & Bottorff (2005), Weaver, Wuest & Ciliska (2004) & Granek (2007). Four studies did not give suggestions for future research (Nilsson & Hagglof, 2006; Lamoureux & Bottorff, 2005; Fedrici & Kaplan, 2008 & Tozzi et al, 2003).

### 3.3 Meta-Synthesis: Extraction and Data Synthesis.

Meta-synthesis is a term used to describe a number of methods developed to synthesise qualitative research (Bernett-Page & Thomas, 2009). These methods are interpretative, allowing the researcher to further develop understanding and explanations of phenomena across different studies (Britten et al., 2002; Walsh & Downe, 2005). Meta-ethnography (Noblit & Hare, 1988), one type of meta-synthesis, was used in the current review. This method was chosen as it allows the synthesis of studies employing a range of qualitative methods whilst preserving the structure of the primary data. The seven stages of meta-ethnography are presented in Table 3 (Atkins et al. 2008; Noblit & Hare, 1988). In sum, relevant empirical studies are selected and read repeatedly noting key 'metaphors' or themes, from quotations in the published studies and the original author's interpretation of these, these are then

translated into each other. A 'third order' interpretation grounded on the findings of the separate studies then goes beyond the meaning of the original results and interpretations, by building a 'lines of argument synthesis' which builds a general interpretation or hypothesis in relation to the area of interest (Atkins et al. 2008; Noblit & Hare. 1988).

### 3.4 Researcher Reflexivity

Due to the interpretative nature of conducting the meta-synthesis care was taken to ensure the researcher was aware of her own experience and understanding of the recovery process of AN whilst undertaking this process.

The author was in her early thirties, was married with two young girls, and training to be a Clinical Psychologist at the time of conducting the literature review. She had personal experience of recovery from AN, and accessing out-patient services from the age of 15-18 years. Conducting this review has therefore involved the author to reflect and consider her own journey to 'recovery' from AN. This frame of reference may have some bearing on the synthesis compared to someone who had never been treated for this eating disorder.

Table 3. Seven Stages of meta-ethnography

Stages	Description
1) Getting started	Determine research question
2) Deciding what is relevant to the initial interest	Defining the focus of the synthesis Locating relevant studies Making decisions about inclusion Quality assessment
3) Reading the studies	Becoming familiar with the content and detail Begin to extract 'metaphors' or emerging themes
4) Determining how studies are related	Create a list of themes and metaphors Juxtaposition of above Determine how themes are related Reduce themes to relevant categories
5) Translating studies into one another	Arrange papers chronologically Compare paper 1 with paper 2, and the synthesis of these papers with paper 3 and so on
6) Synthesising translations	Third order interpretation leading to a line of argument synthesis
7) Expressing the synthesis	Presentation of results Publication of findings

## **Meta-synthesis Findings**

The meta-synthesis elicited the following key factors in women's experience of recovery from AN: (i) [Experience of AN] - Fragmented sense of self (No sense of self, Powerless in Relationships, AN as part of identity) (ii) Turning point, (Insight into consequences of AN, Commitment to recovery, Self-awareness) (iii) [Recovery] - Reclamation of self, (Meaningful relationships – Family, Peers, Professionals, Spirituality; Rebuilding Identity, Self-acceptance). Presented in Table 4.

The over-arching third order theme across all studies was a development, understanding and acceptance of the self, which is achieved in recovery. Women develop their self-worth “the subjective feeling of having value as a human being simply by virtue of existing.” (Granek, 2007 p. 378)

Quotations from study participants appear in italics, quotations from study authors do not.



Table 4. Synthesis

The process of recovery


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<b>Experience of AN –</b>	No sense of self
<b>Fragmented sense</b>	Powerless in relationships
<b>of self</b>	AN as part of identity

---

<b>Turning Point</b>	Consequences of AN
	Commitment to recovery
	Self-awareness

---

<b>Recovery-</b>	Meaningful relationships
<b>Reclamation of self</b>	Rebuilding identity
	Self-acceptance

---

4.1 Fragmented Sense of Self4.1.1 No Sense of Self

In five studies women expressed the development of AN in the context of not having a sense of self or self-worth. (Weaver, Wuest & Ciliska, 2004; Lamoureux & Botoroff, 2005; Granek, 2007; Jenkins & Ogden, 2012; Dawson, Rhodes & Touyz, in press)

“With anorexia they experienced “a *huge sense of no sense*” of who they were... “*What we're all trying to find is ... that sense of self. Who am I? What are my boundaries?*” (Lamoureux & Botorff, 2005 p. 174.)

*“Who I am, what I want, and where I fit in” and “Restricting all your needs: spiritual, personality, nurturing. You live for everybody else.” (Weaver et al 2004 p.192).*

Whilst experiencing AN women judged their personal worth according to external standards; they experienced their life as “out of control” and had rigid expectations of what they thought they should be.

*“I was living with a focus that was outside of myself, so my worth was dependent on what others thought or said about how I behaved or what I accomplished... and how well I did a thing” (Lamoureux & Botorff, 2005 p.181).*

*“I didn’t feel like I was good enough to eat and I felt guilty every time I... took in anything... I thought I shouldn’t feel the feelings I did ... so I decided I was a bad person” (Lamoureux & Botorff, 2005 p.176).*

Weaver et al (2004) describe the impact of not having a sense of self thus:

*“They do not know how to differentiate their own needs and wants separately from what they perceive others expect of them” p. 193.*

#### 4.1.2 Powerless in Relationships

Some women described histories of sexual abuse in which they felt so powerless that they lost sight of their inner self and this sparked a need to be in control.

*“I don’t like being out of control... I think any sort of like, any, again issues of control ... any sort of sexual assault of any kind, someone’s taking some sort of control away from you so, I think, if that something that happens to you, you are going to be a person that wants to be in control.” (Granek, 2007 p. 374)*

*“A memory that I had completely blocked as a child was uncovered. During the course of therapy I suddenly remembered that I had been sexually abused by my brother. This revelation was very distressing and intense for me. My need for control made a lot more sense. It seemed clearer to me why I wanted to torture myself and why I felt so controlled and angry as a child.” (Dawson et al, in press p.16)*

Other women described relationships with partners or parents, or treatment teams that were experienced as controlling, over shadowing or abusive and not meeting their emotional needs (Weaver et al, 2004; Lamoureux & Botorff, 2005; Dawson et al, in press).

*“I started to become aware that the anorexia wasn’t a choice, it was a reaction. As a teenage girl the only thing I could control was my body because I had no power. Exploring the issues behind the eating disorder was helpful for me - knowing where my need to be perfect came from and realizing that I achieved perfection through eating.”* (Dawson et al, in press p.16)

#### 4.1.3 AN as Part of Identity

It appeared that women in the studies included in this review developed AN to manage their inner turmoil, sense of powerlessness and need to feel worthy or valued. However, they then began to lose themselves further into the obsession of AN, and this compounded a lack of a sense of self as AN became a part of their identity (Weaver et al, 2004; Lamoureux & Botorff, 2005; Jenkins & Ogden, 2012; Dawson et al, in press).

*“Women define themselves by the AN, equating self-worth with weight loss”* (Weaver, Wuest & Ciliska, 2004 p. 194)

*“I wasn’t allowed to associate with other people.... I wasn’t allowed to play sports ... so there was nothing else in my life that I was good at. My only other identity was grades and my body.... I was always known as the skinny one.”* (Lamoureux & Botorff 2005 p. 175)

One participant said:

*“At some point the anorexia took over. I didn’t understand why I was doing it but I couldn’t stop.”* (Dawson et al, in press p.13)

This illustrates the internalised nature of AN, which left women struggling to contemplate recovery.

#### 4.2 Turning Point

A ‘turning point’ was expressed by women across most studies to reflect a number of factors that lead them to commit to pursuing recovery (Tozzi et al, 2003; Weaver et al, 2004; Lamoureux & Botorff, 2005; Nilsson & Hagglof, 2006; Federici & Kaplan; 2008; Espindola & Blay, 2013; Hay & Cho, 2013; Dawson et al, in press)

#### 4.2.1 Consequences of AN

Women described how they came to acknowledge that AN was a problem and that the negative consequences and losses associated with AN (physical, psychological & social) led them to make an active decision towards recovery.

*“What am I doing to myself? What the hell is going on here? Like because something’s wrong. Before I didn’t see it as a problem—me not eating and losing weight. I thought it [AN] was the greatest thing in the world.”* (Weaver et al, 2004 p. 196)

*“It was quite shocking as well to see the damage the starvation and restriction can have and how this affect not only your body but also your thought processes”* (Jenkins & Odgen, 2012 p.27)

*“My body was crying out with pain from places I never thought could produce pain. I was thinking, ‘This isn’t fun. Why am I doing this to myself? I don’t deserve this’. From that day on I searched for the right treatment and found a therapist and dietician who led me in the beginning stages of recovery”* (Hay & Cho, 2013 p. 735)

One participant described a sense of “*hitting rock bottom.*” *“After eight years of going in and out of hospital I decided I was sick of it. I was sick of yo-yoing in and out of hospital. ‘That’s it!’ I thought.”* (Dawson et al, in press p.15)

and others of getting to the point where they were:

*“sick of being sick”* (Lamoureux & Bottorff, 2005 p. 177)

#### 4.2.3 Commitment to Recovery

A number of women spoke of their willpower and determination in taking responsibility for their own recovery:

*“I think that my own drive to get better and my commitment to myself had been incredibly important. I’m not doing it for anyone else because, as much as your parents and your friends care for you, it’s not their problem. This is up to me. I have to do this”* (Fedrici & Kaplan, 2008 p. 4)

*“In order to get out of it, I had to decide to do it and also decide on the path to take . . . Nobody else was going to do it for me.”* (Dawson et al. in press p. 18)

Pregnancy, a desire to get pregnant and responsibility towards family also were mentioned as factors that helped this process.

*“I committed myself to recovering for my sake and for the sake of my children”* (Hay & Cho, 2013 p. 736)

*“...my focus changed, it wasn't my body anymore, but my baby's...”* (Espindola & Blay, 2013 p. 2)

#### 4.2.3 Self-Awareness

A number of women began a process of self-awareness and discovering themselves during the turning point; they had begun to see themselves beyond AN but were struggling to “tolerate feelings of inadequacy and powerlessness and limited sense of identity without relying on AN” (Lamoureux & Botorff, 2005 p. 177).

One participant described the need to tolerate her sense of vulnerability and fears of being exposed and not knowing who she was:

*“That's what characterized the struggle for me ... the forward and the back.... It felt ... as I moved forward, I was moving into territory that was unknown ... an identity ... that was unknown ... into behaviours that felt unfamiliar.... So it wasn't a comfortable place. It was more comfortable even though it was torturous, there was some kind of comfort in knowing how to restrict my diet. Trying to let go of that, I felt so vulnerable... And that's where the scariness came from, that vulnerability.* (Lamoureux & Botorff, 2005 p. 175)

The quotation highlights the difficult transition for women when moving towards recovery, as fighting AN is a fight against their own identity.

The process of self-awareness “enabled women to get in touch with previously unknown aspects of themselves” (Weaver et al 2004 p. 196). They began to know who they were based on their own needs, beliefs, likes and choices, not based on others' expectations of them or AN.

*"I went to [name of treatment centre] so I could take the mask off and try to be me, whoever that was. . . . I had a lot of help finding me... You know, when I talk about my sports, that's part of who I was. And still part of who I am."* (Weaver et al, 2004 p.196)

*"I made myself more vulnerable... That was a huge step in finding out who I am"* (Hay & Cho, 2013 p.735)

In doing so, women had to actively ask for help, to let people in and begin to trust others.

*"Trust was ... such a big part [of my recovery] Because I always had a fear ... that I couldn't trust people, they would betray me somehow ... if they knew the real me"* (Lamoureux & Botorff 2005 p.176)

*"My family was very supportive at the beginning of my recovery, and I think that was the most important part... for them to take the illness seriously... their understanding [and] willing[ness] to accept that I wasn't doing this to make myself sick."* (Fedrici & Kaplan, 2008 p. 6)

#### 4.3 Reclamation of Self:

##### 4.3.1 Meaningful Relationships

Women in all studies reflected on meaningful relationships with others as being an integral component of reclaiming a sense of self in their journey to recovery. Relationships, whether with partners, family, friends, others with an ED or therapists, enabled women to learn to accept themselves through the experience of unconditional acceptance by others.

*"The therapist was the most important person during my recovery, because speaking to her about how I felt and what I thought about, and also feeling accepted by her, were the most healing aspects to me..."* (Espindola & Blay, 2013 p.3)

*"What helped me the most, my boyfriend helped me realize that I'm attractive, and that I'm a good person without the need to be skinny, like he made me realize that I'm a worthy person. That I'm a person worthy of loving without being skinny."* (Granek, 2007 p. 372)

*"When your friends just stick by ... you realize people don't like you for your body. They don't appreciate you for your looks. They like you for who you are"* (Lamoureux & Botorff, 2005 p. 180)

Developing skills in expressing thoughts and feelings, and being assertive in relationships helped women to feel validated and respected. In turn, they began to respect and see value in themselves.

*“Going through that process allowed me to reclaim and even discover maybe a sense of self because for the first time in my life I actually set some boundaries.... I actually could speak up for myself and say this was okay or that was not okay.... I'd never done that before about anything.”* (Lamoureux and Bottorff, 2005 p.177)

*“When I overcame my fear of speaking up, of saying ‘no’ and going against my family, I grew stronger and overcame anorexia... leaving my home and my parents being distant for a time, this was essential for my cure.”* (Espindola & Blay, 2013 p.3)

Women began to restructure their relationships to meet their individual needs, to detach from those relationships that did not (e.g. *“leaving husband” “leaving home”* Tozzi et al, 2003 p.148) and develop a capacity to take care of themselves:

*“I’m learning how to take care of me. And I’ve never done that. And that comes along with meeting my own needs, identifying what my needs are, and having the courage and strength to go ahead and meet them. To try to do it, I can only do what I can do. And the thing is, if I don’t meet it not to be really hard on myself. I’m very, very hard on myself. I’ve been hard on myself for years. And I am learning not to be so. So self-care, self-nurturing, I’m learning that. Some people call it selfish. I used to. But I don’t anymore. I call it self-care.”* (Weaver et al, 2004 p. 197)

One woman described this process and a reconceptualization of what defines a worthy person:

*“my own conclusion I came to, was that being a better person in terms of being kind to other people and other beings and being you know, a happy person... surrounding myself by people that I liked, things that I liked, interesting travel, that’s a much better way to, get to be, that’s a better definition of a good person then just being thin.”* (Granek, 2007)

For some women having religious beliefs were identified as an important aspect in their journey to recovery. (Tozzi et al, 2003; Espindola & Blay, 2013; Hay & Cho, 2013).

*"...I didn't feel alone at all, because I believed there was a higher power, stronger than all the ghosts, stronger than this disease."*(Espindola & Blay, 2013 p.3)

*"Spirituality has played a large part in my recovery"* (Hay & Cho, 2013 p. 736)

#### 4.3.2 Rebuilding Identity and Self-Acceptance

From their experience of having relationships with others, the women in the studies began to redefine themselves and their personal worth from within. They described the importance of accepting themselves as they were and rebuilding an identity.

*"I have value just for who I am ... in this very moment, and ... I don't need to improve to have value" and "There was nothing to prove anymore, I had my own approval. [Before] I was seeking it always in others ... and once I gave [it] up ... I did the healing around that"* (Lamoureux & Botorff, 2005 p.182)

*"One crucial lesson for me was that I mattered"* (Hay & Cho, 2013 p 735)

*"I have a new identity, I am a student, a friend, I have a social life and I know that people don't see me as anorexic, I might have a history of that but they see me as other things first"* (Jenkins & Ogden, 2012 p.29)

*"It was like having a valuable smashed plate and putting all the pieces back together to rebuild your identity and reclaim it."*(Dawson et al, in press p. 21)

Developing a capacity to be kind and compassionate to themselves whilst accepting their imperfections was a final stage in the process of recovery (Weaver et al, 2004, Lamoureux & Botorff, 2005; Hay & Cho, 2013; Dawson et al, in press)

*"Above all, I know that I must remain gentle with myself. I must forgive myself, honour my emotions, and allow for room for change and growth. This is how I manage to stay on the 'in recovery' side of that fine line"* (Hay & Cho, 2013 p.735)



## Discussion

This novel review synthesised eleven papers which contain qualitative data on women's experiences of recovery from AN. This review is unique because it looked exclusively at participants who had recovered from AN, and reports a detailed critical appraisal of the methodological quality of the studies included, into a succinct body of evidence. This provides new insights and understandings of the recovery process, which at the time of writing has not been researched elsewhere.

The findings of this review suggest that recovery is a complex psychological process. Initially, when experiencing AN women have no sense of self, feel powerless in their relationships, and AN becomes their life and part of their identity. To move towards recovery the individual reaches a 'turning point' where they develop insight into the function and consequences of AN, and commit and take responsibility for recovery. The experience of meaningful relationships, where they felt accepted and validated, enabled women to reclaim an identity and sense of value and worth separate from AN. According to the women in the studies reviewed, this process of acceptance by others and then the experience of acceptance of the self is an essential factor that facilitates recovery.

### 5.1 Strengths and Limitations of the Review

The current review has a number of strengths and limitations. An in-depth literature search was carried out using different electronic databases, and authors were contacted for 'in press' material. The review utilised the most recent studies on recovery from AN, and used a clear critical appraisal procedure to assess each paper. The meta-synthesis allowed the integration of findings from studies with various qualitative methods to better understand the journey to recovery from AN, whilst increasing the size and diversity of the total sample. The method used (Noblit & Hare, 1988) is well established for synthesising qualitative research and allowed for a clear and detailed synthesis of the research findings whilst taking account of the methodological variability of studies and the transferability of the findings.

However, it is still questioned whether qualitative studies of different theoretical approaches can be integrated (Mays, Pope & Popay, 2005; Dixon-Woods et al, 2006). Although considered, the diversity in the quality of included studies may also have impacted on the findings. Also, some researchers have recruited participants in various “stages of recovery” (Jenkins & Ogden, 2012) or still in the process of recovering (Darcy et al., 2010). Participants’ views of recovery may be influenced by their stage in the recovery process.

Reflexivity was not addressed by the majority of the studies. Therefore study interpretations may have been affected by researchers’ own assumptions and values. This is an area that needs to be addressed in future research and may require researchers to have further training in, in order for them to feel confident in their skills and awareness of their own assumptions and values and how these may influence the data analysis. Only three studies mentioned achieving data saturation, therefore some themes may have been more dominant in the synthesis had larger sample sizes been recruited and data saturation reached. Most studies used vague recovery criteria and lacked objective assessment of recovery status. Future studies need to address this. The sample consisted of only women, there is a gap in the literature on male experiences of recovery and from different cultural backgrounds. A further limitation was that the studies were only rated by one assessor; if additional time and resources had been available a second assessor to score the papers would have helped to add validity and demonstrate reliability of the ratings. However, the thoroughness of the review and the unusual focus of the criteria, which privileges the reporting over the design helps to balance the lack of a second assessor. Finally, whilst the researcher reflected upon her own experiences of recovery from AN, this may well have influenced the meta-synthesis.

## 5.2 Clinical Implications

The studies provide an insight into women’s experiences of the recovery process. The findings support previous research that explain AN as a functional strategy and as a means of asserting control (e.g. Bruch, 1978; Strober, 2004) and suggest that care needs to be taken so that treatment does not get experienced as threatening the women’s sense of control or

exacerbating feelings of powerlessness. In doing so, staff need to be trained to understand the individual function of AN, to meet the emotional needs of patients, and utilise reflective practice to explore personal attitudes towards patients, to facilitate the therapeutic process (Strober, 2010).

The importance of motivation in recovery from AN is well established (Tozzi et al, 2003; Federici & Kaplan; 2008; Dawson et al, in press). The synthesis of the studies reviewed here suggest that women who achieve recovery reach a turning point where motivation to get well increases; the negative consequences of AN are acknowledged and insight into the function of AN is achieved. Women develop a sense of autonomy and take an active part in their recovery. In doing so, they begin to develop a sense of self. This highlights the need for interventions that facilitate self-definition and expression, separate AN from the individual and their healthy qualities, and assesses readiness to change (Dallos, 2004; Espindola & Blay, 2009).

The findings of this review highlight the importance of developing unconditionally supportive relationships in the therapeutic process. Whilst the findings do not suggest one particular approach to use in therapy, it does suggest the need for therapists and therapy teams to validate and respect clients' perspectives. Thus, the findings support the evidence base that suggest that the quality of the therapist-client relationship is the most powerful factor in promoting change (Asay & Lambert, 1999; Wampold, 2001). An awareness of this may influence how treatment teams engage individuals with AN. The influence of meaningful relationships is crucial in recovery and highlights the importance of maintaining and establishing a social support network which can be maintained in the long term.

The themes regarding the development of identity in the process of recovery mirrors the normal adolescent process of the development of self (Erikson, 1982). Erikson (1982) proposed that self-development begins with trust in others to navigate through feelings of doubt, inferiority and confusion over identity. The developmental processes of separation-

individuation, autonomy, achieving a clear identity, are key tasks in the adolescent period, and these are themes that emerged in the reclamation of self during recovery from AN identified by the current review. As AN typically develops during adolescence (Newman & Newman, 2003) this suggests that a struggle with the development of identity is associated with AN onset. In recovery from AN, rather than occurring as a natural developmental task, development of identity becomes a conscious task for the individual (Lamoureaux & Bottorff, 2005) indicating that prevention programmes may benefit from incorporating interventions aimed at developing self-worth, identity and self-esteem at a young age.

### 5.3 Future Research

Participants in this analysis attributed their recovery to various psychological components but very few of the participants attributed their recovery to the physical process of gaining weight, which is the predominant focus of most recovery programmes. Indeed, the finding that treatment focuses too heavily on weight gain with a lack of help to address underlying psychological difficulties was implicated in the experiences of women with chronic AN reported by Stockford, (this volume). This supports the measurement of psychological, behavioural and social functioning in determining the outcome of AN (Bardone-Cone et al, 2010) and a need for incorporating dominant psychological and social components into recovery programmes.

This review has highlighted the need for the development of a clinical measure of identity which would enable practitioners to understand what components of self-identity are important in AN. Currently, various terms are being used interchangeably, therefore there is a need to research the concept of 'self' in the context of AN.

In view of the limitations of the studies reviewed, future research with increased methodological rigour is needed. Also, as the literature on male experiences of recovery and the impact of different cultural backgrounds on AN recovery is scarce, further research could address these omissions and compare the experiences of groups with different demographic characteristics. This would increase the generalizability of the findings and develop deeper

understanding of the recovery process. Finally, further research could also explore family members', partners', friends' and therapists' views on the factors they believe to be important in recovery.

#### 5.4 Conclusion

In conclusion, qualitative research allowed for understanding and exploration of the lived experience of recovery from AN, and recent research in this area has been reviewed. The review indicates that recovery is a complex psychological process, which involves women to reclaim an identity and sense of value and worth separate from AN. The experience of acceptance through meaningful relationships, and then the experience of acceptance of the self are the most important factors in determining long-term outcome. These findings need to be utilised to inform future research and inform service delivery.

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## **Chronic Anorexia Nervosa: The Personal Meaning of Symptoms and Treatment**

### **Abstract**

The current study aimed to explore the experiences of clients with chronic anorexia nervosa. Six women with recurring difficulties of Anorexia Nervosa (AN) for over a decade were interviewed regarding their experiences of their eating disorder and of their treatment. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis. The results identified the functional role of AN to resolve complex underlying psychological difficulties (in particular a lack of sense of self and search for identity), and the role of unhelpful treatment experiences and negative relationships with staff in the maintenance of AN. The themes provide an insight into the problems of women who struggle with their eating disorder for many years. The clinical implications of the findings are discussed in the context of the need for services to move away from focussing too much on weight and eating, towards facilitating clients to address the underlying issues of the disorder.

## Introduction

### 1.1 Anorexia Nervosa

Anorexia nervosa (AN) is a disorder where the outcome is variable and recovery is often a slow process (Strober, 2010). Intensive treatment has been found to be effective in decreasing symptoms in the short term (Steinhausen, 2002). However, a vast majority of patients resist treatment and drop out prematurely, and relapse rates for weight restored patients are high (Cooper, 2005; Eivors, Button, Warner & Turner 2003; Guarda, 2007; Mahon, 2000). Indeed, long term outcome studies of AN have shown that a significant proportion (<50%) of individuals do not fully recover from their anorectic symptoms and up to one-fifth of patients develop chronic symptoms (Steinhausen, 2002). Predictors of outcome have been inconsistently identified in the literature (for a review see Wallier et al, 2009). There is some evidence to suggest that relapse is more likely to occur in those patients who purge, present with a lower body weight, have a longer duration of AN, early age of onset, dysfunctional family environments and significant co-morbidity (Noordenbos, Oldenhav, Muschter & Terpstra, 2002; Steinhausen, 2002; Strober, Freeman & Morrell, 1997). Nevertheless, the role played by such factors in determining the course and chronicity of anorexia nervosa in some patients remain unclear.

### 1.2 Definition of 'Chronic' AN

In recognition of the proportion of individuals who do not recover from their anorectic symptoms, the term 'chronic' AN, or similar constructs, have appeared in the literature over recent years (Geller et al, 2001; Noordenbos et al, 2002; Strober 2004). However, attempts to delineate such cases have lacked definition with length of illness and number of unsuccessful treatment attempts being used as inclusion criteria (Noordenbos, Jacobs & Hertzberger, 1998; Noordenbos et al, 2002; Strober, 2004). In view of this Tierney & Fox (2009) conducted a study to explore healthcare practitioners' views of what constitutes a chronic case of AN. The study identified a lack of readiness to change, maintenance of a low BMI (17.5 or under), and a firm

interconnection of AN with identity as criteria for chronic AN. However, the labelling of a patient as 'chronic' has been debated with no consensus as to the usefulness of such a label (Noordenbos et al, 1998; Theander, 1992; Tierney & Fox, 2009). For the purpose of this study the term 'chronic' will be used for sufferers with recurring difficulties for over a decade, who had onset of AN in adolescence to early twenties and who are now over the age of 30 years. The adverse effects of having AN for a long period of time are multiple and severe and include physical, psychological and social problems (Noordenbos et al, 2002) yet an understanding of the meaning attributed to symptoms by clients with chronic AN has not been adequately explored.

### 1.3 Treatment

The complexity and challenge of working with people with chronic AN has been highlighted and there has been increasing interest into what makes good care and treatment of long term cases of AN, with clinical paradigms and rehabilitative models indicated in the literature (Geller et al, 2001; Strober, 2004; Tierney & Fox, 2009).

There have been a number of studies that have begun to explore AN and its treatment from the patient's perspective, the majority focussing on the recovery process (e.g. Darcy, Katz, Fitzpatrick, Forsberg, Utzinger & Lock, 2010; Federici & Kaplan, 2008; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). The process of change has been found to be complex and involves a variety of factors such as social support, motivation, and treatment specific factors. In a meta-ethnographic analysis of qualitative studies about the treatment of AN published up to 2005, a number of second and third order themes were identified across articles by Espindola and Blay (2009). In particular, professionals' 'rigidity and lack of sympathy' limited change for patients. In addition, the theme 'perception of treatment modalities' suggested that AN needs to be understood in a broad manner considering the individual as a whole including biological, psychological and social aspects, with patients showing a preference for psychosocial interventions. Approaches directed towards nutrition and weight gain were perceived to be ignoring the central psychological aspects of AN. The authors postulate that the difficulty in

treating patients with AN is due to the complex psychological mechanisms involved, especially an impaired sense of identity.

#### 1.4 Resistance to Treatment

Explanations for limited treatment efficacy and poor outcome have largely focussed on factors relevant to the patient. Thus, patients have been characterised as being in denial of their illness, 'difficult to treat', 'uncooperative', 'non-compliant' and 'impervious to treatment' (Kaplan & Garfinkel, 1999; Vandereycken & Vansteenkiste, 2009). AN is one of the few psychopathologies that can be considered ego-syntonic, in that the individual values their symptoms (Schmidt & Treasure, 2006). Strober (2004) suggested that AN is often an ego-syntonic disorder because it serves an adaptive organising function to the individual to fix underlying psychological problems. It is argued that the functional nature of AN contributes to why the disorder is so resistant to treatment, as patients are reluctant to give up something they feel compelled to do and the positive aspects they get from it (Geller, Williams & Srikameswaran, 2001; Nordbo, Espeset, Gulliksen, Skarderud and Holte, 2006).

A number of qualitative studies have explored the meaning of anorectic symptoms with an aim of understanding the maintenance of AN (e.g. Fox, Larkin & Leung; 2011; Nordbo et al, 2006; Serpell, Treasure, Teasdale and Sullivan, 1999). Restrictive symptoms have been found to have a powerful personal significance and value. For example, Serpell et al (1999) in a grounded theory analysis of letters written by patients to their anorexia as a friend and enemy, found that the illness provided protection, control and structure, a sense of specialness and achievement, and allowed the communication of emotions but that the costs of the disorder were damage to personal relationships, constant thoughts about food and feeling taken over. Similarly, Nordbo et al (2006) identified eight constructs regarding the psychological meaning of anorexic symptoms; 1) stability and security; 2) avoiding negative experiences; 3) demonstrating mental strength; 4) deriving a source of worth; 5) creating an identity; 6) eliciting care; 7) communication; 8) to die. All of these constructs indicated that the anorexic behaviour was purposeful and functional to the individual.

Indeed, whilst the restrictive behaviour may provide positive ego-syntonic effects, the negative effects of the disorder (upon the self and others) are also acknowledged by patients resulting in strong feelings of ambivalence. The ambivalence experienced by those with AN has been consistently identified in the research literature (e.g. Colton & Pistrang, 2004; Fox, Larkin & Leung, 2011; Reid, Burr, Williams & Hammersley, 2008; Williams & Reid, 2010). Participants in a study by Fox et al (2011) illustrated the paradox of how the eating disorder behaviour provides a sense of control, order and predictability but as the eating disorder becomes more entrenched they feel that they are now controlled by the eating disorder. Similarly, Williams & Reid (2010) found that participants felt ambivalent about whether AN gave them control or controlled them, and whether it played a positive or negative role. The feeling of losing control to the restrictive behaviours has been shown to lead to treatment seeking behaviour (Reid et al, 2008).

A recent qualitative study by Darcy et al (2010) identified aspects of the treatment setting as the most commonly cited reason as to why patients drop out of treatment, which is in contrast to the bulk of the literature in this area which has tended to report patient characteristics (e.g. clinical presentation or personality factors). Whilst these studies help to unravel the complex processes involved in treating AN, little exploration has specifically focussed on patients with a long history of AN and it is still unclear how clients with chronic AN make sense of their treatment. As such, understanding clients' experiences of their treatment is important in understanding how to help them clinically.

### 1.5 Current Study

The current study aims to address gaps in the literature by exploring the experience of clients with chronic AN and their experiences in regard to their treatment. The study used Interpretative Phenomenological Analysis (IPA: Smith, Flowers & Larkin, 2009), as this allowed the researchers to consider key themes and meanings of participants' experiences of living with and being treated for AN over a number of years, and thus to enrich our understanding of chronic AN and how best to approach treatment.

## Method

### 2.1 Participants

Six women with a diagnosis of AN and experiencing AN symptoms, aged between 33 and 48 years (mean = 35.67 years), participated in the study. N=6 is within the recommended sample size for studies that utilise IPA (Smith, Flowers & Larkin, 2009). Participants had maintained a BMI of below 17.5 and received a variety of clinical interventions over a number of years but had not made sustained progress. An overview of participant characteristics is provided in Table 6, using pseudo names. Age of onset was determined by participants' self-reports as this was thought to represent when it first became prominent for them, as formal diagnosis was often delayed. Exclusion criteria included absence of symptoms or English not being the first language.

Table 5: Participant characteristics

<b>Participant pseudonym</b>	<b>Age</b>	<b>Age of onset of eating disorder</b>	<b>Symptoms and Background Information</b>
Emma	33	19	Restriction, vomiting; also experience of self harm/low mood. She had experience of day care and inpatient treatment, psychology and also seen by community mental health team. Lives in a flat on her own.
Helena	33	10	Restriction; paediatric hospital admission and several specialist inpatient admissions. Received services and transitions across localities. Lives on her own.
Charlotte	48	20	Restriction; received help from local specialist ED team and day care

Beth	35	13	admission. Lives with husband and two daughters. Restriction, vomiting, over exercise; had experience of day care and psychotherapy. Lives on her own.
Sarah	32	15	Restriction, vomiting; received help from local specialist ED team, and had experience of admissions to several specialist inpatient units, and a general psychiatric hospital admission. She had lived on her own, recently living back with parents.
Chloe	33	13	Restriction; has experience of day care and inpatient treatment, also support from community mental health team. Lives in a flat on her own.

## 2.2 Recruitment

Potential participants were given a written information sheet by their treating clinician, along with a reply slip to return to the researcher if they wanted to participate. Four participants were recruited this way. Considerable efforts were made to achieve the final sample size, with many potential participants choosing not to take part in the study. Two further participants were eventually recruited through the snowball technique (word of mouth by a previous participant).

## 2.3 Semi-Structured Interviews

Interviews were semi-structured and non-directive to explore the women's experiences of living and receiving treatment for AN. Care was taken at the start of each interview to emphasise that the researcher was interested in their experiences. Participants were asked to provide a narrative account of their eating disorder history from age of onset until now, in regard to



treatment(s) they had received and what they had found helpful and unhelpful. Questions were also asked about how their eating disorder affected their day-to-day life and how they felt about the future (see Appendix 1 for interview schedule). These questions guided the interview, whilst the interviewer also followed up on different topics raised by participants to open up further areas for exploration.

All interviews were conducted at a location negotiated with participants; two participants were interviewed at their home (Emma & Chloe), one in a quiet room at the local University (Charlotte), three in a quiet room in the outpatient department of the ED service (Helena, Beth & Sarah) and one in a quiet room near the inpatient ward (Emma). Emma completed the interview at two separate times, once whilst she was an inpatient and the remainder as an outpatient. She requested to take a break from the interview as she was feeling unwell. All the other interviews were completed on the same day, and all these participants were outpatients at the time of interview.

Interviews were recorded digitally and lasted between 52 and 96 minutes. Travel expenses to reimburse the cost of public transport to attend the interview were provided to those who had incurred such costs. Prior to the interview commencing, participants were given the opportunity to re-read the information sheet and ask any questions, and they completed an informed consent form (Appendices 2 & 3). Interviews were transcribed verbatim with any identifiable information being removed or modified to retain anonymity. Participants were emailed a copy of their transcript.

#### 2.4 Researcher Reflexivity

Although IPA aims to generate understanding through participants' perspectives, there is an acknowledgment that IPA requires that the researcher uses their own interpretations of the meanings behind the data to generate deeper and more meaningful understandings of individual narratives (Reid, Flowers & Larkin, 2005). Therefore, care was taken to ensure the researcher was aware of her own experiences and understanding of AN whilst interpreting the data.

The researcher was in her early thirties and training to be a Clinical Psychologist at the time of conducting the research. She had personal experience of AN and accessing out-patient services between the age of 15 to 18 years, and felt such personal experiences would allow for deeper interpretations to be made. The researcher was also mindful of being in a similar life stage to participants, she remained aware of her personal feelings about what life may have been like if AN had continued to affect her life as it was affecting the lives of the participants. This frame of reference may have some bearing on the interpretations made compared to someone who had never been treated for this eating disorder.

The researcher had also completed a six month specialist Eating Disorder placement (at the same service that participants had received some of their treatment) as a requirement of her Clinical Psychology doctoral training course and this had provided insight into the challenges for clients and therapists of more intensive treatment.

## 2.5 Ethics

Ethical approval was granted from South Birmingham Research Ethics Committee (see Appendix 4).

## 2.6 Data Analysis

The interview transcripts were analysed using the principles of IPA, as described by Smith and Osborne (2008). This involved repeated and careful reading of the transcripts whilst re-listening to the digital recordings, which allowed the researcher to become immersed in the data. Initial notes and areas of interest were made in the left hand margin on a line by line basis. The researcher then re-read the transcripts to draw out the main emergent themes for each interview, particular emphasis was put on the experiential claims, concerns and understanding of each participant. These were annotated in the right hand margin. The emergent themes were then compared and integrated, noting similarities and discrepancies between them. These were then clustered according to shared meaning, and the relationship between them considered in order to form super-ordinate themes.

To validate the analysis, the researcher and the supervisor met to discuss the themes and the

relationships that emerged. Themes were linked back to quotations from the text to ensure they continued to reflect the experiences of the participants.

## Findings

Presented in Table 7 are the main themes, along with their super-ordinate theme and the participants that contributed to the theme.

Table 6 Super ordinate themes, themes and participants contributing to each.

Supertheme	Theme	P's contributing
<b>Understanding of the development of AN</b>	Specific trigger	All participants
	Perfectionist Personality	Emma, Helena, Chloe
	Chronic low self esteem/worth	All Participants
<b>Experience of AN as functional – a solution to other problems</b>	Distraction to cope/survive	Emma, Helena, Beth, Sarah, Chloe
	Safety in predictability	Emma, Beth
	Focus away from a lack of valued roles	Emma, Helena, Sarah, Chloe
	Who am I? Anorexia Identity	Emma, Helena, Charlotte, Beth, Chloe
<b>Negative effects of AN</b>	Negative impact on life	All Participants
	Family/friends not understanding	Emma, Helena, Beth, Sarah
	Social Life	Beth, Sarah, Chloe
	Impact on family	Emma, Helena, Charlotte,
	Feelings of hopelessness	Emma, Helena, Beth, Sarah, Chloe
<b>Lack of early intervention</b>	Family denial	Emma, Helena, Beth, Sarah
	Waiting lists	Emma, Helena, Beth, Sarah, Chloe
<b>Cycle of accessing services</b>	Feeling desperate for help	All Participants
	Feeling overwhelmed by food/weight gain	Helena, Charlotte, Beth, Sarah, Chloe
	Transitions between inpatients/day care and outpatients	Emma, Helena, Beth, Sarah, Chloe
<b>Negative experience of staff attitude</b>	Focus on food, weight restoration vs psychological understanding	Emma, Helena, Beth, Sarah, Chloe
	Treated as a group of patients	Emma, Sarah, Chloe
	Feeling neglected/judged vs being accepted/cared for	Emma, Helena, Charlotte, Sarah, Chloe
<b>Experience of being with other patients in specialist services</b>	Support/Friendships	Emma, Charlotte & Beth
	Competitiveness/comparisons	Emma, Helena, Sarah & Chloe
	Impact of others distress	Emma, Helena, Charlotte, Sarah & Chloe

### 3.1 Understanding of the Development of AN

#### 3.1.1 Specific Trigger(s)

This theme describes how participants developed a narrative to explain the onset of their difficulties with AN. All of the participants were able to identify specific trigger/event(s) that they felt contributed to the start and/or relapse of AN. For example:

- Beth            “I had problems with eating just generally in a different form from like early teens like my parents were having difficulties when I was eleven and they divorced”
- Sarah           “I’d just gone 15, I was at school; just at that age where you start to realise that your body’s changing with puberty and you are growing up and just a bit of bullying really at school. You always get the girl that thinks they can eat anything and making comments that I had put weight on and stuff.”
- Chloe           “My (family member) had cancer, he had Non-Hodgkin’s Lymphoma and he was having treatment and it was horrible and I was feeling sick with worry a lot of the time and so my eating was affected not because I was consciously trying to cut down but just because sometimes I didn’t feel like I could eat because I felt too anxious.”

Participants mentioned major stressors e.g. house move, feeling extremely unhappy, bullying, relationship breakdown, loss of family member, illness of a family member, parental difficulties/divorce and change in job, as contributing factors. These seem to have left them with significant emotional distress and knocked their confidence, which seemed to trigger AN.

#### 3.1.2 Perfectionist Personality

Participants also identified perfectionist aspects of their personality as contributing to the development of AN.

- Helena           “One of the sort of big aspects of my personality is perfectionism and I think that plays a really big role because it’s the kind of perfectionism that where everything is constantly measured against standards so at school it was fine

because you can measure yourself by expecting yourself to come top in everything and that's really clear and then I think perhaps one of the reasons why the food stuff took over was when I'd finished school because there aren't all those things that you can measure yourself against"

### 3.1.3 Chronic Low Self-Esteem & Self-Worth

Several participants reflected on an underlying chronic low sense of self-esteem and worth and indicated how this perpetuated efforts to achieve goals in relation to food or weight as an alternative means to value themselves. This was compounded by participants' views of themselves as 'not good enough', which was translated into being 'undeserving' of food.

Beth            "Mainly I guess I think because it's been such a long time it feels like it's evolved like with so many different things, I suppose mainly it's just my own self worth my own self-esteem and just like my, the way that I view myself and the value that I've got in my life I suppose is just like really low, so it's hard to look after myself properly I guess. When you don't think that you deserve anything or, yes, it's really hard to just take care of yourself and say you are worth looking after and feeding yourself"

Sarah           "A lot of it is about your self-esteem. I didn't feel worth it, I didn't feel good enough so I didn't understand why I should eat and feed myself when I didn't feel I deserved it."

From Chloe's quote below, it appears that she felt that losing weight became an achievement but that this only made her feel good about herself temporarily. This didn't alter the underlying chronic low sense of self worth. Indeed, participants seemed particularly stuck in this cycle of whatever they did was never enough.

Chloe           "Just kept losing and it became you know I'd got under nine stone and then I wanted to get under eight stone and then I wanted to be under seven stone and it was like I'd get to each target and initially there'd be a sense of achievement but then the goalposts seemed to move"

### 3.2 Experience of AN as Functional

Following on from the understanding of the development of the disorder, participants discussed a functional role that AN took in their life. In particular, it was identified as a solution to other psychological problems, a strategy to help distract attention away from distressing thoughts/feelings for example:

#### 3.2.1 Distraction to Cope

Emma            “Yes because it can, if you’re on a mission to lose weight, it can continue, it can totally continue and in a way that can save you, if your life is so black that thinking about your life would, it would be too distressing then to just spend a day losing weight, it does it does serve a purpose, it does actually really serve a purpose”

Helena           “[AN behaviours] those kind of enable you to get through the days ‘cause ya know if your mood’s quite low and you wake up and you’d don’t really know what you can achieve in the day and you don’t know how you are going to live through the next twelve hours then somehow subconsciously having all these things that you can measure yourself against works for that”

It appears that focussing on weight, food or eating allowed participants to distract themselves away from existential anxieties. Indeed closely linked to this is the experience of safety participants found in the predictability of their AN.

#### 3.2.2 Safety in Predictability

Emma            “The only thing that creeps up is if I stop and think is just fear, it’s just absolute fear of how I will get through the next day and what will happen and what, yes what I will do where at least if you just focused on one coping mechanism you know what to expect and at least there is less volatility, there is less fear I think.”

Beth              “but I would rather just kind of go home after work rather than going out and being social just so I can go home and eat and be sick and eat and be sick, it’s like a comfort blanket sort of thing, but it’s a horrendous thing to do but that’s kind of the paradox to it.”

These descriptions suggest that although the eating difficulties were unwanted they provided some comfort and a relief from anxiety.

### 3.2.3 Focus Away From a Lack of Valued Roles

Participants also explained that the all-consuming nature of AN served a purpose to distract them away from gaps in their life and that this served as a maintaining factor. This is closely linked to the individual's chronic sense of worthlessness.

Helena        “in that way kind of the anorexia thing is self perpetuating because at the moment I'm in receipt of equivalent support allowance because I can't work because of Anorexia and low mood and so I don't have any kind of defining things when people ask you what you do, well not a lot really I don't really do a lot and so it's almost like that allows the illness to become stronger because it feels like it's therefore quite an important role because you don't have another role and then it has to kind of compensate for all the things that aren't in your life like ya know a family or children an academic career or any of those things ya know if you can't be really really any good at those things then being really really good at Anorexia would be a better substitute”

Chloe        “if you're thinking about food you're not thinking about anything else and so there was that period of time when I was turning thirty I was thinking oh but I haven't got a boyfriend and I want to have a family and all of that and I think when you invested in the eating disorder it all just becomes completely unimportant which in a way makes you feel better because at least you're not thinking I haven't got this so. So you're sort of in a bubble really”

### 3.2.4 Who am I? Anorexia Identity

Indeed, several participants also reflected on their lack of self and how their eating disorder had become part of their identity.

Beth        “I guess it just like takes over everything, it becomes your entire life and part of the difficulty I think in trying to get over it is that you feel like you're trying to create a new person because that's all you've ever really known”



Helena            “I didn’t think there was any way that people could know who I was I didn’t know how people would know I was me because I couldn’t work out what defined me...so obviously on a larger scale that becomes Anorexia as part of your identity and that maybe there are things invested in thinking that people need to be able to identify you as that because you don’t find any of your own qualities to be worthwhile”

Overall, it appears that the eating disorder served a functional purpose for participants, as a distraction from distressing thoughts/feelings and gaps in their lives, providing safety in its predictability and bringing about a sense of identity.

### 3.3 Negative Effects of Anorexia

In addition to the functional aspects of AN, participants also described the negative effects of AN on their life. All of the participants explained how they felt AN had had a negative impact on their life, in that they believed their difficulties had prevented them from fulfilling a career/job, had led to the loss of friendships and social life, or had a negative influence on their family.

#### 3.3.1 Negative Impact on Life

Emma            “I think for me when I have in the past it’s been about that survival weirdly... just yes shutting down on everything else and focusing on that one thing, if I had a job, if I’d been able to go back to work that might be different or if I’d got another, you need a reason really don’t you.”

Sarah            “I lost my job, I had to resign in March because I wasn’t well enough to go back I couldn’t do my duties I couldn’t even, my uniform weighs a stone I couldn’t even wear my uniform so I had to give that up because I had to give that up I had to lose my flat, I couldn’t afford the mortgage on that and I’ve just gone bankrupt because my flat was in negative equity and I’m living with my parents now. I have lost everything through the eating disorder absolutely everything”

The quotes above illustrate the pervasive cycle that participants found themselves in; in relation to being unable to work because of their eating disorder and this having a perpetuating

negative effect upon their sense of self and identity. This is closely linked to the role of the eating disorder becoming functional to provide such an alternative focus and sense of identity.

### 3.3.2 Family/Friends not Understanding

Participants felt that their family and friends did not understand their eating disorder and the distress they were going through, and they consequently felt quite alone with it, as it wasn't discussed. Also, participants had lost friendships as a result of their eating disorder.

Beth "I think he's struggling to understand it but we don't talk about it"

Sarah "I had two older sisters and because they just didn't have anything like this I just don't think they could understand why, they couldn't understand why I was doing it to myself. I think they thought they had failed in some way. I don't really know to be honest. That's just the way they deal with things. If they ignore it it's not there kind of thing.... I'd plan to go out with my friends and I'd be getting ready and thinking 'oh my god I look fat horrible and disgusting' and I'd cancel. So I lost quite a lot of friends because of it. Because they didn't understand they didn't know and all they saw they were just getting fed up with it basically. I was arranging to meet and cancelling which obviously after so many months you kind of give up asking."

### 3.3.3 Social Life

Indeed, several participants spoke of the negative impact their AN has on their social life, where they felt unable to take part due to the invasive nature of the eating disorder.

Emma "I used to go out for meals with friends or you know a meals with family or, that kind of thing completely out the window even having my mum over would now be difficult because some form of eating is involved."

Beth "I would never go out for meals or very rarely do I go out you know I have to like really pick and choose whether it's safe to go out somewhere, the food would just like just like conscious of every single like invite that you get. If someone

said to you do you want to pop round you think well is it teatime or is it going to be a social thing where there's like buffet and you are going to have to eat or you know sort of everything that you do so that's like again it's just an automatic response that's going on in your brain but there's food aspects dictating everything that you're doing."

#### 3.3.4 Negative Impact on Family

Participants explained the negative impact they believed their difficulties had on their families.

For example:

Helena        "I think that probably it was more difficult for my family than for me because I was just I mean it felt I was in this awful mental anguish at the time but I don't think it's as bad to be in that anguish as watching somebody you know go completely crazy"

It seems that participants felt detached from their own emotional distress, and felt a sense of guilt for others having to see their own distress. For Charlotte this was a motivating factor to seek help:

Charlotte     "I think it was because the time it had gone on, and also I wasn't happy with myself physically or mentally and it was putting a strain on the family as well and I didn't like that so you know I felt that I needed help if there was help out there to see if I could get it for myself."

#### 3.3.5 Feelings of Hopelessness

Participants described almost a resignation, associated with their beliefs that things were unable to change and they could not imagine a future where they could have a relationship, children or fulfil a meaningful career. This left participants with a deep sense of sadness and despair.

Emma         "I can't I can't see a job, I can't see, I can't see now not caring about what I eat or what my BMI is or feeling fat"

Chloe            “I mean some days I wake up and think no I am going to have a future without illness and some days it just feels like well it’s such an intrinsic part of me but I actually don’t know who I’d be if I didn’t have it so it’s very mixed really”

Helena           “My constant fear is that I can’t see any possibility of it [having a baby] happening”

Overall, this theme appears to reflect an understanding of participants of the negative effects of their AN upon their lives and those around them. However, these effects generally seem to perpetuate those of a functional nature.

### 3.4 Lack of Early Identification/Intervention

Many of the participants described a long period of time where they were struggling with the eating disorder before getting any help. This appears to be both influenced by the problem being ‘ignored’ by parents, or a lack of availability of parents, or when help was sought the impact of waiting lists.

#### 3.4.1 Family Denial

Several participants spoke of telling their parents about their difficulties but this not resulting in help being sought for example;

Helena           “I mean there was one point where when I was 14 that my friends made me tell my parents about the fact I was restricting and throwing up but my parents just said well promise not to do that again which I did but carried on regardless”

Sarah            “My head teacher, head of year phoned my parents because I had fainted quite a few times and he expressed his concerns to them and they just kind of shouted at me really. They didn’t really, they thought it was a phase. They didn’t really understand it and threatened to take me to the doctors but they never did.”

In addition, it appeared that participants felt that their family did not wish to acknowledge the difficulties:

Helena            “the GP said to my mum is she eating properly and she said YES so I think that was a kind of maybe a sort of wilful ignorance that they didn’t really want to face what was going on”

Helena also explained that her decline into her eating disorder had been obvious whilst living with her parents, in that she had stopped eating most things for over six months and had lost a lot of weight.

Helena            “I was living at home with my parents and it was obviously very noticeable because I’d stopped consuming most things.....I’d not really been eating properly for, when I say not eating properly I mean just eating cold vegetables and nothing else for six months”

Linked to this sense of the eating disorder not being picked up or taken seriously by parents, was that of having to protect parents from negative emotions, to the point where participant’s emotional needs were not met and they felt that they were unable to experience/express negative emotions.

Chloe            “I felt that I had to be strong for my mum because, and a lot of people would say to me oh how’s your mum doing she must be finding this all really hard and you know she needs you and things, and so I sort of felt that I wasn’t really allowed to be upset or angry or anything really.”

Beth            “My mum seems quite supportive but she gets quite upset about anything negative or anything that’s just like emotional, she gets really upset so I try not to give her too much information so I don’t upset her”

This appears to link with the development of AN as functional to cope with difficult emotions that participants felt unable to express.

### 3.4.2 Waiting Lists for Service

Participants reflected on the negative impact of NHS waiting lists on accessing treatment when needed, and how this allowed for deterioration in symptoms over months/years. This left participants feeling alone to deal with the problem.

Chloe            “So seven months of basically waiting, and yeh it seemed like quite a long time.”

Beth            “you just know that you’re in like a really bad place and you just feel like you’re on your own and there’s no like help out there.”

### 3.5 Cycle of Accessing Services

This theme describes the narrative participants developed in relation to their access of services. Participants indicated the intensity of treatment as contributing to the ‘in and out’ cycle of accessing service, and descriptions were characterised with ambivalence towards their experiences.

#### 3.5.1 Feeling Desperate for Help

Many of the participants described reaching a point where they felt desperate for help and a recognition that they needed to accept the treatments that were on offer:

Beth            “Yes, I think you just carry on and carry on for so long and then you just kind of hit a brick wall and you think I can’t do it anymore.”

Sarah           “by that time I went in and it was kind of like I’d surrendered it was hands up okay I’m going to do what I’ve got to do I want to get well I’d had enough I was sick of it”

### 3.5.2 Feeling Overwhelmed by Food and Weight Gain

Most participants felt a real sense of being completely overwhelmed when entering intensified treatment, either in day care or as an inpatient. Many of the participants' descriptions of their experience of accessing such treatment seemed to reflect recognition of feelings of ambivalence. On the one hand participants were desperate to be rid of the feelings but on the other did not wish to change their weight and felt overwhelmed by having to eat more than they had been.

Helena            "this sounds completely stupid but it was a real shock to me that they were expecting me to eat and just that was so overwhelming"

Chloe            "It was really traumatic to start with, I think just completely overwhelming like the difference in what I had been eating to what I was expected to eat."

Chloe            "I think I wanted help to feel better but I don't think I wanted to put the weight on, I know I didn't want to put weight on. So when I went in there initially, I think they always say they wish they had a pound for everybody that says that, but I wanted it out of my head but I didn't want to put any weight on but that's not really doable"

This was compounded for some participants by the limited food options available:

Charlotte        "...it was just the afternoon snack because like two hours later, two and half hours later you were then expected to have something else and I normally went for a bag of Maltesers or Smarties and I didn't like that because I'm not a chocolate person, I like dark chocolate. So I used to feel a bit sort of eugh dirty after that you know I didn't like that at all because the menu... I would much rather do it the savoury way because I think it's more healthy than having too much sweet food"

Emma            "I think from a nutritional perspective they're very keen on yeah let's get the calories in and let's make sure but... there's foods that can help and there's foods that don't help, it's just fact that like too much crappy chocolate bar type sugar is not good... I think that nutritionally if you think about what you're giving

these people because it's not just about calories it's about their mind and food...There should be a balance between you know a burger and chips which has got the calories in and some broccoli and fish and olive oil on your salad."

Beth illustrates the battle experienced internally in regard to treatment.

Beth "Yes, yes definitely, because you've definitely got to be able to accept the treatments when you're in there, it's like a real tension all the time, part of your brain's saying don't do it or you can do what you want when you get outside of here but the other part of you is like the rational side, the logical side, you have to make an effort, you have to be willing to do what you don't want to do, it just depends which one's stronger."

For some, this sense of ambivalence appeared to contribute to participants choosing to discharge themselves, and then entering an 'in and out' cycle of access to services;

Beth "Yes I think it's just like such a shock to the system and it is really overwhelming and you're just like, all that goes through your mind is I've got to get out of here, I can't bear it, it's just too much, I don't want the help and I don't want to be back here"

Sarah "I don't know I just hated it. I stopped going and once you drop out the system no one knows if you are ill or not and can't do anything about it. So that happened, that happened throughout my life going for help, dropped out, going for help, dropped out, going for help, dropped out. So that kind of thing all the time. They could never monitor me. It's kind of like if I dropped out the system then I could lose as much weight as I wanted and no one could stop me and then I would get to the point where I was desperate for help. I'd go and then I would think actually no, it was always like that."

### 3.5.3 Transitions between Outpatients, Inpatients and Day Care

Indeed, participants also reflected on their struggle to maintain their eating/weight when back at home in their day to day life, due to the massive contrast in the level of support offered, not



having accountability and not having addressed the difficulties that had led to the hospital admission.

Helena        “because there is a way in which when you are in hospital that you can just go along with it because of your nature as a person is to conform and so you do what people say and whatever but it doesn’t necessarily mean that your waking up in the morning and going yay recovery I’m working towards recovery and I think that’s why it often so difficult to maintain when you get out of hospital because you then don’t have anything to conform to”

Sarah         “When you are in hospital you can battle it because it’s not just one on one you’ve got you and whole team against anorexia you are all fighting it but as soon as you leave here hospital and you get home it’s just one on one again and you are bound to lose kind of thing”

As many participants described the hardest part of managing their difficulties was managing in the ‘real world’, a suggestion for a ‘half way’ service that allowed participants to function in their world, whilst still receiving support in the evenings, or in a shared house was made. Participants felt this would be a way of preventing the ‘in and out’ cycle as it would help to deal with this issue.

Sarah         “it’s one extreme to another you need that integration probably less time inpatient more time ya know half way there is no half way house kind of thing”

Chloe         “It’s almost like there’s a gap for some sort of service where you can go to work and have your normal life during the day and maybe they then support you in the evenings but there’s nothing really like that, it seems to go from being very, very intense to very hands off.”

### 3.6 Negative Experience of Staff Attitude

#### 3.6.1 Focus on Food, Weight Restoration vs Psychological Understanding

Many participants felt that the main aim of their treatment was to restore their weight, without addressing the underlying psychological issues. This, they believed was ineffective, especially in terms of recovery:

Emma            “It put weight on but that is it”

Sarah            “it’s a lot more down it’s about not liking yourself really and I think a lot of people need to quit with working on how much you are eating and work on your self esteem and why you feel like you don’t need to eat ...because basically it’s like you are coming into a feeding farm they just feed you up and leave ya it’s kind of like they feed you up and then discharge you and your head still isn’t fixed you might be a normal weight but your head is still messed up so if they don’t do the two in sync you’re never going to get well because your head is far behind”

This also links to the difficulties participants described in maintaining their weight when they were no longer in intensive treatment.

Worryingly, the focus on weight within services was experienced by some participants as indicating that their weight was not low enough to be deserving of treatment and served as a motivator to lose more weight:

Chloe            “It again makes me think well obviously maybe if my weight was lower they’d be offering me more help so it all gets very tangled up in your head.”

Helena           “I think it’s kind of a BMI thing is quite deceptive in terms of it’s use by medical professions in terms of determining who needs help and therefore it contributes to the anorexic thinking that oh well I’m not actually ill enough I don’t actually deserve the help I need to go out and be more anorexic to get more deserving and achieve more whatever it is”

### 3.6.2 Treated as a Group of Patients

Not being recognised as an individual was extremely unhelpful, in particular with regard to an individual's self-worth.

Emma            “you spent ya know all your time crammed into this tiny room like sardines you were treated very much as just part of a group it was all about group work and there was no individual work or support or anything like that so part so you had no individual worth really it was just a part of a group”

Sarah            “I find a lot of them treat you the same as they treat everyone with an eating disorder yet eating disorders are so complex and so many different behaviours patterns and you can't treat everyone the same so I kind of didn't feel that they got me.”

### 3.6.3 Feeling Neglected/Judged/Abandoned vs Being Accepted/Cared for

Participants experienced some staff within specialist services to be uncaring and judgemental, and therefore felt that this had a negative impact on their already shaky self-esteem. This was especially the case when re-entering intensive treatment where participants felt undeserving and guilty in relation to needing further support. It was felt that staff needed to be able to see the person behind the illness and to be unconditionally accepting, and to retain hope and belief in recovery. The availability of staff and willingness to listen was felt to be important.

Emma            “I think people in that sort of job should be carefully chosen and want to be there... I think in that kind of job you need a special interest you need an actual concern for other human beings I think and the ability to empathise and the ability to unconditionally accept people and care for them... it's more important than the food to be honest to have people that care for you and accept you and that don't look down their nose at you and ya know see you as a worthy human being that's an individual and that can spend time with you not just go shovel you full of cheese and fattening foods with no humanity”

Emma            “So it was refreshing to have people that actually did present as caring and I think for an illness like this where people have really low self-esteem anyway

and feel, most of them feel not worthy of receiving treatment and that they're being a burden on other people and they feel they've brought it all on themselves and actually it's probably not helpful to have that reinforced..."

Sarah "she [service manager] never gives up she no matter what you do she never takes offence at anything I have swore at her I have threw things at her I have done everything yet she will come back and still try and help you she will never like take offence and not just her but all the staff there are all so lovely and understanding and got it"

Helena "I don't actually know in terms of tangible services, I think what I want from them is intangible, in that I want them to keep believing that.... not just for me but for anybody who they've seen a certain number of times, I want them to give them the same treatment opportunities as people they've seen for the first time, so to keep believing that recovery is possible for anyone"

Some participants felt neglected and ignored:

Chloe "I felt quite unimportant when I was in there, it feels like the people who're at their really, really low weight they sort of get a lot of the staff support and sort of time really and also the people who are quite disruptive and will throw things across the room or scream and shout get a lot of the staff's time. If you're there and you're sort of quietly struggling but not actually saying anything and just trying to get on with the meals it feels like you don't really get an awful lot of the staffs input"

### 3.7 Experience of Being with Other Patients in Specialist Services

Participants reflected on the experience of being with other patients with similar difficulties and described this as having both beneficial and negative effects. For some participants, being with others who had similar difficulties provided support and was found to be helpful, but this was also found to be unhelpful by others who found competitiveness amongst patients, and an increase in their own distress caused by the distress of other patients.

### 3.7.1 Support/Friendships

Participants experienced the understanding and support from fellow patients to be a positive influence and found the friendships and sharing of experiences to be beneficial.

Emma            “For me the most helpful were the other patients and the friendships I made”

Beth            “also the rest of time would be spent in like a small little room like this size with six or seven other girls so that would really help you as well because you’d get kind of input from them and you know support, that was really helpful”

### 3.7.2 Competitiveness and Comparison

Despite the positive aspects of being with other patients, participants also described associated difficulties. They reflected on comparisons to other patients both at mealtimes and in relation to their physical health, which resulted in a minimisation of their own difficulties and also a sense of competing with others to be the ‘thinnest’.

Sarah            “I think when you are solely with eating disorder people it’s kind of a bad mix because we are all very competitive and everybody wants to be the best anorexic and everybody wants to be the thinnest so it’s not always a good”

Helena            “I wasn’t getting services there and the last conversation I had with my GP there was she said to me well you’ll never get a bed I’ve got a patient with a BMI of 11 who can’t get a bed and of course my brain interpreted that as well you’re not ill because you’re BMI isn’t as low as this other patient”

### 3.7.3 Impact of Others’ Distress

Participants also described feeling an increase in their own distress by seeing others in a very distressed state e.g. watching fellow patients be restrained and fed via a nasogastric tube. This also caused increased ambivalence around their own position towards recovery, in that they felt they were ‘giving in’ too easily. Participants also reflected on the impact such distress had on the atmosphere on the ward and the staff becoming tense and having less time for others.

Charlotte      “I was seeing people in dire straits that needed to be sectioned you know and coming across people that were in denial as to what was going on and then they were like playing the staff up and things like that only because of their illness but that wasn’t helping me.”

Helena          “There is this intense guilt that you’re complying in a way that they are not and therefore you’re sort of allowing the nurses allowing food to win but because you are just going in and eating it and that whole experience of emotions throws the nature of treatment and recovery into sharp relief”

## Summary of Findings and Discussion

This study is the first to explore in depth the experiences of women who have lived with and been treated for chronic AN, using IPA. A unique factor in this research is the researchers personal experience of AN, which gave her an additional insight into the lived experience of the participants. The six women in this study gave thorough and poignant accounts of their experiences. The analysis identified a range of themes within their descriptions, some of which mirror other themes in the evidence base and add further support to them and others which are novel and offer possibilities for future research. These themes are discussed in further detail below.

### 4.1 Development of AN – Functional Role

As found by previous research, the women in this study reported a range of specific stressors, a perfectionist personality and chronic low self worth as contributory factors to the development of AN (Espindola & Blay, 2009; Tozzi et al, 2003). This study also supports and reiterates the results of previous studies in regard to the functional and ego-syntonic role of AN symptoms (Fox, Larkin & Leung, 2011; Nordbo et al, 2006; Serpell et al, 1999; Williams & Reid, 2009). Participants' accounts expressed how AN provided a form of coping with difficult and distressing emotions, and existential anxiety. AN was also used as a distraction and provided comfort in its predictability. Furthermore, for participants in this study AN served a significant purpose to resolve the individuals' underlying psychological difficulties; in particular a chronic low self worth (Espindola & Blay, 2009). These accounts support the suggestion that eating disorders are in part a solution for individuals and therefore a symptom of deeper underlying issues (Bruch, 1978; Strober, 2004).

The negative effects of the disorder were also acknowledged by participants in this study, which again corroborates previous research (Colton & Pistang, 2004; Fox, Larkin & Leung, 2011; Reid et al, 2008; Williams & Reid, 2010). Participants described a pervasive cycle where they were unable to fulfil a career, had lost friendships and their social life due to their eating disorder. It appears that this then had a perpetuating negative effect upon their sense of self

and identity. Indeed, participants' accounts suggest that in the absence of their own self worth AN provides a sense of identity, again supporting previous literature (Nordbo et al 2006; Fox, Larkin & Leung, 2011; Espindola & Blay 2009). Reflecting on the narratives, there was a sense of deep sadness due to the all-consuming and self-perpetuating role AN then took in the lives of participants, with participants seeming resigned that change was not possible and therefore continued a chronic course.

#### 4.2 Treatment

As has been found in previous studies participants' accounts of their experiences were filled with ambivalence in relation to treatment (Colton & Pistang 2004; Fox, Larkin & Leung, 2011; Reid et al 2008; Williams & Reid, 2010). Indeed, participants described reaching a point where they felt desperate for help but that the intensity of treatment and the focus on weight during treatment appeared to contribute to an 'in and out' cycle of accessing services. A central aim of intervention for AN necessarily involves weight gain, however participants highlighted how treatment focuses too heavily on weight with limited options for food, and a stark lack of help to address the difficulties that had led to hospitalisation. This approach led to participants struggling to maintain healthy eating and their weight when back in their day to day life and consequently a relapse occurring. The results of this study supports views expressed by participants in previous studies (Colton & Pistang, 2004; Williams & Reid, 2009) and suggest that a different approach is needed in the treatment of AN, which focuses on the underlying issues, that facilitates discovery of one's self worth and supports patients in their transitions between different levels of care. A suggestion was made by several participants of the need for a 'half-way' service that allows them to function in their 'real world' whilst receiving additional support in the evenings or 'supported living' arrangements. Whether this has the potential to lead to a more successful approach to assisting those who develop AN and preventing the condition becoming chronic, remains to be investigated.

As with previous studies (Williams & Reid, 2009; Colton & Pistang, 2004) participants' experiences of treatment were at times unhelpful due to professionals' lack of understanding



of the condition and the attitudes of nursing and support staff. Of particular concern was the focus on weight within services which was experienced by some participants as indicating that their weight was not low enough to be deserving of treatment and which then served as a motivator to lose more weight. This along with the sense of rejection that resulted from staff not listening, being uncaring or judgemental, and not being recognised as an individual, was striking and worryingly seemed to exacerbate feelings of worthlessness. This illustrates the role of unhelpful treatment experiences and negative relationships with staff in the maintenance and development of chronic AN symptoms. In contrast, the value of being listened to by staff was felt to be important along with unconditional acceptance and a retained belief and hope in recovery no matter how many times a patient has received treatment. It is possible that feelings of hopelessness and worthlessness are through the process of transference (Strober, 2004) mirrored in clinicians working with chronic AN, and this may negatively impact on the ability to effectively engage patients and provide an attitude of hope for the future to clients. Therefore when clinicians and staff are working with chronic AN, it seems of utmost importance to minimise the harmful impact of clinicians' countertransference, through adequate training and preparation for the range of emotions that are evoked and a reflective space for the acknowledgment of such emotions (Strober, 2004).

Finally, the aspects of intensive treatment where patients are in close contact with each other allowed for support from other patients, which was valued. However, contact with other patients also lead to comparisons and competition to be thinner, and an increase in their own distress of witnessing others in a distressed state, which caused an increase in ambivalence towards engagement in treatment. Participants reflected on the impact other patients' distress had on the atmosphere on the ward and staff becoming tense and having time for only the most distressed patients. This could exacerbate the negative experiences of treatment when staff are stretched and do not have enough time to care for all patients.

### 4.3 Family

Dysfunctional family relationships are commonly cited as a contributory factor in the literature for onset and maintenance of AN (e.g., Minuchin, Rosman & Baker, 1979; Steinhausen, 2002). This was corroborated by participants in this study, in that participants' emotional needs were not met and they felt they needed to protect their parents from their own distress. In addition, a lack of acknowledgment by parents of the difficulties often meant a delay in access to treatment, with participants describing symptoms being ignored by parents over significant periods of time. Whether this is something unique to those who develop chronic AN or those with AN more generally cannot be established from this study and further research is necessary to explore this.

### 4.4 Strengths and Weaknesses

The findings must be considered in light of the following strengths and weaknesses.

This study's sample size, although within the sample size recommended for doctoral level research employing IPA, was difficult to obtain and lower than initially hoped for. As clinicians were relied upon to identify and recruit participants, many participants chose not to take part, this along with recruitment via a previous participant may have posed a sampling bias. The views and experiences of those who chose not to take part may be different, hence alternative routes for recruitment such as service user forums, maybe useful in future studies. Due to the difficulties in recruitment this study did not reach data saturation and further interviews may have brought up additional themes relevant to those with chronic AN.

Although the researcher reflected on the impact of her own experiences and attitudes on the process of interpreting the data throughout, the interpretations made may have been influenced by having had her own experiences of AN and treatment, and by how it would have felt to have continued to be affected by AN for as long as participants had. If the researcher had had more time for the completion of the research, involving participants in the analysis phase of the study would have been useful and provided further validation to the analysis.

A strength of the current study is the consideration of participants with a long history of AN and their experience of treatment. The current participants were a relatively homogenous sample of women who had recurring difficulties with AN for over a decade, with onset of AN in adolescence to early twenties and who were currently over the age of 30 years. Those who took part were keen to discuss their experiences of AN and their experiences of treatment, the richness of data collected suggests that they felt comfortable to talk openly and honestly. It may be that the researcher being a young female researcher with no clinical agenda facilitated this process and although participants were not aware of the researcher's experience of AN, having had this experience may have led to a deeper sense of empathy and understanding in the interview process.

#### 4.5 Implications

As discussed above, one of the main themes that seemed to weave through the entire experiences described by participants was a lack of a sense of self, and therefore a search for self identity which AN provided to participants. This provides an important means of viewing the experience of AN, as a symptom of deeper problems in the journey of establishing self identity, a search for a purpose, and a way to cope with complex challenges. In order for patients to move towards recovery, a resolution of these issues is necessary. This highlights the need for treatment to focus on establishing alternative sources of self-worth through involvement in occupational activities, work, hobbies & meaningful relationships. The findings of this study suggest that certain aspects of medical treatment may hinder progress and services need to move away from focussing too much on weight and eating, and address underlying psychological issues to enable in-patients to maintain their eating in their day to day life. Finally, the findings indicate that early intervention is necessary to prevent the disorder from becoming chronic and that prevention programmes for eating disorders need to focus on supporting young girls/women in developing a strong sense of worth and identity.

#### 4.6 Future Directions

As this study has highlighted the importance of a lack of a sense of self in the development and maintenance of AN, it would be useful for future research to explore what has led to patients sense of self being so impaired. This may provide further insights into how to help those who develop AN and preventing chronicity. Also, interviewing staff working within eating disorder services on their experience of working with chronic AN, and what they believe to be the best approach to providing treatment.

#### 4.7 Conclusion

In addition to supporting key concepts from previous literature, the themes identified in this study offer a unique insight into living with and being treated for AN for over a decade. It also provides an insight into poorly understood issues relevant to those who do not recover; namely a chronic low sense of self-worth and AN as a search for identity, and also points to dynamics at play within treatment that may contribute to the difficulties in treating AN.

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## **Public Domain Briefing Paper**

## **Anorexia Nervosa: Understanding the Experience of Recovery and Chronicity**

### Outline

The research outlined below was conducted by Clare Stockford, Trainee Clinical Psychologist at the University of Birmingham. This research was submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology.

### Anorexia Nervosa

Anorexia Nervosa (AN) is an eating disorder (ED), characterised by significant reduction in food intake, resulting in severe weight loss in relation to age and height. Weight gain is feared and avoided and perceptions of body weight and shape are disturbed. AN is a serious mental health condition with many effects upon the individual. Services for treating AN range from intensive inpatient programmes to outpatient care. Recovery from AN is often a long process, taking on average 6 years. However, some individuals do not fully recover from AN and develop a chronic condition where they suffer for many years.

The review looked at published literature to gain an understanding of what women who have recovered from AN consider to be the important factors in their recovery. The research interviewed women with recurring difficulties with AN for over a decade (chronic AN) regarding their experiences of their eating disorder and their treatment experiences.

### Literature review

This review looked at qualitative studies that considered women's experiences of recovery from AN. In total, eleven studies were selected for review. Themes identified the process of recovery is a complex psychological process. The most important factor identified in recovery was the development of supportive relationships with therapists, friends, family, and others with an ED. The experience of being accepted by others allowed women to accept and value themselves for who they are. Given the importance of psychological and social factors in



recovery, it was recommended that intervention and prevention programmes incorporate these factors.

## Research Component

### *Background*

Little is known as to the reasons why some women do not recover from AN and continue to struggle with symptoms for many years, even after many treatment attempts. The research component used a qualitative design using an interpretative phenomenological design (IPA) to explore the experiences of women who have lived with and been treated for AN for over a decade.

### *Method*

Six women who had experienced recurring difficulties with AN for over a decade, who had onset of AN in adolescence to early twenties, and who were now over the age of 30 years, took part in the study. Interviews took place at a venue chosen by the women (home, University or eating disorder service). Participants were asked to provide an account of their experiences of their eating disorder from when it first started until now, including treatment(s) they had received, and what they had found helpful and unhelpful. Interviews lasted approximately an hour. All interviews were transcribed word for word and analysed using IPA. IPA is an approach that allows the researcher to understand how meaning of experiences is made by participants.

### *Findings*

The findings illustrated the complex experience of living with and being treated for chronic AN. The participants reflected on the development of AN at times of stress and when dealing with complex psychological difficulties. In particular, participants described having no sense of value or worth in themselves, their qualities or their life. They described a cycle where they were unable to fulfil a career, lost friendships and their social life due to AN. This perpetuated a negative view of themselves and their self-worth and AN became a part of their identity.

There was a deep sense of sadness in relation to how consuming AN was of their life and participants seemed resigned that change was not possible.

Participants described a cycle of accessing services; where they felt desperate for help but the intensity of treatment and focus on weight gain led them to disengage from services. Participants felt that treatment focusses too heavily on weight gain with a lack of help to address psychological difficulties. Also, a lack of understanding of the condition, feeling judged and not being recognised as an individual by staff were unhelpful in treatment. The need for staff believing in recovery no matter how many times an individual has received treatment, was highlighted. Finally, participants described a delay in access to treatment due the problem not being acknowledged by parents in the early stages and to waiting lists for services.

### *Clinical Implications*

The findings suggest the need for eating disorder services to move away from predominantly focussing on weight and eating and move towards facilitating individuals to establish sources of value in themselves by providing opportunities for occupational activities, work, hobbies and reliable and long term social support. The need for early detection and intervention for AN was noted and may prevent the disorder becoming chronic. Prevention programmes need to support young people to develop self-worth and a strong sense of who they are.

### *Acknowledgments*

The author would like to thank the six women who agreed to take part in the study. The author is aware how difficult their experiences have been, and admires their courage to share their stories. The author would also like to thank Dr Biza Stenfert-Kroese for her continued support throughout the study and Dr Newman Leung for his support and involvement in recruitment for the study.

## Appendices

## Appendix 1: Interview Schedule

### How do you experience long term Anorexia Nervosa

#### Onset

Can you tell me about the onset of your difficulties with Anorexia Nervosa?

Prompts:

*How old were you?*

*What did you first notice?*

*What did others notice – friends /family?*

Who contacted services?

What was your first experience like of services?

#### Experiences of AN and support/services offered

From the onset of your symptoms at age .... Can you describe your experiences from then until now?

What services, support or treatments have you received?

Prompts:

*What has been helpful?*

*What has been unhelpful?*

#### Day to day experiences

How does AN effect your life?

Prompts:

*What is good about living with AN*

*What is not good about living with AN*

#### Future

How do you see your future?

Prompt:

*Where do you see yourself in five years time?*

## Appendix 2: Participant Information Sheet

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### How do clients make sense of long term difficulties with Anorexia Nervosa.

Hi, my name is Clare Stockford, I am a trainee Clinical Psychologist at the University of Birmingham. I am interested in talking to people who have had contact with eating distress services because of difficulties with anorexia nervosa over a number of years. Before you decide if you want to talk to me or not, please read below and if you have any worries or questions you can get in touch with me, or my supervisor on the number or address below.

Researcher: Clare Stockford, Trainee Clinical Psychologist  
Supervisors: Biza Kroese, Senior Lecturer  
Newman Leung, Consultant Psychologist  
Address: School of Psychology  
University of Birmingham  
Edgbaston  
Birmingham  
B15 2TT

- **What is the purpose of this research?**

The purpose of this research is to help understand how individuals experiencing long term difficulties with anorexia nervosa make sense of their symptoms in their life. I am interested in hearing about what life is like for you and hearing your story of your experiences living with anorexia and your experience of using eating distress services.

- **Why have I been invited to take part?**

You have been chosen to take part in this project because you have been accessing the Birmingham & Solihull Eating Disorder service for a number of years. Little is known about why for some people anorexia nervosa becomes a long term difficulty. Your experiences of using services could be really helpful in helping to improve services for yourself and other people who have similar difficulties.

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

It is your decision whether or not you take part. If you decide to take part you are still free to change your mind and withdraw at any time without giving a reason. If you decide not to take part or to withdraw at any time this will not affect the care you receive.

- **Advice about taking part in research**

You can seek advice about participating in research from the Patient Advice and Liaison Service, Birmingham & Solihull Mental Health NHS Trust, 3 Ardenleigh Way, Ardenleigh Site, Edington, Birmingham, West Midlands. B24 9SA. Telephone **0121 678 4455**.

## Appendix 2 (Continued)

- **What will happen to me if I agree to take part?**

If you agree to take part in the study, I will contact you to arrange a time to meet with you, either at your home, the University of Birmingham or The Barberry. If you need to make a special journey to attend the interview your travel expenses will be reimbursed. You will have the chance to ask me questions or talk through any worries you may have by either emailing me or calling me. When we meet you will have an interview. The interview will mean that you and I will sit together in a room talking for approximately an hour. We can take a break at any time during the interview. In this time I will ask you questions about when you first started to experience symptoms of Anorexia and about what life has been like between then and now. I will also ask you about your experiences of your care by services throughout this time. I will audio record our interview so that I can play them back later to write down exactly what we talked about into a written transcript. When I write this up I will not use your name, so nobody will know that it is what you have said. The audio record will be kept under secure storage at the University of Birmingham and will be destroyed at the end of the study.

- **What will happen if I do not want to carry on with the study?**

You can stop the interview or change your mind about taking part at any time, just let me know.

- **What happens if I get upset when we are talking or have any further concerns?**

There may be times when we are talking that you feel upset, or find it difficult to talk about certain things. If at any time you feel upset or find a subject difficult we can take a break or stop the interview, just let me know. If you have been upset during the interview, I will inform your treating clinician so that they can offer you appropriate support, I will discuss this with you if this were to happen.

If after the interview you have any worries or concerns then you can talk to your treating clinician or, alternatively you can contact Dr Newman Leung, who will be able to provide you with support.

- **Will anyone know what we talked about?**

Everything we talk about will be between me and my supervisors only, unless I have any concerns about your safety from what you have disclosed during the interview. In this case I would always talk to you first about my concerns.

- **What will happen to the results of the research study?**

When I have written up the transcript of what we talked about, I will send you a copy of the transcript. You can then decide if you would like to meet with me to review what was talked about. You will be given a summary sheet of the findings of the research and can get a full copy of the research report if you would like to receive this. The research will be submitted as part of the thesis for the Doctorate in Clinical Psychology. The thesis will be held in the University of Birmingham Library.

Please feel free to contact me on the telephone number or email address at the top of this information sheet. I will be happy to talk through any questions or worries you may have.

## Appendix 3: Consent Form

UNIVERSITY OF  
BIRMINGHAM**CONSENT FORM**

Participant Identification Number:.....

**CONSENT FORM**

How do clients make sense of long term difficulties with Anorexia Nervosa

*Researcher:* Clare Stockford

Please initial box

1. I confirm that I have understood the information sheet dated 25th June for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my care being affected. ☐
3. I understand that the research interview will be audio-recorded and that the audio files will be kept under secure storage at The University of Birmingham and destroyed once the chief researchers' thesis has been examined and passed. ☐
4. I understand that following the research interview I will receive a copy of the written transcript of my interview. I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my care being affected. ☐
5. I understand that I will receive a written summary of the research findings and that I can also receive a full copy of the research report when it is completed. ☐
6. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. ☐
7. I understand that the data collected during the study maybe looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to may taking part in this research. I give permission for these individuals to have access to this data. ☐
8. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments. ☐
9. I agree to take part in the above study. ☐

.....  
Name of participant.....  
Date.....  
Signature.....  
Name of researcher.....  
Date.....  
Signature

#### Appendix 4: Ethics Approval







