A QUALITATIVE EXPLORATION OF SENSE OF SELF AND ANOREXIA NERVOSA

A thesis submitted to The University of Manchester for the degree of Doctor of Clinical Psychology (ClinPsyD) in the Faculty of Medical and Human Sciences

2014

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Word count: 22, 211

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Abstract

A qualitative exploration of sense of self and anorexia nervosa

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June 2014

The thesis has been prepared in paper based format and includes three papers: paper 1 is a literature review, paper 2 is an empirical study and paper 3 is a critical reflection. Paper 1 has been prepared for submission to Clinical Psychology and Psychotherapy and systematically reviews the qualitative literature pertaining to the process of recovery from anorexia nervosa (AN). A metasynthesis of 12 studies was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles. The metasynthesis identified factors that helped and factors that hindered recovery from AN, in addition to offering an interpretation of how these factors underpin the process of recovery. The strengths and limitations of the review are discussed, as are the implications of the findings for clinical practice.

Paper 2 has been prepared for submission to the British Journal of Clinical Psychology and is a qualitative exploration of the nature of the relationship between the self and the eating disorder in individuals with a lifetime history of AN. Semi-structured interviews were conducted with 11 women and the interview transcripts analysed using constructivist grounded theory methodology. The results suggested that the self is shared with AN and separating the self from AN has an important role to play in recovery from the disorder. A theoretical framework explaining the nature of the relationship between the self and AN is presented and discussed. The strengths and limitations of the study are considered, as are the implications of the findings on the content of therapeutic interventions.

Paper 3 is not intended for publication and is a critical reflection of the research process as a whole. It evaluates the strengths and limitations of both paper 1 and paper 2, in addition to offering a critical review of completing a qualitative research project. Paper 3 also discusses issues surrounding reflexivity, implications of the research for clinical practice/working as a clinical psychologist and draws overall conclusions.

Declaration

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Library, The University Library's regulations (see http://www.manchester.ac.uk/library/aboutus/regulations) and in The University's policy on presentation of Theses.

Acknowledgements

I would like to thank my supervisors Dr John Fox and Dr Jane King for their invaluable support and guidance throughout the research process. I would also like to thank all the NHS clinicians and staff members at the charities who helped with recruitment and made the job of finding participants a lot easier.

I am grateful to the individuals who took part in the empirical study and admire their honesty, bravery and desire to help others by telling me their stories. I am also grateful to my family and friends for supporting me through the past few years and believing that I could do this.

Finally, a huge thank you goes to my husband, without whom this thesis would not have been written, as I would not have been the person I am today. Glyn, I am eternally grateful for the unconditional patience, understanding, encouragement, support and love you have given me over the past few years and always. I owe you one!

Paper 1: Literature Review

The process of recovery from anorexia nervosa: a metasynthesis

of qualitative studies

Paper 1 has been prepared for submission to Clinical Psychology and

Psychotherapy in accordance with the guidelines for contributors (appendix 1).

Tables and figures have been incorporated into the text in the thesis for ease of

readability, however, for submission to the journal these will be submitted as

separate sheets as per the guidelines. Formatting guidelines for the journal have

been adhered to as closely as possible, whilst following The University of

Manchester Presentation of Theses Policy.

Paper 1 is a systematic review of the qualitative literature pertaining to the

process of recovery from anorexia nervosa (AN). The review synthesised 12

qualitative studies in order to identify the key factors involved in recovery from

AN.

Word count: 7989

(excluding abstract, tables, figures and references)

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Abstract

Context: Research into predictors of recovery from anorexia nervosa (AN) is inconclusive, but perfectionism, chronic low self-esteem, emotion intolerance and interpersonal difficulties have been proposed as factors influencing the pervasiveness of the disorder.

Objectives: The qualitative literature pertaining to the process of recovery from AN has not been systematically reviewed. The current review aimed to synthesise qualitative studies with a focus on recovery from AN in order to gain an understanding of the key factors involved in recovery.

Method: AMED, EMBASE, CINAHL, OVID, MEDLINE, PsycINFO and Web of Science were searched for articles published between January 1965 and January 2014. A metasynthesis of qualitative data was completed in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles.

Results: Twelve studies, representing the views of 232 women and one man, met the inclusion criteria. Three concepts for second-order interpretation emerged from the synthesis: considering recovery dilemmas, the process of recovery and recovery. Ten themes were incorporated in this second-order interpretation. From the second-order categories, a third-order category was derived: the process of regeneration, which described an individual's battle to recover from AN; separating themselves from the eating disorder and coming out the other side as a different person.

Conclusions: Being supported to increase personal control, learn to manage

emotions and develop a sense of self that is separate to the eating disorder is

crucial in recovery from AN. Psychological interventions, therefore, must be

tailored to meet these needs if their effectiveness and efficacy is to be improved.

Key Practitioner Message

· Recovery rates from AN are poor: there is a need for improved

understanding of the process of recovery in order to improve the

effectiveness and efficacy of treatment for the disorder.

Recovery from AN is dependent upon the presence of key factors,

including: perception of control over the eating disorder, managing one's

own emotions, holding a positive view of treatment, having supportive

and understanding relationships with others and developing a new sense

of self.

Treatment should not be limited to focusing on weight gain.

Psychological interventions should include work on identity and sense of

self.

Keywords: Anorexia nervosa (AN), recovery, treatment, metasynthesis.

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Introduction

Recovery rates for those who survive anorexia nervosa (AN) indicate that 46.9% of people fully recover, 33.5% show some improvements and 20.8% remain ill, with the disorder taking a chronic course. Mortality rates for the disorder stand at 5% (Steinhausen, 2002). Individuals with AN often avoid treatment and for those who do initiate treatment, dropout rates are high (Cooper, 2005). Research on the reasons for dropout is conflicting, but studies have focused on predictors such as; the presence of binge/purge symptoms, body mass index (BMI) on admission to hospital, severity of eating disorder symptomatology, greater psychiatric difficulty in general and denial of difficulties (Vitousek, Watson & Wilson, 1998; Wallier et al., 2009). Current guidelines for the treatment of AN do not recommend any one effective psychological intervention (NICE, 2004), possibly due to uncertainty around predictors of outcome and high dropout rates.

Research into predictors of recovery for AN is inconclusive. Steinhausen (2002) concluded that "chronicity leads to poor outcome" (page 1288), with longer duration of treatment follow-up and younger age at onset associated with better outcomes. Other research, however, has found younger age at onset to be predictive of relapse (Castro, Gila, Puig, Rodriguez & Toro, 2004) or age at onset not to be predictive of treatment outcome (Saccamoni, Savoini, Cirrincione, Vercellino & Ravena, 1998).

The difficulties in identifying predictors of recovery and recommending effective treatments must, however, be considered within the context of there being little consensus on what constitutes recovery from a mental health problem (Davidson, O'Connell, Tondora, Lawless & Evans, 2005; Davidson, O'Connell,

Tondora, Styron & Kangas, 2006). Symptom reduction and discharge from mental health services are often used as indices of a successful recovery; however, recovery is not necessarily equivocal to a cure (Repper & Perkins, 2003). Recovery can be defined as rebuilding a meaningful and valued life, which may include experiencing symptoms in such a way that they interfere less with an individual's life (Davidson & Roe, 2007; Repper & Perkins, 2003).

The evidence base investigating recovery from AN from the client's perspective is growing. A review of qualitative studies on treatment and recovery from AN in adolescents identified the importance of maintaining relationships with peers and siblings before, during and after treatment in order to maintain a sense of normality (Bezance & Holliday, 2013). This is in addition to the importance of families being involved in treatment. Relationships with health professionals were also crucial, with staff needing to be perceived as competent in the field of eating disorders. Inpatient treatment was found to both help and hinder recovery, with the suggestion that inpatient services be mindful of inadvertent reinforcement of some of the key features of AN, which can reduce the opportunity for identity development (Bezance & Holliday, 2013).

In a metasynthesis of qualitative studies on AN treatment from the adult's perspective, Espindola & Blay (2009) postulated that the difficulty in helping individuals with AN relies on the complex psychological mechanisms involved, largely the concept of identity, which is impaired in the disorder. The review also identified that individuals considered treatment that focused exclusively on weight to be frustrating. Factors that favoured recovery were identified as: satisfactory affective relationships, application of cognitive/psychological abilities and nutritional knowledge, increasing time spent on aspects in life other

than the body/AN and spirituality. Factors that limited recovery were identified as: fear of change, lack of motivation, ambivalence, lack of social support, professional rigidity and media influence (Espindola & Blay, 2009).

The present study aimed to review and synthesise studies focused on recovery from AN, with a view to identifying the process of recovery, including factors that help and factors that hinder. This differs from the aforementioned reviews by taking a wider view of recovery in its different forms, including recovery away from mental health services (Anthony, 1993): to date no such review has been conducted. It was anticipated that the review would make a valuable contribution to increasing the evidence-base on recovery from AN, which in turn would have implications for clinical practice and the implementation of psychological interventions.

Method

Research design

A systematic metasynthesis of published, qualitative data examining recovery from AN was completed in accordance with PRISMA principles (Moher, Liberati, Tetzlaff & Altman, 2009) (appendix 2).

Literature search

Published articles examining recovery from AN were identified via computerised searches of the following databases: AMED, EMBASE, CINAHL, OVID MEDLINE, PsycINFO and Web of Science. All peer-reviewed, original articles published between January 1965 and January 2014 were sought to be

included. Prominent qualitative research journals were checked manually (Qualitative Health Research, Qualitative Research, Qualitative Research in Psychology), as were the reference lists of all included articles. The year of 1965 was used as an initial cut-off due to limited qualitative research being conducted before this date. Databases were last searched on 31st January 2014.

The challenge of retrieving all relevant studies for a qualitative literature review is well-documented (Barroso et al., 2003; Evans 2002). Defining clear criteria for the selection of studies is of paramount importance, given that the metasynthesis of qualitative findings rests on a sufficiently exhaustive search (Barroso et al., 2003; Daly et al., 2007). Consequently, to maximise the effectiveness and efficiency of the search, a combination of strategies was used.

Firstly, in accordance with the Evidence for Policy and Practice Information Centre (EPPI-Centre, 2008) search terms were split into three distinct categories: 1. Terms relating to qualitative design; 2. Terms relating to eating disorders; 3. Terms relating to recovery. Secondly, as recommended by Shaw et al. (2004), thesaurus and free-text terms were generated for each of the three categories. Terms relating to eating disorders as opposed to AN alone were used in order to ensure that no relevant articles were missed, which included using the diagnostic labels specified in the DSM-IV-TR (APA, 2000). Thirdly, qualitative methodological filters were used to identify qualitative research (Evans 2002; Shaw et al., 2004; McKibbon, Wilczynski & Haynes, 2006; Walters, Wilczynski & Haynes, 2006; Wilczynski, Marks & Haynes, 2007; Wong, Wilczynski & Haynes, 2004). A full list of search terms is provided in appendix 3.

Inclusion and exclusion criteria

Studies that met the following criteria were included in the review:

- Published, peer-reviewed study
- A study written up in English
- Original study published from January 1965 to January 2014
- A qualitative research study with a clear theoretical framework and analysis based on qualitative methods of data extraction
- A study analysing the perspective of an individual with a lifetime experience of AN
- A study focused on recovery from AN
- A study including participants of any age, gender or nationality.

Studies that met the following criteria were excluded from the review:

- An unpublished study or a study that has not been peer-reviewed
- A study written up in a language other than English
- A study published before 1965
- A study that has conducted a secondary analysis of previous studies
- A study with a quantitative design
- A study analysing the views of others (e.g. relatives, carers, professionals)

- A study lacking a specific focus on recovery from AN
- Case studies
- Books.

Critical appraisal

There are no definitive guidelines on assessing the quality of qualitative research: a plethora of tools exists with the aim of fulfilling this objective (Walsh & Downe, 2006). The quality of studies was appraised using a checklist devised from two of the most widely used critical appraisal tools: the Critical Appraisal Skills Programme (CASP; 2013) qualitative research checklist (appendix 4) and the criteria proposed by Walsh & Downe (2006; appendix 5). Each item on the CASP (2013) checklist was compared to the item of similar content in Walsh & Downe's (2006) criteria and the two combined to form a new item. The subsequent 11 item checklist also included two idiosyncratic items (appendix 6).

Items were rated 0, 0.5 or 1: 0 = the study did not meet the criteria, 0.5 = the study partially met the criteria, 1 = the study fully met the criteria. All studies were rated using this checklist and assigned a quality classification of 'A' (total score ≥ 9.5), 'B' (total score ≥ 6 but < 9.5) or 'C' (total score < 6). A classification of 'A' pertained to the study being of high quality, with no or few flaws, a classification of 'B' pertained to the study being of moderate to good quality, with few or some flaws and a classification of 'C' pertained to the study being of low quality, with significant flaws. No studies were excluded on the basis of quality, with the aim of being as inclusive as possible and ensuring that

relevant studies were not missed (Sherwood, 1997). The quality of studies was, however, taken into consideration in the synthesis, with greater weighting being given to studies of higher quality. A third of the included studies were randomly selected and rated by an independent researcher. Discrepancies of 0 to 1 point occurred, however, there was no disagreement with reference to the classification of studies. Studies where a discrepancy occurred were reviewed and a consensus score achieved.

Synthesis of findings

The synthesis followed the guidance of Noblit & Hare (1988; appendix 7), whose method is the most widely used for synthesising qualitative data (Britten et al., 2002). Noblit & Hare (1988), however, proposed that metasynthesis could only be applied to studies embracing the same method. Recent debate has led to metasyntheses of studies using different qualitative methods to become the norm (Campbell et al., 2003; Sandelowski, Docherty & Emden, 1997), therefore Walsh & Downe's (2005; appendix 8) updated analytic technique was also incorporated. The first author considered the inclusion of studies using different methodologies invaluable in ensuring all up to date qualitative research on recovery from AN was reviewed.

Each of the 12 studies was read thoroughly and key concepts within the studies identified. These concepts were further examined to identify themes across studies, noting their similarities and differences. The findings of the studies were then translated into each other, whereby concepts from one study were applied to another. Careful consideration of where concepts stood in

opposition to one another was also taken. Finally, these translations were synthesised, in order to generate core themes that provided a new interpretation of the topic under review. This process involved both second-order and third-order interpretation. Second-order interpretation was based solely on the original findings and included identifying concepts that related to each study to offer an enhanced understanding of interpretations. Third-order interpretation offered a new representation of the theories concerning recovery by going further than the understanding of the original findings and interpretations. The findings of the initial synthesis were discussed with the research team in order to further refine them and reach a consensus.

Results

Characteristics and quality of included studies

The search identified 2078 potentially relevant studies. After screening for eligibility in accordance with the inclusion and exclusion criteria, 12 studies were included in the review. Figure 1 details the results of the search strategy. The 12 studies represented the views of 232 women and one man aged between 14 and 63 years with a lifetime history of AN. The recovery status of participants was reported in 10 of the 12 studies and studies included participants who were fully recovered, in recovery, unrecovered and those who had recovered and relapsed. Demographic data was sparsely reported, and the marital and employment status of participants varied. Participants came from Brazil, Canada, Sweden, Norway, UK and USA. Data were predominantly collected using interviews. although studies utilised two

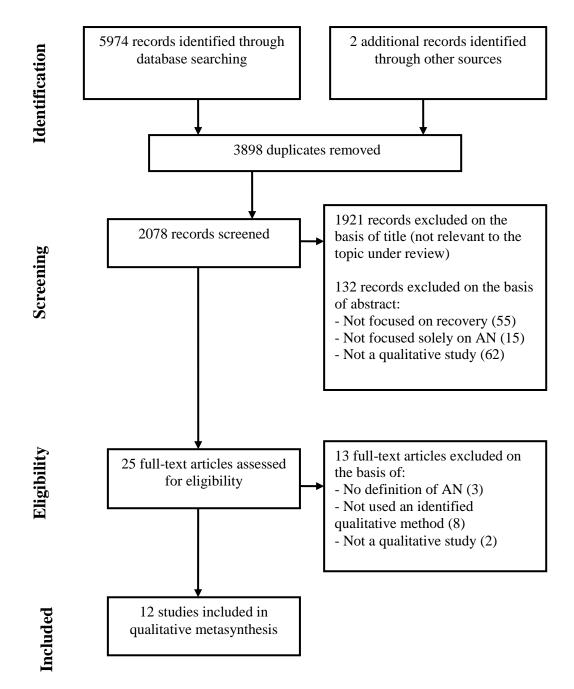


Figure 1: PRISMA flow chart from search to inclusion

focus groups. Data were analysed with a variety of methods, including grounded theory, interpretative phenomenological analysis (IPA), narrative analysis and thematic analysis. Table 1 shows the characteristics of each of the 12 studies.

Table 1: Characteristics and quality of included studies

| Author/year | Country | Participants | Confirmation of AN | Data collection | Data analysis | Quality rating |
|-----------------------------|---------|---|--|-----------------|--|----------------|
| Weaver et al. (2005) | Canada | 12 female (age 14-63): 6 single 3 married 3 divorced/separated 4 with children 8 without children | Screened for DSM-IV criteria (9/12 = professionally diagnosed) | Interviews | Grounded theory | В |
| Lamoureux & Bottorff (2005) | Canada | 9 female (age 19-48): 9 recovered 6 employed 1 unemployed 2 students | Screened for professional diagnosis | Interviews | Grounded theory | В |
| Nilsson & Hägglöf (2006) | Sweden | 68 female (age not specified): 58 recovered 10 unrecovered | Screened for DSM-IV criteria and previous treatment | Interviews | Content analysis | В |
| Granek (2007) | UK | 5 female (age 25-30): 5 recovered 1 married 2 live alone 1 lives with family (married) 2 live with room-mates | Screened for DSM-IV criteria | Interviews | Grounded theory | В |
| Shohet (2007) | USA | 3 female (age 19-29): 1 recovered 2 struggling to recover | Self-reported 3/3 = had received hospital treatment | Interviews | Narrative analysis | С |
| Federici & Kaplan (2008) | Canada | 15 female (age 18+): 7 recovered 8 relapsed | Successful completion of treatment; met diagnostic criteria on admission | Interviews | NVIVO version 2, Analysis of themes | В |

| Author/year | Country | Participants | Confirmation of AN | Data collection | Data analysis | Quality rating |
|---------------------------|---------------|---|--|---|----------------------------------|----------------|
| Nordbø et al. (2008) | Norway | 18 female (18-39): 2 recovered 16 unrecovered | Treatment within last 2 years | Interviews | QSR-NVivo7, Open thematic coding | В |
| Darcy et al. (2010) | USA | 23 female (19-52) | Self-report of lifetime history and participation in treatment | Interviews – either individual or focus group | Thematic analysis | В |
| Williams & Reid (2010) | International | 13 females, 1 male (age 18-36): 14 unrecovered | EDE-Q, self-report | Online focus group | IPA | В |
| Jenkins & Ogden (2012) | UK | 15 females (age 19-49): 9 recovered 6 in recovery | Self-report of diagnosis and treatment | Interviews | IPA | В |
| Nordbø et al. (2012) | Norway | 36 female (age 18-39): 2 recovered 34 unrecovered | Treatment within past 2 years | Interviews | QSR-NVivo7, Open thematic coding | В |
| Espindola & Blay (2013) | Brazil | 15 female (age 22-32): 15 recovered 7 students 8 employed 9 single 4 married 2 divorced 5 with children 10 without children | Met SCID/DSM-IV criteria | Interviews | Grounded theory | В |

The quality ratings of the studies varied from 4.5 to 8.5, which led to 11 of the studies being classified as 'B' and one of the studies being classified as 'C'. Higher weighting was given to the studies with a category 'B' rating in the synthesis. The data from the category 'C' study only served to reinforce the concepts suggested by the category 'B' studies, therefore it can be considered that the credibility and transferability of the findings was protected.

The most prominent weakness of the studies was with regard to reflexivity, with only one of the studies considering this. Seven of the studies made no reference to a meaning/definition of recovery. The method used by all of the studies was clearly stated and appropriate; however, only three of the studies discussed data saturation. Nine of the studies confirmed lifetime history of AN via professional diagnosis or DSM-IV criteria, which gives confidence regarding the generalisability of the findings. All of the studies gave a clear statement of findings, with adequate discussion and justification of the origins of the results. Overall, the studies allocated a 'B' rating were considered to be of reasonable to good quality, having conducted worthwhile pieces of qualitative research. The quality ratings for each of the 12 studies can be seen in Table 1.

Synthesis

The synthesis identified 10 core themes involved in recovery from AN: 1. Denial, 2. Consequences of AN, 3. Recovery position, 4. Fear of recovery, 5. Managing emotions, 6. Control, 7. Treatment, 8. Relationships with others, 9. Sense of self and 10. Moving on: self-acceptance and self-care. These themes were lifted from the data and organised in such a way that reflected their expression in the studies. Figure 2 shows a diagrammatic representation of this

organisation. On identifying the concepts of considering recovery dilemmas and the process of recovery (see below), the first author noticed that the organisation of these concepts bore some resemblance to The Transtheoretical Model of Change (Prochaska, DiClemente & Norcross, 1992). The first author did not routinely use this model in her clinical practice and therefore did not feel that this had influenced her analysis of the data. This likeness was, however, discussed with the research team and her interpretation of the data reviewed to ensure that the data had not been forced into the model. The first author was confident that the themes were organised in such a way to stay close to the data arising from the studies, therefore providing a rational synthesis of the findings.

Second-order interpretation

The process of second-order interpretation led to the identification of three concepts: 1. Considering recovery dilemmas, 2. The process of recovery and 3. Recovery. The organisation of the concepts and second-order interpretations is shown in table 2.

Table 2: Second-order interpretation

| Considering recovery dilemmas | The process of recovery | Recovery |
|---|---|--|
| Denial Consequences of AN Recovery position | Managing emotions Control Treatment Relationships with others Sense of self | Moving on: self-acceptance and self-care |

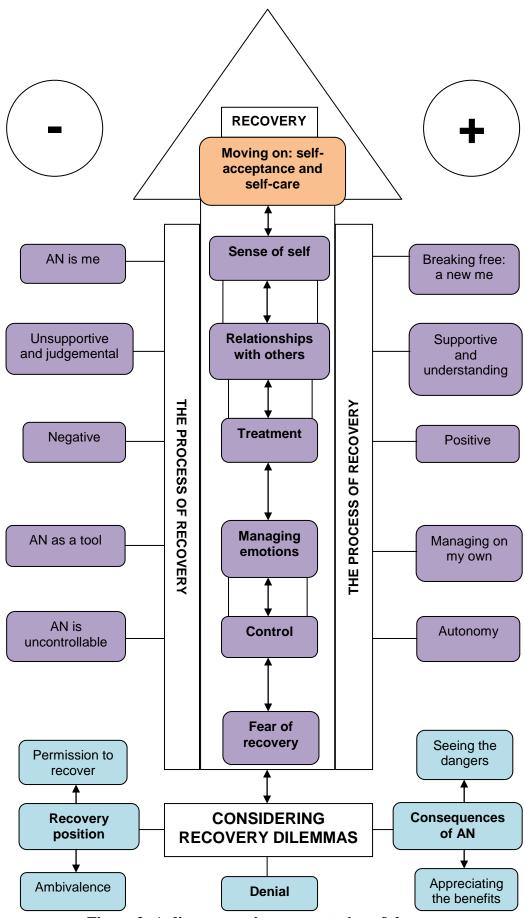


Figure 2: A diagrammatic representation of themes

The synthesis identified that recovery from AN began with considering recovery dilemmas. Individuals who were in denial, felt ambivalent about recovery and/or appreciated the benefits of AN remained stuck in the clutches of AN. Individuals who saw the dangers of AN accepted that recovery was needed and permitted themselves to embark on the journey, which moved them into the process of recovery. Here, they initially held fears for recovery, feeling very unsure about what recovery was, in addition to struggling to understand how they would cope with eating, weight gain and, in their eyes, not being perfect.

The process of recovery included factors that either helped (as indicated in Figure 2 by the plus sign) or hindered (as indicated in Figure 2 by the minus sign) recovery. Individuals remained anorexic if they viewed AN as uncontrollable, used AN as a tool to manage emotions, viewed treatment as negative, perceived their relationships with others as unsupportive and judgemental and felt that AN was who they were. They also often slipped back to considering recovery dilemmas. Conversely, individuals who believed they had autonomy, were able to manage their own emotions, viewed treatment as positive, had supportive and understanding relationships with others and were able to develop a new sense of self were likely to recover and move on, accepting and caring for themselves.

Close links between the themes of sense of self, relationships with others and treatment were also identified. If an individual viewed their relationships with others as supportive and understanding, they were likely to also view treatment as positive, as they would receive this support and understanding from their therapist as well. This support with, and understanding of, their difficulties from others would lead the individual to value themselves more highly, have a

greater sense of self-worth and be determined to break free from AN, becoming a new person, whom they liked and accepted. Conversely, if an individual viewed their relationships with others as unsupportive and judgemental, they were likely to view treatment as negative, holding this view of their therapist as well. This lack of support and perceived judgemental attitude was related to holding on to the view that AN was who they were, believing that other people saw them as an 'anorexic', which they internalised as their identity, thus making it extremely difficult to let go of.

The themes of control and managing emotions were also linked. If an individual believed they had control over AN, they held the view that they could manage their emotions on their own, learning to let go of AN as a 'crutch'. If an individual believed that AN was uncontrollable, however, they tended to also view it as a tool for managing their emotions. Holding the view that AN served a functional purpose in managing emotions and was something over which they had no control led individuals to hold little confidence that they could manage on a daily basis without it.

Figure 2 presents the themes involved in the process of recovery as to their interpreted level of significance. This process is not necessarily linear, but represents the shift towards recovery. Individuals moved forwards or backwards within the process of recovery, as represented by the double-headed arrows, experiencing both factors that help and factors that hinder recovery. All themes are discussed below. For reasons of transparency the number of articles upon which each theme was based is reported in parentheses. A more detailed representation of the contribution of the studies to themes is shown in Table 3.

Table 3: Contribution of studies to themes

| | Denial | Consequences of AN | | Recovery position | | Fear of | Managin | g emotions |
|-----------------------------|--------|--------------------|------------|-------------------|-------------|-----------|-------------|--------------|
| | | | | | | recovery | | |
| | | Appreciating | Seeing the | Permission to | Ambivalence | | Managing on | AN as a tool |
| | | the benefits | dangers | recover | | | my own | |
| Weaver et al. (2005) | V | V | | | | $\sqrt{}$ | | |
| Lamoureux & Bottorff (2005) | | | V | | | | V | |
| Nilsson & Hägglöf (2006) | | | V | | | | | |
| Granek (2007) | | | | | | | | |
| Shohet (2007) | V | V | | √ | | $\sqrt{}$ | | |
| Federici & Kaplan (2008) | | | | | V | $\sqrt{}$ | V | V |
| Nordbø et al. (2008) | | | $\sqrt{}$ | √ | | | | |
| Darcy et al. (2010) | | | | | | $\sqrt{}$ | | |
| Williams & Reid (2010) | | V | | | V | $\sqrt{}$ | | |
| Jenkins & Ogden (2012) | V | | V | V | V | | V | V |
| Nordbø et al. (2012) | V | V | | | | V | | V |
| Espindola & Blay (2013) | | | $\sqrt{}$ | | V | | | |

| | Co | ntrol | Trea | tment | Relationship | os with others | Sense | Sense of self | |
|-----------------------------|----------|----------------|-----------|-----------|----------------|-----------------|-------------|---------------|---|
| | | | | | | | | on | |
| | Autonomy | AN is | Viewed as | Viewed as | Supportive and | Unsupportive | Breaking | AN is me | |
| | | uncontrollable | positive | negative | understanding | and judgemental | free: a new | | |
| | | | | | | | me | | |
| Weaver et al. (2005) | V | V | $\sqrt{}$ | | V | | V | √ | V |
| Lamoureux & Bottorff (2005) | | | V | | V | | V | V | V |
| Nilsson & Hägglöf (2006) | V | V | V | | V | | | | |
| Granek (2007) | | √ | V | | V | √ | $\sqrt{}$ | √ | |
| Shohet (2007) | | | | V | | | $\sqrt{}$ | √ | V |
| Federici & Kaplan (2008) | V | | V | V | V | V | | | V |
| Nordbø et al. (2008) | V | | | | | | | | |
| Darcy et al. (2010) | | | | V | | √ | | | |
| Williams & Reid (2010) | | V | | V | | | | √ | |
| Jenkins & Ogden (2012) | | √ | | √ | | | V | | |
| Nordbø et al. (2012) | | | | | | √ | | | |
| Espindola & Blay (2013) | √ V | | V | | √ V | | | | V |

Considering recovery dilemmas

1) Denial (n=4):

Denial was an important factor that hindered recovery from AN. By not acknowledging the presence of AN, there was nothing to recover from. Despite being severely underweight, some participants did not see themselves as having an eating disorder or did not want to. Other participants were unable to admit that they were unhealthily preoccupied with food, body and weight. As Pauline explained:

"To begin with I didn't really realise that I was ill. So the wish to recover...I didn't really have any." (Pauline; Nordbø et al., 2012).

Difficulties associated with AN were minimised and individuals worked hard to convince themselves and others that they did not have problems with eating. Jill justified the impact of AN on her physical health (cardiac arrhythmia), yet concern was given to aspects that affected physical appearance:

"It [my hair] was starting to fall out. Like I would brush my hair and it was coming out on the floor. It was really scary. I had really long hair and I thought that it would show when it was thinning out...I walked maybe four or five times a day. And I'd go on my mom's treadmill. And my heart — I could feel it beating really, really fast. But I didn't pay much attention to it because I thought that when you exercise; it's supposed to do that." (Jill; Weaver, Wuest & Ciliska, 2005).

2) Consequences of AN (n=9):

Consequences of AN referred to the impact an individual perceived the eating disorder as having on them. This theme had two sub-themes: seeing the dangers and appreciating the benefits.

2a) Seeing the dangers (n=5): Seeing the dangers refers to recognition of the negative consequences of AN, in terms of physical, psychological and social costs, in addition to loss of future. Recognising the potential of dying from the disorder prompted many individuals to contemplate recovery:

"I was almost 30 and I thought, 'I am not going to go through the next 30 years of my life like this...I won't live through it.'" (Diana; Lamoureux & Bottorff, 2005).

Individuals acknowledged that AN made them feel sad, depressed and exhausted: they were tired of being ill and no longer gained anything from AN. Although this awareness was often obscured by fears of weight gain, it provided hope to individuals that life could be different:

"When you haven't been eating for a long period of time, you don't function very well. That's logical. Physically I didn't have any energy to go to work or meet friends...I didn't have any energy at all. I didn't want to do anything. I was really depressed. So then I thought, I have to try at least, 'cause I don't want the rest of my life to be like this." (Annie; Nordbø et al., 2008).

2b) Appreciating the benefits (n=4): Some individuals had little motivation to recover as they attributed greater importance to the benefits of AN than the costs. They used AN as a way of receiving care and support, to feel secure and to have meaning and purpose in life. It was also perceived as an acceptable means of avoiding responsibilities. Individuals viewed AN as a protected area in which they succeeded and it provided comfort, being described by some as a friend on whom they could depend. Recovery would mean losing the benefits of AN, which, as Ann described, was too much to bear:

"I feel this diagnosis is a sort of net beneath me. If I fail or make a fool of myself, it catches me, the anorexia catches me. So if anything goes wrong I could use the anorexia to show that I'm good at something, that I manage something, or have control. So I'm afraid to completely recover because then I won't have any safety net." (Ann; Nordbø et al., 2012).

3) Recovery position (n=6):

Recovery position referred to an individual's perception of where they stood in relation to recovery. This theme had two subthemes: permission to recover and ambivalence.

3a) Permission to recover (n=3): Individuals needed to give themselves permission to recover in order to move forwards. This involved individuals gaining insight into their difficulties, recognising the need for change and allowing themselves to embark on the recovery journey, including accepting help from others. They appreciated the advantages of recovering and reflected on positives such as increased self-awareness, feeling stronger and more content,

and enjoying life. Individuals wanted a different life and gave themselves permission to strive to achieve this:

Greta: "I have a couple of good friends that I talk with a lot, and I really like

that, because it gives me new drive: 'Yeah, now I'm gonna take this thing by the

horns!'"

Interviewer: "What is it that can give you this new drive?"

Greta: "Well, then I figure out myself as I'm sitting talking about it, that it

sounds totally strange why I can't just get healthy. Why do I let this so utterly

run my life? So when I'm sitting talking about it with other people it's like: 'Yes,

now I'm going home and I'll pull myself together.''' (Greta; Nordbø et al., 2008).

3b) Ambivalence (n=4): Feeling ambivalent about recovery hindered an

individual's chances of moving into the process of recovery. Individuals were

unsure of their capacity to change, in addition to recovery appearing 'tricky' or

'difficult' (Jenkins & Ogden, 2012). This ambivalence was linked to a difficulty

in accepting weight gain, as AN provided them with a sense of control and

achievement:

"The main way I can really think of in which anorexia is positive is that it helps

me survive my day to day life with a slight sense of control... I guess in a way it

helps me live. It is negative in the fact that it controls my thoughts and

behaviour." (Emma; Williams & Reid, 2010).

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The existence of an 'anorexic voice' and 'anorexic thoughts' also made individuals question whether recovery would ever be possible:

"You may never fully recover from AN, I think the voice is always there." (Ramilla; Jenkins & Ogden, 2012).

The process of recovery

4) Fear of recovery (n=6):

After contemplating recovery, individuals held fears about the journey that lay ahead. At this point, an individual had accepted that they had an eating disorder from which to recover, but the challenge appeared great and frightening as AN had become a way of life. Recovery was linked with a fear of losing control, which was associated with ceasing restraint and gaining weight. This caused low levels of self-efficacy around changing behaviours:

"I'm terrified of losing control and becoming massive or something." (Maria; Williams & Reid, 2010).

Severe self-criticism, a pervasive sense of worthlessness and feeling hopeless about the future appeared to create an intense fear of failure:

"I think ultimately I got sick because of this incredible unhappiness and dissatisfaction with myself that I haven't resolved, and until that totally resolves, eating is going to be an issue." (Participant; Federici & Kaplan, 2008).

5) Managing emotions (n=4):

Managing emotions referred to an individual's perceived ability to manage their own emotions. This theme had two subthemes: managing on my own, which helped recovery, and AN as a tool, which hindered recovery.

5a) Managing on my own (n=3): Learning to identify and tolerate negative emotions was crucial when working towards recovery. Individuals learnt to connect with their emotions, acknowledge difficult emotions and openly discuss these, which involved a certain level of vulnerability and a feeling of being exposed. Gradually, participants began to feel less overwhelmed and expressed their feelings in healthier ways:

"I am able to tolerate negative emotions and that has had a very positive influence on staying well...on my getting recovered and maintaining it. So, the negative emotions... I'm totally able to feel them and not get overwhelmed by them and have them translate into negative behaviours...that's fundamentally important!" (Participant; Federici & Kaplan, 2008).

5b) AN as a tool (n=3): Recovery from AN was jeopardised when individuals used AN as a tool to manage their emotions, keeping them feeling stuck. It was common for people to feel 'unhappy', 'out of control' and a pressure to 'perform' (Jenkins & Ogden, 2012) prior to developing AN, which appeared to be enhanced by their low self-esteem. Individuals used AN to cope with these feelings and to deal with everyday life, the challenges it presented and early trauma. It was a tool for blocking out emotions and focusing on something

else. Individuals found it difficult to learn how to tolerate distress without turning to AN for support, as Vivian explained:

"My living condition was difficult, I was on sick leave, I felt bad, my boyfriend and I broke up...small things or big things, I'm not sure what to call it...but it made it impossible for me to keep my motivation up or want to recover. The feeling that everything is so horrible that I could just as well bury myself in the eating disorder. Just wanting to resign from the world and...being alone with the food." (Vivian; Nordbø et al., 2012).

6) Control (*n*=8):

Control referred to an individual's perception of how much control they had over AN and had two subthemes: autonomy, which helped recovery, and AN is uncontrollable, which hindered recovery.

6a) Autonomy (n=5): Recovery was more likely when individuals believed that they had control over AN and that they could take responsibility for their own recovery. Individuals accepted that they had responsibility for their own life and realised that recovery depended on their personal choices. There was recognition of control over one's body and that it had to work for them for the rest of their life, as Erin explained:

"I have to treat it as a temple and so I can't continue to do all these horrible things." (Erin; Weaver et al., 2005).

6b) AN is uncontrollable (n=5): Recovery was hindered when individuals viewed AN as uncontrollable. Although individuals could recall initiating weight loss themselves, they described AN as then consuming them, indicating a lack of control over their own behaviour. Individuals felt powerless and weak against the force of AN, as Taylor described:

"I find myself talking to myself in my head begging myself to stop things and I cannot." (Taylor; Williams & Reid, 2010).

This battle inside an individual's head was often referred to as arguing with the 'anorexic voice'. Participants described this 'voice' as dominating and controlling their irrational side. Being driven by the 'anorexic voice' left individuals with a sense that AN was uncontrollable and that they were powerless to go against it. Mary described the 'voice' as:

"something else inside me that would overtake me...it drives you to do the most insane things." (Mary; Jenkins & Ogden, 2012).

7) Treatment (n=10):

An individual's perception of the value of treatment was an influential factor in the process of recovery. Two sub-themes were identified: positive, which helped recovery, and negative, which hindered recovery.

7a) Positive (n=6): Treatment that resulted in individuals feeling safe, supported and validated by professionals was key to recovery. Individuals were intrinsically motivated to enter therapy, not attending just to please others. This

often occurred when individuals believed that they had control over AN. They were also willing to express and manage their emotions on their own, therefore viewing treatment as a positive way of supporting them with this:

"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." (Participant; Espindola & Blay, 2013).

7b) Negative (n=5): Individuals held the view that they had little or no control over their AN and therefore found it difficult to understand how treatment could help them. Treatment had often been experienced as negative in the past, with individuals perceiving therapists as lacking in understanding and being unsupportive, in addition to gaining weight being too narrow a focus:

"I feel like I didn't deal with any of the issues that were there to begin with. The bereavement, the self-esteem issues...I hadn't dealt with why I had this eating disorder. How can I fix something when I don't even know what the cause of it is?" (Participant; Federici & Kaplan, 2008).

8) Relationships with others (n=8):

The relationships that an individual held with others were a crucial part of the process of recovery. This theme had two sub-themes: supportive and understanding, which helped recovery, and unsupportive and judgemental, which hindered recovery.

8a) Supportive and understanding (n=6): Recovery was dependent on having other people to lean on, with an initial recognition that help from others was needed to recover:

"you need support definitely because you're in a hole you can't get out of by yourself." (Michelle; Weaver et al., 2005).

There was a need to 'let others in'; others who validated the participants as people, not eating disorders, and eased the isolation of AN. Feeling understood, accepted and taken seriously by the people in their lives was of paramount importance:

"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 willingness to accept that I wasn't deliberately doing this to make myself sick." (Participant; Federici & Kaplan, 2008).

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

8b) Unsupportive and judgemental (n=4): In contrast, individuals who did not have adequate social support and generally felt misunderstood, unsupported and judged by others in their lives were unlikely to recover.

Individuals were sensitive to the opinions that others held about them and comments made by others regarding their appearance or weight could trigger an increased desire to lose weight. Participants became disappointed and frustrated that other people did not understand their difficulties. There was also a feeling of confusion about how others may perceive them, for example, if a significant other did not express worry about the individual's body weight the conclusion that they had put on weight may be drawn:

"Family and friends, they don't need to say anything, it could be that they react or I feel they react...If I haven't seen them in months and I know I've lost weight, I thoroughly analyse their expressions and check out what they are looking at.

Sometimes I think, 'Uh oh, because they don't say anything, maybe they think I'm too big?'" (Irene; Nordbø et al., 2012).

Additionally, there was considerable difficulty in accepting help from others, as asking for help was often perceived as a sign of weakness and failure:

"I think I have trouble accepting help or accepting that I might need help. I feel that it's a weakness to need help, like...I can do this on my own...just leave me alone." (Participant; Federici & Kaplan, 2008).

9) Sense of self (n=6):

Sense of self referred to an individual's perception of themselves as a person, their identity and their sense of self-worth. This theme had two sub-

themes: breaking free: a new me, which helped recovery, and AN is me, which hindered recovery.

9a) Breaking free: a new me (n=5): Perhaps the most powerful factor in the process of recovery was severing ties with an 'anorexic identity'. In order to recover it was crucial that individuals distanced themselves from AN and identified that it was no longer helpful in attaining life goals and aspirations. Individuals made changes to how they understood and managed their identity, moving away from an identity based on appearance and AN defining them as a person. Participants rediscovered and reclaimed their self as 'good enough' and learnt to see value in themselves. This was facilitated by supportive and understanding relationships with others, who validated and accepted them for who they were. Individuals developed a greater sense of self-worth that was based on things other than AN and consequently found the courage to let go of AN, which helped them develop an identity separate from the eating disorder:

"The other part of me was beginning to grow. The real sense of me and (a sense of) life in that part. So I think I was ready to begin to let go a little bit more of the anorexia." (Anna; Lamoureux & Bottorff, 2005).

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

9b) AN is me (n=5): Individuals who defined themselves by AN and equated self-worth with weight loss were unlikely to recover. Their well-being

was centred on AN; it provided comfort, companionship, pride and identity.

Recovery posed a threat to an individual's sense of self, making letting go of AN difficult. Not only did AN provide an identity, but it made individuals 'special'.

As Kelly recalled, she:

"never really had that search for who I was because who I was was the anorexia. It was something that I could do better than anyone. If I give this up, then who the hell am I?" (Kelly; Weaver et al., 2005).

Recovery

10) Moving on: self-acceptance and self-care (n=5):

Moving on: self-acceptance and self-care referred to having recovered. Having broken free and developed a new sense of self, individuals accepted themselves as they were. They learnt to focus on positive aspects of the self and challenged unhelpful thoughts about appearance and body weight. They were more accepting of their bodies, less self-critical and more assertive. Participants were able to give themselves credit for things they had accomplished and be kind to themselves when things did not go their way, acknowledging the opportunity for growth and discovery. Individuals relied on themselves as opposed to others to care for them and give them approval, they respected themselves, cared for themselves and their bodies; in order to look after themselves as well as possible. This gave individuals a sense of empowerment and of hope for the future:

"There was nothing to prove anymore, I had my own approval. Before I was always seeking it in others...and once I gave it up...I did the healing around that." (Diana; Lamoureux & Bottorff, 2005).

"Life is just beginning because I've been dying for 16 years." (Cally Ann; Weaver et al., 2005).

Third-order interpretation

The second-order categories informed the development of a third-order category: the process of regeneration. This meta-category was not found in the individual articles reviewed, but broadly represents recovery from AN, incorporating the categories of: considering recovery dilemmas, the process of recovery and recovery. The process of regeneration encompasses the journey taken by an individual with AN from denial to recovery. It describes a process of growth, of 'coming out the other side', acknowledging that there is a battle to fight with AN, taking control and battling to be free from its clutches. In surviving this battle a new self is born, separation from AN is achieved and an individual is finally free to live a meaningful and purposeful life that is dictated by the needs of the 'true, regenerated self'. A life where an individual accepts and cares for their new self, open to the opportunities presented by a future that is now theirs for the taking.

Discussion

Summary

Ten core themes emerged from the synthesis, which underpinned recovery from AN. Similarities between concepts were evident across all the studies, providing support that the themes capture experiences common to individuals with AN during their recovery journey. The synthesis identified that recovery from AN involved three different stages: considering recovery dilemmas, the process of recovery and recovery. Individuals moved through these stages akin to a process of growth, during which they learnt how to take back control, manage their emotions, use treatment effectively, seek out supportive and understanding relationships with others and break free from an 'anorexic identity' by creating a new self. In doing this individuals were able to move on, accepting and caring for themselves.

Third-order interpretation

Third-order interpretation identified a meta-category of the process of regeneration. One of the key aspects of AN is a search for an identity. The onset of AN is typically in mid-adolescence (Striegel-Moore & Bulik, 2007), when an individual begins to consider who they are and what makes them a person. In the absence of a clear identity individuals can turn to body weight; a prominent, personally controllable and culturally valued domain, to fill the void (Bruch, 1981). On conducting the synthesis there was a strong sense that the relationship between an individual and AN became so enmeshed that they *became* the eating disorder. Recovery, therefore, involved a separation from AN and a regeneration of the self; encompassing parts of the self that already existed, but generating

new aspects of the self to enable an individual to move on from AN and live a different life. This is echoed in the titles of two of the articles reviewed in the synthesis; "Becoming the Real Me" (Lamoureux & Bottorff, 2005) and "You're a Whole Lot of Person" (Granek, 2007). This interpretation is also consistent with the views of Repper & Perkins (2003) and Davidson & Strauss (1992), who posit that recovery involves integrating what has happened to you into your sense of self, which incorporates rediscovering and reconstructing an enduring sense of the self and developing a new and valued identity.

Second-order interpretation

Second-order analysis identified three concepts: considering recovery dilemmas, the process of recovery and recovery. Considering recovery dilemmas included three factors: denial, consequences of AN (seeing the dangers/appreciating the benefits) and recovery position (ambivalence/permission to recover). The synthesis supported the widely-held view that denial of difficulties is frequently seen in individuals with AN. A passionate refusal to change is viewed as a reason why only an estimated third of people with AN seek treatment (Vandereycken, 2006), with many individuals not welcoming the suggestion of treatment (Strober, 2004). Denial appears to serve a purpose for the individual with AN in that it enables them to maintain a sense of superiority in comparison to other people who are 'weak' and 'give in' to bodily needs and desires. This sense of superiority helps to bolster the extremely fragile self-esteem held by the individual with AN (Pryor, Johnson, Wiederman & Boswell, 1995).

The concept of considering recovery dilemmas supports previous research that outlines the battle of conflicting thoughts and feelings individuals with AN experience. Serpell, Treasure, Teasdale & Sullivan (1999) found that AN was used as a tool to fix underlying psychological and life problems. Individuals needing to see the dangers of AN and give themselves permission to recover is also consistent with research that demonstrated 'being ready' and feeling 'motivated to change' were important factors in the recovery process (Hsu, Crisp & Callender, 1992), in addition to holding a belief that recovery is possible (Jacobson & Greenley, 2001).

The process of recovery included factors that helped and factors that hindered. The following factors were identified as helping recovery: managing emotions on my own, having autonomy, holding a positive view of treatment, having supportive and understanding relationships with others and breaking free from AN (creating a new me). The following factors were identified as hindering recovery: using AN as a tool to manage emotions, believing that AN is uncontrollable, holding a negative view of treatment, having unsupportive and judgemental relationships with others and believing that AN is me. A similar process of change as a stage in recovery from AN was identified by Espindola & Blay (2009) when examining individuals' experience of treatment and recovery.

The presence of supportive and understanding relationships is consistent with previous research that such relationships are a significant factor in recovery (Espindola & Blay, 2009; Hsu et al., 1992), particularly the presence of someone who 'stands by' you and believes in you when you find it hard to believe in yourself (Repper & Perkins, 2003). This includes the relationships that individuals hold with health professionals, as holding a positive view of

treatment facilitates recovery. Dare, Russell, Treasure & Dodge (2001) found a friendly therapist-client relationship to be the most powerful aspect in promoting change, when considering the effectiveness of psychological therapies for AN. Strober (2004), however, warns against moving too quickly with those individuals who are dangerously ill as this can push the individual further into AN, causing a life-threatening exacerbation of symptoms. He advises remembering at all times that what clinicians consider an 'illness', individuals with AN welcome as soothing and enhancing.

The factors of control and managing emotions were found to be closely linked, which is consistent with previous research finding that individuals used AN as a way of coping with negative events that had previously led them to feel lacking in control over their lives, as well as a way of avoiding emotions (Cockell, Gellar & Linden, 2002; Williams & Reid, 2012).

Sense of self was found to be a powerful factor in the process of recovery. This is consistent with the idea that AN is caused by impairments in overall identity development and the failure to establish multiple and diverse areas of self-definition (Bruch, 1982). In a Delphi study by Tierney & Fox (2009), clinicians identified a key concept in understanding chronic AN as that an individual's sense of self had come to be defined by the eating disorder. Individuals often perceive AN positively; it makes them feel better about themselves and gives them positive feelings of empowerment, personal control and identity (Williams & Reid, 2007; Williams & Reid, 2012). Creating an identity separate from issues involving eating, weight and shape was shown to be a prominent theme in articles included in the synthesis, yet despite its identified

importance there is a dearth of literature on the relationship between the self and the eating disorder in individuals with AN.

On recovering from AN, participants moved on; they learnt to accept themselves and care for themselves. This supports the findings of Espindola & Blay (2009), who posited that it is the process of being accepted by the self and others that facilitates recovery. Williams & Reid (2012) also found that recovery was viewed as a process of finding the 'authentic self' through self-care, developing positive views about themselves and celebrating the self.

Implications for clinical practice

The review demonstrates the importance of increasing personal control, learning to manage emotions, having a positive view of treatment, holding supportive and understanding relationships with others and developing a new sense of self in recovery from AN. Consequently, it is imperative that health professionals are not blinded by the need for an individual to gain weight. Risks to physical health must be prioritised of course, but it should be considered that treatment of AN focused solely on weight gain can be frustrating for individuals, therefore this should not be an exclusive objective (Espindola & Blay, 2009). From the first author's experience of working in an eating disorder service, psychological interventions already go some way to increasing an individual's perception of control and supporting people in managing their emotions, in addition to considering relationships with others. This is not, however, consistently the case. There is also somewhat less focus on incorporating work on identity and sense of self. This is consistent with Stein & Corte's (2007) view that current interventions may not have an appropriate focus to promote recovery

from eating disorders. They recommend that interventions designed to promote the development of a new positive self-schema may be more effective in reducing difficulties associated with an eating disorder, which concurs with William & Reid's (2012) assertion that treatment needs to focus on building a client's sense of self.

Strengths and limitations

The review not only identifies the factors involved in recovery from AN but also demonstrates how these factors underpin the process of recovery. Given the lack of other metasyntheses in this area, the review contributes to the further understanding of recovery from AN and identifies the implications of this for clinical practice. The sample of participants upon which the review was based was diverse, which enhances the generalisability of the findings.

The review adhered to rigorous methods for conducting a literature review, including conducting a systematic search in accordance with PRISMA guidelines, appraising the quality of the literature and synthesising the literature in accordance with widely used guidelines (Noblit & Hare, 1988; Walsh & Downe, 2005). The search was limited to original, peer-reviewed articles, with the aim of including research that was both relevant and of a high standard. In adhering to these criteria, however, the search discounted book chapters and unpublished PhD theses/dissertations that may have contributed additional understanding to the topic under review.

The criticism of completing a metasynthesis to review the literature cannot be overlooked. Sandelowski et al. (1997) purport that, by summarising numerous studies, the original findings are destroyed. Similarly, Noblit & Hare

(1988) argue that only studies using the same qualitative method should be synthesised. The findings of the review, however, are offered as an additional understanding of recovery from AN and are designed to be considered in conjunction with the findings from the studies included in the synthesis, not replace them. In addition, recent debate has led to metasyntheses of studies using different qualitative methods to become the norm (Campbell et al., 2003; Sandelowski et al., 1997), with inclusivity being of paramount importance given that knowledge is a constructed phenomenon with multiple perspectives (Sherwood, 1997).

Conclusions

The review provides a valuable insight into the key factors that underpin the process of recovery from AN. The findings highlight the need for individuals to be supported to increase their personal control, learn to manage their emotions and develop a sense of self that is separate to the eating disorder. This has implications for the development of psychological interventions that are tailored to meet the needs of individuals who are in the process of recovery from AN, if the effectiveness and efficacy of such interventions is to be improved.

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Paper 2: Empirical study

Sense of self and anorexia nervosa: a grounded theory

exploration

Paper 2 has been prepared for submission to the British Journal of Clinical

Psychology in accordance with the guidelines for contributors (appendix 9).

Tables and figures have been incorporated into the text in the thesis and single-

spaced for ease of readability; however, for submission to the journal these will

be submitted as separate sheets and double-spaced as per the guidelines.

Formatting guidelines for the journal have been adhered to as closely as possible,

whilst following The University of Manchester Presentation of Theses Policy.

Paper 2 explores the nature of the relationship between the self and the eating

disorder in 11 individuals with a lifetime history of AN and discusses the

implications of the findings on clinical practice. The research team are referred

to in the paper by their initials. They are:

Karen Williams (KW)

- main researcher

Dr John Fox (JF)

- academic supervisor

Dr Jane King (JK)

- field supervisor

Word count: 5600

(excluding abstract, tables, figures and references)

64

Abstract

Objectives: The aim of this study was to explore the nature of the relationship between the self and the eating disorder in individuals with a lifetime history of anorexia nervosa (AN).

Design: A qualitative design was used, given the exploratory nature of the study and the need to gain rich and in-depth data regarding the topic under investigation.

Method: Semi-structured interviews were conducted with 11 women who had a lifetime history of AN. Interview transcripts were analysed using constructivist grounded theory methodology.

Results: A theoretical framework of the nature of the relationship between the self and AN was developed, which included five related categories: AN taking over the self, AN protecting the self, sharing the self with AN, being no one without AN and discovering the real me (accepting the fear).

Conclusion: Participants described a process of the self being taken over by AN to the point where it was shared with the eating disorder. This led participants to fear being no one without AN and to be unable to let go of the disorder, appreciating AN's perceived ability to protect the self. In order to recover from AN participants had to discover the 'real self' by accepting the fear of the unknown and separating the self from AN. The findings have important

implications for the target of therapeutic interventions in order to improve recovery rates.

Practitioner Points:

Clinical Implications:

- The self seems to be shared with the eating disorder in AN and separating the self from AN appears crucial in order to recover from the disorder.
- Therapeutic interventions for AN need to target the enmeshed relationship between the self and the eating disorder, as opposed to focusing exclusively on weight and shape concerns.

Limitations:

- None of the participants had been recovered for more than a few months.
 Replication is therefore needed with individuals who have been recovered from AN for some time, in order to further explore the process of separating the self from AN and the relationship with the self post-recovery.
- Lifetime history of AN was not confirmed by professional diagnosis for all participants, however, data from the EDE-Q and information given by participants was consistent with the DSM-V criteria for AN.

Introduction

The self is conceptualised as a mental schema that organises specific kinds of information: people's beliefs about themselves, their interpretations of past experiences and expectations about their future own worth (Jones, 2004). The concepts of self and identity are integrally related and an individual's self-identity is known to be influenced by multiple internal and external factors, including chronic illness, and can change frequently over the course of a lifetime (Kroger, 2007). Identity is typically formed in adolescence (Caparotta & Ghaffari, 2006), the time at which AN usually develops (Bruch, 1982). Bruch (1982) theorised that AN is caused by impairments in overall identity development, an individual's inability to express a true identity and the failure to establish multiple and diverse areas of self-definition. Consequently, AN can become something by which an individual defines themselves and can provide a sense of self-worth, comfort, companionship and pride, thereby forming an individual's sense of self (Granek, 2007; Lamoureux & Bottorff, 2005; Shohet, 2007; Weaver, Wuest & Ciliska, 2005; Williams & Reid, 2010).

Individuals receiving inpatient treatment for AN have described themselves as containing two selves: an 'anorexic self' and a 'non-anorexic self' (Spivack & Willig, 2010). Individuals who developed AN at a young age considered their sense of self to be intrinsically linked with AN. Those who developed the disorder later in life were still dominated by the 'anorexic self', losing a sense of who they were before AN. Spivack & Willig (2010) found that all their participants described feeling that AN was who they were; thinking of themselves as separate to the eating disorder was extremely difficult. Similarly, Williams & Reid (2012) found that participants described being dominated by an

'anorexic voice' or 'anorexic mind', which battled against and controlled the 'true self', causing them to feel split between their self and the eating disorder. This resulted in AN taking over until their identity became the eating disorder.

The self being dominated by the 'anorexic voice' and an individual's identity being defined by AN are suggested as reasons why recovery from AN is so challenging. Defining one's sense of self by the eating disorder has been identified by clinicians as a key concept in understanding chronic AN (Tierney & Fox, 2009). This has led to the suggestion that separation of the self from AN is a crucial component of recovery (Higbed & Fox, 2010), which is supported by the recovery literature. Individuals who have recovered from AN have been seen to develop an identity separate from the eating disorder, in addition to basing their self-worth on things other than AN (Granek, 2007; Jenkins & Ogden, 2012; Lamoureux & Bottorff, 2005; Shohet, 2007; Weaver, Wuest & Ciliska, 2005).

Identification of the important role sense of self has to play in the maintenance of and recovery from AN has arisen from research investigating recovery from AN (Granek, 2007; Lamoureux & Bottroff, 2005; Shohet, 2007; Weaver, West & Ciliska, 2005; Williams & Reid, 2010), the use of pro-recovery websites (Williams & Reid, 2012) and the experience of inpatient treatment (Spivack & Willig, 2010). To our knowledge, the current study is the first to directly investigate the individual's existential view of the self and how this interfaces with AN. Individuals with a lifetime history of AN were asked to reflect on the self prior to AN and to compare this to the self during AN. This was in addition to considering the impact/potential impact of recovery on the self. Taking a relational approach to exploring the self in detail using a qualitative methodology allowed for consideration of the following questions:

- How do individuals with AN conceptualise their sense of self and in what way does this link to the eating disorder?
- What impact does AN have on individuals' identity?
- What sense do individuals have about who they will/would be as a person without AN?

Despite its identified importance, there is an absence of theoretical understanding of sense of self and AN. Grounded theory was therefore used in order to offer a theoretical framework for the relationship between the self and AN, upon which therapeutic interventions could be based. This is crucial given the absence of convincing evidence for effective therapies for AN (Wilson, Grilo & Vitousek, 2007) and the dearth of literature regarding sense of self and AN.

Method

A constructivist grounded theory methodology (Charmaz, 2006) was employed. Using a process of 'constant comparison', data were compared with data, data with categories and categories with categories. This allowed for exploration of all similarities and differences, in addition to relationships between categories within the data (Charmaz, 2006). The data were analysed alongside the interviewing of participants in order to direct data collection and theory development.

Reflexivity

Theories developed within constructivist grounded theory are dependent on the researcher's view, as the researcher cannot achieve separation from the data (Charmaz, 2006). Researchers must, therefore, take a reflexive stance towards theory evolution, acknowledging the influence of their values, preconceived ideas, assumptions and previous knowledge and experience (Charmaz, 2006; Elliot, Fischer & Rennie, 1999).

Data were collected and analysed by the first author (KW), who is a 36 year old White British woman. The research was part of her doctorate in clinical psychology and she was on placement in an eating disorder service. She also has personal experience of AN, having lived with the disorder during her teens and early twenties. This facilitated an understanding of participants' stories, in addition to having a deeper level of empathy with their experiences. It seemed that this also enabled KW to quickly establish a rapport with participants, which appeared to encourage them to share detailed information. KW felt a strong connection to participants and the data, which helped in teasing out narratives during interviews and understanding the data for analysis. KW did, however, remain aware of the dangers of reading too much into the data from her own story and after interview one changed the way she interacted with the data. This was to ensure that information was given on a level that was not just understood by KW, but made explicit for the purposes of coding. She also took a step back when conducting interviews and coding data in order to ensure that she did not fit the data to her story. KW constantly reviewed her decisions, and regular discussions regarding issues pertaining to reflexivity, interviews and emerging themes were held within supervision.

The research was supervised by the second and third authors. JF has considerable experience of working and researching in the field of eating disorders as a clinical psychologist. He has also conducted several studies using grounded theory. JK works as a clinical psychologist in an eating disorder service and has conducted doctoral level research in the same field.

Recruitment

The study received full ethical and NHS R&D approval (appendix 10). Participants were recruited from two NHS outpatient eating disorder services and two eating disorder charities, including 'beat'. Clinicians from NHS services and one charity identified participants following standard ethical procedures for recruitment (appendices 11, 12 and 13). Theoretical sampling identified a need to sample recovered participants in order to generate further data to confirm or refute themes around sense of self during and after recovery. Consequently, participants were recruited from 'beat' via an advertisement on their website (appendices 13 and 14). Informed consent was taken by the first author.

Participants completed the Beck Anxiety Inventory (BAI; Beck & Steer, 1993), the Beck Depression Inventory-II (BDI-II; Beck, Steer & Brown, 1996), the Robson Self-Concept Questionnaire (RSCQ; Robson, 1989) and the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994) immediately prior to interview. Participants' body mass index (BMI) was calculated from self-report data in the EDE-Q. All of these measures are widely used and considered reliable and valid in both clinical practice and research (Dozois, Dobson & Annberg, 1998; Fydrich, Dowdall & Chambless, 1992;

Mond, Hay, Rodgers, Owen & Beumont, 2004; Rose, Vaewsorn, Rosselli-Navarra, Wilson & Streigel-Weissman, 2013; Wittkowski & Tai, 2006).

Inclusion criteria comprised of: (i) lifetime history of AN as per DSM-V (APA, 2013) criteria, (ii) aged 18 or over, (iii) able to read and write in English at a level sufficient to understand and complete study-related procedures, (iv) able to give written informed consent. Lifetime history of AN was confirmed by professional diagnosis for participants recruited from NHS services and by likelihood of caseness for participants recruited from charities. Individuals were informally assessed as to whether they had met the DSM-V criteria for AN in their lifetime by considering interview and EDE-Q data.

Participants

Eleven women participated in the study: five were recruited from NHS Table 1 shows participant characteristics. services and six from charities. Participants were aged between 18 and 60 (mean 28 years). Participants' ethnic origin was predominantly White British, with all participants living in either England or Wales. Participants began to have difficulties with eating from age 12 to 26 (mean 15 years). BMI ranged from 14.8 to 23.7. There were high levels of anxiety and depression within the sample. Self-esteem was below average, with over half the participants scoring below the expected range for clinical samples, indicating extremely low levels of self-esteem. Nine of the 11 participants classed themselves as 'in recovery' to varying degrees; however, clinically significant levels of disordered eating were

Table 1: Participant characteristics

| Participant | Age | Ethnic origin | Occupation/ relationship status | Age at onset of eating difficulties | Self-reported recovery status | BMI | BAI score Minimal = 0-7 Mild = 8-15 Moderate = 16-25 Severe = 26-63 | BDI-II score Minimal = 0-13 Mild = 14-19 Moderate = 20-28 Severe = 29-63 | RSCQ score Normal mean = 140 Clinical mean = 100-108 | EDE-Q score ≥4 = clinically significant |
|-------------|-----|------------------|---|--|---|------|--|---|---|---|
| 1 | 18 | White English | Unemployed/ Single | 13 | Anorexic | 22 | 26 (Severe) | 46 (Severe) | 85 | 5 |
| 2 | 33 | White British | Unemployed/ Single | 16 | In recovery | 15.8 | 26 (Severe) | 37 (Severe) | 94 | 4 |
| 3 | 60 | White English | Unemployed/ Married | 12 | In recovery | 20 | 48 (Severe) | 47 (Severe) | 102 | 4.8 |
| 4 | 28 | White British | Speech and language therapy student/ Single | 14 | In recovery | 18.8 | 23 (Moderate) | 31 (Severe) | 103 | 4.8 |
| 5 | 22 | White British | Medical student/ Engaged | 12 | Anorexic | 17.2 | 34 (Severe) | 58 (Severe) | 42 | 5.8 |
| 6 | 22 | White British | Photography student/ Single | 13 | In recovery (midway between anorexic and recovered) | 22.5 | 9 (Mild) | 23 (Moderate) | 112 | 4.3 |

| Participant number | Age | Ethnic origin | Occupation/ relationship status | Age at onset of eating difficulties | Self-reported recovery status | BMI | BAI score Minimal = 0-7 Mild = 8-15 Moderate = 16-25 Severe = 26-63 | BDI-II score Minimal = 0-13 Mild = 14-19 Moderate = 20-28 Severe = 29-63 | RSCQ score Normal mean = 140 Clinical mean = 100-108 | EDE-Q score ≥4 = clinically significant |
|-----------------------|-----|-----------------------------|---|--|---|------|--|--|---|---|
| 7 | 20 | White Welsh | Biomedical science student/ Single | 14 | Fully recovered behaviourally; still some anorexic thoughts | 23.7 | 17 (Moderate) | 7 (Minimal) | 107 | 3.1 |
| 8 | 24 | White British | Medical student/ Single | 18 | At the beginning of recovery | 14.8 | 18 (Moderate) | 23 (Moderate) | 89 | 5.3 |
| 9 | 24 | British Asian/ Indian | Assistant psychologist/ Single | 12 | In recovery | 17.7 | 47 (Severe) | 46 (Severe) | 64 | 4.8 |
| 10 | 27 | White English | Doctor/ Single | 26 | Recovering (still a lot of anorexic thinking) | 16.6 | 17 (Moderate) | 49 (Severe) | 73 | 4.1 |
| 11 | 25 | White British | Archives and records management student/ Single | 12 | Pretty much recovered (9/10) | 16.6 | 9 (Mild) | 19 (Mild) | 99 | 1 |

indicated in 82% of the sample (using EDE-Q data).

Interview schedule

The interview schedule was devised through discussion in supervision and a review of relevant literature. It comprised 10 open-ended questions with corresponding prompts, outlining topics pertinent to sense of self. Interviews were semi-structured and focused on the information given by participants, with the interviewer largely responding to their comments in order to tease out relevant information. In accordance with grounded theory principles, the interview schedule was revised in response to themes emerging from the data (appendix 15). Interviews lasted between 49 and 109 minutes: 10 interviews were conducted face-to-face and one over the telephone.

Data analysis

The first author transcribed verbatim and analysed all interviews. The data were initially coded line by line, meaning that segments of the data were named with a label that simultaneously categorised, summarised and accounted for each piece of data. Categories were then identified and links between them established. During this process memos were written, whereby the first author stopped and analysed her ideas about the identified codes and categories (appendix 16). Core categories were then identified and developed into an explanatory framework within which to understand the underlying concepts; linking them to each other and the existing literature (Charmaz, 2006).

The study adhered to the principles of theoretical sufficiency (Dey, 1999).

This was achieved through thorough analysis of the data by coding the data until

these codes accounted for the data and the theory that was emerging made sense. As it developed, the analysis narrowed in focus and the emerging theory was constantly reviewed with regard to its ability to adequately manage new data without further modifications.

Reliability and validity

Elliot, Fischer & Rennie's (1999) guidelines for qualitative research were adhered to in order to protect the quality of the study. The process of analysis was transparent, with the first author holding a reflexive stance and completing an on-going reflective journal. The analysis and developing model was discussed in supervision, as were emerging themes and interpretations. Direct quotes were used to illustrate the model, ensuring that the explanatory framework was grounded in the data. To uphold reliability, a researcher independent of the study checked two randomly selected transcripts, with 98% agreement with the first author.

Results

Grounded theory was used to develop a theoretical understanding of the nature of the relationship between the self and AN. Five theoretical categories were identified: AN taking over the self; AN protecting the self; sharing the self with AN; being no one without AN; discovering the real me (accepting the fear). Figure 1 shows a model depicting this understanding and the relationships between categories (its construction followed the guidance of Charmaz, 2006).

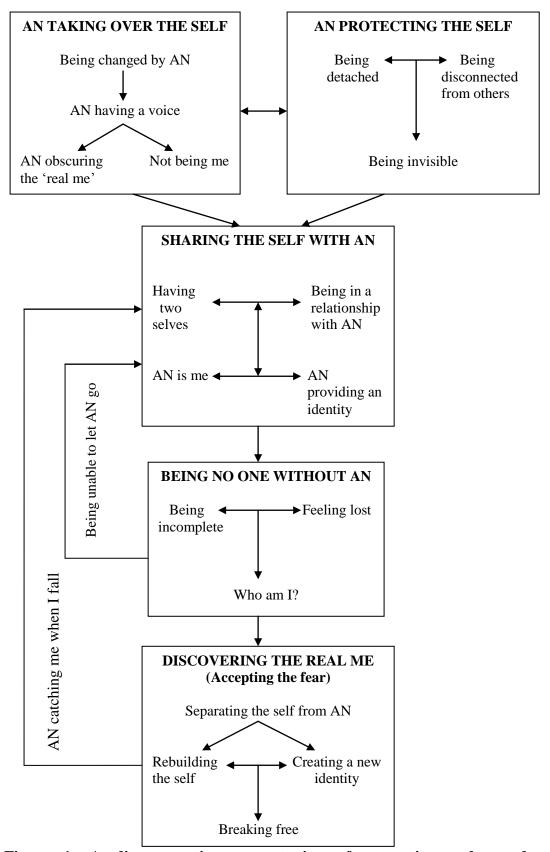


Figure 1: A diagrammatic representation of categories, codes and relationships

Each category is discussed below in terms of the theoretical categories as a whole: bold italics are used to highlight the focused coding that underpins these categories.

Prior to becoming anorexic it was common for participants to strongly dislike themselves, believing they were a bad person who was a failure and inferior to others. A view of not being good enough, being insignificant and lacking confidence was also commonplace. Individuals felt worthless and described needing to find a way to gain a sense of self-worth, which was offered by AN. This information was not coded in order to keep the focus of the study specifically on the relationship between the self and AN.

Although nine of the 11 participants classed themselves as 'in recovery', the results should be considered within the context of the clinically significant levels of disordered eating that were indicated in 82% of the sample. This suggests that most participants would be more likely to be classed as 'anorexic' than 'recovered', which may have shaped their perspectives.

AN taking over the self

Participants described AN as feeling like "something has come in and taken over" (participant 6). It seemed to take over the self, lay down roots inside them and crush the 'real self' to the point where participants viewed themselves as being changed by AN:

"I wasn't really me, I was more like a shell and my eating disorder had took over." (Participant 7).

Participants also described *AN having a voice*. It appeared to take on a persona, become powerful and dominate participants, telling them what to do. The 'anorexic voice' was perceived as bullying and critical: its words seemed compelling and participants felt a need to obey its commands. Participants described fighting a battle against the 'anorexic voice', but more often than not it was victorious. Participants appeared powerless to resist this 'voice' and found it easier to give in to it:

"...at the beginning it was really overpowering.....it was overpowering in the sense that it was 90% an anorexic voice and 10% mine, it was, every time I would try and fight against it, it would, it was, you know, it made, it made things worse, it was harder, I mean it was easier to listen to the anorexic voice."

(Participant 7).

AN protecting the self

Participants described AN as serving a positive function by protecting the small part of the 'real self' that remained. They appeared to use AN to put up barriers: it guarded the 'real self', keeping participants' perceived vulnerability hidden:

"....it's like a protective thing and it feels like round my heart." (Participant 2).

In doing so, AN seemed to become a tool for *being detached* and *being disconnected from others*. It provided a way of being detached from feelings, avoiding painful emotions and protecting the self from experiencing true thoughts and feelings. Participants described not being present in life, which

included feeling distant from others. Individuals appeared to use AN as a shield between the self and others; it pushed others away, meaning that participants did not have to give their full self to others:

"...it made you feel more erm, secluded from the world really, in this like, in this total bubble of your own making." (Participant 3).

"I feel like I've kind of put up barriers to other people so I don't really talk about it to other people and I don't really let them in and it means that I can cope, whereas if you were to take them all down, I don't know, I think I'd feel really, really vulnerable." (Participant 10).

Alongside being detached on an emotional and interpersonal level, AN appeared to provide a way of *being invisible*. Participants wanted to go unnoticed and there was a perception of being able to hide when slim:

"....you can erm, hide more, you know, you're not, you're not as much on display, you can mingle and be in the background, that's the words I'm looking for, be in the background you know, you're not noticed, erm, cause I hate being noticed." (Participant 3).

Sharing the self with AN

Participants seemed to begin to rely on AN to protect the part of the 'real self' that remained and subsequently appeared to share the self with AN. Participants described *having two selves* and being confused as to which person

they were. There was a sense that AN was the dark side of them, an irrational part that gave individuals a 'split personality':

"....it gives you like a split personality. Good and bad, positive yeah, it's like, it's like your evil twin type of thing." (Participant 2).

Participants defined this as *being in a relationship with AN*, leading them to become attached to AN as something they could depend on, despite this relationship being mostly abusive in nature:

"I guess the only way I can describe it is as an abusive relationship, you often think why do you stay in that relationship but because you almost feel helpless without it. Yeah, it's like an abusive partner, you, you know, you don't like it but it's, they promise to look after you so you believe them." (Participant 11).

It appeared that AN quickly became part of participants and the self became intertwined with the eating disorder. Individuals described AN as becoming embedded deep within them, which had a huge impact on their view of themselves. Reflecting on who they were as a person, participants reported that *AN is me*. The eating disorder seemed to provide a sense of self and become all that participants were, making it hard to separate the self from AN. Individuals became 'an anorexic', with *AN providing an identity*. Participants viewed themselves as anorexic and it was what they were known for. The eating disorder seemed to give them a self-image, a persona and it was an identity over which they had control:

".....it's [AN] me, there's nothing else." (Participant 3).

"....my whole identity if in the midst of anorexia is just nothing apart from weight. I'm the girl with the eating disorder, so I'm the one who should be like, thin." (Participant 6).

Being no one without AN

Recovery appeared to threaten participants' sense of self and who they were as a person. Participants described *being incomplete without AN*: recovery meant losing part of them, which would leave a large gap in the self that needed to be filled. This seemed to threaten participants' very sense of being to the extent that they described *feeling lost* without AN. Participants found it hard to imagine life without AN and feared falling to pieces should they recover. Life would be empty as their basis for living would have been taken away:

"I just have no idea what, what would happen, it feels like if someone said to you, well, what would you do if someone just came along and chopped your legs off, well you, I don't know, I'd just flail around and it would just, I think it would just be very, it would be so much more distressing." (Participant 10).

These fears appeared to lead participants to question *who am I* without AN. Individuals felt unsure of themselves without AN and did not perceive that they knew who they would be without the eating disorder. The common view was that, without AN, participants were nothing: they would be insignificant, empty and unreal:

"I think just that anorexia gives you a sense of being that you wouldn't have otherwise..... and I think without that you wouldn't be, well, I wouldn't feel like a person at all." (Participant 10).

The fear of being no one without AN was so strong that many participants were unable to let AN go. They held on to it and the sense of self and identity that it provided, describing recovery as a loss and unattainable. Consequently, participants continued to share the self with AN, seemingly stuck in an abusive relationship from which they felt unable to leave.

Discovering the real me (accepting the fear)

In order to recover from AN participants described needing to accept the fear of the unknown and take a leap of faith into discovering who they were without the eating disorder. The majority of participants described themselves as 'in recovery' and there was an initial recognition that *separating the self from AN* was needed to recover:

"...it's like you know, it's like breaking up with something, it's breaking apart a part of you." (Participant 2).

Separating the self from AN appeared to mean *creating a new identity*. Participants were beginning to find alternative things that were separate to AN to base their identity on. They were starting to drown AN with other things in life and discovering their own desires, likes and dislikes. This seemed to enable a *rebuilding of the self*, whereby participants were becoming a new person without

AN. They felt unable to return to the person they were before AN, feeling somewhat dissociated from this person and became focused on reinventing themselves, becoming a modified version of their former self:

"I had it for so long, that was all I knew, everything was around that, erm, it's like I'm kind of starting to reinvent myself almost, or find out what kind of things I did used to enjoy, what kind of things I would like to do." (Participant 9).

"I used to feel that it would incorporate who I was before but now I think, I just think it's been too long...I feel like I've said goodbye to her. I don't feel that I could ever find my way back to her." (Participant 4).

By creating a new identity and rebuilding the self, participants seemed to be *breaking free* from AN. By learning to live without AN they appeared to be discovering the 'real self', the part of them that had originally been taken over by AN and been hidden but still remained throughout their relationship with the eating disorder. The 'real self' was gradually getting bigger and participants were beginning to become the person they wanted to be:

"I mean I could feel me inside kind of like trying to get out but I wasn't able to do anything about it at that time until I kind of did make that decision...I'd be more free to be me." (Participant 6).

"...when you're well or when it's gone, you'll just be you, you won't be anorexic, you'll be you." (Participant 3).

Many participants, however, seemingly struggled to discover who they were without AN and feelings of being lost and incomplete took over. Being without AN appeared to mean that the 'real self' was vulnerable and exposed, which was overwhelming. Participants also described that AN would always be a part of them and would always return, therefore they continued to seek comfort in AN; they could rely on it, it was predictable and it provided security. Their safety net was AN: it caught them when they fell.

Discussion

Sense of self seems to play a crucial role in AN. The relationship between the self and the eating disorder was an enmeshed one: individuals appeared to share the self with AN and become defined by it. Being unable to let AN go due to fears of being no one without it was common and participants seemingly needed to accept this fear and begin to separate the self from AN in order to break free from the disorder and discover their 'real self'. Participants found it difficult to face this challenge, often returning to the safety and security of AN and its perceived ability to protect the self.

The finding that the self is shared with AN supports previous research conducted with inpatients with AN who described themselves as containing two selves: an 'anorexic self' and a 'non-anorexic self' (Spivack & Willig, 2010). Participants in the current study spoke clearly about 'having two selves'; seeing their 'real self' as 'rational' and their 'anorexic self' as 'irrational' or their 'dark side'. Participants described feeling overwhelmed by AN and stuck in an abusive relationship with it: it seemed to chip away at their sense of self until AN

became them. This is consistent with Spivack & Willing's (2010) findings that participants became dominated by the 'anorexic self' to the point that they lost a sense of who they were before AN.

This domination of the self appeared to be underpinned by AN taking over the self, which included AN having its own 'voice' with which it controlled the individual, dictating their actions and expecting them to obey its commands. This finding is consistent with previous research identifying the presence of an 'anorexic voice' that had a hold over individuals (Higbed & Fox, 2010; Tierney & Fox, 2010; Williams & Reid, 2012). Tierney & Fox (2010) found the 'anorexic voice' to be viewed both positively and negatively, being a comforter and a friend but also a manipulator and a bully. This mirrors participants' descriptions in the current study of being in a relationship with AN, which was viewed positively as something they could rely on, but negatively as abusive in nature, bullying and criticising them.

The current study demonstrated that AN was also viewed positively in terms of its perceived ability to protect the 'real self' by keeping individuals detached from their feelings and disconnected from others. This is consistent with Schmidt & Treasure's (2006) cognitive-interpersonal maintenance model of AN, which asserts that AN has an adaptive function in that it meets a need to avoid the experience and expression of powerful negative emotions and the close relationships which may initiate such emotions.

On considering recovery from AN participants described an intense fear that without AN they would be no one. Their sense of self had become so intertwined with AN that recovery seemed unattainable; they could not imagine who they would be without AN. This supports research in the recovery literature, which posits that an individual defining themselves by AN and equating their self-worth with weight loss is a significant barrier to recovery (Granek, 2007; Lamoureux & Bottorff, 2005; Shohet, 2007; Weaver, Wuest & Ciliska, 2005; Williams & Reid, 2010). Recovering from AN meant accepting the fear of the unknown and discovering the 'real self' by separating the self from the eating disorder. This finding is consistent with research purporting that an individual's sense of self becomes defined by AN (Tierney & Fox, 2010) and subsequently psychological distance between the self and AN is needed for recovery (Higbed & Fox, 2010). For participants in the current study this seemed to involve breaking free from AN's entrapment and creating a new identity that was independent of eating, weight and shape concerns. This supports the proposition that establishing an identity that is not defined by AN and basing self-worth on alternative things are helpful factors in the recovery process (Granek, 2007; Jenkins & Ogden, 2012; Lamoureux & Bottorff, 2005; Shohet, 2007; Weaver, Wuest & Ciliska, 2005).

Limitations

Participants recruited from NHS services and one of the charities were approached by clinicians in accordance with the inclusion criteria and professional judgement as to an individual's 'suitability' to participate in the research. Consequently, not all individuals interested in taking part may have been approached, although posters were displayed within waiting rooms in order to publicise the research.

Six participants were recruited from charities, therefore lifetime history of AN was not confirmed by professional diagnosis. These individuals were

informally assessed as to whether they had met the DSM-V criteria for AN in their lifetime by considering interview and EDE-Q data. There was no cause to dispute the validity of participants' narratives, given the consistency of their stories in comparison to others. The homogeneous clinical presentation upon which a diagnosis of AN is based makes it relatively easy to diagnose (Hebebrand, Casper, Treasure & Schweiger, 2004) and the first author was confident that she had enough information to conclude the likelihood of caseness.

The BMIs of participants were self-reported. Participants were not weighed as part of the study given how uncomfortable they may have felt being weighed in front of the first author and the potential for this to impact negatively on engagement and levels of distress. Research suggests, however, that individuals with AN are very accurate at reporting their weight (McCabe, McFarlane, Polivy & Olmsted, 2001).

The BAI and BDI-II scores indicated high levels of anxiety and depression in the sample, which is consistent with the high level of co-morbidity of affective and anxiety disorders in individuals with AN (Godart, Flament, Perdereau & Jeanmet, 2002; Halmi et al., 1991; Kaye, Bulik, Thornton, Barbarich & Masters, 2004; O'Brien & Vincent, 2003). It is hypothesised that the AN underpinned participants' view of the self, given the uniformity of participant responses and the consistency with previous research. It is possible; however, that anxiety and/or depression exacerbated these views.

Recommendations for future research

Nine of the 11 participants reported themselves as 'in recovery' as opposed to 'anorexic', yet only two of the 11 participants scored below 4 on the

EDE-Q and none of the participants had experienced being recovered for longer than a few months. Although recovery from a mental health problem is not always considered as an absence of symptoms (Davidson & Roe, 2007; Repper & Perkins, 2003), it is hypothesised that the maintenance of clinically significant levels of disordered eating would have had an impact on an individual's view of the self, given the strong relationship identified between the self and AN. It would therefore be useful to sample individuals who have been recovered for some time and score below 4 on the EDE-Q. This would allow for further investigation of the relationship with the self post-recovery and how this differs to sharing the self with AN, including unpicking the process of separating the self from AN and how this is maintained.

Implications for clinical practice

The findings of the current study emphasise the impact of sharing the self with AN. Individuals with AN appear to experience a sense of loss when recovering from the disorder, which participants expressed as comparable to ending a relationship. Subsequently, the nature of this relationship needs to be afforded the respect it deserves by being a focus for intervention. This supports William & Reid's (2012) assertion that building a client's sense of self should be the focus of treatment for AN.

It is proposed that supporting individuals to understand the relationship between the self and AN would assist them in being able to sever their tie with AN and find their 'real self', thus creating a new identity. This in turn would help them to accept the self and move on from the disorder. Evidence-based interventions that target changes in the self-concept as the mechanism for

recovery are currently lacking, although a randomised clinical trial of an identity intervention programme for women with eating disorders has recently been shown to be equally effective as supportive psychotherapy in reducing eating disorder symptoms at 1 month and 12 months post-intervention (Stein, Corte, Chen, Nuliyalu & Wing, 2013). Additionally, McIntosh et. al. (2005) found non-specific supportive clinical management to be more effective than interpersonal therapy and cognitive behavioural therapy for AN (with weight and shape concerns as its focus).

Emotion-focused therapy has also been used to target changes in self-concept by utilising techniques for dealing explicitly and effectively with the 'anorexic voice', in addition to emphasising greater acceptance of the self and internal experiences (Dolhanty & Greenberg, 2009). This is important as the current study demonstrated that participants often returned to AN because their 'real self' felt vulnerable and exposed without AN: they sought comfort and security in the disorder as it helped them to avoid emotions and certain aspects of the self.

It has been proposed that this poor sense of self and detachment from emotional experiences stems from developmental attachment difficulties (Lafrance & Dolhanty, 2010); with AN being viewed as providing a secure base (Hochdorf, Latzer, Canetti & Bachar, 2005). Consequently, understanding how AN is incorporated into an individual's internal world to the extent that it defines their identity may also be useful (O'Shaughnessy & Dallos, 2009). Cognitive analytic therapy may be helpful here, as it places the early relationship patterns experienced by an individual and their subsequent impact at the heart of therapy (Newell, 2012). The therapist can also offer the development of an alternative

secure base and through the therapeutic relationship support the individual to construct an internal sense of security (O'Shaughnessy & Dallos, 2009). In doing so, the individual can then be encouraged to discover who they really are and where they would like their life to take them.

Conclusions

The current study has built on previous research identifying the role of sense of self in AN by understanding the relationship between the 'real self' and the 'anorexic self'. The impact of the enmeshed relationship between the self and the eating disorder in individuals with AN and the challenges this presents for recovery have been highlighted. This suggests the need for novel interventions, placing the self at the centre of these. Using a qualitative methodology to explore this relationship has allowed for an in-depth understanding of how the self comes to be shared with AN and the identification of a need to separate the self from AN in order to recover from the disorder.

The current study has also highlighted the dearth of research conducted in this area and the subsequent need for more research. Exploring the nature of the relationship with the self further will help to increasingly identify the mechanisms of this relationship and allow for recognition of other areas to target with therapeutic interventions. This is invaluable if the efficacy and effectiveness of therapeutic interventions for AN are to be improved.

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Paper 3: Critical Reflection

A qualitative exploration of sense of self and anorexia nervosa:

my journey.

Paper 3 is not intended for publication. This paper evaluates the strengths and

limitations of both paper 1 and paper 2. It also discusses my reflections on the

research as a whole, including the implications for my clinical practice.

Word count: 7055

(excluding references)

98

Introduction

This paper critically reviews my experience of completing a qualitative exploration of the relationship between the self and the eating disorder in individuals with anorexia nervosa (AN). I have reviewed the process of completing the literature review, developing the research, my thoughts on theories of the self and my reflections on carrying out the empirical study in practice. I have also discussed the implications for my clinical practice, what I have learnt from conducting the research, the relevance of the research to my career as a clinical psychologist and the conclusions that can be drawn from the research as a whole.

The literature review

Rationale for topic

The primary aim of the literature review was to contribute an additional understanding to the field of eating disorders. The advantages of conducting systematic reviews are well-known and long-standing (Mulrow, 1994) and it was important that by efficiently integrating information and presenting a clear and concise review of data, I offered something useful to clinicians working with individuals with AN. Consequently, it was important that the review reduced a gap in the literature.

Given that recovery rates for AN remain low, with only 46.9% of individuals who survive the disorder making a full recovery (Steinhausen, 2002), there is a need for continued exploration and understanding of recovery from AN. On conducting preliminary searches around this topic I discovered that there was substantial interest in recovery outcomes and rates of relapse, which

were quantified primarily using medical parameters. Literature considering the actual *process* of recovery from AN and an individual's perception of this appeared lacking, as much of the research was conducted quantitatively to assess whether recovery had been 'achieved'.

It appeared that in order to gain a more detailed understanding of the process of recovery, including the factors that helped and the factors that hindered, I would have to look to the qualitative literature and consider conducting a metasynthesis of published research. Further exploration identified two metasyntheses that reviewed the qualitative literature regarding treatment for AN and its relationship with recovery (Bezance & Holliday, 2013; Espindola & Blay, 2009), but none that focused specifically on recovery itself and the process that underpins it.

Completing a qualitative as opposed to quantitative review of the literature on recovery from AN seemed logical as I thought it would be harder to gain detailed information on the process of recovery from quantitative studies. It appeared to me that the rich data gained from the client's perspective would be much more informative and useful to clinicians in considering how best to work therapeutically towards recovery with their clients. Although it may be possible to deduce from a statistically significant result that a certain factor is implicated in recovery, I think the value of qualitative findings is that it adds an understanding of the mechanism of why that factor is implicated in recovery and how this can be nurtured within therapy.

Literature search

The literature search was conducted in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles (Moher, Liberati, Tetzlaff & Altman, 2009) in order to ensure that the search was systematic and transparent. Having not completed a systematic review before, I was surprised at the sheer number of articles produced by the search, despite using different strategies to maximise its effectiveness and efficiency. It was important that the search identified all articles of possible relevancy, therefore I decided against making the search terms too narrow. Thorough searching and review of the articles found meant that I could hold greater confidence that important articles were not missed.

Setting the parameters of the inclusion and exclusion criteria (appendix 17) was also important in ensuring the search identified articles of interest. These were discussed within supervision and designed to be strict in order to afford the topic the narrow focus it needed to explore the actual process of recovery. A disadvantage of these criteria is that some important studies may have been missed. For example, it is possible that some of the studies excluded due to being written in a language other than English may have added valuable insight to the topic under review. Unpublished literature, such as PhD theses, may also have been able to contribute to the review; however, it would be important to know the reasons for their absence of publication, as this could be for reasons of quality or publication bias (Dickersin, Scherer & Lefebvre, 1994). On the whole, I believe that the inclusion and exclusion criteria identified a focused set of articles that helped me to understand the process of recovery from AN.

Critical appraisal of studies

Appraising the quality of qualitative research remains an active debate, with no single appraisal tool being considered the 'gold standard'. I reviewed the published literature on this debate, in addition to previously conducted metasyntheses to inform a decision on how to critically appraise the studies included in the review. I was drawn to the most widely used checklists of the Critical Appraisal Skills Programme (CASP; 2013) (appendix 4) and Walsh & Downe (2006) (appendix 5). I decided to trial each of these checklists in order to consider which to use, or indeed whether to appraise the studies using both.

The Walsh & Downe (2006) checklist includes eight items, each of which is judged on whether or not a study has met certain essential criteria. I found this checklist to be somewhat ambiguous and did not feel confident that I was applying consistent judgement to each of the articles. Although the checklist includes a number of specific prompts to elicit the detail needed to inform a decision as to whether or not the essential criteria are met, I found it difficult to decide what level of information would be enough to agree that the criteria had been met and what would not. The CASP (2013) checklist presented me with something more tangible as it generated a score out of 10; however, there are no guidelines as to the interpreted significance of this score. A further concern was that neither of the checklists allowed for the rating of information pertinent to the topic under review, namely diagnosis of AN and a definition of recovery.

Consequently, I chose to amalgamate the CASP (2013) and Walsh & Downe (2006) checklists, in addition to including additional idiosyncratic items. I constructed this 11 item checklist (appendix 6) in such a way that each item could be attributed a score of 0, 0.5 or 1 in response to the information I

prompted myself to elicit from the studies. The total score then indicated a quality category of 'A', 'B' or 'C'. Although Walsh & Downe (2006) are opposed to rating individual items to produce a total quality score, I found it much easier to appraise the studies using this method and believe that I was more consistent in my ratings. This agrees with Cesario, Morin & Santa-Donato (2002), who suggest that this method of appraising qualitative research is useful. The structure also allowed for focused discussion of similarities and discrepancies when reviewing the ratings with the independent researcher, who rated a third of the studies for reliability purposes.

I agree with Walsh & Downe's (2005) assertion that "If one is urging the research community to embrace qualitative meta-synthesis, then the use of robust quality markers to judge qualitative research is crucial for the credibility of this method" (page 208). This is one of the reasons I aimed to make the appraisal of the quality of the studies increasingly 'robust'; however, it still felt that the critical appraisal of qualitative research was open to interpretation. On discussing the rated studies with the independent researcher it became clear that, although my checklist appeared to go some way to providing more focus, the scoring of each item was still subjective. This may be due to the very nature of qualitative research being a researcher's interpretation of a particular experience or phenomenon. It may not be possible to eradicate such difficulties, but I think that, as proposed by Lincoln & Guba (1985), we should always strive to ensure that any form of literature review at least includes studies with a basic level of credibility, transferability, dependability and confirmability.

Conclusions

The metasynthesis offered a new interpretation of recovery from AN. In doing so, the review offered an understanding of the key factors implicated in the process of recovery. This review may be criticised for its perceived lack of scientific credibility (as discussed in paper 1), however, I believe that the completed review offers useful information on recovery from AN. This understanding is offered as my interpretation, not new data, but still has important implications for improving the effectiveness and efficacy of interventions for AN and the role that the identified factors have to play in such interventions.

The empirical study

Developing the research

I chose to complete research into sense of self and AN due to having an interest in the area of eating disorders, in addition to separating the self from the eating disorder and creating a new identity being crucial in my recovery from AN. In addition, prior to being a trainee clinical psychologist I had worked as a nursing assistant in an eating disorders unit and was struck by the almost exclusive focus on encouraging individuals to eat and gain weight. The routine appeared to be one of reward and punishment, with goals being based on weight gained and adherence to diet plans. Despite the obvious need for this in terms of risks to physical health, I questioned how successful this approach would be with regard to long-term outcomes. Although regular therapeutic sessions were scheduled with a clinical psychologist or nurse therapist, the listening ear I

provided to individuals heard tales of target weights and challenging beliefs about the over-evaluation of weight and shape, as opposed to what I viewed as the fundamental question: who am I without AN? I can recall at the time wondering whether I was profoundly different to others with a diagnosis of AN, whether individuals did not feel comfortable talking about this issue with me or whether the relationship between the self and the eating disorder was not emphasised in interventions for AN.

Conducting my doctoral research gave me an opportunity to explore this question. On reviewing the background literature on the topic of sense of self and AN I realised how little published research there appeared to be on the topic. From my own experience and the literature available, it seemed to be an integral part of the maintenance of AN that deserved further attention in order to unpick the detail of how the eating disorder interacted with the self.

Theories of self

Theories of the self (Burkitt, 2008; James, 1890; Mead, 1934) suggest early experiences as central in shaping the self, in addition to the self being something within which we encompass society's norms, values, ideals and expectations. Burkitt (2008) attests to the importance of the environment into which we are born as affecting the self, suggesting it as something that is malleable and shaped by our social interactions. It seems logical that experiences in our childhood shape the person we become as an adult, which led me to reflect on the early experiences encountered by the participants I interviewed. All the participants described either being bullied or abused by the age of 13, which appeared to lead participants to question their self-worth and

who they were as a person. Common themes included worthlessness, being valueless and not being good enough. This seemed to instill a poor sense of self in individuals, which then appeared to lead them to search for a way to improve their sense of self.

The results of my empirical study showed that AN seemed to come along and assist with the search for a sense of self by taking over and providing an identity, which compensated for the negative view individuals held of themselves. If the self is viewed as malleable, however, this implies that the self can then be further shaped by separation from AN during recovery and finding a new identity. Participants spoke about 'rebuilding' and 'reinventing' the self, which suggests to me that the self is continually perceived as something that can be changed and moulded. This is interesting given the fact that, although the self seems to be there for the changing, recovery rates for AN are comparatively low. This makes me wonder whether how much time and effort we put into shaping the self with regard to certain values and ideals dictates the permanency of the self and its potential to be changed. Chronicity has long been associated with poor outcome in AN (Steinhausen, 2002), therefore there is obviously a strong barrier to recovery from the disorder. I wonder whether this barrier is put in place by the impact of AN on an individual's sense of self and the perceived threat to the self that recovery represents. Consequently, I believe that exploring the self and its relationship with AN should be a priority in therapeutic interventions for the disorder.

Rationale for the use of grounded theory

The aim of the research was to understand the nature of the relationship between the self and the eating disorder in individuals with AN. It was proposed that understanding this relationship would aid insight into the maintenance of the disorder, which would allow for the identification of targets for therapeutic intervention. The study used a qualitative design as quantitative data would only show how individuals with AN scored on a self-concept questionnaire; for example, identifying that they had a poor sense of self or low self-esteem. A qualitative design could go further than this by exploring the mechanisms of the relationship between the self and AN, whether or not sense of self related to the eating disorder and how AN impacted on the view individuals held of themselves as a person. Qualitative exploration of how sense of self and AN interacted had the potential to lead to the development of a theory of the nature of this relationship.

Qualitative research within the field of AN is commonplace, with many studies successfully producing good quality research using grounded theory (Fox, 2009; Granek, 2007; Higbed & Fox, 2010; Koruth, Nevison & Schwannauer, 2012; Whitney, Easter & Tchanturia, 2008; Williams & Reid, 2007) and interpretative phenomenological analysis (Goddard, Macdonald & Treasure, 2011; Jenkins & Ogden, 2012; Sternheim, Konstantellou, Startup & Schmidt, 2011; Williams & Reid, 2010). On considering which qualitative methodology to use, the aim of developing a theoretical explanation of the relationship between the self and AN was crucial. Grounded theory was used as opposed to other qualitative methods as the study aimed to offer this theoretical understanding as opposed to just capturing the texture of individual experience.

Interpretative phenomenological analysis may have offered a more detailed and distinct analysis of the lived experience of participants, however, grounded theory allowed for the study of the same topic on a more conceptual and explanatory level (Smith, Flowers & Larkin, 2009).

Recruitment

I initially intended to recruit individuals from a specialist eating disorder inpatient service, in addition to NHS outpatient services. Unfortunately, the inpatient service withdrew their agreement to assist with recruitment when the study commenced. Participants were recruited from NHS and charitable organisations, which allowed for a broad range of individuals to be recruited. This was beneficial to the generalisability of the results and comparison of themes across different types of individuals with the commonality of a lifetime history of AN. In accordance with NHS ethics, the initial contact with participants from NHS services was via their clinician. Clinicians were asked to consider their caseload and mention the research to individuals who met the inclusion criteria. This caused some frustration when discussing potential participants with clinicians, as it became apparent that some clinicians chose not to mention the research to certain individuals because they did not think they would want to take part or they decided "it would not be good for them". This meant that some individuals who may have wanted to take part were not aware of the research and raised the question of how we can provide equal access to research opportunities. The research was publicised via posters placed in waiting rooms to ensure that as many potential participants as possible were aware of the research.

Enquiries about the research from individuals who had seen the study advertised on the website of 'beat' (a national charity promoting recovery from eating disorders) were numerous. Seventeen individuals were keen to take part and contacted me for more information. Five of these individuals were recruited to the study. Feedback from the remaining participants as to why they did not wish to take part (where given) was that they did not want me to inform their GP that they were participating in the study, as mentioned on the consent form (appendix 13). Potential participants were mostly in a position of having been recovered from AN for some time and described not wanting to be associated with the disorder due to concerns such as it impacting on occupational health checks for future jobs and the stigma associated with the disorder. participant's GP was contacted to inform them of an individual's participation should they have any concerns regarding this, in addition to having a point of contact regarding any risk issues that arose, particularly for individuals who continued to have difficulties with AN. For recovered participants, however, it could be argued that this need is less or that GP details could be taken purely for the purposes of risk. This may have facilitated increased recruitment and wider access to participation in research.

Interviews

The interview schedule

The interview schedule was developed from discussions in supervision and consideration of the research literature. The guidance of Charmaz (2006) was followed in developing questions that were open-ended and included probes designed to gather specific data for developing theoretical frameworks. The

schedule began with broader questions that encouraged the participant to reflect on their experiences before moving on to narrower questions, which were focused questions geared to obtain more detailed information regarding sense of self. The schedule was devised to ensure that the interview was focused on the topic being explored, in addition to increasing my confidence in carrying out the interview as a novice researcher. In reality, as the interviews progressed I began to rely less and less on the interview schedule, in order to keep the interview informal and more conversational (Charmaz, 2006). This became easier as my confidence grew and I learnt how to tease information out of individuals by responding to what they said. This way of interviewing felt more natural and less structured, although it was the structure that I craved during the initial stages of the research.

Experience of interviewing

Interviews were conducted on NHS premises, at the individual's home or over the telephone, depending on participants' preference. Five participants chose to be interviewed on NHS premises, five participants chose to be interviewed at home and one participant chose to be interviewed over the telephone. A distress protocol was devised and followed for each of the NHS services from which participants were recruited (appendix 18) and for the two charities (appendix 19). Participants were also given a debrief sheet on completion of the interview, with telephone numbers to contact should they experience any distress due to their participation (appendix 20). When visiting participants at home, The University of Manchester's lone working policy was followed. For each home visit I ensured that my research supervisor was aware

of the details of my visit, which included checking in and out at pre-agreed times, in addition to the use of a code word to request immediate support in the event of an emergency.

Establishing a rapport quickly with participants was crucial to the research, given the fact that all study procedures were conducted at a one-off visit. Although I did not share it with participants, I believe that my personal experience of AN was beneficial here, in that it made it easier for me to understand the narratives given by participants, in addition to having a deeper level of empathy with their experiences. This seemed to lead to participants feeling comfortable sharing painful and personal experiences within the interview that were invaluable to my theoretical understanding of the relationship between the self and the eating disorder. This is not to say that a researcher without personal experience of AN could not have achieved the same results via being empathic, warm and genuine in interviews, but rather that it made the process easier for me as a researcher.

Carrying out my first research interview was a daunting task, fraught with anxieties around the similarities and differences to a clinical interview and ensuring that I got the balance right. I was mindful of not asking leading questions, or making interpretations that may have led the participant down a particular path. I wanted to ensure that participants were free to tell their story without expectations, pressure or feeling judged. I think these are some of the reasons as to why individuals participate in research, in that it is a different experience to that of therapy, therefore fulfilling this remit was important to me.

My initial thoughts after completing my first interview were that I had succeeded in establishing a good rapport with the participant, which had enabled

her to feel comfortable expressing her thoughts and feelings, as it seemed that I came away with a large amount of interesting information. On transcribing the interview, however, I was surprised by how much of this information had been 'unsaid' and therefore for the purposes of coding – absent. I soon realised that, because I had understood the experiences that the participant was describing having been in that position myself, when she gave information followed by "you know what I mean?", I often answered "yes". In my head, I did understand what she meant, but of course further probing was needed in order to gain the detail of the phenomenon being explained and to make this detail explicit for the purposes of coding. This resulted in me taking a step back for the subsequent interviews and ensuring that I took as objective a stance as possible, considering what an individual who had no personal experience of AN would need to hear in order to make sense of the participants' experiences. This also helped in guarding against forcing the interview data into predetermined categories I may have subconsciously held (Glaser, 1978) and ensuring that I stayed vigilant and open to interesting leads (Gubrium & Holstein, 2001; Rubin & Rubin, 1995).

Developing my interview style took time and effort. Through completing the interviews I developed a more and more curious position, in terms of exploring points of interest at length, until nothing further was being discussed on that particular topic. This came as my confidence in interviewing grew, as initially I was wary about appearing too 'pushy' to participants, which I worried would have a negative effect on engagement and therefore participant disclosure. For me, this was one of the biggest differences between a clinical interview and a research interview. Following a clinical interview I would have further sessions in which to explore points of interest and be able to take a more tentative

approach. Ensuring I had built a good rapport with participants appeared to allow me to take this more direct, curious stance within the stand-alone research interviews and for it not to be perceived as threatening or forceful.

Despite my confidence growing with experience, when it came to completing an interview over the telephone I found this much harder than the face-to-face interviews. I realised how reliant I was on body language for establishing a rapport and providing feedback to the participant. I initially found it harder to connect with the participant and gain her trust, with a view to engaging her in talking about her experiences on a deeper level. Although it seemed to take longer to engage the participant, the information she shared was as in-depth as the face to face interviews I completed. This led me to wonder about the benefits of completing the interview over the telephone for the participant, predominantly the maintenance of anonymity. Although I knew the participant's name, I did not meet her in person; therefore I could not make the same judgments about her weight, shape, home environment or lifestyle for example, that she may have perceived I would have made had I met her in person. I can see the advantages of this and would imagine it gave the participant a sense of safety in completing the interview. She was also freer to withdraw at any time, as she could have chosen not to answer the telephone when I rang or to end the call at any point.

Telephone interviews have been used successfully in previous qualitative research studies where good relationships have been established that have elicited rich data (Epiphaniou & Ogden, 2010; Jenkins & Ogden, 2012; Ogden & Hills, 2008), in addition to participants expressing a preference for telephone

interviews for reasons such as not having to tidy the house and it needing less organisation (Jenkins & Ogden, 2012).

It was only towards the end of the interviews that I felt I was on the road to mastering how to complete a research interview. Unfortunately time and practical constraints prevented me completing more interviews than I did. This was somewhat frustrating in that I would have welcomed the opportunity to complete further interviews to add to my confidence in the data that was generated for analysis.

Analysis

I made the decision to transcribe all the interviews myself as I viewed this as a way of familiarising myself with the data. Transcription can be seen as a chore (Agar, 1996) or a pivotal aspect of qualitative investigation (Oliver, Serovich & Mason, 2005). For me, transcribing the interviews in addition to then analysing them led me to feel fully immersed in the data. This was invaluable in really hearing participants' stories, understanding what they were trying to tell me about their experiences and reflecting on my interviewing technique. At times, however, this was overwhelming. The individuals I interviewed appeared very open and honest in their accounts of their past and current experiences, in addition to their hopes and fears for the future. Consequently, this meant I 'relived' the stories of past trauma and emotional distress told by participants during transcription, often when I was tired and following a day of clinical work. I was saddened by a lot of the stories I heard and found it frustrating that I was unable to 'do' anything with this information. This scenario was very different to the one I am used to in clinical practice,

whereby weekly supervision would serve the purpose of processing this information, guiding reflection on it and considering the best ways in which to support an individual at the next session. Subsequently, in addition to discussion of these issues in research supervision, I developed an 'internal supervisor' in order to manage my emotional reactions towards hearing individuals' stories and to reflect on my style for future interviews. This was with a view to encouraging participants to tell an open and honest story, but to end the interview at a point where they would feel heard and empathised with, but not left feeling vulnerable and exposed.

Following transcription, data were analysed in accordance with constructivist grounded theory principles (Charmaz, 2006), which includes analysing the data concurrently with data collection, in order to allow for modification of the interview schedule and theoretical sampling. Due to time constraints there were occasions when this was particularly challenging, for example when two participants were interviewed in the same week due to accommodating participant availability. This meant that there were times when the interview was transcribed and then analysed in a more informal manner, before returning to it at a later date to confirm codes. This led to a number a transcripts being formally analysed at a single time point, which was far from ideal. If I was to replicate the study I would pay closer attention to time management and aim to plan the research to give more time between interviews, in order that I could devote my full attention to transcription and coding between the interviews.

In accordance with guidelines for carrying out qualitative research (Elliot, Fischer & Rennie, 1999) two of the interview transcripts were randomly chosen

and subjected to credibility checks by an independent researcher. These checks yielded an agreement of 98%. I would also have liked to have subjected my analysis to member validation, whereby participants were given the opportunity to express whether my interpretation of the data was an accurate reflection of their experiences (Lincoln & Guba, 1985). Time constraints, however, precluded this and it must also be considered that there are both advantages and disadvantages to this approach. The very nature of qualitative research is that it is the researcher's interpretation of the phenomenon being explored and by that token it is one version of multiple truths. Consequently, it can be argued that it is not necessarily appropriate for that truth to be proven or disproven (Seale, 1999).

Implications for my clinical practice

Undertaking the research had significant implications for my clinical practice. I was on placement in an eating disorder service for the majority of data collection and analysis and closely considered the emerging themes from my analysis in relation to my clinical work. The self being shared with AN and a fear of being no one without it were issues consistently brought up by clients on my caseload, in addition to being themes identified in my empirical study. This led me to pursue discussions around this within therapy sessions, helping clients to become increasingly self-aware and to consider the barrier this placed to recovery. In doing so, I have incorporated work around identity and sense of self into my clinical work, which clients have reflected back as helpful in understanding why they have been struggling to move forward. This has included working together to strengthen an individual's sense of self and build an identity separate to the eating disorder. Clients have found this approach a

hopeful one, as it recognises them as an individual, acknowledging their 'real self' and its strengths, personality traits, likes and dislikes, which has helped them to consider the person that they would like to be without AN. It is this separation of the self from AN that appears to be one of the most crucial parts of recovery, yet one of the most challenging.

Reflexivity

The need to take a reflexive stance throughout the research was of paramount importance, given my personal history of having lived with AN and my subsequent recovery. When interviewing participants I remained mindful of the risk of leading participants down a particular path that concurred with my own experiences. It was important that I took an objective and curious stance, putting myself in the position of someone without personal experience of AN as much as possible. I constantly took a step back when interviewing and analysing data and reviewed the decisions that I made in order to ensure that I did not fit the data to my story.

Of course, full separation from my past experiences could never be achieved: I am who I am because of the experiences I have lived through. I am confident, however, that I have not moulded the data to fit a theory, rather the theory has emerged from the data. Issues relating to reflexivity were frequently discussed in supervision, where excerpts from interviews were also listened to, in addition to coded transcripts being reviewed. As previously discussed, an independent researcher also checked the coding of two full transcripts in order to further uphold reliability, with agreement of 98%.

I believe that my past experience of AN was more of a help than a hindrance to the project, with regard to the connection I had with participants and the data. I gave my all to the research because of it being something close to my heart, but also because of my desire to do justice to the participants who had opened themselves up to me and told me their stories. This is not to say that a researcher without personal experience of AN could not have completed the research with the same passion and enthusiasm, rather that I found my personal experiences to be useful as opposed to distracting or a barrier. I approached the research with a great deal of caution, however, because of these experiences, which I believe only served to enhance the reflexive stance I took. This in turn enhanced my engagement with the process of completing a qualitative study that was grounded in the data.

What I have learnt from conducting the research

As a novice researcher, completing a doctoral level qualitative research study was both exciting and challenging. My passion for the project never waned, although there were times when engaging with the research was a lot more challenging than others. Completing a study using a qualitative methodology has changed the way I view qualitative research. I now have a lot more respect and admiration for qualitative researchers after learning by experience the amount of time, effort and dedication that goes into a qualitative study. Although this may also ring true for quantitative studies, I believe that the qualitative project is all-consuming: I feel like I have lived and breathed my project constantly for the past 12 months. By collecting, transcribing and analysing the data I was fully immersed in that data, which I have learnt to be

invaluable in completing qualitative research. I have also learnt first-hand the value of the findings of qualitative research as I do not believe that the conclusions I have drawn from my study would be as detailed as they are had I tried to design a quantitative study to investigate the relationship between the self and AN.

Reflecting back on the research I have learnt the importance of time management in carrying out such a project. My study would have benefitted from participant interviews being further apart to allow more time for transcribing, analysing and reflecting, which would have allowed more time to consider issues pertaining to theoretical sampling, modification of the interview schedule and data saturation.

I have also considered the possibility that including participants at various stages of the recovery process made the sample too varied and caused the research to lose its focus. The study could have recruited only individuals who currently met the DSM-V criteria for AN and scored above 4 on the EDE-Q. Having a more homogenous sample would have allowed for a more detailed investigation of the phenomenon of sharing of the self with the eating disorder in individuals meeting the diagnostic criteria for AN. The participants in my sample who considered themselves towards the recovered end of the scale, however, did not appear to have any difficulties in recalling episodes of AN when they were at their lowest weight and their sense of self was enmeshed with the eating disorder. In addition, although my sample included individuals who classed themselves at varying stages of recovery, nine of the 11 participants scored 4 or above on the EDE-Q, which indicated clinically significant levels of disordered eating. I would therefore hypothesise that they continued to have a

strong identification with AN and objectively may be more likely to be classed as 'anorexic' than 'in recovery'.

Including a wider sample of participants who had either experienced recovery and then relapsed or were on the road to recovery allowed for theory development regarding the need for separation of the self from AN to occur in order for recovery to be achievable. This identified a need for further research with individuals who have been recovered for some time and score below 4 on the EDE-Q (as discussed in paper 2). Again, obtaining a more homogenous sample of individuals who have recovered from AN would allow for a detailed investigation of the process of separating the self from the eating disorder and discovering the 'real self', in addition to how an individual relates to the self post-recovery. This may have been better conducted as a separate study, as many of my participants were in the position of considering this, as opposed to having lived through it.

The stringency of the research could have been improved by confirming the lifetime history of AN of the participants from 'beat', which would give greater confidence in the generalisability of the results. This, however, would have involved gaining permission to contact medical professionals to confirm a diagnosis, which may have deterred individuals from taking part.

Completing the project has improved both my reflective and analytical skills, which I believe has benefitted my clinical practice in terms of how I approach the problems brought by clients. Holding a reflexive stance throughout the research has also led me to become a more reflective clinician, having greater awareness of the relationships I build and maintain with clients, including the contribution of my own assumptions, beliefs and values to that relationship. This

is in addition to being more aware of the impact of how participants may perceive me and what they may perceive me as representing.

Conclusions

Completing the empirical study gave me first-hand experience of the importance of research within the profession of clinical psychology. Training to be a clinical psychologist has long been designed to prepare the trainee to work as both a scientist and practitioner (Raimy, 1950). Consequently, this would suggest a need to be involved in both research and clinical practice postqualification (Overholser, 2010). In my experience this is rarely the case, although I am aware that there are significant barriers to carrying out research whilst holding a clinical post, for example time and financial constraints. There is also an argument that the scientist-practitioner model refers to the ability to critically evaluate research and use good quality research to inform clinical practice (Barrom, Shadish & Montgomery, 1988; Long & Hollin, 1997). I have valued completing research that will give back to the evidence-base upon which my profession is built. The process has been a frustrating and challenging one at times, but one which I have enjoyed and been enthused about. I shall certainly welcome any opportunities in my future career to carry out more research and will use the skills I have gained to critically appraise the evidence-base that informs my clinical practice.

Overall conclusions

Sense of self was identified as a key factor in the maintenance of and recovery from AN in both the literature review and the empirical study. Papers 1

and 2 demonstrated a need to consider the nature of the relationship between the self and the eating disorder within therapeutic interventions for AN. Sharing the self with AN appeared to maintain the disorder; thus hindering an individual's recovery. Paper 2 has provided a theoretical framework of the relationship between the self and AN upon which novel interventions can be based. Targeting sense of self alone, however, may not be enough. As discussed in paper 1, having supportive and understanding relationships with others was also a key factor that helped recovery and went a long way to improving an individual's sense of self. This demonstrates the importance of including the system around an individual in interventions. Groups for carers and individual work with family members may be just as important as direct work with individuals in improving their sense of self and self-acceptance. We therefore need to recognise the additional challenges that individuals with a limited social network and lack of positive relationships with significant others may face when embarking on their recovery journey.

Paper 1 also indirectly identified a need for individuals to gain an understanding of where their poor sense of self originated from and why they may have difficulties in finding the 'real self' and separating this from the eating disorder. As one participant described:

"How can I fix something when I don't even know what the cause of it is?" (Participant; Federici & Kaplan, 2008).

The need for a therapist to support an individual in developing their sense of self and identity, therefore, needs to be set within the wider context of

exploring the historical aspect of the relationship with the self and the impact of past experiences on this. As discussed earlier in this paper, the self we become is affected by the position into which we are born as an individual, including the social network within which we interact and the beliefs and values in which we are educated. Essentially, it is our social interaction that shapes our sense of self (Burkitt, 2008), therefore we need to consider the proposition that early attachment experiences shape our ability to form and maintain relationships with others, in addition to our perception of ourselves as worthy of love and affection (Bowlby, 1980). Attachment disruption has been suggested as a contributory factor in the development of eating disorders (O'Kearney, 1996), with particular emphasis being placed on insecure attachment styles (Ramaciotti et al., 2001; Ringer & Crittenden, 2007; Zachrisson & Kulbotten, 2006). Consequently, if our sense of self is shaped by such interactions with others (Burkitt, 2008); we must consider the relevance of past and current interpersonal relationships when attempting to nurture an individual's sense of self within therapeutic interventions.

Papers 1 and 2 attest to the established complexity of AN and the challenges to clinicians in helping individuals recover from the disorder. Each of the papers, however, have identified factors that help recovery and give hope that individuals with AN can be supported to develop a robust sense of self that is separate from the eating disorder and facilitates living a more meaningful and purposeful life. Clinical psychologists have a crucial role to play in offering a secure base and a supportive and understanding relationship that provides a sense of safety. This relationship can help to encourage an individual to learn to manage their emotions on their own and create an identity separate to AN, in

addition to helping them accept the fear of recovery and believe that it is possible. In doing so, individuals can break free from AN and move on from the disorder, learning to accept and care for their 'real self'.

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Appendix 1: Clinical Psychology and Psychotherapy author guidelines

Clinical Psychology and Psychotherapy author guidelines

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Reference style. The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

Appendix 2: PRISMA checklist

PRISMA checklist

| Section/topic | # | Checklist item | Reported on page # | |
|---------------------------|----------|---|--------------------|--|
| TITLE | | | | |
| Title | 1 | Identify the report as a systematic review, meta-analysis, or both. | 14 | |
| ABSTRACT | ABSTRACT | | | |
| Structured summary | 2 | Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | 14 | |
| INTRODUCTION | | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. | 17-18 | |
| Objectives | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | - | |
| METHODS | | | | |
| Protocol and registration | 5 | Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | - | |
| Eligibility criteria | 6 | Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | 18-20 | |
| Information sources | 7 | Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | 18-19 | |

| Section/topic | # | Checklist item | Reported on page # |
|------------------------------------|----|--|--------------------|
| Search | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | Appendix 3 |
| Study selection | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | 18-22 |
| Data collection process | 10 | Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | 22-23 |
| Data items | 11 | List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | - |
| Risk of bias in individual studies | 12 | Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | - |
| Summary measures | 13 | State the principal summary measures (e.g., risk ratio, difference in means). | - |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis. | 22-23 |
| Risk of bias across studies | 15 | Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | 27 |
| Additional analyses | 16 | Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified. | - |
| RESULTS | | | |
| Study selection | 17 | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | 23-24 |
| Study characteristics | 18 | For each study, present characteristics for which data were extracted (e.g., | - |

| Section/topic | # | Checklist item | Reported on page # | |
|-------------------------------|----|--|--------------------|--|
| | | study size, PICOS, follow-up period) and provide the citations. | | |
| Risk of bias within studies | 19 | Present data on risk of bias of each study and, if available, any outcome-level assessment (see Item 12). | 27 | |
| Results of individual studies | 20 | For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group and (b) effect estimates and confidence intervals, ideally with a forest plot. | - | |
| Synthesis of results | 21 | Present results of each meta-analysis done, including confidence intervals and measures of consistency. | 28-47 | |
| Risk of bias across studies | 22 | Present results of any assessment of risk of bias across studies (see Item 15). | - | |
| Additional analysis | 23 | Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]). | - | |
| DISCUSSION | - | | | |
| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers). | | |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias). | 53-54 | |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | 48-54 | |
| FUNDING | | | | |
| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | No funding | |

Further information

| Item | Discussion |
|------|---|
| 11 | Data were not sought for individual variables as the objective of the metasynthesis was to review all findings discussed within each article. |
| 12 | Risk of bias was assessed in terms of critical appraisal regarding the quality of the study as a whole and the likelihood of flaws. See critical appraisal section on page 7. |
| 13 | Summary measures were not applicable to the metasynthesis due to the studies under review employing qualitative methods. |
| 16 | Additional analyses were not applicable to the metasynthesis due to the studies under review employing qualitative methods. |
| 18 | Study characteristics were not used to extract data. All data presented within the studies was reviewed and synthesised. |
| 20 | The studies under review do not discuss outcomes. |
| 22 | The limitations of the use of the metasynthesis method are discussed on page 32. |
| 23 | Additional analyses were not applicable to the metasynthesis due to the studies under review employing qualitative methods. |

Appendix 3: List of search terms

List of search terms

| Design | Search Terms |
|--|---|
| Qualitative | 1. qualitative |
| | 2. qualitative research |
| | 3. qualitative stud* |
| Ethnographic research | 4. ethnograph* |
| Phenomenological research | 5. phenomenolog* |
| | 6. phenomenolog* research |
| | 7. phenomenolog* stud* |
| Interpretive phenomenological analysis | 8. interpretive phenomenological analysis |
| Grounded Theory | 9. grounded theor* |
| , | 10. grounded stud* |
| | 11. grounded research |
| Constant comparative method | 12. constant comparative method |
| F1 11 11 11 11 11 11 11 11 11 11 11 11 1 | 13. constant compar* |
| Focus groups | 14. focus group* |
| Observational methods | 15. observational method* |
| | 16. participant observ* |
| Field studies | 17. field stud* |
| | 18. field research |
| Narrative | 19. narrative |
| Discourse analysis | 20. discourse analysis |
| Content analysis | 21. content analysis |
| Interviews | 22. interview* |
| | 23. semi-structured interview* |
| Thematic | 24. thematic |
| | 25. theme* |
| Conversation analysis | 26. conversation analysis |
| Eating Disorders | Search Terms |
| Anorexia nervosa | 27. anorexia nervosa |
| | 28. anorexia* |
| Bulimia nervosa | 29. bulimia nervosa |
| | 30. bulimia* |
| Eating disorder | 31. eating disorder* |
| Binge eating disorder | 32. binge eating disorder* |
| Mixed eating disorder | 33. mixed eating disorder* |
| Eating disorder not otherwise specified | 34. eating disorder not otherwise |
| | specified |
| | 35. EDNOS |
| | 36. NOS |
| Recovery | Search Terms |
| Recovery | 37. recovery |
| | 38. recover* |
| Rehabilitation | 39. rehabilita* |
| | 40. rehab |
| Remission | 41. remiss* |
| | 42. remit |
| 1 | 1 |
| Well-being | 43. well-being* |

| Outcome | 45. outcome |
|-------------|-----------------|
| Improvement | 46. improvement |
| | 47. improve* |
| Adjustment | 48. adjustment |
| | 49. adjust* |
| Better | 50. better |
| Successful | 51. success* |
| Change | 52. change |

Combination of search terms = (or/1-26) and (or/27-36) and (or/37-46).

Appendix 4: Critical Appraisal Skills Programme (2013) guidelines

Critical Appraisal Skills Programme (2013) guidelines



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- · Are the results of the review valid?
- · What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

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| Screening Questions | | |
|---|-----|---------------|
| 1. Was there a clear statement of the aims of the research? HINT: Consider What was the goal of the research? Why it was thought important? Its relevance | Yes | Can't tell No |
| 2. Is a qualitative methodology appropriate? | Yes | Can't tell No |
| If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative research the right methodology for addressing the research goal? | | |



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| Detailed questions | | |
|---|-----|---------------|
| 3. Was the research design appropriate to address the aims of the research? | Yes | Can't tell No |
| If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? | | |
| 4. Was the recruitment strategy appropriate to the aims of the research? | Yes | Can't tell No |
| HINT:Consider | | |
| If the researcher has explained how the participants were selected | | |
| If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study | | |
| If there are any discussions around recruitment (e.g. why some people chose not to take part) | | |
| | | |

| HINT: Consider If the setting for data collection was justified If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g. tape recordings, video material, notes etc) If the researcher has discussed saturation of data 6. Has the relationship between researcher and participants been adequately considered? HINT: Consider If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design | tell No | Can't t | Yes | . Was the data collected in a way that addressed the research issue? |
|---|--------------|---------|-----|--|
| participants been adequately considered? HINT: Consider If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes | | | | If the setting for data collection was justified If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g. tape recordings, video material, notes etc) |
| | an't tell No | res Can | Ye | Articipants been adequately considered? NT: Consider If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes |

| . Ha | ve ethical issues been taken into consideration? | Yes | Can't tell | □ N |
|--------|---|-----|------------|------|
| INT: C | Consider If there are sufficient details of how the research was explained | | | |
| | to participants for the reader to assess whether ethical standards were maintained | | | |
| • | If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) | | | |
| • | If approval has been sought from the ethics committee | | | |
| | | | | |
| | | _ | - | _ |
| . Wa | as the data analysis sufficiently rigorous? | Yes | Can't tell | □ No |
| | as the data analysis sufficiently rigorous? | Yes | Can't tell | □No |
| | Consider If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the | Yes | Can't tell | No |
| INT: C | Consider If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate | Yes | Can't tell | No |
| INT: C | Consider If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented | Yes | Can't tell | No |
| INT: C | Consider If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | Yes | Can't tell | No |
| INT: C | If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process If sufficient data are presented to support the findings | Yes | Can't tell | No |

| q | Is | th | ere | a | clear | statement | t of | findings? |
|----|----|----|-----|---|-------|-----------|------|-------------|
| J. | 13 | | CIC | a | CICai | statemen | U | IIIIuiiiga: |

| Yes | Can't tell | L No |
|-----|------------|------|

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix 5: Walsh & Downe (2006): Quality appraisal checklist

Walsh & Downe (2006): Quality appraisal checklist



D. Walsh, S. Downe

| Table 4 | C | | | | - unlikativa | research studies |
|---------|---------|----------|-----|------------|--------------|-------------------|
| lable 4 | Summary | criteria | TOL | appraising | qualitative | research studies. |

| Stages | Essential criteria | Specific prompts |
|-------------------|--|---|
| Scope and purpose | Clear statement of, and rationale for, research question/aims/purposes | Clarity of focus demonstrated Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing Link between research and existing knowledge demonstrated |
| | Study thoroughly contextualised by existing literature | Evidence of systematic approach to literature review, location of literature to contextualise the findings, or bot |
| Design | Method/design apparent, and consistent with research intent | Rationale given for use of qualitative design Discussion of epistemological/ontological grounding Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims Setting appropriate |
| | Data collection strategy apparent and appropriate | Were data collection methods appropriate for type of dat required and for specific qualitative method? Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? Was triangulation of data sources used if appropriate? |
| Sampling strategy | Sample and sampling method appropriate | Selection criteria detailed, and description of how samplir was undertaken Justification for sampling strategy given Thickness of description likely to be achieved from samplir Any disparity between planned and actual sample explaine |
| Analysis | Analytic approach appropriate | Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) Was it appropriate for the qualitative method chosen? Was data managed by software package or by hand and who Discussion of how coding systems/conceptual frameworks evolved How was context of data retained during analysis Evidence that the subjective meanings of participants were portrayed Evidence of more than one researcher involved in stages appropriate to epistemological/theoretical stance Did research participants have any involvement in analysi (e.g. member checking) Evidence provided that data reached saturation or discussion/rationale if it did not Evidence that deviant data was sought, or discussion/rationale if it was not |
| Interpretation | Context described and taken account of in interpretation | Description of social/physical and interpersonal contexts of data collection Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena |
| | Clear audit trail given | Sufficient discussion of research processes such that other can follow 'decision trail' |

| Stages | Essential criteria | Specific prompts |
|----------------------------------|--|--|
| | Data used to support interpretation | Extensive use of field notes entries/verbatim interview quotes in discussion of findings Clear exposition of how interpretation led to conclusions |
| Reflexivity | Researcher reflexivity demonstrated | Discussion of relationship between researcher and participants during fieldwork Demonstration of researcher's influence on stages of research process Evidence of self-awareness/insight Documentation of effects of the research on researcher Evidence of how problems/complications met were dealt with |
| Ethical dimensions | Demonstration of sensitivity to ethical concerns | Ethical committee approval granted Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants Evidence of fair dealing with all research participants Recording of dilemmas met and how resolved in relation to ethical issues Documentation of how autonomy, consent, confidentiality, anonymity were managed |
| Relevance and transferability | Relevance and transferability evident | Sufficient evidence for typicality specificity to be assessed Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar setting and studies Discussion of how explanatory propositions/emergent theory may fit other contexts Limitations/weaknesses of study clearly outlined Clearly resonates with other knowledge and experience Results/conclusions obviously supported by evidence Interpretation plausible and 'makes sense' Provides new insights and increases understanding Significance for current policy and practice outlined Assessment of value/empowerment for participants Outlines further directions for investigation Comment on whether aims/purposes of research were achieved |

Appendix 6: Critical appraisal checklist

Critical appraisal checklist

| | CATEGORY | |
|-----|---|--|
| | TOTAL SCORE | |
| | TOTAL SCODE | |
| | discussed. The contribution made by the study to existing knowledge or understanding is also discussed. Limitations of the study are made explicit. | |
| 11. | The relevance and transferability of the research is clearly | |
| 10. | A clear statement of the findings is given and discussed in relation to the original research question. There is adequate discussion of the evidence both for and against the researcher's arguments. | |
| 9. | Ethical issues are considered, including discussion of ethics committee approval, how consent was sought, confidentiality and maintenance of participant anonymity. | |
| 8. | Researcher reflexivity is explicitly discussed. The researcher has critically examined their role and potential biases. | |
| 7. | Method of data analysis is clearly stated, including explicit reference to the use of software packages, coding systems and data saturation. | |
| 6. | Method of data collection is clearly stated, including explicit information on its form and any modifications. | |
| 5. | The sampling strategy for the study is clear and appropriate. Justification for the sampling strategy used is given. | |
| 4. | A qualitative methodology is an appropriate research design to address the study's aims and purpose. The method used is apparent. | |
| 3. | There is a clear statement of the aims and purpose of the research, including a rationale for this. | |
| 2. | The study makes reference to a meaning/definition of recovery. | |
| 1. | The study includes participants with a lifetime history of anorexia nervosa (professional diagnosis/meets DSM-IV criteria = 1; self-report =0.5) | |
| | | |

 $A = \ge 9.5$

 $B = \ge 6 \text{ but} < 9.5$

C = < 6

Appendix 7: Guidance for metasynthesis (Noblit & Hare, 1988)

Guidance for metasynthesis (Noblit & Hare, 1988)

This approach consists of a process of seven stages that overlap and repeat as the metasynthesis progresses:

- (a) Getting started and deciding on a phenomenon of study.
- (b) Deciding what qualitative studies are relevant to the initial interest.
- (c) Reading the qualitative studies.
- (d) Determining how the studies are related to each other. In this phase, the synthesizer makes a list of the key metaphors in each study and their relations to each other. The term metaphor refers to themes, concepts, or phrases. Three different assumptions can be made about the relationships between the studies to be synthesized. These key assumptions are: (1) the accounts are directly comparable as "reciprocal" translations; (2) the accounts stand in relative opposition to each other and are essentially "refutational"; or (3) the studies taken together present a "line of argument" rather than a reciprocal or refutational translation" (Noblit & Hare, 1988, p.36).
- (e) Translating the studies into one another.
- (f) Synthesizing translations. This involves creating a whole as something more than the individual parts imply. The translations as a group are one level of a metasynthesis. Next, the translations can be compared to decide if the same metaphors/themes or concepts can be encompassed into those of others. This is a second level of synthesis.
- (g) Expressing the synthesis through the written word, plays, art, videos, or music.

Appendix 8: Guidance for metasynthesis (Walsh & Downe, 2005)

Guidance for metasynthesis (Walsh & Downe, 2005)

Practically, this process begins with the first reading of the studies and is completed with the creation of a grid of key concepts. These findings are then juxtaposed to both identify homogeneity of categories/codes/themes and, crucially, to note discordance and dissonance. Jensen and Allen (1996) identify two processes here. The first, or hermeneutic, aspect consists of accurately capturing individual or cultural constructions. This is the art of respecting and representing context as intended through the original research. Second is the dialectic aspect, which relates the studies to each other. This can be achieved through juxtaposition of the parameters identified by the compare and contrast exercise.

Reciprocal translation

The next phase begins the translation of one study's findings into another, usingmetaphors and concepts that could be applied to both. Sometimes commonalities will be only too apparent and reciprocal translations are relatively straightforward. At other times they will stand in opposition as a "refutational translation" (Noblit & Hare, 1988), or they may overlap without being substitutional. Refutation and overlap may contribute to another, emergent, category or understanding which has not been identified in the original accounts. It is crucial to the method that differences are not glossed over or subsumed. Deviant data may be the raw material of another perspective, making a new space for understanding. In fact the absence of divergent or deviant data may arouse suspicion as to the rigour of the reciprocal translation, as qualitative inquiry rarely results in complete congruence of meaning.

Synthesis of translation

The final phase is synthesizing the translations to elucidate more refined meanings, exploratory theories and new concepts. Clusters of metaphors become progressively more refined and a consensus emerges as to core themes or explanatory, mid-level, or substantive theory (Sherwood 1997b; Strauss & Corbin, 1998; Campbell et al. 2003). The synthesis needs to reflect the tension between contradictory or alternative explanations if reciprocal translations

suggest a lack of congruence. Ultimately, the final synthesis will be the grounds on which the value of meta-synthesis is judged and it therefore needs to convey explicitly how the whole is greater than the sum of the constituent parts.

Appendix 9: British Journal of Clinical Psychology author guidelines

British Journal of Clinical Psychology author guidelines

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations
- Theoretical papers, provided that these are sufficiently related to the empirical data
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
- Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjcp/. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

- 4. Manuscript requirements
- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.
- All Articles must include Practitioner Points these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the <u>APA Publication Manual</u> published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000

words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information be about this service can found http://authorservices.wiley.com/bauthor/suppmat.asp

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more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site: http://www.adobe.com/products/acrobat/readstep2.html.

This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Appendix 10: Ethics and R&D approval letters

Ethics and R&D approval letters



NRES Committee Yorkshire & The Humber - South Yorkshire

North East REC Centre Unit 002, TEDCO Business Centre Rolling Mill Road Jarrow Tyne and Wear NE32 3DT

Telephone: 0191 428 3387

17 June 2013

Mrs Karen Williams Trainee Clinical Psychologist Manchester Mental Health and Social Care Division of Clinical Psychology 2nd Floor Zochonis Building The University of Manchester Oxford Road, Manchester M13 9PL

Dear Mrs Williams

Study title: The relationship between sense of self and the eating

disorder in individuals with anorexia nervosa.

REC reference: 13/YH/0206

Protocol number: n/a IRAS project ID: 120438

The Proportionate Review Sub-committee of the NRES Committee Yorkshire & The Humber - South Yorkshire reviewed the above application on 13 June 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Sarah Grimshaw (nrescommittee.yorkandhumber-southyorks@nhs.net)

Ethical opinion

The Committee considered that as the research included the use of questionnaires it should be considered quantitative as well as qualitative.

Members queried whether the posters used for recruitment would be for the outpatient areas only. Furthermore they questioned whether the inpatients would be approached by the clinician, and if so, how the researchers would ensure that no coercion was involved.

You responded that posters will be placed in both the inpatient and outpatient areas, as in either setting the participant is required to express their interest in the study to a member of the care team. You continued to clarify that the initial approach to inpatients will be by clinicians. Patients will be informed by the clinician that the study is separate to their clinical care and is completely voluntary. You confirmed that clinicians will not place any pressure on patients to participate in the study and to help ensure this a box will be placed in the ward clerk's office for patients to place signed consents forms to express their interest in the study, or if they felt comfortable doing so can hand the form back to the clinician. This box, therefore, negates the

A Research Ethics Committee established by the Health Research Authority

need for clinicians to re-approach patients, which should ensure that they do not feel any pressure to participate in the research.

You added that you will also be available to meet with patients to discuss the research before they decide to take part, should they wish to speak to you, and at this point you would also reiterate that participation in the study is voluntary, does not affect any aspect of their clinical care and they can withdraw at any time. You noted that Dr John Fox also has a long history of conducting research on the ward at The Priory and, as such, is sensitive to this issue when making approaches to potential participants.

The Committee requested clarification regarding where the interviews would take place as in the response to A6-1 of the IRAS form one option was stated, whereas in the Participant Information Sheet participants were given two options.

You replied that patients on the ward at The Priory will complete the interview in a private room at the hospital, whereas outpatients from Whiston Hospital will have the option of completing the interview in a private room at the hospital or at their home, according to their preference.

The REC requested confirmation that a lone worker policy would be followed.

You confirmed that the University of Manchester Lone Working Guidance would be followed, which includes completing a full risk assessment prior to interviews and having a 'buddy' who will be fully aware of the researcher's movements, including having details of the location and anticipated time of return. Regular contact would be maintained with the 'buddy' and a code word will be agreed and used in emergencies.

You provided a copy of the full lone worker policy.

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

| Document | Version | Date |
|---|---|------------------|
| Advertisement | 1 | 18 March 2013 |
| Covering Letter | Email from Karen Williams | 06 June 2013 |
| Evidence of insurance or indemnity | Letter from Lynne MacRae | 15 May 2013 |
| Evidence of insurance or indemnity | Lockton Policy Nos 36345G12AA & 36345G12AC | |
| Evidence of insurance or indemnity | Zurich Municipal Policy No NHE- 07CA03-0013 | 13 June 2012 |
| Evidence of insurance or indemnity | Marsh Ltd Policy No 003210MMA073 | 11 June 2012 |
| GP/Consultant Information Sheets | 1 | 18 March 2013 |
| Interview Schedules/Topic Guides | 1 | 18 March 2013 |
| Investigator CV | Karen Williams | |
| Investigator CV | Dougal Hare | |
| Investigator CV | John Fox | |
| Investigator CV | Jane King | |
| Letter from Sponsor | Lynne MacRae | 15 May 2013 |
| Other: Distress Protocol, The Priory Hospital, Cheadle Royal | 1 | 18 March 2013 |
| Other: Distress Protocol, Whiston Hospital | 1 | 18 March 2013 |
| Other: Procedure Flowchart | 1 | 18 March 2013 |
| Other: University of Manchester Guidance on Lone Working | 2.0 | 20 July 2012 |
| Participant Consent Form | 1 | 18 March 2013 |
| Participant Information Sheet: The Priory Hospital, Cheadle Royal | 1 | 18 March 2013 |
| Participant Information Sheet: Whiston Hospital | 1 | 18 March 2013 |
| Protocol | 1 | 18 March 2013 |
| Questionnaire: Beck Depression Inventory-II | | |
| Questionnaire: Beck Anxiety Inventory | | |
| Questionnaire: Eating Disorder Examination Questionnaire | | |
| Questionnaire: Robson Self-Concept Questionnaire | | |
| REC application | IRAS Version 3.5, 120438/461036/1/ 738 | |
| Referees or other scientific critique report | Ltr from D Hare | 29 November 2012 |
| | | |

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Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review - guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- · Notifying substantial amendments
- Adding new sites and investigators
- · Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

information is available at National Research Ethics Service website > After Review

13/YH/0206

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days - see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Ms Jo Abbott

Enclosures:

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

List of names and professions of members who took part in the review

"After ethical review - guidance for researchers"

A Research Ethics Committee established by the Health Research Authority



Our Ref: Trust ID 312

Your Ref:

Date: 8th July 2013

Research Department Hollins Park Hospital Hollins Lane Winwick Warrington WA2 8WA

Tel: 01925 664475

Fax:

Email: sue.kirby@5bp.nhs.uk

Karen Williams, Trainee Clinical Psychologist, Manchester Mental Health and Social Care Division of Clinical Psychology 2nd Floor Zochonis Building The University of Manchester Oxford Road, Manchester M13 9PL

Dear Karen,

Re: Research Governance Decision Letter

Project Reference: Trust ID 312

Project Title: Sense of self and anorexia nervosa

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study. With regard to your study, we would like you to note that it is required to acknowledge the Trust when publishing your work and this also applies to any posters that maybe produced. The form of acknowledgement should be as described on the 5 Boroughs website. Please note when contacting the Research Office about your study you must always provide the project reference numbers provided above.

Trust research approval covers all locations within the Trust; however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached 'Information for Researchers – Conditions of Research Governance Approval' leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the Research Office should you require any further information. You may need this letter as proof of your approval.

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research. We can confirm that in this instance we will not charge for these. However we would like



to remind you that Trust costs should be considered and costed at the earliest stage in the development of any future proposals.

May I wish you every success with your research.

Yours sincerely

Anthony Hodgson Head of Research

cc : Research Governance Sponsor

Employing Organisation

Dr Jane King, Local Collaborator

Enc: Approval Conditions Leaflet V3 11

Induction & ID Badge Information 13

Chief Executive: Mr. Simon J. Barber
Chairman: Mr. Bernard Pilkington
Trust Headquarters, Hollins Park House, Hollins Lane, Winwick, Warrington, WA2 8WA
Mini Com Number 01925 664094





R&D Department Building V7 Mersey Care NHS Trust Offices Kings Business Park Prescot Merseyside L34 1PJ Tel: 0151 471 2638

Mrs Karen Williams
Trainee Clinical Psychologist
Manchester Mental Health and Social Care
Division of Clinical Psychology
2nd Floor Zochonis Building
The University of Manchester
Oxford Road,
Manchester M13 9PL

15th October 2013

Dear Mrs Williams

FORMAL LETTER OF APPROVAL

Project 2013/32: The relationship between sense of self and the eating disorder in individuals with anorexia nervosa.

Thank you for your research application which was reviewed by the Trust's Research Governance Committee on the 19th September 2013.

The Committee noted ethical approval has been given by NRES Committee Yorkshire & The Humber – South Yorkshire under reference 13/YH/0206. Ethical approval had also been received for Substantial Amendment No. 1. The Committee were willing to approve the study subject to confirmation of service support. Mrs Ruth Carson, Consultant Lead Psychotherapist Head of Liverpool and Sefton Eating Disorder Service has confirmed support.

Accordingly, please take this letter as confirmation of Trust R&D approval for the study and for Substantial Amendment 1. Please read the attached 'Information for Researchers – Conditions of Research Governance Approval' leaflet. When contacting the R&D office please quote the above trust reference.

Cont.../

Chairman: Beatrice Fraenkel

Chief Executive: Joe Rafferty

May I wish you every success with your research.

Yours sincerely

Mrs Pauline Parker R&D Manager

cc.. sponsor contact: lynne.macrae@manchester.ac.uk Dr. David Powell, R&D lead Liverpool Ruth Carson, Head of Service

Chairman: Beatrice Fraenkel

Chief Executive: Joe Rafferty

Appendix 11: Recruitment flowchart

Recruitment flowchart



Procedure Flowchart - Version 1 18.03.13

· The chief investigator will provide clinicians with information about the study.

Recruitment

 Potential participants will be informed about the study via posters displayed in the eating disorders services, presentation of the study at community meetings on the ward and clinician approach.

Recruitment

- Once a potential participant expresses an interest in hearing more about the study they will be provided with a copy of the participant information sheet and consent form.
- Participants will return consent forms if they wish to take part.

Study participation

- · Informed consent will be confirmed with participants.
- · Participants will complete the BDI-II, BAI. EDE-Q and RSCQ.
- Participants will be interviewed by the chief investigator.

Data analysis

 Interviews will be transcibed verbatim and analysed using grounded theory.

Following participation Participants will be provided with a summary of the study's findings, if they have indicated that they would like to receive one.

Appendix 12: Participant information sheet and consent form: NHS

Participant information sheet and consent form: NHS



Version 1 - 18.03.13

The University of Manchester

Sense of self and anorexia nervosa: Participant Information Sheet

REC Reference number: 13-YH-0206

Please read this sheet carefully

I am asking you to take part in a research study. Before you make a decision whether or not to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please also ask me if there is anything that is not clear or if you would like more information. Take as much time as you need to decide whether or not you would like to take part in the study. Thank you for reading this.

What is the study about?

The study is designed to look at how people with anorexia view themselves as a person and how this relates/does not relate to the eating disorder.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form to say you understand it and agree to take part. You will also be given a copy of the signed consent form to keep. If you decide to take part you are still free to withdraw from the study at any time and without giving a reason. If you decide to withdraw from the study, or not to take part at all, it will not affect the services you currently using.

What does the study involve?

The study involves completing four questionnaires and being interviewed. The interview is audiotaped and transcribed for the purpose of data analysis. Everyone taking part in the study will be interviewed once – there is no follow-up for the study. The study will not involve any physical or psychological treatment or interventions.

What will happen if I take part?

If you would like to take part in the study you should sign the consent form and give it back to the person who gave it to you when you next see them. They will then pass the consent form and your contact details to me and I shall telephone you to arrange a date and time for you to complete the questionnaires and interview. This can take place at your home or at the hospital, depending on what is most convenient for you. The questionnaires will take approximately 20-30 minutes to complete and the interview will last approximately one to two hours. You will be able to have breaks during the visit.

Before you complete the questionnaires and interview I shall go through the consent form with you and you will have to chance to ask questions about the study. If you are still happy



MANCHESTER 1824

to take part in the study I will sign the consent form and you will complete the questionnaires and interview.

What are the benefits of taking part?

The study will help us to understand the relationship between how people view themselves and the eating disorder in individuals with anorexia. This will also help us to think about what kinds of support are likely to be most useful for people with anorexia.

What are the risks?

There is a minor risk of minimal distress resulting from talking about your thoughts and feelings.

Will my personal details be kept confidential?

All information that is collected about you during the study will be kept strictly confidential and will be anonymous. This means your identity remains private.

Will I be compensated for taking part?

You will be compensated £5 for your time.

What if I change my mind?

You do not have to take part in the study. If you have agreed to take part, you can stop at any time without giving a reason. This will not affect any of the services you are currently using.

Who can I talk to for further information?

Karen Williams (Trainee Clinical Psychologist)
Division of Clinical Psychology
2nd Floor, Zochonis Building
University of Manchester
Oxford Road
Manchester
M13 9PL

Email: Karen.williams-4@postgrad.manchester.ac.uk

Tel: 0161 306 0400

What if something goes wrong?

The research team will endeavour to ensure that your participation in the research is fully and appropriately supported, however, should you wish to make a formal complaint about the conduct of the research you should contact the University Research Practice and Governance Coordinator on 0161 275 7583/ 0161 275 8093 or by email research.complaints@manchester.ac.uk.

PLEASE DO NOT HESITATE TO ASK IF YOU HAVE ANY MORE QUESTIONS, EITHER NOW OR LATER.

Thank you for reading this information sheet.

Version 1 - 18.03.13



The University of Manchester

| _ | CONSENT FORM | |
|---|---|------------------|
| Study: | Sense of self and anorexia nervosa | |
| REC Reference number: | 13-YH-0206 | |
| Researchers: | Karen Williams; Dr John Fox; Dr Dougal Hard | e; Dr Jane King |
| Please read each statement the study. | and initial each box to confirm that you agre | e to take part i |
| | d understood the participant 03.03 for the above study and ask questions. | |
| | pation in the study is voluntary and t any time, without giving any reason, legal rights being affected. | |
| | forming my GP and my clinician at the t l am taking part in the study. | |
| I agree to the interview bein purposes of data analysis. | g audiotaped and transcribed for the | |
| I agree to direct quotes from publications. I understand th information will not be used will be allocated a false nam | at personally identifiable in publications and the quotes | |
| by responsible individuals fro regulatory authorities or from | cted during the study may be looked at om the University of Manchester, from m the NHS Trust, where it is relevant to ch. I give permission for these individuals to | |

| | MANCHESTER 1824 | | | Version 1 – 18.03.13 |
|---------------|------------------------------------|------|-----------|----------------------|
| of Manchester | I agree to take part in the study. | | | |
| | Name of participant | Date | Signature | |

Date

Signature

Name of researcher

Appendix 13: Participant information sheet and consent form: charities

Participant information sheet and consent form: charities



Version 1 - 10 07 13

The University of Manchester

Sense of self and anorexia nervosa: Participant Information Sheet

REC Reference number: 13/YH/0206

Please read this sheet carefully

I am asking you to take part in a research study. Before you make a decision whether or not to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please also ask me if there is anything that is not clear or if you would like more information. Take as much time as you need to decide whether or not you would like to take part in the study. Thank you for reading this.

What is the study about?

The study is designed to look at how people with anorexia view themselves as a person and how this relates/does not relate to the eating disorder.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form to say you understand it and agree to take part. You will also be given a copy of the signed consent form to keep. If you decide to take part you are still free to withdraw from the study at any time and without giving a reason. If you decide to withdraw from the study, or not to take part at all, it will not affect the services you currently using.

What does the study involve?

The study involves completing four questionnaires and being interviewed. The interview is audiotaped and transcribed for the purpose of data analysis. Everyone taking part in the study will be interviewed once – there is no follow-up for the study. The study will not involve any physical or psychological treatment or interventions.

What will happen if I take part?

If you would like to take part in the study you should sign the consent form and post it back to me. I shall then telephone you to arrange a date and time for you to complete the questionnaires and interview. This can take place at your home or over the telephone, depending on what is most convenient for you and where you live in relation to Manchester. The questionnaires will take approximately 20-30 minutes to complete and the interview will last approximately one to two hours. You will be able to have breaks during the interview.

Before you complete the questionnaires and interview I shall go through the consent form with you and you will have to chance to ask questions about the study. If you are still happy



to take part in the study I will sign the consent form and you will complete the questionnaires and interview.

What are the benefits of taking part?

The study will help us to understand the relationship between how people view themselves and the eating disorder in individuals with anorexia. This will also help us to think about what kinds of support are likely to be most useful for people with anorexia.

What are the risks?

There is a minor risk of minimal distress resulting from talking about your thoughts and feelings.

Will my personal details be kept confidential?

All information that is collected about you during the study will be kept strictly confidential and will be anonymous. This means your identity remains private.

Will I be compensated for taking part?

You will be compensated £5 for your time.

What if I change my mind?

You do not have to take part in the study. If you have agreed to take part, you can stop at any time without giving a reason. This will not affect any of the services you are currently using.

Who can I talk to for further information?

Karen Williams (Trainee Clinical Psychologist)
Division of Clinical Psychology
2nd Floor, Zochonis Building
University of Manchester
Oxford Road
Manchester
M13 9PL

Email: karen.williams-4@postgrad.manchester.ac.uk

Tel: 0161 306 0400

What if something goes wrong?

The research team will endeavour to ensure that your participation in the research is fully and appropriately supported, however, should you wish to make a formal complaint about the conduct of the research you should contact the University Research Practice and Governance Coordinator on 0161 275 7583/ 0161 275 8093 or by email research.complaints@manchester.ac.uk.

PLEASE DO NOT HESITATE TO ASK IF YOU HAVE ANY MORE QUESTIONS, EITHER NOW OR LATER.

Thank you for reading this information sheet.

Version 1 - 18.03.13



he University f Manchester

| _ | CONSENT FORM | |
|---|---|------------------|
| Study: | Sense of self and anorexia nervosa | |
| REC Reference number: | 13-YH-0206 | |
| Researchers: | Karen Williams; Dr John Fox; Dr Dougal Hard | e; Dr Jane King |
| Please read each statement the study. | and initial each box to confirm that you agre | e to take part i |
| | d understood the participant 07.13 for the above study and ask questions. | |
| | pation in the study is voluntary and t any time, without giving any reason, legal rights being affected. | |
| | forming my GP and my clinician at the t l am taking part in the study. | |
| I agree to the interview bein purposes of data analysis. | g audiotaped and transcribed for the | |
| I agree to direct quotes from publications. I understand th information will not be used will be allocated a false nam | at personally identifiable in publications and the quotes | |
| by responsible individuals fro regulatory authorities or from | cted during the study may be looked at om the University of Manchester, from m the NHS Trust, where it is relevant to ch. I give permission for these individuals to | |

| | MANCHESTER 1824 | | | Version 1 – 18.03.13 |
|---------------|------------------------------------|------|-----------|----------------------|
| of Manchester | I agree to take part in the study. | | | |
| | Name of participant | Date | Signature | |
| | | | | |

Date

Name of researcher

Signature

Appendix 14: Recruitment advertisement for 'beat'

Recruitment advertisement for 'beat'



Version 1 - 10.07.13

Volunteers needed for a study of sense of self and anorexia nervosa

I am carrying out a study into what people think makes them a person. If you currently have anorexia or have experienced anorexia in the past and are aged 18 or over I would like to invite you to participate in my research study. In return you will be reimbursed for your time.

The research involves completing four questionnaires and an interview with the researcher. These can take place at one visit at your home or by post and telephone at a time to suit you.

If you are interested in finding out more about the study please contact Karen Williams on 0161 306 0400 or

karen.williams4@postgrad.manchester.ac.uk. I will post/email you an information sheet that tells you more about the study and what it involves so you can decide whether or not you would like to take part.

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Appendix 15: Interview schedule with amendments

Interview schedule with amendments



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Interview schedule

- Can you tell me about what life is like with anorexia?
 - How does this compare to your life before anorexia?
 - Are there any positive/negative aspects of having anorexia?
 - In what way, if any, does the anorexia impact on how you think about yourself as a person?
- How would you describe yourself as a person?
 - In what way, if any, is this different to the person you were before you had anorexia?
 - How, if at all, have your thoughts and feelings about yourself changed since you became anorexic?
 - What do your value about yourself? What do others most value in you?
- What sense do you have about who you are?
 - How do you think other people see you? What do you think about that?
- What do you think are good, worthwhile characteristics in a person?
 - How do you compare to that?
 - What has made you that way?
- In what way, if any, is your sense of identity linked with your anorexia?
- How do you like to spend your time? What do you enjoy doing? Why do you enjoy this?
- Where do you see yourself in 5 years time?
 - Describe the person you hope to be then?
 - How would you compare the person you hope to be with the person you see yourself as
 - Would you still have anorexia? How would that change you?
- What would life without anorexia be like?
 - In what way, if any, would you be different?
 - What would need to change for you to live a life without anorexia?
- Is there anything else you think I should know to better understand how you view yourself as a person?
- Is there anything you would like to ask me?

Questions added after interview 5:

- On what did you/do you base your self-worth?
- Would you say you are the real you now/when you were anorexic?

Appendix 16: Transcript excerpt with codes and memos

Transcript excerpt with codes and memos

| Theoretical | Raw data | Initial |
|---|--|---|
| comments | | coding |
| | R: So to start with, can you tell me a little bit | |
| | about what life was like with anorexia? | |
| | P: Erm, okay well, for a long time I didn't really know that I had anorexia, I knew I struggled with weight and food but for me it felt as though I need, it wasn't because I had anorexia, it was because you know I believed I was overweight and that I needed to lose weight. Yeah, I didn't ever feel like I was bad enough to have anorexia erm, or an eating disorder, erm, so I think I very much, it was always there but you know it was taking over my life but | Being unaware of being anorexic Having difficulties with weight and food Eating difficulties not being due to AN Believing self to be overweight Needing to lose weight Minimising severity of eating difficulties AN always having been present AN taking over life Denving AN |
| She describes AN as taking over her life and it's like it has just waded in and taken control, as if she was powerless to prevent it, it feels like such a strong and overpowering force. AN TAKING OVER | there but you know, it was taking over my life but not to an extent where kind of I let that affect my life if that makes sense. But then erm, when it, when it did get really, really out of hand, erm, I just erm, just took over, it did take over my whole life, I mean, erm, I lost all of my, all of my interests, I wasn't interested in anything other than losing | Denying AN affecting life AN getting out of control AN taking over whole life Losing interests to AN Being focused on losing weight Being focused on food Everything requiring effort Finding it hard to see friends Keeping up an act Playing a role Not caring about seeing friends Feeling isolated Feeling detached Being disconnected from the world |
| | weight and food and erm, yeah, I wasn't, everything became like an effort, seeing, seeing friends and stuff, that I wasn't you know, that was keeping up an act you know I didn't, no longer really cared about seeing my friends or erm, I don't know, I felt like all the, I was really isolated and detached from | |
| The AN appears to have taken over who she was and now she becomes an anorexic version of herself, it's like the AN corrupts her and moulds her into what it wants her to be LOSING SELF TO AN | everything that was going on around me. Erm, there was, I don't know, I guess, I wasn't, I wasn't myself anymore at all, like all my personality traits had gone, I felt, yeah, I often felt like I was, looking back on it, it was like I wasn't, you know I wasn't really me I was more like a shell and my eating disorder had took over. | Not being myself when anorexic Losing personality traits to AN Not being me when anorexic Being empty when anorexic Being hollow when anorexic Losing self to AN AN taking over the self |

Appendix 17: Inclusion and exclusion criteria

Inclusion and exclusion criteria

Studies that met the following criteria were included in the review:

- Published, peer-reviewed study
- A study written up in English
- Original study published from January 1965 to January 2014
- A qualitative research study with a clear theoretical framework and analysis based on qualitative methods of data extraction
- A study analysing the perspective of an individual with a lifetime experience of AN
- A study focused on recovery from AN
- A study including participants of any age, gender or nationality.

Studies that met the following criteria were excluded from the review:

- An unpublished study or a study that has not been peer-reviewed
- A study written up in a language other than English
- A study published before 1965
- A study that has conducted a secondary analysis of previous studies
- A study with a quantitative design
- A study analysing the views of others (e.g. relatives, carers, professionals)
- A study lacking a specific focus on recovery from AN
- Case studies
- Books.

Appendix 18: Distress protocols: NHS

Distress protocols: NHS



Version 1 - 18.03.13

Sense of self and anorexia nervosa - Distress Protocol, Rathbone Hospital

- Should a participant become distressed during the interview an acknowledgement of their
 distress will be made and they will be asked if they would like to pause or end the interview.
 The participant's decision will be respected. If a participant wishes to continue, their level of
 distress will be monitored throughout the rest of the interview.
- The research includes a one-off interview; therefore the researcher would not provide any
 direct input for any participant who becomes distressed as a result of the interview. As a
 trainee clinical psychologist, however, a participant's emotional distress would be assessed
 and clinical judgement used as appropriate.
- The participant would be encouraged to contact their GP or a member of the Eating Disorder Service but the decision regarding whether or not they access help would remain theirs.
- If a participant showed a level of distress assessed by the researcher as making them a risk
 to themselves or others the researcher would seek further assessment. The participant's
 clinician at the Eating Disorders Service would also be made aware of any risks identified.
- If the risk is considered to be immediate the researcher will inform the participant's GP and seek advice from the Liverpool CRHT Access and Home Treatment Service (0151 250 5056) and facilitate access to further assessment/attendance at A&E as necessary.
- If the risk is not considered to be immediate the researcher will contact appropriate
 members of the Eating Disorder Service immediately to make them aware of any risks
 identified and facilitate access to any further assessment as necessary.

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Sense of self and anorexia nervosa - Distress Protocol, Whiston Hospital

- Should a participant become distressed during the interview an acknowledgement of their
 distress will be made and they will be asked if they would like to pause or end the interview.
 The participant's decision will be respected. If a participant wishes to continue, their level of
 distress will be monitored throughout the rest of the interview.
- The research includes a one-off interview; therefore the researcher would not provide any
 direct input for any participant who becomes distressed as a result of the interview. As a
 trainee clinical psychologist, however, a participant's emotional distress would be assessed
 and clinical judgement used as appropriate.
- The participant would be encouraged to contact their GP or a member of the Eating Disorder Service but the decision regarding whether or not they access help would remain theirs.
- If a participant showed a level of distress assessed by the researcher as making them a risk
 to themselves or others the researcher would seek further assessment. The participant's
 clinician at the Eating Disorders Service would also be made aware of any risks identified.
- If the risk is considered to be immediate the researcher will inform the participant's GP and seek advice from the Knowsley and St Helen's Assessment Team (0151 676 5263) and facilitate access to further assessment/attendance at A&E as necessary.
- If the risk is not considered to be immediate the researcher will contact appropriate
 members of the Eating Disorder Service immediately to make them aware of any risks
 identified and facilitate access to any further assessment as necessary.

Appendix 19: Distress protocol: charities

Distress protocol: charities



Version 1 - 10.07.13

The University of Manchester

Sense of self and anorexia nervosa – Distress Protocol, Eating Disorder Charities

- Should a participant become distressed during the interview an acknowledgement of their
 distress will be made and they will be asked if they would like to pause or end the interview.
 The participant's decision will be respected. If a participant wishes to continue, their level of
 distress will be monitored throughout the rest of the interview.
- The research includes a one-off interview; therefore the researcher would not provide any
 direct input for any participant who becomes distressed as a result of the interview. As a
 trainee clinical psychologist, however, a participant's emotional distress would be assessed
 and clinical judgement used as appropriate.
- The participant would be encouraged to contact their GP or a member of an Eating Disorder Service if they use one, but the decision regarding whether or not they access help would remain theirs.
- If a participant showed a level of distress assessed by the researcher as making them a risk
 to themselves or others the researcher would seek further assessment. If the risk is
 considered to be immediate the researcher will inform the police and request a welfare
 check is completed.
- If the risk is not considered to be immediate the researcher will contact the participant's GP
 immediately to make them aware of any risks identified and facilitate access to any further
 assessment as necessary.

Appendix 20: Debrief sheet

Debrief sheet



Version 1: 10th October 2013

The University of Manchester

Sense of self and anorexia nervosa

REC Reference number: 13-YH-0206

Researchers: Karen Williams, Dr John Fox, Dr Dougal Hare and Dr Jane King

Thank you for participating in the above study. The research aims to investigate sense of self in individuals with anorexia nervosa and how this relates to the eating disorder. By taking part in the study you have provided important information on the nature of this relationship, which will help us to understand it better. This may help us to consider alternative ways of helping people recover from anorexia nervosa in the future.

If talking about your thoughts and feelings during the interview has caused you any distress we would advise that you speak to your GP or someone at your eating disorder service (if you attend one) about this. Alternatively, the following services can be contacted confidentially:

Beat Helpline 0845 634 1414 (Mon – Thurs 1.30pm – 4.30pm) (Beating Eating Disorders)

The Samaritans 0845 790 9090 (24 hours a day, 7 days a week)

If you have any further questions or concerns about the research, please do not hesitate to contact Karen Williams on 0161 306 0400 or karen.williams-4@postgrad.manchester.ac.uk.

If you wish to make a formal complaint about the research, you should contact the University Research Practice and Governance Co-ordinator on 0161 275 7583/ 0161 275 8093 or research.complaints@manchester.ac.uk.

Once again, many thanks for your participation.