

**The psychosocial and support experiences of individuals who are
identified as having severe and enduring anorexia nervosa: an
Interpretative Phenomenological Analysis**

Thesis submitted in part fulfilment of the degree of Doctorate in Clinical Psychology
(DClinPsy)
University of Leicester

By
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Declaration

I confirm that this thesis and the research reported within it is an original piece of work and was written and submitted in part-fulfilment of the degree of Doctorate in Clinical Psychology. It has not been submitted for any other piece of work.

Jessica Conrad-Czaja

The psychosocial and support experiences of individuals who are identified as having severe and enduring ‘anorexia nervosa’: an Interpretative Phenomenological Analysis

Jessica Conrad-Czaja

Abstract

Eating disorders are complex difficulties that can have a significant impact upon all realms of an individual’s life. It is estimated that 70-80% of individuals diagnosed with an eating disorder will experience recovery. However, others will go on to experience a severe and enduring eating disorder. Research in this field has tended to focus on adolescent experiences, treatment efficacy and outcomes.

The current literature review aimed to explore the ways in which adult individuals experience, and make sense of, recovery from an eating disorder. Four electronic databases were searched and nine studies met the inclusion criteria. The findings suggested that recovery is a complex, dynamic and subjective process that involves the choice to change, a variety of transitional processes and a conceptualisation of recovery. Recovery was understood to be a comprehensive experience in which hope and interpersonal relations are particularly crucial.

The current empirical study aimed to explore the psychosocial and support experiences of individuals identified as having severe and enduring anorexia nervosa, as well as their future hopes and needs. Semi-structured interviews were conducted with six females identified as having severe and enduring anorexia nervosa and these were analysed using Interpretative Phenomenological Analysis. The analysis generated four super ordinate themes and 13 corresponding sub-themes. The themes were discussed in relation to relevant psychological theory and previous research and the clinical implications and recommendations for future research also discussed.

The critical appraisal offers a reflective account of the research process and includes the professional and personal development of the researcher from undertaking the current study. This aims to maximise transparency and offers a critique of the current research.

Acknowledgements

To the six individuals who took part in this study, thank you for openly sharing your experiences with me and for investing yourselves in this project. Your stories of strength and resilience inspired and moved me. Without you, this project would not have been possible.

To my research supervisor, Dr Steve Allan, thank you for your support and encouragement, not only throughout the research process, but also throughout my journey to becoming a qualified Clinical Psychologist. To my field supervisors* and recruiting service, thank you for your dedication and support.

To my cohort, we have laughed (and cried) and I am so grateful for this journey we have shared together. To my friends and family, thank you for your unwavering support and for helping me to maintain balance and perspective in my life throughout this journey.

To my mum – I could not begin to thank you enough. Without you, none of this would be possible. Thank you for your love, your support and your endless encouragement. Thank you for modelling the importance of endlessly and unconditionally seeing the best in people and the value of listening to others and supporting them. And thanks a bunch for feeding me and making me laugh when I've needed it most.

Finally, I wish to dedicate this work to the memory of my dad. For believing in me long before I believed in myself and always encouraging me to push myself further. For endlessly dedicating himself to ensuring I had access to every opportunity. For showing me the importance of human connection, regardless of positions of power. And most importantly, for loving and inspiring me.

* Names not presented to protect anonymity of the service.

Word Count

Overall abstract	268
Literature review	
Abstract	299
Full text (excluding figures and tables)	6,513
References	1,355
Research report	
Abstract	270
Full text (excluding figures and tables)	11,730
References	1,955
Critical appraisal	
Full text	3,451
References	277
Mandatory appendices (excluding figures, images and tables)	2,456
Non-mandatory appendices (excluding figures, images and tables)	3,689
Whole thesis (excluding references)	22,531
	(without non-mandatory appendices)
	26,220
	(with non-mandatory appendices)

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PART ONE: LITERATURE REVIEW

A Meta-Ethnography of Qualitative Research Exploring the Experiences of Recovery from an Eating Disorder

*(Guidelines to authors for journal targeted for literature review can be found in
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LITERATURE REVIEW

A Meta-Ethnography of Qualitative Research Exploring the Experiences of Recovery from an Eating Disorder

By Jessica Conrad-Czaja

ABSTRACT

Aim

Despite a growth in the amount of research relating to recovery from ED, this is still a poorly understood phenomenon. The aim of this paper was to review and integrate qualitative evidence on the ways in which adult individuals experience, and make sense of, recovery from an 'eating disorder' to build on the existing knowledge base.

Method

The review followed Noblit and Hare's (1988) meta-ethnographic approach, a method that allows for the synthesis of qualitative research to develop a more in-depth understanding. Four electronic databases (PsycINFO, PubMed, Scopus, Web of Science and Cumulative Index to Nursing and Allied Health (CINAHL)) were systematically searched in September 2017 and inclusion criteria were applied. The final studies for inclusion were quality appraised, key data was extracted and reciprocal translations were used to synthesise the themes that were shared across the papers.

Results

Nine qualitative studies were included, two of which included male participants. All studies considered individual experiences of recovery. A range of methods and analyses were used based upon the approach of meta-ethnography. The synthesis of the data revealed several similar themes within the studies. Three superordinate themes were identified: *a choice to change*; *conceptualisation of recovery*; *a process of transition*. Staying close to the primary data, key extracts from the studies were used to explain the themes and their subthemes.

Conclusions

The nine studies included in the review showed significant overlap in the key themes and findings identified. The synthesis revealed that recovery is a complex, dynamic and subjective process that involves the choice to change, a variety of processes of transition and the conceptualisation of recovery. Recovery was seen to include a variety of physical, psychological and social elements. Hope and interpersonal relations are seen as crucial factors in encouraging the initiation and maintenance of the recovery process.

1. INTRODUCTION

1.1 Clinical context

1.1.1 *Eating disorders*

Eating disorders (ED) are a diagnostic classification group that are typically used to describe an individual's experiences of a disturbed diet, a complex attitude towards food and a pre-occupation with body weight and shape (National Institute of Mental Health, 2017) (see Appendix B for a note on the use of diagnostic language). In 2015 it was estimated that more than 725,000 individuals in the United Kingdom (UK) were diagnosed with an ED, such as anorexia nervosa (AN) or bulimia nervosa (BN), and the rate of incidence has been estimated to be increasing by 5% every ten years (BEAT, 2015; Micali *et al.*, 2013). ED impact upon an individual's physical, social and psychological wellbeing (NICE, 2004) and are frequently identified as being serious and difficult to treat (Fassino & Abbate-Daga, 2013). Outcome studies have estimated that 70-80% of individuals diagnosed with an ED will experience recovery (Berkman *et al.*, 2007; Fairburn & Harrison, 2003; Treasure *et al.*, 2010), although the accuracy of these estimates are difficult to establish due to differences in definitions of recovery (Couturier & Lock, 2006).

1.1.2 *Defining and understanding recovery*

For ED, and the field of mental health more generally, 'recovery' has proven to be a concept that is difficult to define, measure and understand (Bonney & Stickley, 2008). However, the literature in this area can be understood within the context of two predominant models; the medical model and the recovery model.

The medical model adopts an objective approach to understanding recovery and is largely associated with quantitative research. Within this model, recovery is understood as the absence of symptoms outlined by the DSM or ICD diagnostic criteria, thereby focusing on weight gain and behavioural change as the key indicators of recovery (Kordy *et al.*, 2002; Roberts & Wolfson, 2004). In contrast, the recovery model views recovery as a more subjective process involving a personal journey towards an improved quality of life. The recovery model typically incorporates more psychological and relational elements as indicators of recovery and is more aligned to qualitative methods of research (Anthony, 1993; Jacobson, 2001; Jarman & Walsh, 1999). Clinical guidance, such as that published by the National Institute for Health and Care

Excellence (NICE, 2016), has attempted to incorporate both of these models by recognising the importance of focusing on both the physical and the psychological components of ED. However, the medical model has continued to be the dominant approach to recovery in practice, mainly due to difficulties in assessing the subjective aspects of psychological and environmental change that are emphasised in the recovery model (Couturier & Lock, 2006; Noordenbos & Seubring, 2006).

In addition to the two predominant approaches to defining and conceptualizing recovery from ED, research has also given attention to understanding the process of recovery and the factors associated with recovery. The Transtheoretical Model of Change (TMC; DiClemente & Prochaska, 1998) proposes five key stages to change. These are pre-contemplation, contemplation, preparation, action, and maintenance. Individuals diagnosed with ED often experience ambivalence towards change. This is often attributed to lack of motivation, and the TMC has been seen as helpful in making sense of this (Vitousek *et al.*, 1998; Wilson & Schlam, 2004). However, it remains unclear whether the TMC can effectively explain the process of recovery from ED or whether it is more complex and dynamic than this allows for (Dray & Wade, 2012).

1.1.3 Previous Research

Within the field of ED recovery, most research has adopted a medically-orientated approach to recovery and utilised quantitative research methods to try to define and predict the process and outcomes of recovery from an objective perspective. Although it is generally accepted that ‘chronicity leads to poor outcomes’ (Steinhausen, 2002), there is variable and inconclusive evidence about other factors, such as length and type of treatment, ED subtype and age of onset (Steinhausen, 2002; Vall & Wade, 2015). In line with the medical model, quantitative studies exploring the conceptualisation of recovery have typically focused on physical variables, such as weight gain and menstruation, and behavioural variables, such as bingeing and purging episodes (Treasure & Schmidt, 2003). In a systematic review of this area, it was highlighted that over 80% of the 126 included studies reported ED outcomes based on symptom remission alone (Vall & Wade, 2015). Although these aspects are important, they do not predict long-term ED recovery alone and individuals who identify as recovered from ED have highlighted the importance of psychological, emotional, and social criteria (Fennig & Roe, 2002; Noordenbos & Seubring, 2006). Some quantitative studies have therefore aimed to explore recovery as a comprehensive concept inclusive

of psychosocial factors. However, where these factors have been explored using quantitative methods, there has been great variability in definitions across different studies, making it difficult to draw out conclusions in these areas (Bardone-Cone *et al.*, 2010; Courtier & Lock, 2006).

Due to the difficulties in utilising quantitative methodologies to explore ED recovery as a comprehensive concept, there has been an increasing interest in qualitative research, which has begun to explore the subjective experiences of individuals who are identified as having ‘recovered’. In doing so, research has begun to explore how these individuals define recovery. Although a reduction in ED diagnostic pathology has been identified as important, it appears that this is to facilitate change in interpersonal and psychological functioning, rather than as a goal in itself (Pettersen & Rosenvinge, 2002). Furthermore, there is concern that a medically orientated construction of recovery minimises the importance of psychosocial and relational factors (D’Abundo & Chally, 2004). Qualitative research has recognised that the process of ED recovery is also often impacted by patients’ experiences of ambivalence, as the ED is experienced as both helpful and harmful; both ‘a friend and a foe’ (Serpell & Treasure, 2002; Treasure & Schmidt, 2001). It appears that, whilst professionals tend to recognise objective aspects of recovery, participants’ notions of recovery are more complex, comprehensive and subjective in nature (Treasure & Schmidt, 2003; Pike, 1998).

1.2 Previous literature reviews

Reviews of the quantitative literature have focused on what happens after treatment and have aimed to review definitions and rates of relapse and recovery (Pike, 1998; Khalsa *et al.*, 2017). Khalsa *et al.* (2017) conducted a meta-analysis of 27 studies and concluded that there are almost as many definitions of relapse and recovery as there are studies of these phenomena. In line with previous quantitative literature, this review concluded that standardised, transdiagnostic definitions of ED recovery are crucial to increase the utility of research in this area and to support communication amongst clinicians, individuals diagnosed with ED and their carers (Khalsa *et al.*, 2017).

A search of the review literature identified two previous qualitative literature reviews that consider the experiences of recovery from ED. Bezance and Holliday (2013) reviewed the literature about the experience of treatment and recovery for adolescents diagnosed with anorexia nervosa. The authors utilised thematic analysis to synthesise

11 qualitative studies and this highlighted the importance of family, peers and professionals in supporting recovery for this group. The experience of family therapy and the inpatient setting were highlighted and participants appeared to place emphasis on physical versus psychological elements of recovery. There were individual differences in the conceptualisation of recovery.

Duncan *et al.* (2015) adopted a meta-ethnographic approach to synthesise eight qualitative studies with the aim of exploring the phenomenon of recovery from the perspective of those who had experienced it. This study did not adopt a criterion based upon age and included adolescents and adults who identified as having recovered from anorexia. The findings from this study centered round the importance of empowerment and self-reconciliation. These overarching themes represented participants' experiences of a search for identity and truth, while repossessing control and power.

1.3 Rationale and aims for current review

Despite an increase in research relating to recovery from ED, this is still a poorly understood phenomenon. It is clear that the individuals who identify as having experienced this process can offer important contributions to the way we make sense of recovery and how it might be helped or hindered. Qualitative research allows for a focus on these lived experiences and has become increasingly valued by practitioners, policy makers and commissioners in healthcare services (Dixon-Woods *et al.*, 2007).

The Bezance and Holliday (2013) qualitative review considered both treatment and recovery experiences and focused only on adolescent participants. There are considerable differences in the approaches towards ED in adolescence and adulthood (Treasure *et al.*, 2005) and it is important to independently explore any issues that may be salient for adults. Duncan *et al.* (2015) did not implement an inclusion criteria based on age and considered the experiences of those who experienced recovery during adolescence and adulthood. However, they recognised that the findings of this review were limited by a lack of representation of male experiences. The current review distinguishes itself from previous qualitative reviews by focusing solely upon the experiences of adult recovery from an ED and also by incorporating recent research concerning the experiences of males who identify as having experienced recovery.

Therefore the aim of this synthesis is to use a meta-ethnographic approach to integrate and synthesise qualitative findings that explore the ways in which adult individuals experience, and make sense of, recovery from an ED. The research questions were as follows:

- a) What are individuals' experiences of recovery from an ED?
- b) How do these individuals make sense of recovery?

2. METHOD

2.1 Meta-Ethnography

Consideration was given to the range of methods available to synthesise qualitative research (Barnett-Page & Thomas, 2009). It was decided that the aims of the current review would be best met through an interpretative meta-synthesis informed by Noblit and Hare's (1988) meta-ethnography approach, alongside more recent developments in meta-ethnography (Britten *et al.*, 2002; Atkins *et al.*, 2008). Meta-ethnography is a well-established method that involves induction and interpretation, thereby resembling the qualitative methods of the studies it aims to review and preserving the meaning of the experiences explored within the included studies (Britten *et al.*, 2002). The current review utilised the seven-step process of meta-ethnography (Noblit & Hare, 1988), as outlined in Figure 1.

Figure 1: Noblit & Hare's meta-ethnography method

Seven-step process of meta-ethnography

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how studies are translated
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

2.2 Search strategy

The search strategy was created in consideration of the studies research questions and using Shaw's (2010) CHIP tool for qualitative studies (Context, How, Issues of interest, Population): Context – recovery from ED; How – utilised qualitative methodology; Issues of interest – how individuals experience and makes sense of recovery from ED; Population – individuals over the age of 18 years who identify as 'in recovery' or 'recovered' from ED.

The current study adopted a systematic search strategy to ensure a comprehensive and reproducible search. Prior to the main search, a scoping exercise was conducted with the aim of ascertaining the amount and type of literature available. This initial search utilised the Google search engine and also specific websites including Beat and The Eating Disorder Institute. A search of the Cochrane Database of Systematic Reviews was also conducted to identify relevant previous reviews. This exercise shaped the aims for the current study and informed the search terms used.

Electronic searches of the following four databases were undertaken in September 2017: PsycINFO, PubMed, Scopus, Web of Science and Cumulative Index to Nursing and Allied Health (CINAHL). The final search terms were selected based upon the scoping search and in consultation with a specialist librarian. They included: recover* OR 'get* better' AND 'eating disorder*' OR anorexi* OR bulimi* AND experience* OR qualitative* (Appendix C). The chosen databases were selected with the aim of including a wide variety of literature from a range of perspectives. Where possible, searches were conducted using University of Leicester access and NHS Athens access, to ensure the availability of a wider range of journals.

2.3 Inclusion and exclusion criteria

A number of a priori limits were set, the first of which was for papers to be in English. The second was a cut-off date, set at 2012-2017, with the aim of including any papers that may have been published at the time of, and after, the search completed by Duncan *et al.* (2015). This appeared to be effective, as there were only two papers that were included in both the current review and in the Duncan *et al.* (2015) review, evidencing the need for an updated review. Further inclusion and exclusion criteria were developed in light of Shaw's (2010) CHIP tool and can be found in Table 1.

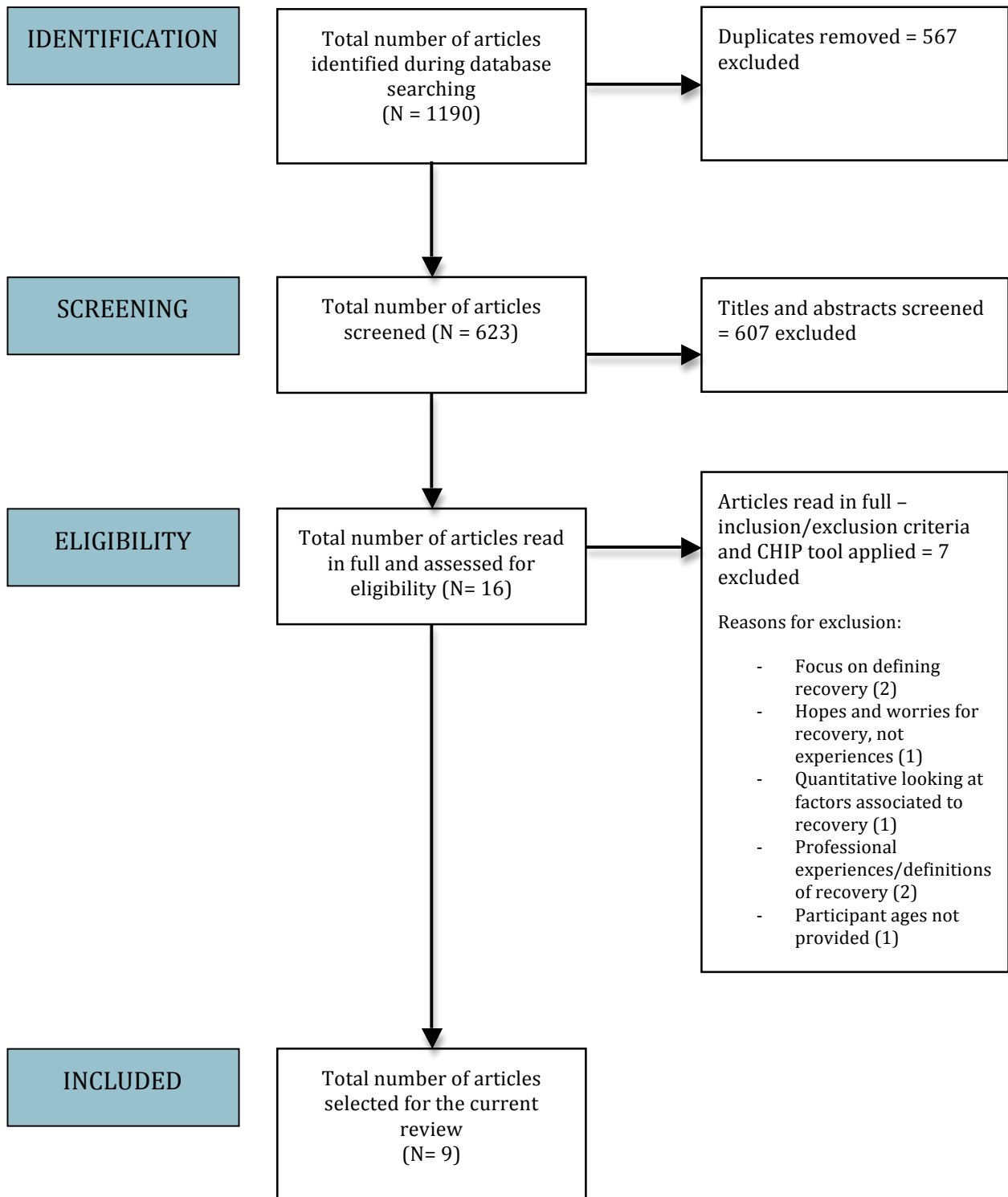
Table 1: Inclusion and exclusion criteria

Inclusion	Exclusion
<ul style="list-style-type: none">- Primary data pertaining to the experiences and sense-making of recovery from an ED- Perspectives of those identifying as ‘in recovery’ or ‘recovered’- Adults – 18 years or older- Qualitative studies or mixed methods with a substantial qualitative component	<ul style="list-style-type: none">- Non-primary data- Quantitative only or predominantly quantitative in mixed methods study.- Perspectives of those who do not identify as ‘in recovery’ or ‘recovered’ from ED- Participants under 18 years old

2.4 Study selection

The initial database search produced 1190 results, all of which were exported to bibliographic referencing software. Duplicates were removed and this left 623 articles. The titles and abstracts of these articles were screened alongside the inclusion and exclusion criteria and the majority of articles were excluded. The main reasons for exclusion included the article being irrelevant, focusing on defining recovery or on ED interventions. At the end of this process 16 articles remained. The full text of the remaining articles was read and nine studies were found to meet the criteria for the current review (see Appendix D for study characteristics). The reference lists of these key papers were manually searched, however no further relevant studies were identified. The selection process of the final nine papers is outlined in a PRISMA flow chart in Figure 2.

Figure 2: PRISMA flow chart



2.5 Quality assessment

The quality of the nine key papers was assessed using the Critical Appraisal Skills Programme (CASP, 2014) qualitative checklist. This tool was adopted as it is frequently used in qualitative research reviews and has been identified as a useful tool to make judgements on the procedural aspects of included studies (Dixon-Woods *et al.*, 2007). Each study was awarded a ‘yes’, ‘no’ or ‘can not tell’ rating for each item in the checklist (Appendix E). The quality of all the studies was judged to be good and no studies were excluded following this appraisal. The information from the appraisal was considered throughout the process of meta-synthesis.

2.6 Data synthesis and analysis

In accordance with Noblit and Hare’s (1988) seven-step process, the nine key papers were read numerous times to ensure familiarity with the content of each paper. The studies were then analysed using the method of reciprocal translational analysis (RTA), which allowed the author to explore the key concepts from each individual study and identify the overlapping themes across studies, which were then translated into one another to develop overarching themes. This approach was supported by the notion of ‘first’, ‘second’ and ‘third’ order constructs (Atkins *et al.*, 2008). These terms have been defined within Appendix F to explain this process further and to highlight the level of interpretation used.

2.6.1 First order constructs

A data extraction form (Appendix G) was used to draw out important characteristics from each study. These characteristics included information on theoretical framework, participant details, methods used, procedures, analysis, findings and validity of findings. Within this, the first order constructs were established by extracting the key findings of each study using the language adopted by the participants and authors.

2.6.2 Second order constructs

The data extraction form also supported the development of the second order constructs (Appendix H). These were formed by staying close to the language used within the original data, although the focus here was on the authors’ interpretations of the findings, rather than the findings themselves.

2.6.3 Third order constructs

As the first and second order constructs were developed, it became apparent that the accounts across the primary studies were consistent and reciprocal translations were therefore undertaken to develop third order constructs. This involved pulling together the shared meaning across different accounts. Although these translations use the concepts from the original studies, they can be understood as the reviewer's interpretations of original author's interpretations of the participant's interpretations. This level of analysis was expressed through the use of conceptual themes, which offered a hypothesised understanding of the ways in which individuals experience and make sense of recovery from an ED. The taxonomy of findings can be found in Appendix I.

3. RESULTS

3.1 Characteristics of the included studies

The key characteristics of the nine key papers are outlined in Appendix D. All nine papers explored the experiences of recovery from an ED, although there were different focuses across the studies. Two papers solely focused on the experiences of males (Bjork *et al.*, 2012; Pettersen *et al.*, 2016); the other seven studies were made up of female participants. One study focused on the experiences of therapists who identified as being in recovery from an ED and also worked within ED services (Bowlby *et al.*, 2012).

All nine key studies adopted a purely qualitative approach. They all collected data through the use of semi-structured interviews and included an interview topic guide. Analysis included a phenomenographic approach (Bjork *et al.*, 2012; Bowlby *et al.*, 2012), interpretative phenomenological analysis (Jenkins & Ogden, 2012), content analysis (Lindgren *et al.*, 2014; Pettersen *et al.*, 2012; Pettersen *et al.*, 2016), grounded theory (Espindola & Blay, 2013), narrative inquiry (Dawson *et al.*, 2014) and narrative thematic analysis (LaMarre & Rice, 2016). All studies utilised semi-structured interviews as their method of data collection. Four studies were conducted in Norway and Sweden (Bjork *et al.*, 2012; Lindgren *et al.*, 2014; Pettersen *et al.*, 2012; Pettersen *et al.*, 2016), while the others took place in America (Bowlby *et al.*, 2012), England (Jenkins & Ogden, 2012), Brazil (Espindola & Blay, 2013), Australia (Dawson *et al.*, 2014) and Canada (LaMarre & Rice, 2016).

Quality appraisal, using the CASP qualitative checklist, indicated parity across the included articles. All of the studies were thereby given equal attention and weighting throughout the analysis and synthesis processes. Upon completion of these processes, the table in Appendix J was utilised to ensure validity of the themes by ensuring that they were reflected in the majority, if not all, of the included studies and to ensure that all included studies had been given attention.

3.2 Meta-synthesis

The findings were synthesised into three super ordinate themes; a choice to recover, conceptualisation of recovery, and a process of transition. Each of these themes, as

described below, included conceptual headings to illustrate the concepts reflected by each theme.

As previously indicated, meta-ethnography aims to preserve the meaning of the experiences explored within the included studies (Britten *et al.*, 2002). In order to maintain this connection with the original data, and to ensure clarity, double quotation marks are used to indicate direct participant quotes and single quotation marks to indicate the article author's words.

3.2.1 A Choice to Recover

3.2.1.1 Ambivalence

Participants' expressed mixed feelings towards their experience of an ED and this appeared to contribute to feelings of ambivalence. Although they were aware of the limitations of the ED, they also recognised the benefits it brought to their life (Jenkins & Ogden, 2012; Lindgren *et al.*, 2014; Pettersen *et al.*, 2012; Pettersen *et al.*, 2016). Although participants seemed to have a 'longing for a life without limitations' (Lindgren *et al.*, 2014, p.864), they also expressed feelings of fear when contemplating recovery, as they had come to experience the ED as their "best friend" or "life jacket" (Pettersen *et al.*, 2012, p.94), which had been a functional coping strategy for managing stressors in their lives. Recovery was therefore seen as "a huge risk" (Jenkins & Ogden, 2012, p.29), even more so because the ED was seen as a key part of their identity (Pettersen *et al.*, 2016).

Furthermore, participants reported feelings of powerlessness and hopelessness in relation to recovery, whether this was because they were uninformed about the possibility of recovery (Espindola & Blay, 2013) or because they felt like there was no possibility for them to recover (Dawson *et al.*, 2014). Such hopelessness was often reinforced by multiple hospital admissions and 'failed treatments' and was perceived as being shared by clinicians, family members and friends (Dawson *et al.*, 2014). Feelings of hopelessness appeared to reinforce ambivalence towards recovery and led to individuals avoiding support or accessing support with little intention of progressing.

3.2.1.2 Tipping Point

After experiencing ambivalence towards recovery, participants often experienced a ‘tipping point of change’ (Dawson *et al.*, 2014, p.499), which instigated a ‘final decision’ to commit to recovery (Bowlby *et al.*, 2012, p.7). At this point, the ED seemed to change from something of value to something that was damaging and unproductive. This often involved participants “hitting rock bottom” and feeling they could no longer sustain life with an ED (Dawson *et al.*, 2014, p.499; Jenkins & Ogden, 2012; Pettersen *et al.*, 2016). This tipping point could arise from an internal or external factor; such as pregnancy, physical complications or occupational and environmental consequences (Espindola & Blay, 2013). Regardless of the factor, this was associated with a shift from ambivalence to acknowledging the negative consequences of the ED and demonstrating agency and an internal locus of control to engage in the process of recovery (Dawson *et al.*, 2014; Jenkins & Ogden, 2012; Pettersen *et al.*, 2012)

3.2.2 Conceptualisation of Recovery

3.2.2.1 Comprehensive

Bowlby *et al.* (2012) identified the importance of recovery being ‘comprehensive’ (p.5) and this was identified across a number of studies. Participants felt that the conceptualisation of recovery needed to broaden ‘beyond biometrics’ (LaMarre & Rice, 2016, p.142) and also focus on psychological, emotional, environmental and social factors (Bowlby *et al.*, 2012; Espindola & Blay, 2013; Jenkins & Ogden, 2012; Pettersen *et al.*, 2012). For some, it was also important to address existential and spiritual values, (Espindola & Blay, 2013; Pettersen *et al.*, 2016). One participant concluded, “you do have to worry about the physical aspects, obviously, but you have to come at the emotional aspect just as hard” (LaMarre & Rice, 2016, p.142). Recovery was thereby understood as a process of becoming ‘whole again’ (Jenkins & Ogden, 2012) and “learning to live a full life” (Bowlby *et al.*, 2012, p.8).

In line with this, it could be seen that there was a hope that treatment would also be comprehensive, involving multi-disciplinary approaches and including medication, psycho-education, psychotherapy, alternative therapies and social support (Espindola & Blay, 2013; Pettersen *et al.*, 2016). Recovery was also understood to involve a developed understanding of the cause and function of the ED in order to address the

underlying process and support long-term recovery (Bowlby *et al.*, 2012; LaMarre & Rice, 2016).

3.2.2.2 *Unique and Individual Experience*

Across all nine papers it was evident that recovery was conceptualised as a process that is unique to the individual. It appears that recovery cannot be viewed as a unidirectional, positively skewed development from illness to ‘wellness’ (Pettersen *et al.*, 2012, p.96), but rather as a non-linear process, during which individuals will be impacted by their individual tipping points, goals and challenges (Bowlby *et al.*, 2012; Espindola & Blay, 2013; Jenkins & Ogden, 2012; Lindgren *et al.*, 2014). This was most evident through the different conceptualisations of recovery as a process or a goal. While some people conceptualised recovery as an end state, others saw it as a dynamic process in which they were “living [their] recovery every day” (LaMarre & Rice, 2016, p.145). In line with this, some viewed themselves as ‘recovered’ and developed a new identity free of their history of an ED, while others perceived themselves as ‘in recovery’ and acknowledged their ED as an ongoing part of their identity, but a part that they were in control of (Bjork *et al.*, 2012; Bowlby *et al.*, 2012; Espindola & Blay, 2013; Jenkins & Ogden, 2012). Whichever way they made sense of this concept, they reported feeling free of their ED (Dawson *et al.*, 2014). Having recognised the individual and unique ways in which people may experience the process of recovery from ED, it was recognised that treatment and support should be tailored to the individual’s needs and adopt a collaborative approach (Espindola & Blay, 2013; Jenkins & Ogden, 2012).

3.2.3 *A Process of Transition*

3.2.3.1 *Identity and Self-Efficacy*

As participants moved from a stage of ambivalence to a process of recovery, they seemed to experience a transition in their identity and self-efficacy. There was sense that, prior to recovery, they had internalised the ED and this was “somehow [their] whole identity” (Lindgren *et al.*, 2014, p.5). However, during recovery they went through a process of de-identification with the ED and came to externalise the ED, perceive an internal locus of control and develop an alternative identity (Bowlby *et al.*, 2012; Dawson *et al.*, 2014; Lindgren *et al.*, 2014; Pettersen *et al.*, 2012). However, this transition could be complicated by concerns about what ‘normal’ means and feeling

caught between ED discourses and those attributed to the broader population (LaMarre & Rice, 2016; Pettersen *et al.*, 2016).

Participants also appeared to move from self-hatred and blame towards accepting, loving and prioritising themselves (Bjork *et al.*, 2012; Bowlby *et al.*, 2012; Dawson *et al.*, 2014; Espindola & Blay, 2013; Jenkin & Ogden, 2012; Lindgren *et al.*, 2014; Pettersen *et al.*, 2012; Pettersen *et al.*, 2016). They began to understand the function of the ED and recognise “perhaps I wasn’t to blame for it” (Dawson *et al.*, 2014, p.500). They transitioned from being ‘pleasers’ to ‘boundary setters’ (Pettersen *et al.*, 2016, p.5), as they felt in control of attending to their own needs. These processes of self-reconciliation seemed to increase the individual’s level of autonomy, which aided the recovery process further (Bjork *et al.*, 2012; Espindola & Blay, 2013; Lindgren *et al.*, 2014).

3.2.3.2 *Interpersonal Relationships*

During their recovery process, people went from a position of living isolated with only the ED as their ‘best friend’ (Pettersen *et al.*, 2012, p.94), to a position of prioritising relationships and engaging in supportive and meaningful relationships (Bjork *et al.*, 2012; Bowlby *et al.*, 2012; Lindgren *et al.*, 2014). Alongside this, they also appeared to transition from a stage of resistance to treatment to one of engagement and finding value in professional support (Jenkins & Ogden, 2012; Pettersen *et al.*, 2012).

These changes were experienced as crucial to the recovery process, as they provided participants with an increased motivation to pursue recovery; a more helpful and empathic way to manage their emotions; and also confirmed the legitimacy of their experiences, which supported the process of self-reconciliation (Dawson *et al.*, 2014; Espindola & Blay, 2013; Jenkins & Ogden, 2012; LaMarre & Rice, 2016; Pettersen *et al.*, 2016). Most importantly, these relationships “instilled hope” that the individual was capable of recovery, which was frequently identified as a central element of recovery (Dawson *et al.*, 2014, p.501; Jenkins & Ogden, 2012; Lindgren *et al.*, 2014).

3.2.3.3 *Alternative Coping*

Another transition that was experienced as part of the recovery process involved moving away from utilising ED symptoms as the regulators of emotions and stressors and instead finding alternative ways of coping that were more functional (Jenkins &

Ogden, 2012; Lindgren *et al.*, 2014; Pettersen *et al.*, 2012). One participant explained how this “felt like reprogramming myself...it took a long time” and required a lot of persistence (Dawson *et al.*, 2014, p.501). The specific functional coping strategies that were adopted depended on the individual and varied from communication strategies, such as verbalising emotions or writing a diary, to removing scales or engaging in activities, such as yoga (Bjork *et al.*, 2012; Espindola & Blay, 2013; Jenkins & Ogden, 2012). As these strategies were developed, individuals were able to positively re-frame ED behaviours as ‘logical coping mechanisms’ (LaMarre & Rice, 2016, p.141) and ED cognitions as “red flags that something else is going on” (Bowlby *et al.*, 2012, p.7). Participants seemed to highly value alternative strategies as a way of communicating and managing their psychological distress in adaptive ways, rather than using bodily means to do so (LaMarre & Rice, 2016).

4. DISCUSSION

This meta-synthesis aimed to integrate qualitative studies that explore the experiences of recovery from an eating disorder. The question asked was: how do individuals experience and make sense of recovery from an ED? Existing research had given attention to the experiences of adolescents and had been dominated by female experiences of recovery. This study aimed to add further insights into the existing literature in this area by using recently published research that focuses on adult experiences of recovery and by incorporating studies that have explored experiences of males. Quality appraisal indicated parity amongst the included articles and the findings from each paper were therefore given equal weighting throughout the current review.

4.1 Discussion of Findings

4.1.1 *Summary of findings and links to existing literature*

The current review supports previous reviews in finding that recovery is experienced as a complex process, entailing a self-determined search for identity, the repossession of personal control and a process of self-reconciliation (Duncan et al., 2015). It also supports the finding of previous reviews that, although recovery is comprehensive and includes physical and psychological components, it is conceptualised differently by each individual (Bezance et al., 2013; Duncan et al., 2015). The current review has also added new findings to the evidence base. Despite two studies focusing purely on male experiences, the themes expressed across all papers were similar (Appendix J) and reciprocal translations were possible across all papers. Although it was evident that there are differences in the clinical presentation and treatment of males and females with eating disorders, there was no evidence that they experience recovery in different ways. As such, the current study came to identify recovery as a gender-neutral process, whereby the experiences of males and females can be understood similarly. Future research will be needed to corroborate this preliminary finding, as it has not been given attention in previous reviews in this area.

The current review also highlighted the differences between the recovery experience for adolescents and adults, which had not been recognised by previous reviews. Adolescent experiences appear to be dominated by family relationships and systemic interventions, whereas the adult experience appears to be one that is much more independent and

autonomous. This appears to be reflective of the wider evidence and approaches towards working with ED and how this alters between adolescence and adulthood (Treasure *et al.*, 2005).

4.1.2 A choice to recover

The current review demonstrated that individuals who have experienced recovery recall the power of ambivalence towards recovery. While this has often been viewed as the result of a lack of motivation (Vitousek *et al.*, 1998), the current review highlighted that ambivalence was more often associated to a fear of losing the ED as their primary coping strategy, despite its negative impact. This complex dynamic resonated with previous literature that has conceptualised ED as both a friend and a foe (Serpell & Treasure, 2002; Treasure & Schmidt, 2001). Furthermore, the findings suggest that individual experiences of ambivalence towards ED recovery were often enhanced by a lack of hope that recovery was possible. Perhaps, this hopelessness could also be attributed to the lack of consensus about the prevalence and conceptualisation of recovery (Bardone-Cone *et al.*, 2010; Courtier & Lock, 2006), which may make it an illusive concept that feels unknown or unattainable. It was apparent that the individual's feelings of hopelessness were often reinforced by experiences of isolation and by the perceived hopelessness of significant others, such as clinicians, family members or friends.

However, people appeared to experience a tipping point at which they decided to commit to recovery. This concept was strongly identified across most of the included studies (Appendix J) and yet appears to be a new contribution to the field. This 'tipping point' was personal to the individual, but involved reaching a point where the costs of living with ED outweighed the benefits. Reaching this point often occurred after the individual came to understand the function of the ED and its impact, which allowed them to understand it as a logical response to their experiences and something they could replace with alternative, more functional, coping strategies.

4.1.3 A process of transition

It is evident that, after making the choice to recover, individuals experienced recovery as a process of multiple transitions: from an identity built upon ED to discovering one's true self; from a position of self-blame to one of self-acceptance; from internalising and

identifying with the ED to externalising and de-identifying with it; from social isolation to engaging in interpersonal relationships; from hopelessness to hope; and from using bodily means to express psychological distress to adopting alternative functional ways of coping. The findings suggested that individuals experience the ED and the process of recovery in a cyclical nature as part of an autocatalytic process. While the ED was experienced as a downward spiral, recovery was conceptualised as an upward spiral. It appears that once the individual experienced a tipping point and committed to recovery, this acted as a catalyst for further change and they began to experience a variety of transitional processes. In turn, as they began to notice improvement in these areas, their commitment and determination to pursue and maintain recovery appeared to continue to develop.

The cyclical nature of this process resonated with the concept of the ‘stages of change’ proposed by the Transtheoretical Model of Change (DiClemente & Prochaska, 1998). However, while this model helps to make sense of the cyclical nature of recovery and the ambivalence often seen in this process, it appears too simplistic in its construction of the stages of ‘action’ and ‘maintenance’ to effectively explain the complex and dynamic transitional processes involved in recovery (Dray & Wade, 2012).

4.1.4 Conceptualisation of recovery

Although the transitional processes of recovery were viewed positively, they were also experienced as challenging and ongoing. Furthermore, it was evident that recovery was not experienced as a positively skewed, uni-directional process from illness to wellness (Prochaska et al., 1994). Instead, the current review demonstrated that recovery is an individual process and highlighted the importance of understanding how the individual conceptualises this phenomenon, a finding that corroborates previous research (Benzance *et al.*, 2013). While some individuals found it helpful to identify as ‘recovered’, others preferred to perceive themselves as ‘in recovery’. While some believed it was important to incorporate past experiences of ED into new identity, others felt it was important to leave this behind.

Although recovery was predominantly conceptualised as a unique process, there was one concept that appeared unanimous across the key studies (Appendix J), and that was the belief that recovery should be a comprehensive process. Although physical and behavioural changes were seen as important elements of recovery, it was highlighted

that recovery should also incorporate psychological, social and environmental change. This finding supported recent developments in clinical guidelines to encourage a more comprehensive approach to recovery, in which physical and psychological elements are considered (NICE, 2017) and a variety of interventions are offered to allow each individual to construct the most useful recovery process for them. This finding also reflected developments in the wider literature, where there has been a transition from constructing recovery in a reductionist medically-orientated way, focusing on physical and behavioural change, to a more comprehensive and subjective approach to recovery that incorporates psychological, emotional, social, relational and environmental change. However, while research has highlighted the importance of conceptualising recovery as a subjective process, there has also been recognition of the need for a standardised, objective definition of ED recovery, to facilitate outcome studies and to allow for shared understandings of this concept (Khalsa *et al.*, 2017).

4.2 Limitations of the Current Review

The current review was subject to certain limitations. As recognised, there is no universal definition of recovery. Therefore, while some studies recruited participants based upon self-defined recovery, others recruited based upon an absence of diagnostic symptoms. There were also differences amongst participants, as some identified as being ‘in recovery’, while others identified as ‘having recovered’. This compromised the homogeneity of the included participants and future research and reviews may find it useful to explore whether there are differences between the different stages of recovery. A second limitation related to the use of meta-ethnography. The nature of this approach relies upon interpretation and is therefore open to possibility of being interpreted through the researcher’s individual lens based upon their own experiences and views. Finally, this paper is limited by its inclusion of participants who have accessed support and reported recovery. It is recognised that there are other individuals who do not access support and yet still go on to experience recovery (Musolino *et al.*, 2016). It may be useful for further attention to be given to this group of individuals and their experiences of recovery, which may differ from those who have accessed support.

4.3 Conclusions, Clinical Implications and Future Research

The current review highlights that recovery from an eating disorder is possible and that it is a complex, dynamic process that involves the choice to change, a variety of processes of transition and the conceptualisation of recovery. Bandura (1998, p.52) reported that, ‘unless people believe that they can produce desired effects by their actions, they have little incentive to act’, and this appears to represent the importance of hope in the process of recovery. Hope was seen as a crucial element to initiate and maintain recovery and support from others was also identified as crucial, including professional and non-professional support. It appears that it would be clinically useful for clinicians to share recovery narratives and to encourage and hold hope for the individual, even when this may be challenging. Furthermore, in support of previous literature, the current review recognised the fear associated with leaving the ED behind to move towards recovery and how participants often internalised their eating disorder and were typically unaware of the function it may have served as a coping strategy for their emotional distress. Therefore it would seem useful for clinicians to sensitively, but honestly, highlight the potential costs and implications of maintaining an ED, as well as the possible function of the ED, as this can often support the choice to change, reduce feelings of self-blame and introduce the idea of adopting alternative ways of coping.

The findings from this review highlighted the importance of interpersonal relationships in the process of recovery. As such, it may be helpful for clinicians to give consideration to incorporating therapeutic interpersonal interventions. Alongside this, it would seem important for support to be extended to family and friends around the individual, so that these people are sufficiently resourced in supporting the individual in recovery. The current review highlighted that individuals conceptualise recovery as a comprehensive process that should include physical, psychological, social and environmental change. The value placed on each of these elements may be different for each individual and clinical practice should ensure that patients are given the space to develop their unique conceptualisation of recovery, an approach that is supported by current clinical guidelines (NICE, 2004). Alongside this, treatment should also be comprehensive and tailored to individual needs, even if this means accessing a variety of interventions and includes interventions that do not currently have a considerable evidence base, such as yoga. The current meta-synthesis added to the existing research

base by highlighting the experiences of adults who identify as recovered from an ED and also by considering the experiences of males who have recovered from ED.

Further research is needed to explore the experiences of recovery for males to corroborate the finding that recovery appears to be a gender-neutral experience. It would seem useful for future research to also work towards developing a new model, or developing existing models like the TMC model, to support those working with ED and those diagnosed with ED in making sense of recovery. The findings from the current review emphasise recovery from ED as a subjective experience. As such, it would seem useful to move away from a focusing purely on objective outcome measures and work towards developing subjective measures of recovery. These could be used alongside existing objective measures to ensure that interventions and outcomes are meaningful and effective for the individual.

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*Denotes studies included in the current review.

PART TWO: RESEARCH REPORT

The psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa: an Interpretative Phenomenological Analysis

RESEARCH PROJECT

The psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa: an Interpretative Phenomenological Analysis

By Jessica Conrad-Czaja

ABSTRACT

Aim

Although most individuals diagnosed with anorexia nervosa go on to recover, some go on to experience severe and enduring anorexia nervosa (SEAN). Individuals with SEAN are considered to be some of the most complex and costly cases within healthcare services. There has been an increasing interest in the treatment and outcomes of this group, however little attention has been given to their experiences. The current study aimed to explore the psychosocial and support experiences of individuals living in the community with SEAN.

Method

Semi-structured interviews were conducted with six women identified as having SEAN to explore their psychosocial and support experiences and future hopes. Interview data were transcribed and analysed according to Interpretative Phenomenological Analysis (IPA). Emergent themes were derived from each participant's lived experiences and deeper levels of interpretation were sought across all transcripts.

Results

The analysis produced 13 sub-themes, which were positioned within four super-ordinate themes: '*SEAN as a friend and a foe*'; '*Internal conflict*'; '*Inpatient or nothing*' and '*Valuing others but not themselves*'. The relationships between themes and the convergence and divergence of the participants' experiences were explored.

Conclusions

The findings of the study highlight SEAN as a complex experience that significantly impacts an individuals psychosocial functioning. The findings were discussed in relation to existing psychological theory and research literature. Links were also made to existing policy and guidance surrounding individuals identified as having SEAN and the services they use. A number of clinical implications are presented, including the need for comprehensive and collaborative care, the importance of co-production, the potential value of peer support and social engagement and the possible value of intensive community support.

1. INTRODUCTION

1.1 Anorexia Nervosa

Anorexia nervosa (AN) is an eating disorder (ED) that is typically characterised by a persistent restriction of dietary intake, an intense fear of gaining weight and distorted body image (American Psychiatric Association, 2013) (see Appendix B for a note on the use of diagnostic language). Individuals diagnosed with AN experience impairments with their physical health and psychosocial wellbeing and will often experience co-morbid difficulties, within the realms of both physical and mental health (Joint Commissioning Panel for Mental Health; JCPMH, 2013; NICE, 2017). These individuals are typically considered high-risk, due to the increased risk of physical health complications, self-harm and suicide (JCPMH, 2013; Swanson et al., 2011).

AN is frequently identified as being serious and difficult to treat (Fassino & Abbate-Daga, 2013). There has been suggestion of a critical window of time during which interventions should be offered, as the prognosis worsens over time (JCPMH, 2013). With early identification and appropriate intervention, many individual's report having recovered from AN. However, a number of factors can prevent recovery, such as the functionality of the ED (JCPMH, 2013; Lavender & Schmidt, 2006; Serpell et al., 1999), the shame, deniability and stigma that many individuals diagnosed with ED experience (Beat, 2016) and the ego-syntonic attachment to maintaining a low weight (Hay et al., 2012; Schmidt & Treasure, 2006). Recovery can also be impacted by the service context surrounding the individual, within which they may only have access to non-specialist treatment as a result of the disparate commissioning of services across the UK (Hudson et al., 2013; JCPMH, 2013). Therefore, although most individuals diagnosed with AN report full recovery, it has been estimated that around 20% go on to experience severe and enduring AN (SEAN) (Steinhausen, 2002; Strober et al., 1997).

1.2 Severe and enduring anorexia nervosa

Although there is an increasing awareness of the possibility of SEAN, there are currently no guidelines based on empirical research to guide how one might define SEAN. Different researchers have considered the role of chronicity, severity and motivation; however the relative weighting of these constructs remains unclear and no consensus has been reached as of yet (Ciao et al., 2016).

Individuals with SEAN are considered to be some of the most challenging clients within healthcare services and pose a heavy burden on services, public resources and carers (JCPMH, 2013; Strober, 1997). These individuals have been found to present the highest cost-per-patient in comparison with any other group accessing mental health services (Birmingham & Treasure, 2010; Robinson, 2009). SEAN also has the highest mortality rate of any mental health difficulty, with around 20% dying as a result of suicide, emaciation or inter-current diseases (Steinhausen et al., 2002). Professionals in this area often experience high levels of burnout and hopelessness, due to the perceived failure of past treatments, the high mortality risk, and the lack of evidence for how to support for this group (Ciao, 2016; JCPMH, 2013). Many people with SEAN rely on carer support but carer burden is also significantly high and, as AN becomes increasingly severe and enduring, many carers are no longer able to offer support (Treasure et al., 2001). This often leaves the individual with SEAN feeling socially isolated, which again increases their reliance upon services (JCPMH, 2013).

As a result of these challenges, ‘recovery’ can be very difficult for individuals who experience severe and enduring difficulties (Roberts & Wolfson, 2004). However, recent exploration has shown that ‘recovery’ is indeed possible but may require thinking of recovery as a rehabilitative process and adaption to symptoms, rather than striving for a traditional definition of recovery; that is, absence of symptoms (Dawson et al., 2014; Anthony, 1993).

1.3 Previous research

1.3.1 Eating disorders and the development of SEAN

Poor treatment outcomes and the development of SEAN have often been attributed to internal factors, such as the individual being in denial of their illness, unmotivated to change and ‘non-compliant’ with treatment (Kaplan & Garfinkel, 1999; Vandereycken & Vansteenkiste, 2009). Such difficulties have come to be understood as the result of the ego-syntonic attachment that the individual has to AN, which they perceive as serving an adaptive function (Schmidt & Treasure, 2006). AN is often perceived as providing the individual with protection, control and a way of avoiding or communicating distress and becomes not only an achievement, but also their identity (Nordbo et al., 2006; Serpell et al., 1999). However, individuals with AN are also able to identify the cost of their behaviour, particularly due to the damage it causes in their

relationships and the feeling of being taken over by AN (Serpell et al., 1999). This may result in a paradox whereby the AN develops to provide a sense of control and yet, as it becomes more entrenched, the individual begins to feel a loss of control and as though they are controlled by the AN itself (Fox et al., 2011). This may result in ambivalence towards recovery, as the individual battles between seeing AN as both a friend and an enemy and struggles to imagine life without AN (Fox et al., 2011; Williams & Reid, 2010). This functionality of AN and ambivalence towards recovery is therefore understood to increase the difficulty of engaging in treatment and recovering from AN (Nordbo et al., 2006).

In addition to internal factors that can prevent recovery from AN, there has also been recognition of limitations in treatment. Traditional ED interventions and definitions of recovery have typically focused on the reduction of medical symptoms. It is suggested that this can lead to a perceived overemphasis on weight gain in treatment and lack of attention on other domains of the individual's life (LaMarre & Rice, 2016). It is therefore recommended that AN needs to be understood comprehensively, with attention given to biological, social and psychological aspects and also by focusing on improving the individual's quality of life (Espindola & Blay, 2009; Wonderlich, 2012). Better outcomes have also been associated to multidisciplinary team working that focuses on treatment readiness, therapeutic alliance and continuity of care (Long et al., 2012; Mander et al., 2013; Stiles-Shields et al., 2016).

1.3.2 Qualitative research exploring experiences of SEAN

Only four studies have been identified as exploring the experiences of individuals identified as having SEAN using a qualitative methodology.

Noordenbos et al. (1998) analysed letters written by former patients identified as having a 'chronic' ED. The findings suggested negative experiences of treatment, especially nasogastric tube feeding and inpatient admissions. Although many of the participants described feeling hopeless about future treatment, it was highlighted that being 'chronic' does not mean being 'incurable'.

Dawson et al. (2014) used narrative inquiry to explore recovery from chronic AN. The accounts of eight women were analysed and the findings provided a framework for understanding recovery as a complex process. The authors emphasised the possibility of

recovery from chronic AN and the importance of hope, motivation, self-efficacy, and support from others.

Robinson et al. (2015) used thematic analysis to explore the experiences of eight individuals identified as having SEAN. Analysis revealed that SEAN had an impact on all realms of life, although psychological and social realms were most affected and severe physical problems were reported. The findings highlighted difficulties with negligible social networks, depression and hopelessness, while also recognising participants' sense of pride at their endurance and survival. This study highlighted the value that participants placed on professional support.

Fox and Diab (2015) utilised IPA to explore the experiences of living with chronic AN in an ED unit. Six participants were interviewed and the analysis revealed five superordinate themes: 'making sense of AN', 'experience of treatment', 'interpersonal relationships', 'battling with anorexia' and 'staff pessimism in the treatment of chronic AN'. These results highlighted experiences of the self as being entwined with AN and how this made it difficult to perceive a life without AN.

1.4 Rationale, aims and objectives of the current study

Individuals who are classified as experiencing SEAN are viewed as one of the most complex and challenging groups presenting to healthcare services (JCPMH 2013; Strober, 1997). This is a client group whose difficulties have an impact on all areas of their lives and who highly value professional support (Arkell et al., 2008; Robinson et al., 2015). Despite an increasing interest in SEAN, there are gaps in the knowledge base and a very limited amount of qualitative research exploring the experiences of these individuals. Although qualitative research has highlighted that those diagnosed with SEAN have reported negative experiences of support, it is unclear how they make sense of these experiences and what support that they value as being helpful and meaningful. Furthermore, thus far, no research has focused on those living with SEED in the community and accessing outpatient services.

The current study was designed in consideration of these gaps, and the suggestion that 'experts by experience' should be included in the planning and improvement of services (Care Quality Commission, 2012). The primary objective of the current study was to make a unique contribution to the field of SEED research by using qualitative methods

to explore the experiences of living with severe and enduring ‘anorexia nervosa’ in the community and to understand how individuals with SEAN make sense of their psychosocial and support experiences and their future hopes and goals.

The current study aimed to answer the following questions:

- What are the psychosocial experiences of living with severe and enduring ‘anorexia nervosa’ (SEAN)?
- How do individuals identified as having SEAN make sense of their experiences of care, treatment and support?
- How do individuals identified as having SEAN make sense of their future hopes and needs?

Secondary research questions that were considered were as follows:

- What psychosocial factors influenced experiences of past treatment and support?
- What motivates individuals identified as having SEAN to continue accessing support?
- In which areas do individuals identified as having SEAN value professional support?
- What services and settings do they envisage being most helpful to them?
- What would ‘recovery’ mean to individuals identified as having SEAN?

2. METHOD

2.1 Research Design

The current study aimed to explore the experiences of individuals seeking outpatient support who are identified as having severe and enduring ‘anorexia nervosa’ and to understand how they make sense of their psychosocial and support experiences, as well as their future hopes and needs. A qualitative methodology was adopted to suit the aim of the study as it allows for a rich description of complex phenomenon, an exploration of the deeper meaning that individuals give to their experiences and gives voice to individuals whose experiences are often overlooked (Biggerstaff, 2012).

Interpretative Phenomenological Analysis (IPA) was selected as the best suited approach for the current study as it adopts a bottom up approach that focuses on exploring the lived experiences and personal meaning of individuals within a particular context (Smith & Osborn, 2008). IPA is both phenomenological and interpretative in its nature and therefore acknowledges the importance of the participants’ meaning making and the active role of the researcher in interpreting this (Willig, 2008). In this way a double hermeneutic occurs – the researcher makes sense of the participant making sense of a particular experience (Larkin et al., 2006). IPA has been effectively utilised by other researchers when exploring psychosocial and treatment experiences of individuals diagnosed with eating disorders (Fox et al., 2011; Fox & Diab, 2015; Williams & Reid, 2010).

2.2 Epistemological position

The current study was conducted from a critical realist position (Appendix K).

2.3 Ethical considerations

Prior to recruitment, the research proposal was peer-reviewed by University staff and by a service-user group. The Independent Research Application System (IRAS) was then utilised to seek and obtain Ethical approval from the NHS Research Ethics Committee (Appendix L) and to assure governance and legal compliance of the current study, as approved by the Health Research Authority (Appendix M). Research Sponsorship was also obtained via the University (Appendix N). A chronology of the research process is detailed in Appendix O.

Each participant was provided with information about confidentiality, the study procedures and the right to withdraw. Participants were informed that any disclosure of possible risk to others, from others or to themselves, would be shared with relevant professionals. This information was provided verbally and within the participant information leaflet (Appendix P) and time was allowed for any questions before written consent was sought (Appendix Q). At the end of each interview the researcher sought feedback and invited the respondent to contact them or follow NHS protocol if any concerns should arise.

The data collected from the demographic information sheet was stored securely at the University and was not linked to the corresponding interview transcript. The audio recordings were also stored securely at the University and subsequent transcripts were stored in an encrypted file. Any identifiable information within the transcripts was removed and pseudonyms were assigned.

2.4 Participants

2.4.1 *Sample size*

IPA is an idiographic approach that places value on rich detailed analysis of individual accounts and so a sample of four to ten participants is considered to be reasonable for professional doctorate research from this approach (Smith et al., 2009).

2.4.2 *Inclusion criteria*

Homogeneity of the sample is valued within IPA (Smith et al., 2009) and so a number of factors were identified as criteria for participant selection:

- 18 years or over at the time of recruitment;
- A current diagnosis of anorexia nervosa (as classified in the DSM-5);
- Accessing outpatient treatment from an ED service at the time of recruitment;
- Accessed support from an eating disorder service for at least 7 years or have had at least 5 admissions to inpatient care. Their individual case will have also been discussed at a senior clinician review, with the senior specialist ED clinicians agreeing that the individual's difficulties are best understood as 'severe and enduring anorexia nervosa'.

As previously recognised, there is yet to be a consensus on a definition of SEED (Ciao et al., 2016; Noordenbos et al., 2002; Tierney & Fox, 2009;). Therefore, this study did not adopt a standardised definition of SEED or SEAN. Instead it relied upon the criteria utilised by clinicians as part of their pathway for individuals diagnosed with ‘anorexia nervosa’.

2.4.3 Exclusion criteria

The following criterion were adopted to exclude potential individuals from the current study:

- Insufficient English to participate in the interview, as the study is qualitative in nature and a distortion of meaning could therefore occur through translation.

2.4.4 Participants

The current study successfully recruited six participants in accordance with the inclusion and exclusion criteria.

As can be seen, the criteria did not include or exclude participants based on gender. It has been suggested that approximately 10% of individuals who access eating disorder services are male (Touyz et al., 2016) and it is acknowledged that a number of these males will go on to experience a severe and enduring eating disorder. However, this appears to present differently to females, with more emphasis on body image, including an increased desire for muscularity, and excessive exercise as a core element (Touyz et al., 2016). The recruiting service and other local services were consulted about the prevalence of males classified as having severe and enduring anorexia nervosa and they could not identify anyone who met these criteria, stating that males with a severe and enduring presentation tended to fall within other eating disorder diagnostic classification groups. As such, no male participants were identified for the current study, which seemed to represent the clinical population and ensured homogeneity in relation to gender differences within the included participants.

Table 1 summarises some relevant demographic details of the participants, with pseudonyms used to ensure anonymity. As can be seen, there were differences in the ages and the ethnic backgrounds of the included participants. However, despite these demographic differences, their narratives of the psychosocial and treatment experiences of having SEAN were similar, as can be seen through the prevalence of themes

(Appendix V) across all participants. This is likely to be due to the shared, homogenous experiences of a long duration of illness, multiple inpatient admissions, ongoing outpatient support, severe consequences of their eating difficulties and a sustained low body weight. It therefore seems that the current study sample was homogenous in terms of their experiences of SEAN and their experience of treatment and support for SEAN and, perhaps, the evaluation of homogeneity thereby goes beyond demographic information.

Table 1 - Participant information

Pseudonym	Age	Ethnic background
Dorothy	70	White British
Betsy	48	White British
Edith	68	White British
Meredith	67	White British
Sienna	30	Arab British
Vera	64	White British

2.5 Procedure

2.5.1 Recruitment

A purposive sampling technique was utilised due to the specific characteristics of the population needed. Clinicians from the recruiting service facilitated the identification of participants and provided them with an invitation letter (Appendix R) and participation information leaflet (Appendix P) which detailed the study aims and processes.

Participants could then either provide their contact details on the invitation letter and return this to the service to pass on to the researcher, or contact the researcher directly. Contact was then made and the study information was discussed and, if participants agreed to take part, an interview was arranged.

2.5.2 Interviews

Semi-structured interviews were utilised, as this facilitated a ‘conversation with purpose’ and helped the researcher to remain responsive to the narratives shared (Smith et al., 2009, p. 57). The flexible interview topic guide (Appendix S) was developed in line with the study aims and discussions with the research supervisors and was used for all six interviews. Five of the interviews were conducted in a private office of the outpatient ED service and one took place over the telephone at the participant’s request. When the researcher and participant met, time was offered for any questions. If the participant was keen to proceed, a consent form was signed (Appendix Q) and the principles of confidentiality and the right to withdraw were reiterated. In the case of the telephone interview, verbal consent was obtained. These procedures also provided an opportunity to build rapport with participants. Each participant then completed a short demographic questionnaire and then the semi-structured interview began. The interviews lasted between 57 and 84 minutes and were audio-recorded. At the end of the interviews participants were given the opportunity to discuss any concerns and were reminded that, should any concerns arise, they could contact the researcher, their allocated clinician or utilise standard NHS complaints procedures. After each interview, the researcher spent time recording reflective process notes. Each of the interviews was transcribed and coded by the researcher.

2.6 Analysis

Data analysis was conducted using the stages outlined by Smith et al. (2009). A detailed description of these stages is offered in Appendix T. The analytic process is also

illustrated by Appendix U, which includes a section of one participant's anonymised coded transcript and the case level summary for this participant.

2.7 Quality issues

2.7.1 *Quality*

Yardley's (2000) four essential criteria was used as a guide to ensure quality and validity of the research (Shenton, 2004). These criteria included sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

These criteria were considered from the outset by setting the study up in an ethical manner, engaging in the peer-review process and extensively exploring previous literature in this field. The study also utilised a well-established research method and the researcher attended two IPA workshops facilitated by a reputable researcher. These workshops offered the opportunity for peer scrutiny and ensured rigour within the collection and analysis of data.

During data analysis, each transcript was analysed in isolation before moving on to explore the similarities and differences across the data. All emerging themes were checked alongside the original data to ensure that the participant experiences were portrayed accurately. This supported the researcher in ensuring that deeper levels of interpretation had been developed without losing sight of the lived experiences of the participant-in-context. Regular supervision was used to consider the impact and importance of the current study. An audit trail was kept throughout to ensure transparency and a chronology of the research process can be found in Appendix O.

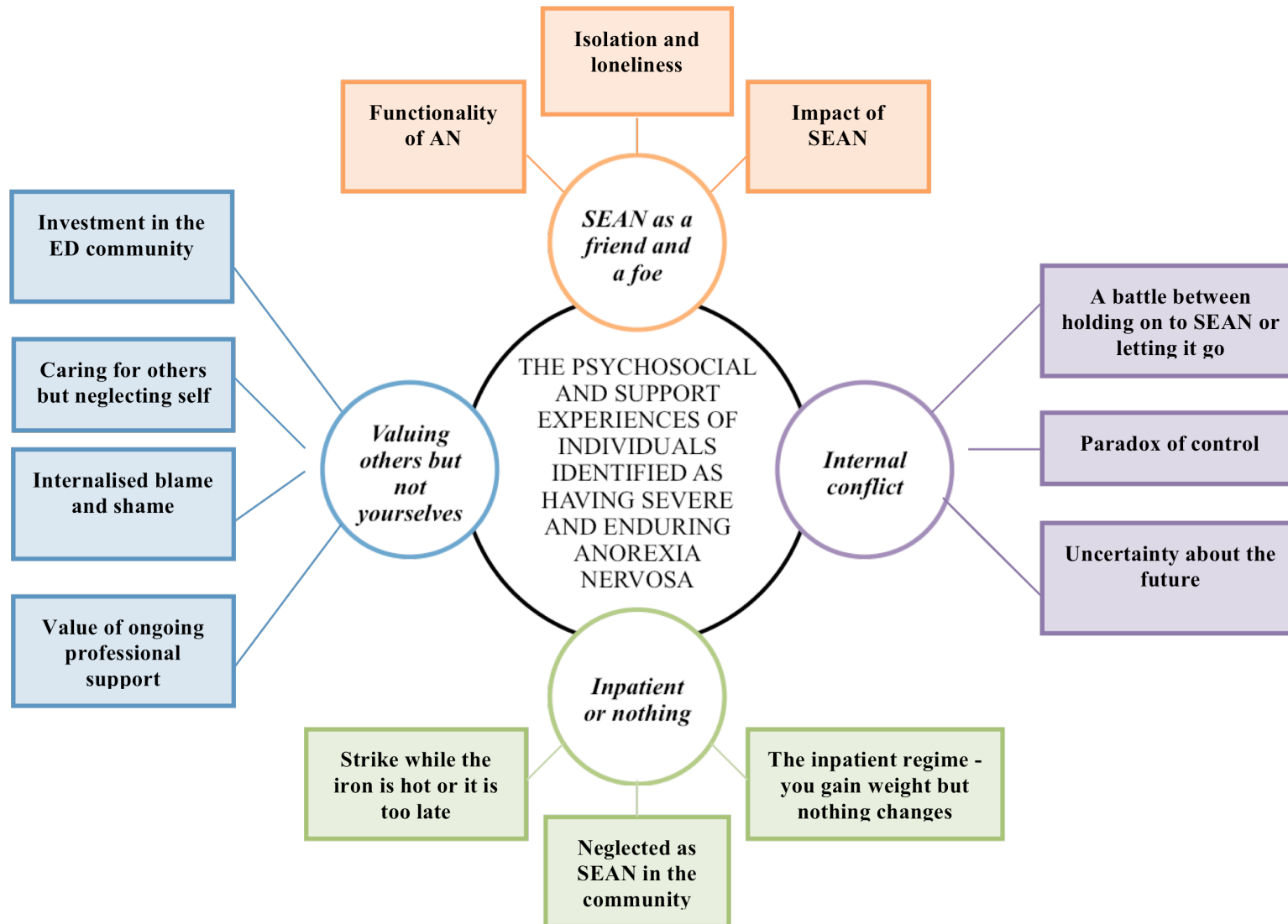
2.7.2 *Reflexivity*

IPA highlights how the research relationship is bidirectional and encourages the researcher to remain reflexive and be aware of this dynamic (Smith & Osborn, 2008). The researcher reflected on their own personal experiences, feelings, and values that may have influenced the engagement with the data. As a Trainee Clinical Psychologist, the researcher acknowledged their experience of working with individuals with ED and their theoretical knowledge of this field, having completed an extensive literature review. The impact of this experience was considered throughout, particularly through the use of supervision and a reflective diary, which helped the researcher to detach their reflections from the analysis.

3. RESULTS

A detailed case-by-case analysis of the six interview transcripts revealed four super-ordinate themes. The super-ordinate themes originated from 13 sub-themes, as shown in Figure 1. The frequency of themes across participants is detailed to enhance transparency and evidence validity Appendix V. The first super-ordinate theme '*SEAN as a friend and a foe*' considered how participants experienced AN as serving an important function but also coming at a high cost. The second super-ordinate theme '*Internal conflict*' explored the conflict and contradictions that participants expressed in making sense of their experiences and the future. The third super-ordinate theme '*Inpatient or nothing*' considered the dominance of the inpatient experience, as well as the difficulties in seeking further help as someone living in the community with SEAN. The fourth, and final super-ordinate theme '*Valuing others but not themselves*' explored the value that is placed on relationships with others, including professionals, family and members of the ED community, while experiencing unhelpful feelings towards themselves.

Figure 1: Super-ordinate themes and sub-themes



3.1 SEAN as a friend and a foe

This super-ordinate theme aimed to capture the sense of AN as serving an important function for each individual, while also having a negative impact upon their lives, in which the experience of isolation was dominant.

3.1.1 *Functionality of AN*

All participants spoke about ‘anorexia’ as having developed and been maintained over a long period of time due to the valuable function it served in their lives. There was a sense of it providing the individual with a belief of being in control when their world felt out of control and a way of coping with difficult experiences, relationships and emotions.

My step-dad is very strict – like he didn’t allow me to go out when I was young...so when I first started when I was 12 it gave me something to do (...) ¹ it made me feel good about myself (...) and you know he was violent as well, towards my mum and towards me... ² urm...yeah the eating disorder kept me going, it was my way of coping at that time, 100% (Sienna).

It protects me against things I can’t do anything about. Urm. My oldest son, the first bout of mania he had, we didn’t know what we were dealing with (...) having something that you can control, like your eating, is, it’s a protection. It’s a protection...it’s the way I cope with things (Dorothy).

Dorothy’s repetition of anorexia as a protection was suggestive of a fear of living without it, due to the sense of safety it offered her. This belief, of anorexia as providing protection and safety, was echoed by Sienna:

¹ Illustrates words have been removed if they are not adding meaning

² Illustrates a pause

Whether it's like to starve yourself, or to binge and purge or just purge anyway, just to have the security and stability of being a low weight (Sienna).

Similarly, Betsy reported that AN “makes me able to cope with my life”. This represented the value placed on the functionality of AN by the participants and was suggestive of a belief of being unable to cope without it. In this way, anorexia was not only functional but also a rational “response to having to cope with the world” (Edith).

3.1.2 The impact and cost of SEAN

Although each of the participants portrayed AN as functional, they all also recognised the negative impact and the cost of coping in this way over a long period of time. Edith recognised the significant physical impact of having SEAN:

Physically it has taken its toll (...) I've got the probability of me developing osteoporosis (...) the bronchiectasis might have been exacerbated by the fact that I was anorexic (...) So physically yeah it's taken its toll. Lack of periods, I mean, I haven't menstruated for...about 20 years (Edith).

These physical complications of SEAN appeared to be accepted as part of the package. Vera conveyed not only an acceptance of physical complications, but also an expectation of them:

If I hadn't had the stroke, I'd have been dead. I knew something was going to happen to me but I honestly believed I was going to have heart failure, I honestly believed my heart was just going to pack up or that my organs were going to pack up (Vera).

In addition to the physical impact of anorexia, the participants also conveyed the psychological and cognitive impact of anorexia. All of participants reported co-morbid mood and anxiety difficulties. Meredith noted that, when you restrict your dietary intake over a long period, “you're not thinking clear or right, you have lots of doubts, you question yourself all the time”.

While participants appeared to be accepting of the physical and psychological impact of SEAN, they conveyed frustration and regret when they considered the occupational and relational cost of SEAN. Some participants expressed regret over a wasted life and the loss of their imagined, or hoped for, life:

Hindsight is a wonderful thing (...) I think I'd change just about everything (...) I think when you get to the stage I'm at with an eating disorder, you do realise that it's a waste of your life. I had a career as a teacher and that went down the pan (...) anorexia has had a very big impact. In many respects I'll be glad when it's all over (Vera).

If I hadn't developed anorexia my life might have been totally different. I might have been married with children...you just don't know (Edith).

Dorothy summarised that living with SEAN “makes life hard...it's a miserable problem to have”.

3.1.3 Isolation and loneliness

When participants talked about the impact of SEAN, they appeared to be most affected by the social impact and their narratives were dominated by experiences of isolation and loneliness. Most of the individuals recognised that they withdrew themselves from relationships and interactions to protect themselves from situations in which their eating behaviours may be compromised:

When I was about 16 or 17 I used to go to the cinema. When I became anorexic I stopped going to the cinema because I might have an ice cream. You stop doing things 'cause you may do something (Vera).

Betsy spoke about relationships and social interactions as possibly putting her in “jeopardy”. Meredith spoke about going into “panic mode” when facing social situations. These accounts were suggestive of feelings of fear and risk when entering social situations. This appeared to be rooted in a concern shared by many participants, that the majority of social occasions are defined by food and drink.

The problem about eating disorders is, it is in it's nature a very solitary kind of disorder...people don't want to eat together, and you know eating is quite a social activity and when you don't want to eat, its like what is there to join them with (Sienna).

Sienna acknowledged that it was not just the individual's avoidance of food that prevented social engagement, but also other people's worries about their physical ability to take part:

My brother goes camping every year but he couldn't ever take me. And when they do day trips, like to the safari park, they say no, the day is too long for me. Urm....so you cant go anywhere (Sienna).

This feeling of not being able to go anywhere, led to participants feeling “cut off” (**Dorothy**) and “isolated and alone...kind of stranded” (**Meredith**). A couple of participants also noted how they had fewer friendships over time, due to the difficulties of social engagement:

I had a friend I was in school with, but that sort of dwindled out 'cause she always wanted to go to café's and it gets a bit complicated when you're searching through the menu for something (Vera).

These social situations appeared to highlight the individual's difficulties with food and often left them feeling different to other people, which heightened their feelings of isolation.

3.2 Internal conflict

This super-ordinate theme aimed to illustrate the conflicts and contradictions expressed by participants when considering their attachment to AN and their future hopes.

3.2.1 *A battle between holding on to SEAN or letting it go*

As illustrated above, the participants acknowledged both the function and the cost of SEAN. However, they did not appear able to simultaneously hold these contradictory beliefs and instead appeared to experience cognitive dissonance, which was often portrayed as an internal battle between holding on to anorexia for its functionality and letting it go due to its impact:

That's where the double edge sword is, it helps me, it keeps me alive but it kills me at the same time. And I can't work that out because I know what's happening, I know it's killing me (Betsy).

This extract was also representative of the frustration that participants appeared to experience in trying to 'work out' this conflict and not being able to let go of anorexia despite its consequences. Vera appeared to resolve this internal conflict by splitting and assigning different parts of her self to her differing beliefs:

Part of you realises that you just can't go on as you are, part of you wants to improve and part of you doesn't (...) the part that wants to improve is so you can have a more normal life (...) but, although you realise in order to be able to achieve these things you need to be a more normal weight if you like, you can't really cope with it (Vera).

Similarly, other participants appeared to manage this cognitive dissonance by externalizing anorexia as a separate entity within them:

I have arguments in my head...my anorexic, my toxic friend as I call her, talking to me and the other part's my rational self (Edith).

Although the participants all seemed to express a desire of letting go of anorexia, they also seemed to experience a fear of what this would involve:

I am an anorexic and if you take that away then I am not anything, you know, I am just an old lady (...) it's who I am. If you take that away, I am no longer me (Dorothy).

These extracts are suggestive of 'anorexia' being experienced as an entire identity and as such, there appears to be a fear of who they would be without it. Betsy also recognised that, despite its consequences, she would experience a great loss if she were to let go of anorexia:

It swamps me, it controls me but I would be bereft without it and unable to cope (Betsy).

Betsy concluded: "psychologically it helps but physically it makes things worse". This appeared suggestive and representative of a position shared by the other participants at this stage of the 'battle', whereby the functionality of AN still outweighed the costs.

3.2.2 Paradox of control

The paradoxical nature of control associated to SEAN was represented by all of the participants. As noted previously, anorexia often developed when the individual felt out of control, as controlling their diet and weight provided them with a sense of control in other areas of their life:

It helps you to control your life (...) it helped me control my relationships, how I viewed things, aspects of my life (Meredith).

However, as Sienna articulates, at some point this changed and there was instead a sense of losing control and beginning to feel controlled by the anorexia:

Somewhere, at some magic point, which you're not quite sure of, the weight of power between you making the choice and it making the choice for you, it somehow flips. It's flipped before you know it (Sienna).

Sienna's extract implies that this happened gradually and she did not recall any agency in this process. Dorothy and Betsy both described themselves as having come to live under anorexia's 'dictatorship', which was again suggestive of a lack of agency and control in their lives and represented the power of anorexia:

I live my life according to what anorexia dictates, rather than I dictate (...) it's a controlling force, there's no doubt about it, it controls what I do (Dorothy).

There is not one aspect of my life of my life that isn't...dictated by the anorexia. It rules everything (Betsy).

This implies a paradoxical effect in that the attempt to gain control resulted in a perceived loss of control. Sienna recognised that the difficulty of this loss of control, was that she then did not believe she had the control to “get rid of it”. Therefore, any support appears to have been perceived as a threat:

[Treatment] will basically fuel the fire of the eating disorder and it will go bezerk and it will be ruthless (Sienna).

Vera similarly recognised this and appeared to value feeling in control when accessing support:

I don't think sectioning works. And I'm sure things like force-feeding don't. I think part of the trouble that anyone with anorexia has, is that almost instinctively, when people try to force you to do something, you fight against it and you think, well you're not going to win (Vera).

3.2.3 Uncertainty about the future

Most of the participants expressed a level of uncertainty about their future. There appeared to be a dominant narrative of being resigned to SEAN. Sienna described feeling “doomed to it, it's like a life sentence”, which suggested this would not be her preferred outcome but it was not something she could control. Similarly, Dorothy appeared to share a sense of hopelessness about the future and about the efficacy of treatment:

I don't believe that my anorexia will ever go away. I can't see that happening (...) I...don't think there's a treatment out there that will work, I don't. I think I'm stuck with it. So I have no hope that I will get better (Dorothy).

Vera attributed her hopelessness about the future to her age and the duration of her difficulties, which appeared representative of other participants' narratives. Despite this overarching sense of having resigned themselves to living with anorexia, the participants often talked about the possibility of improving their quality of life, particularly by increasing their social engagement, expanding their identity and feeling more in control:

The anorexia would still be there but I wouldn't be so driven to do the same thing and the same time every day (...) I could go to social occasions and join in (Dorothy).

It's probably going to be there for the rest of my life but it's not going to be huge...I don't want to be defined by it...if people think of me I don't want them to think of 'Edith the anorexic' (Edith).

Betsy reported that “sometimes” she had resigned herself to anorexia, which was suggestive of changeability in her vision of the future. Similarly, other participants who had, at times, insisted they had resigned themselves to anorexia went on to talk about the possibility of there being variability in its presence. Edith described herself as a “remitting anorexic” and implied a belief that anorexia will continue to be her primary way of coping with difficult experiences.

I've often said it's a bit like going into remission. You know, I could have a couple of years when everything seemed to be absolutely fine and then for some reason there would be a trigger (Edith).

Despite most of the participants conveying a belief that in ‘reality’ they were resigned to anorexia, they frequently referred to a ‘fantasy’ about recovery. Dorothy spoke about needing a “magic wand” to recover. Sienna spoke about recovery needing a series of “minor miracles”. Betsy concluded that, although she fantasised about recovery, she did not believe this could become a reality:

*I fantasise about it (...) [but] there's no way in a million years
(...) no chance (Betsy).*

3.3 Inpatient or nothing

This super-ordinate theme aimed to capture participants' focus on inpatient experiences and how they felt relatively neglected by community services. It also aimed to explore their unhelpful experiences of having to wait too long for support when they needed it.

3.3.1 The inpatient regime – you gain weight but nothing changes

Over half of the participants described inpatient care as a 'regime' and their narratives were suggestive of a lack of control and agency in this setting.

They said you're coming into hospital but this is the proviso. You surrender your rights. We feed you up and you eat what we tell you to and you follow our regime (Betsy).

In this way inpatient admissions appeared to be experienced as mimicking the 'dictatorship' of anorexia from which they were attempting to escape. Vera spoke of inpatient treatment as having "actually reinforced the anorexia". Others spoke of difficulties arising in the transition from inpatient to the community upon discharge:

You've got this sort of artificial ward regime, where, you know, you're told what to eat, when to eat it etc – then you go out to, basically what you were doing before and you just slip back into your old ways (Dorothy).

[Inpatient was] horrendous. It was very, urm, regimental and your regime, it was (...) institutionalised (...) You got into that routine, where when you came home you couldn't deviate and there was no support when you got home (Meredith).

Dorothy's experiences of 'slipping back into her old ways' were suggestive of a difficulty in maintaining any positive changes that had been made during the inpatient admission. Meredith's extract also conveyed a difficulty in re-adjusting to life in the community after having become "institutionalised".

Another concern raised across a number of transcripts was that inpatient care was narrowly focused on weight gain alone and therefore, although weight was gained, this was not for the right reasons and was not maintained after discharge:

The weight I'd put on, I'd been forced to put on...they made me do it. I hadn't decided to do it...within the year I lost that weight (Dorothy).

You did get to what your target weight was because it was the only way you were going to escape but nothing else changed (Vera).

Similarly to Vera, Meredith expressed that, although she had gained weight as an inpatient, these changes could not be maintained once she left, as nothing else had changed:

[After being discharged] you've got the same problems that are still there and aren't resolved and so they impact on you again and then you're in that vicious cycle again. The situation that got you into that mess is still there (Meredith).

3.3.2 Neglected as SEAN in the community

As noted above, Meredith had highlighted the lack of support upon returning back into the community after an inpatient admission. Each of the participants was under the care of a consultant psychiatrist or a therapist. However, this sense of being neglected as someone living in the community with SEAN was suggested by most participants:

Inpatients get lots of attention and the outpatients much less and when you have got it like I have, there isn't very much out there at all (Dorothy).

Sienna spoke of how lonely and isolated she felt due to the lack of support in the community compared to inpatient support:

Living in the community with an eating disorder is the most loneliest thing (...) that is actually the one thing I like about coming into hospital...you don't feel lonely...in the community it is so lonely – it is soooo lonely (Sienna).

Dorothy spoke about being “dependent” on her husband “because there’s nobody else”. This was something that Edith echoed, as she relied on her sister to provide support. However, Edith reported that her sister was unaware of the physical risk Edith was at, as she did not want to worry her.

Betsy spoke about being in “an unusual bracket” because “it’s such an unknown thing for an older person to have anorexia and it be a long term thing” and she believed “professionals are not sure what to do” to help individuals with SEAN. Meredith echoed this concern:

I think sometimes because I’m so chronic, I mean it’s such a long while, they don’t try and address that as much. They focus on the young ones (Meredith).

These extracts were suggestive of a belief that professionals were unsure of how to help individuals with SEAN and that they perceived professionals as having given up hope of recovery, which seemed to enhance the participant’s own feelings of hopelessness.

3.3.3 Strike while the iron is hot or it is too late

When considering the factors that may have contributed to the experience of SEAN, and the prevention of recovery, one of the reasons identified by the participants was a delay in accessing support. Dorothy spoke about a delay in her difficulties being recognised and supported:

By the time I did get help, it was too ingrained (...) if I had to say one thing that would have made a difference to me, [it] would have been getting treatment earlier...I had it for decades before I got any treatment (Dorothy).

Dorothy’s expression of anorexia becoming “ingrained” over time was suggestive of a belief that, the longer the delay in support, the harder it is to recover. Her extract also appeared to suggest having reached a saturation point at which her difficulties were “too ingrained” for support to make a difference. Dorothy and Edith both acknowledged long waiting times between a referral and being offered support. Dorothy highlighted the problematic nature of this delay, as her difficulties continued to worsen while she waited for support:

There was an awfully long wait and I was ill. By the time I got there I was worse (Dorothy).

Sienna also recognised the problematic nature of long waiting times and conveyed this as being particularly problematic for individuals diagnosed with anorexia due to the internal battle for control and the threat that treatment posed to this:

Waiting lists should be shorter (...) you need to strike while the iron's hot (...) don't waste any time (...) otherwise it's too late, the eating disorder creeps in again and the insecurity and fears creep in again and then they convince you no, no, no. Each night you go on thinking you wanna get better, the eating disorder fights back and provides you with reasons you can't (Sienna).

3.4 Valuing others but not themselves

The final theme aimed to explore the value that participants placed on professionals, family members and other individuals with eating disorders when making sense of their difficulties and needs. It also attempted to capture that, while they valued others, they did not experience themselves as deserving and expressed internalised feelings of blame, shame and stigma.

3.4.1 Investment in ED community and peer support

In making sense of their future hopes, most of the participants spoke about the importance of being involved with other people diagnosed with ED. Sienna described a desire to support other people within the ED community:

If I could make a difference in anyway for people who suffer with eating disorders, for people who work in eating disorders, for carers (...) I would be very keen to. If I never got better and just did a bit of that, I suppose that would be something (Sienna).

Sienna had previously expressed regret that she had failed to achieve her academic goals and hopes of pursuing a career helping others, due to the impact of her eating difficulties. The final sentence of this extract suggests that being able to support others would be a way of still achieving her goal, even if she were resigned to life with SEAN.

Edith also expressed an investment in the ED community and spoke about informally supporting a number of other people diagnosed with anorexia. The following extract conveys a sense of becoming an expert by experience over the course of SEAN:

I'm now very conscious of other anorexics around me...they really matter to me (...) my own journey has given me the skills, because of the way I've been treated, to give support to other people with eating disorders (Edith).

However, it was evident that the participants were not only keen to support others in the ED community, but also hoped to seek support from others in the form of peer support:

If other people did exist at my age who had this problem, that would be kind of handy to know what they were feeling (Betsy).

You're all with the same sort of people and you can help and guide each other. You can gain great strength, great strength and erm, understanding and compassion from them (Meredith).

These accounts highlighted the value of peer support due to the “great strength” gained by being understood by others similar to themselves. Sienna also conveyed a belief that peer support groups could act as a springboard for increasing her social engagement:

If there was a group, I would go to them and if I made friends and we arranged something extra outside the group I'd be willing to join in (...) hopefully give us a bit of motivation to get better, maybe it would feel less lonely (Sienna).

3.4.2 Caring for others but neglecting self

Four of the participants had a role as a carer and expressed the importance of caring for others. However, it appeared that this was often at the cost of, or in place of, caring for themselves:

I know how to keep everybody else well and if they have problems I know they can come to me and tell me...just can't do it for myself (Betsy).

You know, when you're caring for four people at a time and there's only you then, you know, there are things like your own meals that go by the board. It's more important that they get their care – not realising that actually the fact that your health is deteriorating means you're not going to be much use to them (Edith).

Edith's extract appears to convey a sense of irony in that she seemed to prioritise other people's care at the cost of her own, which inadvertently reduced her ability to continue caring for them, due to the impact of anorexia.

Dorothy and Vera were both mothers and recalled how they had been able to gain weight and let go of their body image concerns during pregnancy, due to the importance of caring for their children:

'Cause I wasn't eating for me. I was eating because I had an important job to do (Dorothy).

I knew that I couldn't starve. If I was pregnant I had to eat because I couldn't effect, I didn't want to effect the baby (Vera).

These accounts were suggestive of being able to overpower the anorexia, but only if it was integral to caring for someone else. Dorothy echoed this sentiment when she asserted that she would only be able to consider eating again if her husband was "very ill" and needed care.

Throughout all of these extracts, there was a sense of others being important and deserving, whilst the participant was not. The importance of others was also conveyed as the primary motivation for continuing to access support for these participants:

My family [motivates me] really (...) because both my boys have problems, I've always had to fight to get them the best education, the best schools, get them the help they've needed and that still goes on (Vera).

If I lived on my own on a desert island then I could just give up which I could do tomorrow but the fact that I can't...like I know today I've got to go and cook my parents' dinner and I've got to

make sure my brother eats (...) had I not got any of that, I wouldn't bother (Betsy).

Betsy's extract is suggestive of feelings of hopelessness and despair, which seem to manifest in a desire to "give up". It would seem that caring for others provides a protective factor for her safety and wellbeing in this way.

3.4.3 Internalised blame and shame

As has been seen, the participants identified a number of external factors to attribute the chronicity of their difficulties to. However, there was also a sense of the women having internalised unhelpful feelings of blame and responsibility for not achieving recovery. Sienna appeared to hold herself accountable for past treatment 'failures':

I would say it was more the responsibility for myself. I think it's just me. I just didn't...urm, I wasn't on the ball enough (Sienna).

Meredith also expressed a level of internalised blame for having SEAN in the first place and her extract suggested that professionals are limited in what they can do alone:

That's my own fault to a degree – I'm the only one who got me into this situation. I just blame myself. They can only do what they can (Meredith).

These extracts suggested that the participants had a belief that, if they had engaged with support more, the outcome may have been different and they may have avoided SEAN. Dorothy concluded, "the only person who can change it is me".

In addition to these internalised feelings of blame and responsibility, Betsy's narrative was indicative of internalised feelings of shame, particularly in relations to being an older woman with SEAN:

I'm very ashamed of it because anorexia...I mean, that's what 16 year old girls get who want to look like supermodels. Not 48-year-old women who know better (Betsy).

Betsy's experience of shame appeared to be routed in her perception of a stereotyped view of anorexia as being experienced by younger girls based purely on aesthetic gain.

Such an internalisation of stigma was also conveyed by Sienna, in relation to being described as ‘living in the community’ with SEAN:

I actually hate that phrase – ‘in the community’ – it sounds like you’re some sort of animal, some kind of lunatic living in the community (Sienna).

3.4.4 Valuing ongoing professional support

When considering their hopes for the future, all of the participants expressed a desire for, and value of, ongoing professional support. For Dorothy this was framed as being crucial, as she tried to keep her family “away from the anorexia” and was otherwise incredibly isolated. In contrast to this, Sienna’s family had experienced high levels of carer burnout and so this support was no longer available for her:

My mum was literally hanging on, it was like, you have to get better or you cant come home (...) I went to my dad’s hoping he’d have me (...) I lasted about a week there and he couldn’t cope with me either (Sienna).

Participants also appeared to value the specialist knowledge and understanding that professionals were able to offer. Specialist ED knowledge was conveyed as important by the majority of participants and general psychiatric support was perceived as inferior. Betsy appeared to value her relationship with her therapist as this seemed to provide her with a helpful other to internalise:

If I don’t want to eat I try to think of her encouraging words or you know, the way she’s perhaps thrown me a look, and think oh yeah I’ve got to do it (Betsy).

Edith spoke about professional support being important in providing her with a sense of a “safety net”:

If I can just be monitored every so often, you know, just having an eye kept on me and then if there’s a crisis, then I could just slip back into the system without needing to be referred – its like a safety net (Edith).

This extract implied a fear of how she may deteriorate if she were not monitored and a fear of having to wait a long time again if she were to be discharged and re-referred.

Vera seemed to share this worry about being left with no support:

It's certainly true that left to own devices, I'd just carry on going down until something goes wrong (Vera).

4. DISCUSSION

4.1 Summary of findings

The current study aimed to explore the psychosocial and support experiences of individuals who were outpatients identified as having SEAN. Four super-ordinate themes were identified; ‘SEAN as a friend and a foe’, ‘internal conflict’, ‘inpatient or nothing’, ‘valuing others but not themselves’. The use of IPA allowed for a rich exploration of how participants made sense of past experiences and future hopes.

4.2 Links to existing theory and literature

The emergent themes embodied concepts that relate to psychological and social processes. In order to examine these themes, they are placed in a wider context of psychological theory and previous research (Smith et al., 2009).

4.2.1 *SEAN as a friend and a foe*

This super-ordinate theme captured the experience of anorexia as being both functional and costly, especially within the individual’s social realm. Participants alluded to anorexia as a rational response to the context within which they lived, predominantly as a way of responding to threat and attempting to regain power. In this way it resonated with the recent developments to understand emotional distress as an intelligible response to social and relational adversities and their cultural and ideological meanings (Johnstone & Boyle, 2018). The portrayal of anorexia as serving an important adaptive function resonated with previous research, which also highlighted the protection, control and sense of coping it can provide (Nordbo et al., 2006; Strober, 2004).

Alongside the functionality of their difficulties, participants also spoke about the impact of SEAN across a range of realms, which supported previous findings when exploring the impact of SEAN (Robinson et al., 2015). Robinson et al. (2015) suggested that psychological and social realms were most affected. Although all of the participants in the current study reported a psychological impact, their narratives of social isolation were consistently dominant. This requires clinical attention, as social relationships are an important factor in effective treatment of ED (Pettersen & Rosenvinge, 2002). A number of the participants also conveyed a sense of regret that their commitment to SEAN had inadvertently resulted in them missing out on their imagined life. For some

participants this appeared to leave them with a sense of having wasted their lives. As far as the author was aware, this did not appear to have been highlighted in other literature in the field. Overall, SEAN was framed as being both a hindrance and a help and could be understood as both a friend and a foe, as it has been previously (Serpell & Treasure, 2002).

4.2.2 *Internal conflict*

The narratives of the participants indicated an experience of internal conflict in a number of areas. Firstly, most of the participants conveyed a sense of conflict in making sense of their attachment to SEAN. As noted above, they viewed their difficulties as both helpful and problematic. However, they were unable to hold, and accept, these two opposing beliefs simultaneously with ease. Instead they appeared to experience a level of cognitive dissonance, whereby these incongruent beliefs lead to psychological tension (Festinger, 1957). Previous research has acknowledged how an ego-syntonic attachment to ED behaviours is likely to create ambivalence towards treatment (Fox et al., 2011; Schmidt & Treasure, 2006). However, the current study suggests that this ambivalence, or avoidance of treatment, could also be influenced by an experience of cognitive dissonance. Support and treatment approaches for anorexia typically attempt to explore and resolve this conflict (Treasure & Schmidt, 2001). However, Festinger (1957) suggested that people often avoid information and situations that are likely to magnify their experience of cognitive dissonance due to the psychological stress this causes.

A second area of internal conflict was suggested in all of the participants' accounts of a 'paradox of control'. This echoed previous research of the ED having developed to provide a sense of control and yet, as it become more ingrained over time, it led to feelings of losing control and instead feeling controlled by anorexia itself (Fox et al., 2011; Reid et al., 2008). Tan et al. (2003) highlighted this as problematic both when the patient is attempting to make autonomous decisions about care and also when professionals are attempting to take charge through compulsory treatment. This difficulty appeared to be reflected by the participants' accounts of treatment as a threat to the control of anorexia, particularly inpatient care, which was frequently described as "regimental".

When discussing their hopes for the future, it became apparent that participants spoke of recovery as a fantasy, whereas they believed the reality was that were resigned to a life of SEAN. It has been suggested that individuals experience feelings of hopelessness in relation to recovery because they are uninformed about the possibility of recovery (Espindola & Blay, 2013). It seems to be important to remember that, although full recovery may become less likely with the passage of years (Robinson, 2014), it always remains a possibility, regardless of how long a patient has experienced SEAN (Dawson et al., 2014).

4.2.3 Inpatient or nothing

The current study was designed to fill a gap in the literature by focusing on the experiences of outpatients with SEAN. However, the participant narratives were dominated by experiences of inpatient care. Previous research suggests that patients with SEAN find the inpatient experience to be complex and contradictory (Fox & Diab, 2015). Within the current study, inpatient settings were generally framed as being regimental and involving a lack of choice and agency. This appears problematic in light of the desire for control that is typically experienced by individuals with anorexia (Reid et al., 2008). The participants generally concluded that inpatient admissions were effective in achieving weight gain but failed to facilitate lasting change due the wider systemic maintenance factors. Previous research emphasises the importance of looking ‘beyond biometrics’ (LaMarre & Rice, 2016, p.142) and it has been suggested that management of SEAN should transcend all realms of an individual’s life (Robinson et al., 2015). Participants in the current study also highlighted difficulties with poor discharge plans and lack of support in transitioning into the community. This problem has been acknowledged across the literature and is understood to be the result of increasing economic restraints, which have resulted in a reduction of sufficient transition services and an increase in managed care policies that limit the length of admissions (Vandereycken, 2003).

When participants were encouraged to consider their experiences of outpatient support for SEAN, there was a sense of being neglected. They appeared to attribute this to a belief that professionals had given up on them. It has been acknowledged that professionals working with SEAN can feel hopeless, due to the perceived failure of past treatments and the lack of evidence in how to support them (Ciao, 2016; JCPMH,

2013). However, this can again be understood within the context of economic restraint and a reduction in services, rather than simply a representation of hopelessness and abandonment.

Overall, participants expressed a desire for intensive community support. Although short-term inpatient treatment can be useful for the physical consequences of anorexia, there is no evidence that inpatient treatment is more, or less, effective than intensive community support in the long-term (Herpertz-Dahlmann et al., 2014; Meads et al., 2001). It would appear to be useful to replicate these studies and evaluate these different approaches for individuals with SEAN. If intensive community support is evidenced as comparable or better than inpatient care, this could result in economic gains, due to the reduced cost of intensive community care compared with inpatient admissions.

4.2.4 Valuing others but not themselves

It has been suggested that individuals with SEAN are often highly reliant on family members and carers (Treasure et al., 2001) and much attention has been given to the high levels of burnout experienced by those caring for someone with anorexia (Hillege et al., 2006; Whitney et al., 2007). The findings of the current study suggest that the participants were not reliant on carers by choice, but as a result of insufficient community support. They acknowledged that this could negatively impact their carers and expressed a desire to protect their loved ones from this role. Instead, they expressed a desire for ongoing professional support. Robinson et al. (2015) similarly found that, even when past experiences of support were negative, individuals with SEAN valued professional support. Research, including the current study, has also indicated that this professional support is most helpful when provided by a specialist ED service, rather than a generic psychiatric team. However, these services are not evenly spread across the UK and there is a 'postcode lottery' as to who accesses specialist services (Escobar-Koch et al., 2010).

The participants in the current study expressed an investment in other members of the ED community. This is something that has not been reported in previous research as far as the author was aware. A number of participants expressed a sense of caring for others who experienced ED and hoped to be able to offer support to them directly and

through their participation in research. This contrasted previous findings that emphasised the competitiveness between individuals with anorexia, particularly when they are younger (Lavis, 2011; Offord et al., 2006). Lavis (2011) suggested that this competition can be a way of using other people's experiences as a motivation to continue restricting their food and striving for thinness to be a 'better anorexic'. It seems that this motivation may lessen as patients get older and their eating difficulties become severe and enduring and they no longer have to 'prove' themselves due to the sense of 'achievement' in SEAN (Robinson et al., 2015). The current study highlights that individuals with SEAN seem to not experience the same sense of competition as other individuals diagnosed with anorexia and instead have a desire to support others with an ED.

Not only did the participants express a desire to support others but, after experiences of SEAN and long history of support, there also appeared to be a belief of having developed a sense of expertise and skills to offer support. This echoed a previous suggestion that individuals identified as having SEAN are often prepared to work collaboratively with professionals as 'Experts by Experience' (Care Quality Commission, 2012) to support the development of services (Robinson et al., 2015). Including these individuals in the planning and delivery of support would not only support recent initiatives of co-production in the services (Clark, 2015), but would also satisfy the desire of these individuals to support others within ED services.

In addition to wanting to support others, the participants also expressed a desire to seek support from others with SEAN. They believed that other people did not understand them and felt isolated in their experience of SEAN, particularly as they were often in the minority as an older person with anorexia. They spoke of finding strength in other people with SEAN and expressed a desire to seek peer support from individuals who they perceived as being similar to themselves. This was not only perceived as having possible benefits for accessing support, but also for reducing experiences of social isolation. Although there may be problems with this type of support, such as the potential for some members becoming more dependent on others, it is suggested that peer support warrants further development within the field of SEAN (Bamford et al., 2016).

4.3 Clinical implications

Some interesting avenues that might inform the practice of professionals working with individuals identified as having SEAN could be inferred from this study.

4.3.1 Collaborative and comprehensive care

The findings suggest that individuals with SEAN are often in a complex cycle of seeking control and feeling out of control. It appears that support, such as compulsory treatment or inpatient admissions, can sometimes reinforce this and pose further threats to the individual's sense of control (Tan et al., 2003). Although it can be difficult to involve the client in collaboratively planning their care, this could be beneficial by providing them with the sense of control that they desire and otherwise lack.

The findings suggest that although weight gain is an important part of treatment, there is a need to also focus on other realms of the individual's life to encourage long-lasting change. The current study suggests that psychological and social realms are particularly impacted during the experience of SEAN and these individuals often feel that being 'an anorexic' is their only identity. It therefore seems important to provide comprehensive packages of care involving multi-disciplinary approaches to include medication, psycho-education, psychotherapy, alternative therapies and social support (Espindola & Blay, 2013; Pettersen et al., 2016). It can also be helpful to support the individual in a process of de-identification with the ED so they may come to externalise the ED, perceive an internal locus of control and realise they could develop an alternative identity (Bowlby et al., 2015; Dawson et al., 2014).

4.3.2 Co-production and experts by experience

The findings suggest that individuals with SEAN should not only be included in the planning of their own care through collaboration, but also in the planning and delivery of ED services more generally through co-production. The idea of co-production can be seen across health and social care in policy and the rhetoric of legislation, such as 'No Decision About Me, Without Me' (Department of Health, 2012). In light of this, there is an increasing interest in, and encouragement of, working with service users as 'experts by experience' (Care Quality Commission, 2012) when planning and delivering services (Clark, 2015). The findings suggest that individuals with SEAN not only have the experience to be useful in this process but also have a desire to engage in this due to their investment in the ED community. Furthermore, the women interviewed

for this study recalled a history of high academic achievement and professional careers, which had regretfully been compromised due to SEAN. Involvement in co-production could therefore benefit these individuals by offering them a sense of occupational engagement in which their experiences of SEAN were valued.

4.3.3 Peer support and social engagement

The current study highlighted the experiences of isolation in SEAN and suggested a desire for peer support and social engagement. It seems that the majority of ED peer support is accessed online or through telephone services. However, it would seem important to explore the development of face-to-face peer support for individuals with SEAN, as this could validate the nature of their experiences and reduce internalised feelings of shame and stigma. There appears to be a lack of literature considering face-to-face peer support and so it would require careful panning and monitoring.

Individuals with anorexia have been described as having deficient social networks (Tiller et al., 1997) and the current findings suggest a desire for improved social engagement that is not centred round eating. Services may benefit from considering the use of social interventions for SEAN. This could be particularly beneficial as interpersonal relationships are seen to motivate the individual to continue accessing support and to instil hope that the individual is capable of recovery (Dawson et al., 2014).

4.3.4 Support transitions into community and intensive community support

The findings suggest that there is a need for improved transitions from inpatient to community services for individuals with SEAN. The difficulties in transitions from inpatient to outpatient mental health services are well documented and are associated with high risks in relation to suicide and relapse (NICE, 2016). The current study also suggested a perceived sense of being neglected as an outpatient with SEAN and a desire for intensive community support. It would seem clinically useful to explore options for increased outpatient support for these individuals who value professional involvement. Some of the participants in the current study had accessed a day patient programme. Although this was perceived as useful, it was suggested that an increased level of access to this service would enhance its benefits. Even if ‘full recovery’ remains a “fantasy”, it would seem that ongoing outpatient support could contribute to improvements in quality of life. Turton et al. (2009) demonstrated that recovery model principles,

including social inclusion and recovery as a long-term process, were particularly relevant to patients who value regular contact with a knowledgeable professional, such as those in the current study.

It is possible that one of the reasons for a reduction in support of individuals with SEAN is due to a sense of professional hopelessness about how best to help them (Ciao, 2016; Tan, 2003). However, this sense of hopelessness can be experienced by both the professional and the service user, through experiences of transference and counter transference (Strober, 2004). It is therefore important for professionals working with SEAN to be supported through training and clinical supervision to prepare for, and reflect upon, the complexity of working with this group and to prevent burnout (JCPMH, 2013; Strober, 2004). Lastly, it should be remembered that however long a patient has suffered SEAN, full recovery always remains possible and stories of hope and motivation should be shared amongst clinicians, carers and individuals with SEAN (Dawson et al., 2014).

4.4 Strengths and limitations

The current study is the first known attempt to explore the psychosocial and support experiences of individuals identified as having SEAN and accessing outpatient support. These individuals are often difficult to engage in research (Robinson et al., 2015), however the richness of the data collected suggests the participants provided open, honest accounts of their experiences. The study sample was homogenous in terms of their experiences of SEAN and current use of outpatient services. The sample size was within the recommended range for IPA (Smith et al., 2009). IPA allowed for an in-depth exploration of this relatively neglected area, whilst also allowing connections to be made with existing theory, research and legislation. Although the researchers' interpretations are inevitably open to further discussion, the current study is strengthened by the transparency of its methodological process, as well as the consideration of the researchers' reflexive and epistemological influences.

Nevertheless, this study has some key limitations. The researcher acknowledged their role as a Trainee Clinical Psychologist working in an ED service and the potential impact this could have on the research process. Codes and themes were discussed with the research supervisor to increase reflexivity and quality of the study. Experienced clinicians were responsible for the classification of each participant as experiencing

SEAN. A validated measure may have been preferable to enhance validity and the recruitment of a homogenous sample, however there continues to be a lack of consensus about how best to define SEAN (Ciao et al., 2016). It is also acknowledged that the perceived experiences of participants might be subject to memory biases (Tekcan et al., 2008), particularly due to the age of some participants and the possible cognitive impact of SEAN.

4.5 Recommendations for future research

The participants in the study were all female and, although they had accessed services across the UK, they were recruited from a single ED service and were all currently accessing support from that service. The findings may therefore not be representative across other settings due to the variable provision of ED support across the UK. The literature base and the current findings would benefit from this study being replicated in other areas and including male participants. The current study has also raised important questions about the way that inpatient care is used for this group and the possible benefit of intensive community support, as well as peer support and social interventions. These areas appear to be under represented in the literature and require further exploration. Having recognised the value of ongoing professional support for this group, it would seem important to give attention to exploring the experiences of professionals and carers who support individuals with SEAN. This might explore their hopes and expectations when supporting this group and their experiences of doing so.

4.6 Conclusion

This study has provided an in-depth exploration of the psychosocial and support experiences of a group of females identified as having SEAN and accessing outpatient support. The study has contributed towards existing research aimed at understanding the experiences of those identified as having SEAN and has highlighted a number of clinical implications for consideration.

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PART THREE: CRITICAL APPRAISAL

1. Introduction

The doctoral research journey has been an invaluable learning opportunity characterised by personal and professional challenges and achievements. Within this critical appraisal I will reflect on this journey and summarise key events and reflections on my experience as a researcher throughout the different stages of the process. Throughout the research process a reflexive diary was kept and observations and supervision discussions were recorded to facilitate the reflections that are made. I will also reflect on the strengths and the weaknesses of the research using Yardley's (2000) evaluative criteria for qualitative research as a framework.

2. Choosing a research topic

Prior to starting the doctoral training programme I worked in a CAMHS service and entered training with a particular interest in the organisational practices of CAMH services and a clinical interest in the experiences of eating and body image difficulties. My first year literature review explored the experiences of transitioning from CAMHS to AMHS and highlighted that this transition was particularly challenging for those diagnosed with an eating disorder. In choosing a research topic, I was therefore initially motivated to draw on this work and my clinical interests by conducting a study to explore the experiences of individuals who were diagnosed with an eating disorder and had transitioned from CAMHS to AMHS. To my disappointment, this idea was met with several obstacles due to originality and feasibility issues.

I was eager to choose a research topic with clinical utility and so discussed ideas with clinicians who worked in eating disorder services. They expressed a sense of hopelessness and frustration in knowing how best to support individuals who were considered to have severe and enduring 'anorexia nervosa'. They spoke of the challenges in working with this group and also the high level of resource they often required. I explored the literature in this area and was surprised to find a lack of conclusive evidence for a group that were widely considered to be complex, high risk and to pose a heavy burden on eating disorder services, public resources and carers (JCPMH, 2013). It came as a further surprise that only two notable qualitative studies had explored the subjective experiences of individuals identified as having severe and

enduring anorexia nervosa (Fox & Diab, 2015; Robinson *et al.*, 2015). I was eager to understand this area more and add to the existing research base.

2.1 The use of language

I began this research process with a basic awareness of the debate about the most helpful way of referring to experiences of psychological distress. I was aware of concerns about the medicalisation of such distress and how this can be seen to neglect or minimise the psychosocial factors that may predispose and maintain such experiences (BPS, 2013). I was also aware of the highlighted limitations (Bentall, 2004) in the reliability and validity of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases: Classification of Mental and Behavioural Disorders (ICD-10).

In consideration of this debate, I was eager to adhere to the BPS guidelines on language in relation to functional psychiatric diagnosis (2015) by attempting to predominantly use terms that were as neutral as possible and did not imply one correct way of understanding these experiences. However, when I discussed this with clinicians working in eating disorder services, they believed it was important to incorporate diagnostic language to encourage recruitment, enhance clinical utility and also due to concerns that not doing so may confuse or patronise potential participants. This clinical opinion was adopted due to the expertise of the clinicians and also the importance of collaborating with them to ensure the development of the study.

2.2 Deciding on a methodological approach

Given the nature of the research topic, I felt that a qualitative approach to research would be most aligned to the study aims. However, I also believed that a qualitative methodology aligned with my personal views and the way that I understand human experiences and social phenomena. As a Trainee Clinical Psychologist, I am encouraged to consider multiple perspectives when formulating the experiences of others. Furthermore, I have a keen interest in systemic and narrative therapeutic approaches, which are well aligned with qualitative methodology, particularly IPA, as they involve deconstruction of the ‘problem’ and consideration of deeper meanings (Johnstone & Dallos, 2013).

When considering the most appropriate type of analysis to use, I considered IPA, Thematic Analysis and Grounded Theory. Ground Theory is often utilised when exploring social and psychological topics where there is limited information. It involves the construction of theory through the analysis of data (Corbin & Strauss, 1990). While the information available about SEAN is relatively limited, the aim of the current study was to develop a theoretical understanding of SEAN, but to explore at an idiographic level what it was like for these individuals. Thematic analysis is one of the most widely used qualitative methods and is utilised to identify, analyse and report patterns across data (Braun & Clarke, 2006). However, I was mindful that recruitment of an adequate sample size might be challenging in the time constraints of the research process. I was also keen to obtain rich and detailed accounts from a smaller sample size and thereby prioritise depth over breadth of data, which IPA allowed for (Smith *et al.*, 2009). Although IPA findings cannot be generalised, they can provide accounts to inform future research and service development. I had not used IPA before and so spent time familiarising myself with the method by reading core texts and articles, by attending an IPA training course and by engaging with an online forum used IPA researchers.

3. Navigating research ethics

Prior to starting training my research experience was limited to that undertaken as part of my undergraduate and masters degrees. I had not encountered the IRAS form, Good Clinical Practice or HRA guidelines previously and was apprehensive about these requirements and processes, particularly as I had heard about the challenges that had been faced by the previous cohort in navigating this process due to changes in requirements. However, I was pleasantly surprised by this part of the research journey and was fortunate enough to get through each stage with little difficulty and through REC approval with no questions and no changes required.

4. Collating data

4.1 Recruitment

Recruitment took place within an adult eating disorder service that offered inpatient and outpatient support. The links with the service were established through a clinical psychologist who worked in this service and taught on the training programme. She introduced me to a consultant psychiatrist and researcher within the team and I remained in regular contact with these three members of staff throughout the research

process. I also attended one of the service's CPD events to present my research to the wider team in the hope that this would support recruitment. Recruitment was initially very positive and three participants were recruited in the first few weeks and interviewed soon after over the summer. Unfortunately, recruitment then slowed down and despite frequent liaison with the service there was difficulty in identifying appropriate potential participants. The service explained that some of the people they had initially hoped to recruit had been admitted to the inpatient unit or were going through a particularly difficult phase and so would either not be eligible or suitable to take part in the study at that time. Over the Christmas period, one more participant was recruited.

I became concerned about the impact this would have upon the research process timeline (Appendix O) . At this time I explored the ethical processes that would be required to extend the study to an extra site. I was glad to find out that this would only require a non-substantial amendment and approached another adult eating disorder service that provided outpatient support and where I had since begun a clinical placement. This service was keen to support further recruitment and I notified the existing site that I was planning on extending the study. Luckily, prior to submitting the amendment, the existing service recruited two final participants and these interviews were completed. On reflection, I have wondered if being more present in the service would have aided recruitment. However, I think it was helpful to be separate from the service as it allowed me to simply adopt the researcher role, rather than negotiating my role as both a clinician and a researcher.

4.2 Developing a topic guide

The topic guide was informed by discussions with my academic supervisor, field supervisors and other staff from the recruiting service. Various versions were created and edited based on these reflections prior to the final topic guide. The main challenge at this stage of the process was to find a balance in creating a topic guide that would allow for time to develop rapport and also elicit rich narratives. This proved challenging due to the importance of ensuring the interview could be completed in a reasonable time, as the clinicians were mindful that many of the potential participants were likely to struggle with their concentration and energy levels over a long period due to the impact of their eating difficulties and low weight.

The topic guide aimed to allow for a ‘one-way’ conversation that was open and exploratory (Smith *et al.*, 2009) by keeping the number of questions asked to a minimum. The guide also included a number of prompts to encourage the participant to reflect upon their experiences and thereby develop an in depth understanding of their experiences.

4.3 The interview process

As a ‘novice’ IPA researcher and someone who had never worked with anyone considered as having severe and enduring eating difficulties, I was apprehensive about the interview process. I spent time reading about the interview process in IPA and discussing my concerns with supervisors. This helped me to feel more confident and, I believe, prepared me well for the interviews. As previously highlighted, I aimed for the interview to remain open and exploratory and was keen to remain aware of any assumptions I was making so that I continued to ‘dig deeper’ for the individuals meaning of an experience, rather than to project my own understanding onto them. I was aware of the importance of remaining neutral as part of my researcher role to minimise bias. At times this was difficult due to my instinct to adopt a position of reflecting and offering an empathic response, as I do within my role as a reflective practitioner. I believe that practicing the interview process with peers was helpful and I practiced focusing on expanding the narratives offered, rather than reflecting and interpreting what was being said. I found myself becoming increasingly comfortable in the researcher role as the interviews progressed and would feel more secure in adopting this role again in the future.

Due to the concerns about possible inattention and fatigue, all participants were offered the opportunity to have a break during this interview as needed and were reminded they could end the interview at any time. None of them felt this was needed, although some of the participants commented on their difficulty in maintaining concentration towards the end of the interview and others were keen to end at an agreed time due to their wish to keep very closely to their daily plan. This did not cause any problems in the interviews but I remained mindful of the cognitive impact of their eating difficulties and how this may influence the research.

5. Data analysis

5.1 Homogeneity of sample

After each interview, I took time to reflect on the interview and to note my reflections and reactions to the participant and their narrative. I came to recognise the individual differences between participants and how this influenced the interviews. For example, one participant was very focused on the positive aspects of her eating difficulties and the treatment and support she had accessed over the years. In comparison, other participants framed their experiences as being mostly unhelpful and seemed to find it much more difficult to consider their future hopes. Although the stance of these participants was different, they still had a common experience of severe and enduring eating difficulties. Furthermore, I reflected upon the differences between younger and older participants. While the older participants appeared to focus on how much better support is now in comparison to the unhelpful support that was offered decades ago, the younger participants were able to adopt a more critical stance on current approaches to eating difficulties. To a certain extent, these differences are unavoidable, as there will always be individual difference between participants and each participant will have unique individual experiences. From a critical realist epistemological standpoint I was also able to recognise that reality is constructed from multiple perspectives and there is an extent to which I can access these differing layers as a researcher.

5.2 Coding and developing emergent themes

As a novice IPA researcher, I spent time familiarising myself with the IPA analysis process outlined by Smith *et al.* (2009). I also attended an IPA workshop hosted by a highly regarded researcher in the field. This training event offered an outline of the IPA research process and also provided me with the opportunity to engage in practicing IPA analysis on interview material with fellow researchers.

By the time I started the transcription and analysis process, I had conducted the literature review and I had started a clinical placement in an eating disorder service. Throughout my engagement with the data I was aware that these experiences may influence my interpretations and therefore I attempted to stay close to the data and remain reflective of any potential biases I may be experiencing.

I began the analysis process by immersing myself in the data by listening to the audio-recordings and noting down areas of interest. I was apprehensive about the time required for transcription but found this to be a valuable way of connecting with, and exploring, the data further. I was surprised by, and grateful for, the richness of the data from each participant, but also overwhelmed by the volume of it. As I began to interpret the meaning of participant experiences and reduce this data into themes, I noticed myself constantly questioning whether I was being 'too descriptive' or 'overly interpretative'. I managed this by ensuring that all of the themes could be related back to the original transcripts while also adding a deeper level of understanding. I was struck by the quantity of emergent themes that arose from the data and the richness of these themes. I was eager to give attention to these concepts, while also remaining mindful of the limited word count and needing to ensure there was space to evidence and discuss each of these concepts. At times it proved a challenge to collate these emergent themes into coherent super-ordinate themes that effectively represented the experiences included within them. This was discussed in supervision and time was given to considering the coherence of super-ordinate and sub-themes, which was very helpful in ensuring clarity in the final themes.

5.3 The write up

Over the course of my interviews with the six participants I had reflected on my sense of privilege and gratitude for their willingness to share their experiences with such openness and honesty. I had also been struck by their sense of investment in the eating disorder community and their hope for the value that the current study could add to the experiences of others. In light of this, I began the process of writing up the findings with a great sense of responsibility to capture their experiences in a meaningful way. However, this resulted in a tendency to want to be over-inclusive and to capture every detail within each theme. This was impossible within the word count restrictions, particular as this also needed to incorporate my own interpretations of their experiences as part of the double hermeneutic process that is integral to IPA (Larkin *et al.*, 2009). I continually reminded myself of the importance of being selective, however I was left with a reflection that, part of the value of qualitative research is it's ability to provide rich accounts, and yet some of this richness is lost in the need to be selective.

As I attempted to find the balance between being selective and ensuring rich accounts of the participants' experiences, and between staying close to the data and adding in my interpretations, I found it helpful to keep in mind a quote shared by trainee who had also experienced this research process: 'don't let the perfect be the enemy of the good'. This quote, originally offered by Voltaire, a French writer and philosopher, resonated with me and provided a helpful reminder of the importance of focussing on achieving a 'good enough' final piece of work.

6. Strengths and weaknesses

Yardley's (2000) criteria for evaluating qualitative research was utilised to consider the strengths and weaknesses of the current study.

6.1 Sensitivity to context

Throughout the research process I reflected on the possible role and influence I may have had upon the research process. I was conscious of my vested interest in this project. I was also mindful of the potential bias that could occur due to my experiences of completing a literature review in the field of eating disorders and undertaking a clinical placement in an eating disorder service alongside the research process. I was also aware of my role as a researcher and how this may have been influenced by my role as a Trainee Clinical Psychologist with a therapeutic style. Although I was mindful to try and maintain a neutral and curious position, there were times when this was difficult, such as when a participant would share an experience that elicited an emotional reaction and it felt important to offer an empathic response or reflection. However, this appeared to be an important part of rapport building and ensuring that the participants felt safe and comfortable to continue sharing their experiences in an honest and open way throughout the interview.

6.2 Completeness of data collection, analysis and interpretation

Six participants were recruited for the current study and this was in line with the recommendations offered by Smith *et al.* (2009) and the requirements outlined in the training programme guidelines. Everyone who expressed an interest in the study met the inclusion criteria and was included in the study. Every stage of the analysis process was recorded to ensure transparency. As previously discussed, the word count of the current project was limited and therefore the results were limited to selective quotes,

however these quotes were chosen to effectively represent the experiences that each theme hoped to capture.

7. Personal and professional development

I began the research process with an experience of research that was limited to my previous academic degrees. This was my first experience of conducting a major project, applying for ethical approval and recruiting within a clinical setting. Although the journey has been challenging, I am proud of the development of this study from an idea to a completed study. My primary aim in entering this research process was to conduct a project that did not simply meet the academic requirements of the training programme, but also had clinical utility and would be a contribution to a field that I am passionate about, which I believe that this has been achieved.

This research process has shown me the importance of planning ahead and anticipating obstacles from the start. With the support of my academic supervisor, I have recognised the importance of keeping ahead of the timeline where possible to allow for any delays that may occur further down the line. For example, the early drafts of my literature review were completed in sufficient time, which meant that when recruitment difficulties were experienced I still had enough time to manage this and meet the original deadline. Furthermore, I have appreciated the importance of developing strong connections with the recruiting service. I was fortunate enough that the recruiting service were invested in this project from the beginning to the end. This not only aided me in the development of a robust study design, but also ensured that the target sample was achieved despite difficulties in recruitment.

I finish this research process with a greater understanding of the experiences of individuals identified as having SEAN and also with an improved confidence and capability to undertake future research projects. I will hold on to the findings and clinical implications of this research as I progress into my role as qualified Clinical Psychologist in an eating disorder service. I will equally hold on to the skills and lessons I have learnt about conducting research in a clinical setting and progress forward in my career with a desire to undertake further research in this field.

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APPENDICES

Appendix A* - Author guidelines for target journal

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.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

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

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#). You may also like to use the [Submission Checklist](#) to help you prepare your paper.

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. You may like to use [this](#) template. When entering the author names into Editorial Manager, the corresponding

author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.

- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- 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 but they must be mentioned 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 figures must be mentioned in the text.
- 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.
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If you need more information about submitting your manuscript for publication, please email Melanie Seddon, Managing Editor (bjc@wiley.com) or phone +44 (0) 1243 770 108.

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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>.

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Appendix B – A note on diagnostic language

There is a debate about the most helpful way of referring to the experiences that are discussed within the current review. Traditionally, difficulties and distress around eating and body image have been thought of as symptoms of mental illnesses known as ‘eating disorders’. However, concerns have been raised about the medicalisation of such distress, which often neglects or minimises the psychosocial factors that may predispose and maintain such experiences (British Psychological Society, 2013). Limitations in the reliability and validity of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases: Classification of Mental and Behavioural Disorders (ICD-10; World Health Organisation, 1992) have also been highlighted (Bentall, 2004). As such, not everyone finds the use of diagnostic and medical language to be the most helpful way of thinking about such experiences. It is recognised that while many people do not see themselves as having an illness or a ‘disorder’ and may reject this terminology, others may in fact value it.

The current review has therefore attempted to predominantly use terms that are as neutral as possible and do not imply one correct way of understanding these experiences. However, the terms ‘eating disorder’, ‘anorexia nervosa’ and ‘bulimia nervosa’ are also used because they are terms commonly used within society and within the articles that were used to inform the current review. The use of these terms will therefore serve a purpose of maximising clinical utility.

References:

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World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Appendix C – Search terms and results

Database	Search terms	Search years	Number of results
PsycINFO	(recover* OR 'get* better') AND ('eating disorder*' OR anorexi* OR bulimi*) AND (experience* OR qualitative*) - Limit to academic journals	1967 – 2017	369
PubMed	((experience OR qualitative)) AND recovery) AND eating disorder	1971 – 2017	160
Scopus	(TITLE-ABS- KEY (recover*) AND TITLE-ABS-KEY ('eating AND disorder') AND TITLE-ABS- KEY (experience* OR qualitative*)) - Limit to journals	1975 – 2017	305
Web of Science	TOPIC: (recovery*) AND TOPIC: ('eating disorder' OR anorexi* OR bulimi*) AND TOPIC: (experience* OR qualitative*)	1991 – 2017	284
CINAHL	Recover* AND experienc* AND 'eating disorder' - Limit to academic journals	1989 – 2017	72
Total			1190

Appendix D –Study characteristics

Title	First author and date	Aims of study	Setting	Sample	Method of data collection	Method of data analysis
1. Male Experiences of Life After Recovery from an Eating Disorder	Bjork (2012)	To describe how former male patients perceive life after recovery from an eating disorder and identify ways of experiencing recovery	Norway and Sweden	15 males 19-52 yrs old (MD = 23 yrs)	Face-to-face semi-structured interviews	Phenomenographic approach
2. Recovered Professionals Exploring Eating Disorder Recovery: A Qualitative Investigation of Meaning	Bowlby (2012)	To explore the phenomenological experience of recovery of ED therapists who had recovered from ED to gain insight into the recovery process.	USA	13 women 30-53 yrs old (M = 41.3 yrs)	Face-to-face, semi-structured interviews	Moustakas' (1994) modification and adaptation of the Stevick-Colaizzi-Keen method for the analysis of phenomenological data
3. Becoming 'Whole' Again: A Qualitative Study of Women's Views of Recovering from Anorexia Nervosa	Jenkins (2012)	To explore the process of recovery from AN from the patients perspective as a means to gain insights into what patients believe are the active mechanisms of change for their condition	Not stated but evident it is UK	15 females 19-49 yrs old (average = 28 yrs)	Semi-structured telephone interviews	Interpretative Phenomenological Analysis (Smith & Osborn, 2003)
4. Eating Disorders: Challenges in the Later Phases of the Recovery Process: A Qualitative Study of Patients' Experiences	Pettersen (2012)	To describe patient experiences of challenges during the later phases of recovery from eating disorders	Norway	13 females 18-54 yrs old (average = 29 yrs)	Semi-structured interviews	Content analysis (Graneheim & Lundman, 2004)

5. Long Term Remission of Anorexia Nervosa: Factors Involved in the Outcome of Female Patients	Espindola (2013)	To elicit, describe and characterize factors involved in successful AN remission for at least five years and post-recovery life; to exam the inner experiences and external factors associated with young women with AN in remission for at least five years	Brazil	15 females 22-32 yrs old (average = 27 yrs)	Ethnographic, semi-structured, face-to-face interviews	Grounded theory (Strauss & Glaser, 2008)
6. “Doing the Impossible”: The Process of Recovery from Chronic Anorexia Nervosa	Dawson (2014)	To explore the process of recovery over time from the perspective of those who had fully recovered from chronic anorexia nervosa (AN) using stringent criteria	Australia	8 females 31-64 yrs old	Face-to-face interviews	Narrative inquiry (Clandinin & Connelly, 2000)
7. A Qualitative Study of Young Women’s Experiences of Recovery from Bulimia Nervosa	Lindgren (2014)	To describe experiences of recovery from bulimia nervosa among young adult women who had undergone treatment	Sweden	5 females 23-26 yrs old	Semi-structured narrative interviews – mix of telephone and face-to-face	Content analysis (Graneheim & Lundman, 2004)
8. Normal Eating is Counter-Cultural: Embodied Experiences of Eating Disorder Recovery	LaMarre (2016)	To better understand the embodied, socio-culturally situated stories of young women in recovery	Canada	10 females 20-31 yrs old (average = 25 yrs)	Semi-structured interview	Narrative thematic analysis (Reissman, 2007)
9. How do Males Recover from Eating Disorders? An Interview Study	Pettersen (2016)	To investigate what males experience as helpful in their recovery process from ED	Norway and Sweden	15 males 19-52 yrs old (mean = 23 yrs)	Face-to-face interviews	Content analysis (Graneheim & Lundman, 2004)

Appendix E – Quality appraisal using CASP checklist

<i>First Author</i>	<i>Aims</i>	<i>Method</i>	<i>Design</i>	<i>Sampling</i>	<i>Data collection</i>	<i>Reflexivity</i>	<i>Ethical Issues</i>	<i>Data analysis</i>	<i>Findings</i>	<i>Value of research</i>
Bjork (2012)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓
Bowlby (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jenkins (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pettersen (2012)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓
Espindola (2013)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓
Dawson (2014)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓
Lindgren (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
LaMarre (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pettersen (2016)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓

Appendix F – Definition of meta-ethnography terms

Term	Definition
<i>First order construct</i>	Constructs that reflect participants' understandings, as reported in the included studies (usually found in the results section of an article)
<i>Second order construct</i>	Interpretations of participants' understandings made by authors of these studies (and usually found in the discussion and conclusion section of an article)
<i>Third order construct</i>	The synthesis of both first and second order constructs into a new model or theory about a phenomenon
<i>Reciprocal translation</i>	The comparison of themes across papers and an attempt to "match" themes from one paper with themes from another, ensuring that a key theme captures similar themes from different

Appendix G – Data extraction form template

Study Title:

Date:

Author:

Eligibility

Question	If YES	If NO
1 Is the study about recovery from an ED?	Continue	Exclude
2 Does the study discuss the participants' own experiences of recovery from an ED?	Continue	Exclude

Study Characteristics

Study details	Location	
	Research question	
	Theoretical Framework	
Participants	Population	
	Age (range, mean)	
	Gender	
	Ethnicity	
	Recruitment/sampling method	
Data collection	Method (interviews, focus groups)	
	Who collected the data?	
	How were the data prepared for analysis? (e.g. interviews transcribed)	
Analysis	Method (thematic analysis, interpretative phenomenological)	

	analysis, grounded theory)	
Validity	What validation methods were used?	
Reflexivity	Did the study report engaging in reflexivity?	

Findings	How are results presented?	
Category 1 (including title, description as given, verbatim extracts of data and/or author's analytic commentary of the data)	Title:	

Category 2	Title:	
Category 3	Title:	

Author's conclusions	Conclusion (author's concluding remarks, key findings)	
	Limitations identified by authors	
	Implications identified by authors	
	Key references (not identified by search strategy)	
Comments	Anything of note about his study not covered already	

Appendix H – Extract of first and second order constructs

Title	First author and date	Aims	Themes	Author's comments and conclusions
1. Male Experiences of Life After Recovery from an Eating Disorder	Bjork (2012)	To describe how former male patients perceive life after recovery from an eating disorder and identify ways of experiencing recovery	<p><u>Acceptance of body appearance</u></p> <ol style="list-style-type: none"> Physical training without compulsion – Frequency and intensity reduced – “I still train a lot, but not nearly as much as I did...I have become more relaxed” Relaxed in relation to food – more permissive and flexible regarding food and eating – no longer controlled their life. “Food is no longer a problem” Strategies to avoid relapse – tools to keep distance from ED thinking (e.g. not having scales) <p><u>A sense of self-esteem</u></p> <ol style="list-style-type: none"> Self-acceptance – caring for themselves and reducing demand for high performance, which contributed to a sense of freedom. Autonomy – less attention to others’ opinions and more to own wishes – feel a right to assert their rights and make own decisions. Enjoy a social life – more relaxed in social situations. Prioritising social relationships – “I contact my friends. This is a very big difference.” 	<ul style="list-style-type: none"> With a sense of self-acceptance and autonomy, they now appreciate their social life. Some perceive recovery as coping with remaining impulses to diet or exercise, others experience themselves as fully recovered. Mostly in line with findings of female studies – although males emphasised need to manage compulsive exercise and utilised relapse avoidance strategies.
2. Recovered Professionals Exploring Eating Disorder	Bowlby (2012)	To explore the phenomenological experience of recovery of ED therapists who	<ol style="list-style-type: none"> Non-linear process – “recovery...is definitely a process. It doesn’t really have a specific starting point or ending”. Preference for term ‘in recovery’ over ‘recovered’. Comprehensive – recovery requires more than 	<ul style="list-style-type: none"> Broaden the conceptualisation of recovery beyond the minimal criteria of abstinence from behaviour symptomology, weight restoration, and cessation of obsessional thinking.

Recovery: A Qualitative Investigation of Meaning		had recovered from ED to gain insight into the recovery process.	<p>behavioural change and physical stability. “Address the food first in order to get them to address the underlying psychological stuff, but both are necessary” – internal and external change.</p> <p>3. Understanding and valuing the self – improved personal self-relationship. Moving from a place of self-hatred and self-betrayal to a place of self-love and acceptance</p> <p>4. De-identification with the ED – ED separate from one’s identity. Learning to differentiate between voice of ED and true self. ED thoughts as “red flags that something else is going on” that needs attention. A final decision not to return.</p> <p>5. Finding purpose and meaning in life – “it is really learning to live life and not just living on an eating disorder island...learning to live a full life”.</p> <p>6. Developing meaningful relationships – reaching out and relying on others. Learning to communicate effectively to build support and fellowship. “In recovery you get more involved in relationships”</p>	<p>Long-term recovery requires more comprehensive changes, involving identity, meaning and purpose in life.</p> <ul style="list-style-type: none"> • Recovery is an ongoing process – rejects minimalist perspective of recovery as obtainable – prefer to see selves as “in recovery” not “recovered” • Recovery should explicitly include psychological and emotional factors, as well as behavioural and physical ones. • Importance of attitudes towards the self and de-identification with ED – meaning and purpose also central to recovery.
3. Becoming ‘Whole’ Again: A Qualitative Study of Women’s Views of Recovering from	Jenkins (2012)	To explore the process of recovery from AN from the patients perspective as a means to gain insights into	<p>Being anorexic</p> <p>1. Anorexic behaviour – feeling compelled to diet, restrict and control food intake. AN was exclusive focus in their life</p> <p>2. Anorexic cognitions – “anorexic me and normal me” – one side rational, one irrational – at this stage AN side wins – denial of problem.</p> <p>3. Anorexic voice – “you listen to that [AN side] and ignore what your body actually needs”</p>	<ul style="list-style-type: none"> • Series of dichotomies involving splits between mind and body, AN behaviour and cognitions, and their rational and irrational side. Recovery reflects a time when these many different components are no longer divided – this was often facilitated through therapy and close relationships, which enabled them to

Anorexia Nervosa		<p>what patients believe are the active mechanisms of change for their condition</p>	<p>4. Anorexia as a means of communication – used their bodies to communicate distress about feelings and experiences to those around them</p> <p>Process of change</p> <ol style="list-style-type: none"> 1. Difficult journey – Health improved gradually but a difficult journey and felt treatment rushed 2. Limitations of therapy – difficult to get diagnosis; treated as ED stereotype, not individual; too much focus on weight, body & behaviour, not enough on mind & cognitions. 3. Using therapy/ relationships – Therapy helped when intrinsically motivated; shocked by damage AN caused to body; shift from denial to acknowledgement; relationships also helped (partner, family, friends) – confidence, self-acceptance & hope. 4. Managing emotions – Through Ther&Rel's they could connect with emotions; eating more also did; starting to use language as communication tool, not body. 5. Acknowledging consequences of AN – Recognising losses from AN = deciding better off without it – 'sick of anorexia' 6. Controlling the AN voice – gradual process – varied between women how they did this but many associated control of voice with recovery <p>Being recovered</p> <ol style="list-style-type: none"> 1. Ambivalence about recovery – Defining recovery is difficult – “you may never fully recover from AN, I think the voice is always there” – AN provided sense of control and achievement – weight gain very difficult. 	<p>find non-bodily means to express their psychological distress.</p> <ul style="list-style-type: none"> • Treatment should be paced to the individuals needs and take collaborative approach to treatment. It should focus aim to facilitate a sense of becoming 'whole again' • Close relationships central to becoming able to manage emotions and controlling AN voice. • Ambivalence about recovery – it's costs and benefits; and finding a new identity outside of it.
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			<p>2. Benefits of recovery – Advantages outweigh disadvantages of recovery</p> <p>3. Managing an identity – Giving up AN as a “huge risk because I was convinced I couldn’t be anything else”. Some incorporated AN in new identity, others rejected AN as part of new self-identity.</p> <p>4. Description of full recovery – Ending obsession with food and weight; changing cognitions; target weight is only a starting point – recovery also incorporates physical and psychological recovery – not necessarily in that order.</p>	
--	--	--	--	--

Appendix I – Taxonomy of findings: third order constructs

A choice to recover
<p><u>Ambivalence</u></p> <ul style="list-style-type: none"> • Mixed feeling towards ED and recovery – limitations and benefits • Leaving behind the good and the bad • Unaware of, or hopeless about, the possibility of recovery <p><u>Tipping point</u></p> <ul style="list-style-type: none"> • Recognising the losses / negative consequences and reaching a tipping point • Can be internal or external • Leads to autonomy – self-motivation, own choice
Conceptualisation of recovery
<p><u>Comprehensive</u></p> <ul style="list-style-type: none"> • More than physical – psychological, social, environmental, emotional, spiritual elements too • Understanding of recovery should be comprehensive and so should treatment and support <p><u>Unique individual experience</u></p> <ul style="list-style-type: none"> • Recovery is not the same process for all – different triggers, support etc. • Some view recovery as a process, others view it as a goal – ‘in recovery’ or ‘recovered’? • Treatment and support should be collaborative and tailored to the individual
A process of transition
<p><u>Identity and self-efficacy</u></p> <ul style="list-style-type: none"> • From a person with ED to new identity; from ED in control to authentic self in control; locus of control – external to internal; de-identification with ED • Understanding and valuing the self; learning to love myself – the good and the bad • Understanding function/cause of ED <p><u>Interpersonal relations</u></p> <ul style="list-style-type: none"> • From withdrawn to engaged, which supported recovery; from ED as best friend and being isolated to engagement in interpersonal relations • Interpersonal support necessary; therapy/support as important throughout. In early phases and later phases, there is a different need but just as important. • Hope is crucial. <p><u>Alternative coping</u></p> <ul style="list-style-type: none"> • From expressing psychological distress through bodily means to new ways to communicating/managing psychological distress. • Practical strategies to avoid relapse

Appendix J – Presence of themes

	1 Ambivalence	2 Tipping Point	3 Comprehensive	4 Unique & Individual Process	5 Identity & Self- Efficacy	6 Interpersonal Relations	7 Alternative Coping Strategies	TOTAL N. OF THEMES IN PAPER
1. Bjork (2012)	N	N	N	Y	Y	Y	Y	4
2. Bowlby (2012)	N	Y	Y	Y	Y	Y	Y	6
3. Jenkins (2012)	Y	Y	Y	Y	Y	Y	Y	7
4. Pettersen (2012)	Y	Y	Y	Y	Y	Y	Y	7
5. Espindola (2013)	Y	Y	Y	Y	Y	Y	Y	7
6. Dawson (2014)	Y	Y	N	Y	Y	Y	Y	6
7. Lindgren (2014)	Y	Y	N	Y	Y	Y	Y	6
8. LaMarre (2016)	N	N	Y	Y	Y	Y	Y	5
9. Pettersen (2016)	Y	Y	Y	Y	Y	Y	N	6
TOTAL N. OF PAPERS WITH THEME IN	6	7	6	9	9	9	8	

Appendix K* – Epistemological position

The researcher took a critical realist epistemological position, which integrates realism and relativism. This stance rejects the naïve realist position that suggests reality is universal and quantifiable. It also rejects the radical constructionist standpoint, from which it is thought that reality is constructed from discourse. Instead, a critical realist position acknowledges that there is a reality but there are aspects of reality that exist independently of our knowledge of them (Sayer, 1992). Furthermore, this stance recognises that we are not able to access every aspect of reality, and reality is not confined to the aspects that we can directly observe alone (Fade, 2004). As such, human knowledge only captures a small part of reality and each person will experience different parts of reality, due to differences in the individual meaning-making (Bhaskar, 1978; Fade, 2004). Therefore, as a researcher adopting a critical realist stance, it is acknowledged that ‘truth’ is understood through the subjective interpretation and representation of reality and each individual will hold a different experience of reality (Madill *et al.*, 2000).

A critical realist stance is well aligned to IPA’s methodological framework. IPA is interested in the lived experiences of individuals and acknowledges that the ways in which people make sense of their experiences is located within the context of their own reality (Smith *et al.*, 2009). IPA also encourages the researcher to interpret the deeper levels of meaning beyond the spoken word, while recognising that this is influenced by the researcher’s own lived experiences and perception of reality. A critical realist standpoint is an integration of realism and relativism. From a relativist position, it is recognised that researcher influences the analysis and interpretation of the data. As such, the researcher in the current study acknowledged that her prior experiences and beliefs, as well as her current perception of the social, cultural and political context surrounding individuals identified as having SEAN, would shape the research findings. Alongside this, the realities portrayed by each participant are equally influenced by their own beliefs and perceptions and also inevitably influence the findings that emerge. Within a realist stance, these influences can be believed to reflect a range of realities that are very real and the researcher acknowledges that the understanding of this real world is limited within the context of the researcher, the participant and the interview.

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Appendix L* – REC approval letter



03 May 2017

Miss Jessica Conrad-Czaja
Trainee Clinical Psychologist

Dear Miss Conrad-Czaja

Study title: A qualitative study of the psychosocial and support experiences of individuals identified as having severe and enduring 'anorexia nervosa'

REC reference:
Protocol number:
IRAS project ID:

Thank you for your submission. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 April 2017

Documents received

The documents received were as follows:

Document	Version	Date
Other [HRA Research Protocol v1.1 tracked changes]	1.1	28 April 2017
Research protocol or project proposal [HRA Research Protocol]	1.1	28 April 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

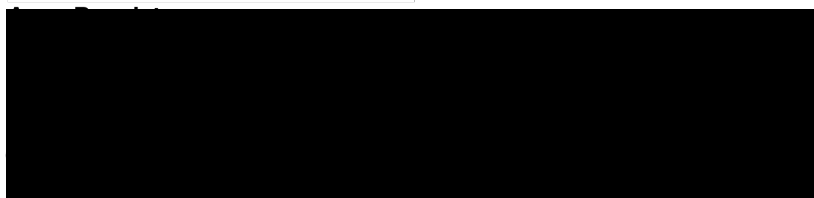
Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Indemnity Letter]		15 March 2017
Interview schedules or topic guides for participants [Flexible Interview Guide]	1.0	10 March 2017
IRAS Application Form [IRAS_Form_17032017]		17 March 2017
IRAS Application Form XML file [IRAS_Form_17032017]		17 March 2017
IRAS Checklist XML [Checklist_17032017]		17 March 2017
Letters of invitation to participant [Letter of invitation and expression of interest]	1.0	10 March 2017
Other [Lay Summary Service User Feedback]		21 January 2017
Other [Sponsor verification of insurance]		15 March 2017
Other [HRA Research Protocol v1.1 tracked changes]	1.1	28 April 2017

Participant consent form [Participant Consent Form]	1.0	10 March 2017
Participant information sheet (PIS) [Participant Information Leaflet]	1.0	10 March 2017
Research protocol or project proposal [HRA Research Protocol]	1.1	28 April 2017
Summary CV for Chief Investigator (CI) [CI summary CV]	1.0	21 January 2017
Summary CV for student [Research CV for student (CI)]	1.0	21 January 2017
Summary CV for supervisor (student research) [CV for academic supervisor]	1.0	21 January 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of protocol]	1.0	10 March 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/NW/0219	Please quote this number on all correspondence
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Yours sincerely

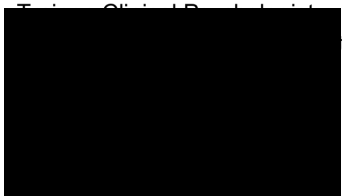



Appendix M* - HRA Approval



Miss Jessica Conrad-Czaja

Email: hra.approval@nhs.net

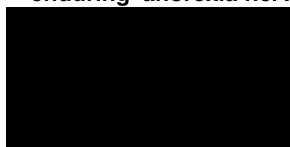


Dear Miss Conrad-Czaja

Letter of HRA Approval

Study title: A qualitative study of the psychosocial and support experiences of individuals identified as having severe and enduring 'anorexia nervosa'

IRAS project ID:
Protocol number:
REC reference:
Sponsor



I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

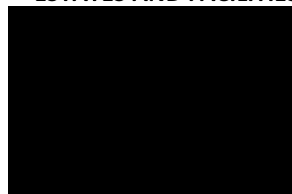
Appendix N* – Sponsorship letter



15th March 2017



ESTATES AND FACILITIES



To whom it may concern,

UNIVERSITY OF LEICESTER CLINICAL TRIAL/PROFESSIONAL INDEMNITY INSURANCE

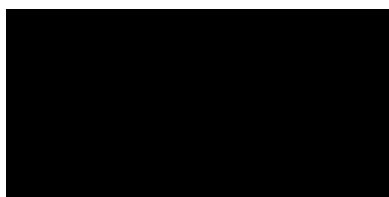
Title of Study: A qualitative study of the psychological and support experiences of individuals identified as having severe and enduring 'anorexia nervosa'

Chief Investigator: Miss Jessica Conrad-Czaja

I confirm that the University of Leicester will provide Clinical Trials and Professional Indemnity insurance cover in respect of its legal liability in relation to the above trial.

Any significant departure from the programme of research as outlined in the application (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be communicated to us.

The cover is provided subject to normal policy terms and conditions.



University of Leicester

Appendix O* - Chronology of the research process

Research Stage	Timescale
Consultation with academic supervisor	October 2015
Developing initial research proposal	December 2015 to May 2016
Internal panel review at the University of Leicester	June 2016
Re-development of research proposal and development of research documents	June 2016 to December 2016
Peer review at the University of Leicester	December 2016
Service User Reference Group (SURG) review	January 2017
Refinement of research proposal and development of research documents	January 2017
Obtained study sponsorship	January 2017
Submission of IRAS for HRA approval and REC review	March 2017
Favourable opinion from REC	
HRA approval	May 2017
R&D approval	
Recruitment and interviewing participants	May 2017 to March 2018
Analysis	November 2017 to March 2018
Write up	February 2018 to April 2018
Thesis submission to the University of Leicester	April 2018
Preparation for viva	May 2018 to July 2018
Dissemination of findings	August 2018 to September 2018
Poster presentation preparation	August 2018 to September 2018

Appendix P* - Participant information leaflet



Participant Information Leaflet

Study Title: A qualitative study of the psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa

Chief Investigator: Jessica Conrad-Czaja (Principal Researcher)

Invitation

You are being invited to take part in a study that is being undertaken by Jessica Conrad-Czaja (Principal Researcher), as part of a Doctor in Clinical Psychology Course at the University of Leicester. The research will be supervised by Dr Steven Allan (Academic Supervisor, University of Leicester).

Joining the study is entirely up to you. Before you decide whether to take part, it is important for you to understand the purpose of the study and what it will involve. Please take your time to read the following information carefully and to decide whether you wish to take part. You might find it helpful to talk to others about this. If you have any further questions about the study you can contact the chief investigator, whose contact details are provided at the end of this leaflet.

What is the purpose of the study?

The aim of the study is to explore the experiences of living with anorexia nervosa. In particular this study is interested in the following: how individuals who have had anorexia nervosa for several years and may have struggled to recover make sense of their diagnosis; their experiences of past treatment, care and support; and also their hopes and expectations for the future.

Why have I been invited to take part in the study?

You have been asked to take part in this study because you are currently receiving support for a long-term eating disorder.

Do I have to take part?

Participation in the study is completely voluntary. You do not have to take part if you do not want to. If you decide to take part, you will be asked to sign a consent form to show your agreement. Regardless of whether you choose to take part in the study or not, your care will not be affected in any way, currently or in the future. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will be involved if I take part in the study?

The researcher will contact you to arrange this once you have consented for her to do so. The interview will last a maximum of 90 minutes and you can take a break if you need to during this time. The researcher will ask you questions about your experiences of living with an eating disorder. They will be interested in any aspects that you consider to be important. This interview will be audio recorded and then written up

PIL Version 1.0 10th March 2017

1 of 4

subsequently. This is to help the researcher to recall exactly what you have said. You will also be required to complete a short questionnaire of your details, which will include information about yourself such as your height, weight and diagnosis.

What are the possible advantages of taking part?

The information that you share with me will support future service improvements and enable better support for people with similar difficulties. Although there is no guaranteed personal benefit to taking part in the study, you may find it helpful to have an opportunity to discuss your experiences and possibly influence how services are offered in future.

What are the possible disadvantages of taking part?

It is unlikely that taking part in this study will cause a disadvantage or pose a risk to you. The interview might prompt you to think about some sensitive topics, but you will not have to answer any questions that you do not wish to discuss and you will not have to provide a reason for this. You can also withdraw from the study at any time before the interviews have been analysed, without giving any reason. The researcher will support you throughout the interview.

What if something goes wrong?

If you wish to complain or have any concerns about the way you have been approached or treated in connection with the study, you should ask to speak to Jessica

Disorder Service and they will do their best to support you. The normal NHS complaints procedure will also be available to you. Information on this will be provided.

Will my taking part in the study be kept confidential?

All information that you share will be handled in the strictest confidence and stored securely. Any information that you provide that could be used to identify you (which will be obtained from the demographic information form, consent form and invitational letter) will be stored separately from your interview data. All interview transcripts will be anonymised, stored electronically and securely under password protection. If, during the course of the interview, you decide to tell the researcher information beyond what is being asked and that suggests a risk to you or to others, they would not be able to guarantee anonymity. In such circumstances, the researcher would need to pass on the information you disclosed, along with your personal details, to your named clinician or other agencies for safeguarding purposes. If this were to be the case, the researcher would inform you of this action.

What will happen to the results of this study?

The results of this study will be written up as a thesis for the Doctor in Clinical Psychology training program. It is anticipated that the findings will also be published in peer-reviewed academic journals, made available on relevant websites and

Adult Eating Disorder Service. No personally identifiable information will be included in any publication or presentation

You will also be given the opportunity to request that a summary of the findings will be sent to you in the post or by email.

What happens if I change my mind?

You have the right to withdraw from the study at any time prior to the completion of the data analysis, without giving any reason. If you withdraw from the study, the researcher will destroy any information that may identify you (your name, address, telephone number etc.) but will keep any non-identifiable data. If you lose capacity you will also be withdrawn from the study and only non-identifiable data will be kept.

Who is funding the research?

The University of Leicester are sponsoring and funding this research study.

Who has reviewed the study?

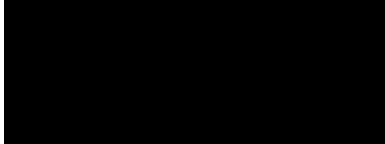
To protect your rights and safety this research will have been reviewed and approved by the University of Leicester and also by an independent group of individuals within the NHS Research Ethics Committee.

Who is the lead researcher/ person responsible for the research?

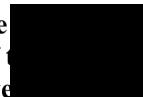
Jessica Conrad-Czaja (Trainee Clinical Psychologist, Doctorate Clinical Psychology Training Programme, University of Leicester).

If you have any queries or would like any further information please contact:

Jessica Conrad-Czaja (Chief Investigator)



If you are interested in taking part in this study, please complete the of Interest Form attached to this leaflet and hand it to a member of team or contact the Chief Investigator on the details provided above your interest. Thank you for taking the time to read this information.



Appendix Q – Consent Form



Consent Form

Title of Study: A qualitative study of the psychosocial and support experiences of individuals identified as having severe and enduring anorexia nervosa

Principal Researcher: Jessica Conrad-Czaja

Participant Identification Number:

Please initial each box

1. I confirm that I have read and understood the Participant Information Leaflet (Version 1.0 10th March 2017) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time before the data analysis is completed, without giving reason and without medical care or legal rights being affected.

☐

3. I understand that my data will be held securely and confidentially at the University of Leicester and that only Jessica Conrad-Czaja (Chief Investigator) and Dr Steve Allan (Academic Supervisor) will have access to the data. I understand that authorised individuals from the University of Leicester, and Leicestershire Partnership NHS Trust may look at the data collected during the study for audit purposes.

☐

4. I understand that my interview will be audio recorded, transcribed and written up and that the data will be anonymised at transcription.

☐

5. I understand that direct quotes from my interview may be used in the final write up but no names or identifiable information will be used.

☐

6. I understand that if the researcher is concerned about me being at risk of harming myself, harming others or being harmed by others, that they have a duty of care to break confidentiality and share this with the relevant people.

☐

7. I understand that my interview will be included as part of a thesis, and that the results will be made available in the public domain.

☐

8. **I agree to take part in the above study**

☐

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Consent Form Version 1.0 10th March 2017

1 of 1

Appendix R – Participant invitation and expression of interest letter



Letter of Invitation to Participants

A qualitative study of the psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa

Dear Participant,

You are being contacted about a study that may be of interest. The study is being conducted by Jessica Conrad-Czaja, a Trainee Clinical Psychologist on the Leicester Doctorate of Clinical Psychology.

Aim of the study: The purpose of this study is to explore the experiences of people with long standing anorexia nervosa and to understand how individuals with this diagnosis make sense of past experiences of treatment and support and also their future hopes and goals.

Please take your time to read the Participant Information Leaflet that is attached, as this will provide further details about the study. If you decide that you would like to take part, you will be asked to sign a written consent form before participating in an interview. The interview could last up to 90 minutes and you can take a break during this time if you would like to. The interview is likely to take place at the

[REDACTED]. The interview will take place on a one-to-one basis with Jessica Conrad-Czaja (Chief Investigator) and you will be asked questions relating to your experiences of living with an eating disorder, the treatment and support you have accessed in the past and your future hopes. Your input would be incredibly valuable and it is hoped that the results of this study will help to improve our understanding of the experiences of people who continue to experience difficulties with their eating and body image for a long time.

If you would like to take part in the study, you can contact Jessica (Chief Investigator) [REDACTED] 'expression of interest' form to [REDACTED] Leicestershire Adult Eating Disorder Service who will return this form to Jessica. If you decide to take part, please express your interest within 7 days of receiving this letter either by contacting Jessica or by returning the form to your clinician from the Leicestershire Adult Eating Disorder Service. If you do not express your interest within this time we will assume you do not want to take part in the study.

Please feel free to contact Jessica with any questions you have about the research on the contact details below. Thank you for taking the time to read this letter.

Yours Sincerely,

Jessica Conrad-Czaja

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

University of Leicester

Invitation Letter and Expression of Interest Version 1.0 10th March 2017 1 of 2

Expression of Interest

A qualitative study of the psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa

I am interested in hearing more about the above study. I am happy for Jessica Conrad-Czaja, the Chief Investigator, to contact me to discuss the study further.

Please contact me on the following details:

Name:

Phone number:

If you do not answer, can the researcher leave a voicemail? (Please circle): Y/N

Best time to be contacted by telephone:

Email:

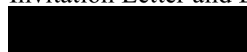
How would you prefer to be contacted? (Please circle): Phone/ Email

Thank you for your interest in taking part in the research study. I will be in contact



Thank you,

Jessica Conrad-Czaja



Appendix S* – Flexible interview guide



Flexible Interview Guide

Title: A qualitative study of the psychosocial and support experiences of individuals who are identified as having severe and enduring anorexia nervosa

This interview guide has been developed to aid the researcher in enquiring about certain topic areas. However, it is not prescriptive and the questions that will be asked to each participant will be guided by their responses.

Introduction to self, purpose of the interview, confidentiality issues, consent

1. Before we begin, I just wondered what you were thinking when you were reading the information about the study?
2. Can you tell me about the ways in which living with anorexia has impacted your life? *Prompts: Psychological impact? Social impact? Physical impact? Has it ever stopped you or limited you from doing something? Has it helped you in any way?*
3. Can you tell me about your experiences of the treatment and support you have accessed in the past? *Prompts: Experience of different staff groups or services? Experience of non-voluntary treatment?*
4. What has been helpful or unhelpful about the treatment and support you've accessed? *What's helped or hasn't helped to get better? Relationships with professionals? Motivation and choice? Why do you think changes in your relationship with eating and body image have not maintained? What could have been different? What motivates you to continue accessing support?*
5. What would 'recovery' mean to you? *Prompts: Hope for recovery or maintenance or improved quality of life? Hopes and expectations for the future? Which areas are important (QoL)?*
6. Can you tell me about anything else you'd like to add?

Appendix T – Stages of the IPA research process

The analysis process followed recommendations outlined by Smith et al., (2009). Although this process has several defined stages, it is acknowledged that the author should adopt a level of flexibility and use of personal intuition in accordance with their research project. These stages are therefore not prescribed, but are there to guide and facilitate an in-depth analysis process (Smith *et al.*, 2009).

Reading and re-reading

After transcribing each data set, the researcher read and re-read each transcript to become familiar with the data. This involved listening to the interviews, via the audio recording (before deletion), alongside reading the transcript in order to facilitate immersion in the data.

Initial coding

Following this, each transcript was analysed line-by-line and was incorporated three types of code; descriptive, linguistic and conceptual. The researcher took a stance of ‘free association’ and noted down any thoughts or responses to the data that arose. Descriptive comments involved describing the content of the data. Linguistic comments attended to the language used in the data. Conceptual comments focused on interpretative and exploratory engagement with the data. Different coloured pens were used for the different codes to enhance clarity and reflection (appendix U).

Developing emergent themes

Once the coding was complete, the initial codes were then grouped into “emergent themes”. These emergent themes attempted to capture pertinent chunks of data and express what appeared important about them. During this stage of analysis the researcher also noted down any potential assumptions that may be guiding the analysis, for example, the researchers own experience of working in an eating disorder service. This supported the researcher in engaging with the “double hermeneutic” aspect of IPA in which “participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008, p. 51).

Looking for patterns across emergent themes

After establishing the emergent themes, the researcher began to look for patterns between the emergent themes across each individual transcript. Through a process of abstraction (Smith *et al.*, 2009) the researcher mapped out how emergent themes might fit together to develop themes. It was deemed crucial to stay close to the original data and so this process involved noting down quotes from each respondent to reflect back to the initial codes. This stage involved compiling emergent themes on a computer file and visually moving them around to explore similarities and differences across the transcript. Once these had been collated into themes, the supporting extracts were then added in to produce a case level summary.

Looking for patterns across cases

Once this process had been completed for each participant, the next stage involved looking for patterns across the cases and considering how each participant's experiences related to the others. Where themes appeared to relate to each other, they were clustered together and given a descriptive label to capture the idiosyncratic experiences and conceptual characteristics. A variety of creative methods were utilised to facilitate this process, including post-it notes and coloured card to allow the researcher to visually manipulate the themes and to ensure that all of the participants were being given attention. A table was also created to record the frequency of themes and capture any divergence between the participants.

Translating themes into a narrative account

After comparing and contrasting clusters of themes and cross checking these with the original data, the final analysis resulted in four super ordinate themes with three or four sub-themes in each. These were then organised into a narrative account, which was facilitated by further interpretation by the researcher.

References:

- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Smith, J. A., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In J. A. Smith, (Ed.) *Qualitative Psychology: A Practical Guide to Research Methods* (2nd Edn. pp.51-80). London: Sage.

Appendix U – Extract of initial coding and case level summary of one participant

<p>What would it take for "enough" to be enough? - don't know?</p>	<p>Acceptance of being "underweight" Self criticism / judgement. Still some positives. Thinks she's too thin. Implies it could be worse?? Even though not many still some - would there need to be none?</p>	<p>I'm not... I'm not diabetic, so you know I... there are still some positives from being too thin but not many.</p>	<p>Pride in achievement. See-saw - not quite reached tipping point.</p>
<p>WHEN discussing the negatives, neglects physical impact / but positives - focuses on physical.</p>	<p>Positives of eating difficulties = exercise: flexibility. PHYSICAL POSITIVES. Comparison to others - views self in context of others rather than own well being? Pride? Achievement??</p>	<p>I: Can you tell me about the positives that there still are at this stage?</p> <p>P1: Well, I'm... bendable. I'm flexible. You know... I... I walk quite a long distance every morning with the dog. Urm, so I do quite a lot of exercise in various ways. And a lot of people, it seems, when they get to be 70, they can't bend down and touch their toes.</p> <p>I: So you see quite a lot of physical benefits from having anorexia at your age...</p> <p>P1: Yeah, yeah.</p>	<p>Emphasise +ive physical consequences Minimises -ive physical consequences.</p>
<p>If there was a magic wand - she would make it go away - hasn't ever believed in treatment/support efficacy?</p>	<p>PROTECTION (MAGIC WAND) (MIRACLE) only a protection - acknowledging not valuable?? Tails off "magic wand" -> would require magic / miracle to make it go away? Fantasy? Not possible in reality? Hopelessness? Or glimmer of hope but resigned to "probably not". Emphasises "genuinely" - even when it gets better it's still there - 'engrained'</p>	<p>I: Have there been any other benefits from having anorexia?</p> <p>P1: Oh, it's only a protection. It's not something... if I could wave a magic wand and make it go away... genuinely go away, I would. I don't think it does me any favours</p> <p>I: What do you think stops it from going away?</p>	<p>Need a magic wand. Recovery not a realistic possibility. Resigned / hopeless. Always there - engrained!!!</p>
	<p>under the surface - waiting to resurface as a protection when things get difficult. Don't think it does me any favours - "benefits" are spoken of but not believed?</p>	<p>Cost of this protection. Conflict between benefits/drawbacks?</p>	<p>Hidden shield.</p>

27

repetition - stuck in habit/cycle.

<p>Engrained — so deep can't get rid of it?</p> <p>Engrained habit — gives her routine & structure</p> <p>↳ Safety of sticking to rigid structure/routine.</p> <p>We all — normalising importance of structure! Hers just more than average.</p> <p>↳ It's 'normal' to have routine — she's just a bit diff to others.</p> <p>↳ Importance of predictable structure.</p> <p>Recovery wld be flexibility</p> <p>↳ Desire for flexibility — break out of rigid chains of AN — food, structure, routine etc.</p> <p>a way of organising chaos?</p> <p>Given up/resigned to AN.</p>	<p>P1: Habit. It's habit. It's engrained. I've been like this for 20 plus years and it's habit, it's triggers, you know...this is the time I do my exercise, this is the time I walk the dog, this is the time I eat my lunch...it's...it's all very rigid. Which is, it is just habit. Cuz we all, you know we all get up and have our breakfast at about the same time, and we have the midday meal at about the same time and so on. But it's...it's more constrained than average.</p> <p>I: You sort of say, if you could wave the magic wand and make it go away, you would. If there was a magic wand...what would recovery look like to you?</p> <p>P1: It would be being able to eat anything, well up to a limit, you know what I mean...not having a restricted diet and to eat at different times in the day...so more flexible. My life would be more flexible. Less...compartmentalised and you know I've got to do this now, I've got to do that now. It's very rigid at the moment</p> <p>I: So as you continue to access support, what is your hope for the future?</p> <p>P1: Well, I don't believe that my anorexia</p>	<p>IT'S ENGRAINED!</p> <p>Too late.</p> <p>Trapped in rigid cycle.</p> <p>Fear of losing control / desire for control.</p> <p>Desire for flexibility/choice.</p> <p>Resigned to AN.</p>
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someone telling her it will? Doesn't believe them?

Needs to see evidence to believe?

Fear of losing control if "got better"?

↳ Wld like some control bk.

Disbelief that recovery is possible.²⁸

Dorothy's Case Level Summary

<i>Super-ordinate/ subtheme</i>	<i>Page/ line in original transcript</i>	<i>Key words</i>
Conflict and contradictions		
Anorexia as a problem and a solution – give it up vs. function	24/21-28 26/21-23 20/1 3/9-11 6/16 36/16 8/11 9/1 24/24 12/16	Its pointless...it doesn't do any good but...I need it to survive Regularly decide enough is enough...but still some positives to being too thin Manipulative type of habit It makes life hard...miserable problem to have Best time of my life was when...anorexia just went away It's not all negative by any means It protects me against things I can't do anything about It's a protection...it's the way I cope with things It's a safety behaviour I use anorexia to get help for my children
Recovery as possible and impossible – maintenance vs. fluidity in severity vs. recovery	30/19 35/13 29/4 6/4 ... 40/8 28/28 35/2 29/7	I see Dr Smith because it stops me getting worse It's a case of managing it rather than getting over it Don't think there's a treatment out there that'll work Family just accept that's what I'm like...they accept I am an anorexic I don't believe my anorexia will ever go away Can't think of anything that will make a dramatic difference now I will have times when it less and more difficult but it won't go away

	27/18 35/ 8 28/16 29/21...30/13	If I could wave a magic wand and make it go away...genuinely go away...I would Maybe if my husband was very ill I would consider...start eating I wouldn't have a restricted diet...my life would be more flexible I could go to social occasions and join in...I might decide I'm better off isolated...but I'd like to have the opportunity
Carers and family as helpful and problematic	4/20 5/4 5/30 20/30...22/16 6/9 23/2 37/7	I need him around...[or] I'll cut corners I depend on [my husband] to keep me at the level I'm at My husband and I are carers for [our son] More notice now on carers and trying to involve family members...which is positive When I pregnant and bringing them up...anorexia just went away Cuz I wasn't eating for me. I was eating because I had an important job to do I try to keep [my family] away from my anorexia...I don't involve them
Relating to anorexia		
A whole identity	4/8 25/11	I see myself as an anorexic I am an anorexic and if you take that away then I am not anything, you know, I am just an old lady...I am no longer me
Investment in ED community	40/8 18/18 39/15	I am an anorexic My husband runs the carers group for the eating disorders and we hear via him what they're doing now and how its improved Understanding anorexia and improving treatment is very important
Isolation	2/7...3/11 7/22 11/10 14/30 30/3 5/6	It's made me isolated...that's the main thing...so many situations revolve around food and drink...it cuts you off It stops me going out for the Christmas meal...things like that...because social events are so often food orientated and drink orientated They didn't want me at university in that state I don't really remember having much to do with them (other gen psych pts) I need to see more people...I am very isolated... I'm dependent [on my husband] because there's nobody else

Appendix V – Presence of themes

Themes	Presence in participant's interviews						Total
	Dorothy	Betsy	Sienna	Edith	Vera	Meredith	
SEAN as a friend and a foe	Y	Y	Y	Y	Y	Y	6
Functionality of AN	Y	Y	Y	Y	Y	Y	6
The impact and cost of SEAN	Y	Y	Y	Y	Y	Y	6
Isolation and loneliness	Y	Y	Y	N	Y	Y	5
Internal conflict	Y	Y	Y	Y	Y	Y	6
A battle between holding on to SEAN or letting it go	Y	Y	Y	Y	Y	N	5
Paradox of control	Y	Y	Y	Y	Y	Y	6
Uncertainty about the future	Y	Y	Y	Y	Y	N	5
Inpatient or nothing	Y	Y	Y	Y	N	Y	5
Inpatient regime – gain weight but nothing changes	Y	Y	Y	N	Y	Y	5
Neglected as SEAN in the community	Y	Y	Y	N	Y	Y	5
Strike while the iron is hot or it is too late	Y	N	Y	Y	N	N	3
Valuing others but not themselves	Y	Y	Y	Y	Y	Y	6
Investment in ED community	Y	Y	Y	Y	N	Y	5
Caring for others but neglecting self	Y	Y	N	Y	Y	N	4
Internalised blame and shame	Y	Y	Y	N	Y	Y	5
Value of ongoing professional support	Y	Y	Y	Y	Y	Y	6