SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

Experiences of Eating Difficulties in Siblings of People with Anorexia Nervosa: A Reflexive Thematic Analysis

Submitted by Eleanor Scutt in partial fulfilment of requirements for the Doctoral Degree in Clinical Psychology

Primary Research Supervisor: **Dr. Janet Smithson**, Senior Lecturer

Secondary Research Supervisor: **Dr. Jasmin Langdon-Daly**, Clinical Psychologist

Word Count:

Literature Review: 5951 (Resubmission)

Empirical Paper: 8580 (Resubmission)

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Table of Contents

Acknowledgements

I would like to thank my supervisors Janet Smithson and Jasmin Langdon-Daly for their guidance in the development and writing of this research. Thank you to my friends and family for their support throughout my clinical psychology journey, and to Matt for endless moral support, cups of tea and proof reading. I am grateful to those who assisted with the development of this research through helping me to develop interview questions, piloting the interview and advertising for participants. Most of all I am indebted to my participants who generously gave their time and bravely shared their stories, this would not have been possible without them.

SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

SYSTEMATIC LITERATURE REVIEW

Patient Perspectives of the Positive and Negative Aspects of Inpatient Treatment for Anorexia Nervosa: A Systematic Review

Trainee Name: **Eleanor Scutt**

Primary Research Supervisor: **Dr. Janet Smithson**, Senior Lecturer

Secondary Research Supervisor: **Dr. Jasmin Langdon-Daly**, Clinical Psychologist

Target Journal: Journal of Eating Disorders

Word Count: 5946

Submitted in partial fulfilment of requirements for the Doctoral Degree in Clinical Psychology

Abstract

Background

Inpatient treatment for Anorexia Nervosa (AN) can lead to both beneficial and adverse outcomes for people of all ages. Through building a better understanding of what constitutes positive and negative experiences of inpatient admissions from a patient's perspective, we may be able to reduce the occurrence of adverse outcomes such as readmission and increased psychopathology. This paper reviews the positive and negative aspects of inpatient treatment for AN from the perspective of those who have experienced it.

Method

A systematic search identified 24 unique studies into patients' qualitative experiences of inpatient treatment for AN.

Findings

Participants described feeling both reassured and trapped by a loss of control upon inpatient admission. Psychological support and a good therapeutic relationship with staff could help motivate participants towards recovery and help them to manage the more difficult aspects of inpatient treatment. Staff who treated patients as individuals and were neither overly punitive nor permissive in the enforcement of rules were valued. Peers could act as a valuable source of support in the absence of friends and family, but could also cause distress and increased drive towards AN behaviours.

Conclusion

Relationships with staff are critically important to the experience of inpatient treatment for AN. Staff treating people with the illness should have appropriate knowledge and expertise, such that they are able to carefully balance the enforcement of rules without being overly punitive and have an understanding and appreciation of each individual patient. The needs of patients in terms of contact with the outside world, psychological support and mitigating potentially harmful effects of peers on the unit should be carefully considered.

Keywords

Anorexia Nervosa, Inpatient, Patient perspectives

Plain English Summary

People who are admitted to inpatient treatment for anorexia nervosa can have both good and bad experiences. By understanding what makes for a good experience we may be able to improve people's chance of recovery from their eating disorder. This systematic review aims to investigate the good and bad aspects of inpatient treatment for anorexia nervosa from the perspective of the patient. Findings suggest that staff on the inpatient unit can have an important role in patients' experiences of inpatient treatment. Staff that are knowledgeable, caring, and value each patient as an individual were seen by patients as helpful in their treatment. Patients did not like being treated as a diagnosis or being forced to comply with rules that are not clearly explained to them. Staff could also be helpful in allowing patients to connect with the outside world and, where possible, to have some agency in their treatment.

Background

Anorexia nervosa (AN) can lead to severe physical health consequences: due to complications associated with low body weight and high rates of suicide, this population has the highest mortality rates of any psychiatric illness (Arcelus et al., 2011, Anderson 2007). Inpatient treatment is often used to manage the risk of severe illness and death in those most unwell. This can be beneficial in helping patients to gain weight, thereby reducing the physical health risks associated with being very underweight (Meczekalski et al., 2013). The intensive nature of the inpatient environment may offer opportunities for recovery and may help patients to acknowledge their illness and become more accepting of treatment (Guarda et al., 2007). Conversely, negative experiences during inpatient treatment may reduce patients’ sense of self-efficacy, cause poorer mental wellbeing and lead to a long-term lack of trust in professionals (Gowers et al., 2000; Karlsson et al., 2021; Rich, 2006; Vandereycken & Vansteenkiste, 2009). Aspects of the inpatient environment, including rigid and inflexible rules and disengagement from the outside world, may also unwittingly perpetuate eating disorder psychopathology (Gowers et al., 2000; Treasure et al., 2011). A better awareness of patient experiences of inpatient treatment may help to ameliorate some of the negative aspects of the treatment whilst maximising the potential for better treatment outcomes (Chew-Graham, 2018).

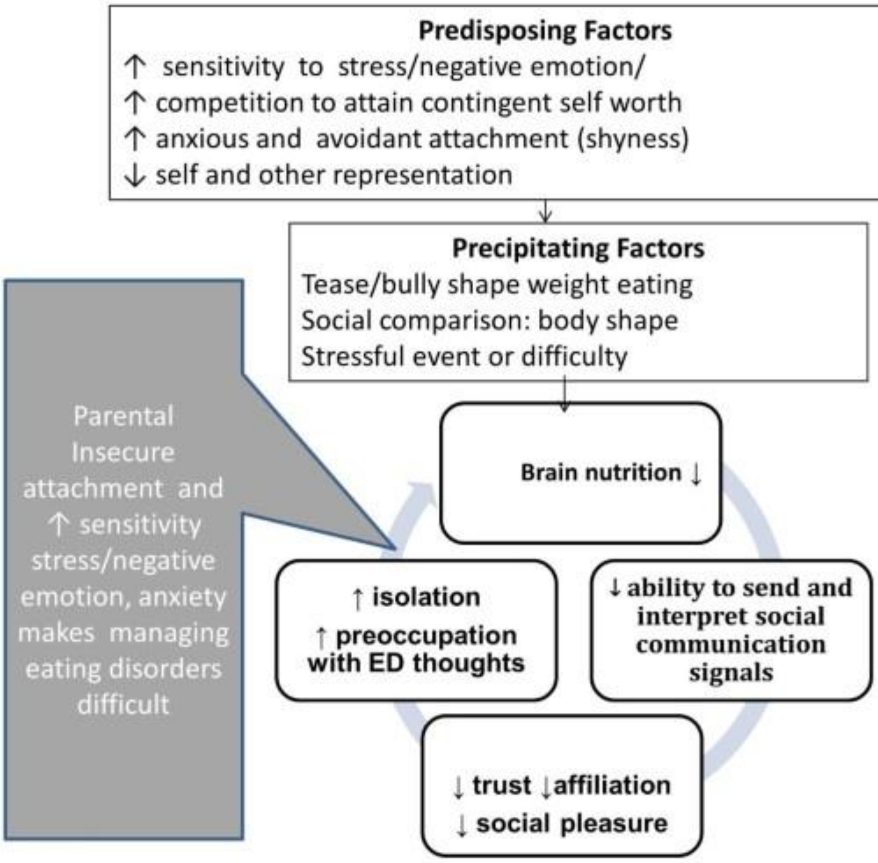
In the UK and in many countries worldwide, inpatient treatment is reserved for those whose risk is deemed to be too great to manage in the community (National Institute for Health and Care Excellence, 2017; Shepperd et al., 2009). In some cases, admission to an inpatient unit may also be considered as a means of respite for carers, for continued assessment or for managing comorbidities (Royal College of Psychiatrists, 2012, 2014). UK guidelines for inpatient treatment of adults and young people with AN offer best practice advice, including the recommendation that patients be admitted to a specialist unit where staff are well-trained and prepared for the needs of patients with AN (Royal College of Psychiatrists, 2012, 2014, 2017).

Inpatient treatment can be effective in weight restoration, but this may not translate into reductions in AN symptomology (Goddard et al., 2013; Schlegl et al., 2014). Remission rates following inpatient treatment for AN are estimated at 30-50% over the long term (Fichter et al., 2017; Löwe et al., 2001; Zipfel et al., 2000). Furthermore, readmission rates are high with estimates suggesting that 39% of adult patients are readmitted within a year of discharge (Murray et al., 2019; Steinhausen, 2002, Marzola et al., 2021). In adolescents, recovery rates following inpatient admission range from 33% making a full recovery after two years, to 67% after ten years (Gowers et al., 2007; Herpertz-Dahlmann et al., 2001). Readmission rates have been estimated at 44.8% over several years (Steinhausen et al., 2008). AN commonly starts during adolescence and the average duration is six years, meaning that many patients will experience treatment in both child and adult services (Morris & Twaddle, 2007; Treasure et al., 2005). This research covers people of all ages in recognition that many adult participants will also have experienced adolescent inpatient treatment.

The cognitive interpersonal maintenance model of AN suggests that several factors involved in the perpetuation of the condition may be encouraged in an inpatient unit (Treasure et al., 2011, 2020; Treasure & Schmidt, 2013). The structured and inflexible environment may fit well with a tendency for patients with AN to be rigid and detail-focussed in their thinking styles. This may be comforting for patients initially but could lead to increased difficulties upon discharge when needing to adapt to the changing demands of everyday life (Treasure et al., 2011). The model also posits that AN is both precipitated and maintained by interpersonal difficulties and isolation (see Figure 1). Being admitted to inpatient treatment may cause people to be disconnected from friends and family, thereby increasing isolation and entrenching eating disorder symptomology. The presence of peers on the ward may mitigate this by offering opportunities for connection, however, there is a danger that peers with AN may share pro-anorexia beliefs and behaviours (Allison et al., 2014; Vandereycken, 2011).

Figure 1

A Model of Interpersonal Difficulties in People with AN (from the Cognitive Interpersonal Maintenance Model (Treasure & Schmidt, 2013)*).*



Staff in the inpatient unit may be well placed to offer connection and compassion and influence motivation for recovery (Federici & Kaplan, 2008; Zaitsoff et al., 2016). They are also tasked with compelling patients to engage in treatment, often against their will, and need to carefully balance ethical principles, such as the patient's right to autonomy, with a duty to protect them from their illness (Matusek & Wright, 2010). Staff need to have sufficient expertise in the treatment of AN to be able to respond appropriately to patients (Royal College of Psychiatrists, 2012, 2014; Westwood & Kendal, 2012). Being overly critical or enabling of AN behaviours in patients may entrench the illness further; compassion, respect and understanding towards patients is paramount (Royal College of Psychiatrists, 2017). The role of staff may be particularly important in adolescent units where they take on the role of caregiver for patients. In the UK, adolescents are less likely to be admitted to specialist inpatient units and therefore may have reduced access to appropriately trained professionals (Royal College of Psychiatrists, 2012). Other issues, such as low levels of staffing, the use of temporary or untrained staff and compassion fatigue, may also be evident in many inpatient settings, and could increase the challenge to clinicians in providing individualised and empathic support (Graham et al., 2019). Patients in such environments may find their views and emotions pathologised, which could be detrimental to their experience of inpatient treatment and their recovery. Where inpatient treatment is considered ethical and appropriate, thought should be given to this, with evidence suggesting that programmes that promote autonomy and choice where possible are preferable to more restrictive ones (Vandereycken & Vansteenkiste, 2009).

Aims and Research Question

Inpatient treatment for people with AN is associated with both positive and negative consequences for patient health. Ensuring that inpatient admission has therapeutic benefit for patients is essential in avoiding unnecessary deprivations of liberty, multiple admissions and further entrenchment of AN psychopathology. Patient perspectives on what constitutes helpful and unhelpful inpatient treatment experiences are invaluable to improving outcomes. This review aims to explore qualitative research into patient experiences of inpatient treatment for AN and answer the following question:

What are patients' perspectives on the positive and negative aspects of inpatient treatment for AN?

Method

Search Strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021) was used to structure this systematic review, omitting some guidelines that are more appropriate for quantitative reviews.

Specifically, the SPIDER tool was used (Cooke et al., 2012) to develop a search strategy as this may be preferrable to the PICO framework for qualitative reviews (Slevitch, 2011). Inclusion and exclusion criteria are detailed in Table 1. Papers that focussed on patient experiences of inpatient treatment for Anorexia Nervosa were included. Studies that focussed on specific interventions or aspects of inpatient treatment that are not widely experienced were excluded. Research that focussed on perspectives of recovery or discharge was also excluded. Studies on people of any age were included to gain perspectives from patients who had experienced multiple admissions in different units. Case studies were excluded from this review in line with PRISMA guidelines (Page et al., 2021). To ensure academic rigour, only studies that had been published in a peer reviewed journal were included.

Table 1

Inclusion and Exclusion Criteria Using the SPIDER Tool

	Inclusion	Exclusion
Sample	• People of all ages who have been diagnosed with anorexia nervosa	• Patients admitted for an illness other than anorexia nervosa • Paper focusses on all eating disorders and does not identify specific perceptions of people with anorexia nervosa

Phenomenon of Interest	• Patient perspectives on an aspect of inpatient treatment for anorexia nervosa that is common to inpatient treatment e.g. meal support	• Exclusively focusses on a specific treatment or aspect of inpatient admission that would not be common across inpatient experiences
Design and Evaluation	• Uses any qualitative methods	• Case Studies
Research Type	• Qualitative research or mixed methods with qualitative element	• Quantitative research
Other Criteria	• Published in the last 20 years (since 2001) • Published in English • Primary research • Published in a peer reviewed journal • Includes full method and results	

After developing a research question, the SPIDER tool was used to identify preliminary search terms. Search terms were identified from relevant articles following scoping searches and through the use of thesaurus to look for synonyms (Bramer et al., 2018). Initial full-text searches gave large numbers of irrelevant papers, and the strategy was focussed by searching only titles and abstracts for sample and phenomenon of interest criteria. The search was limited to human participants, English language and journal articles.

The search strategy detailed in Table 2 was conducted in September 2021 on three databases: PsychInfo, Embase and PubMed.

Table 2

A Description of the Search Strategy

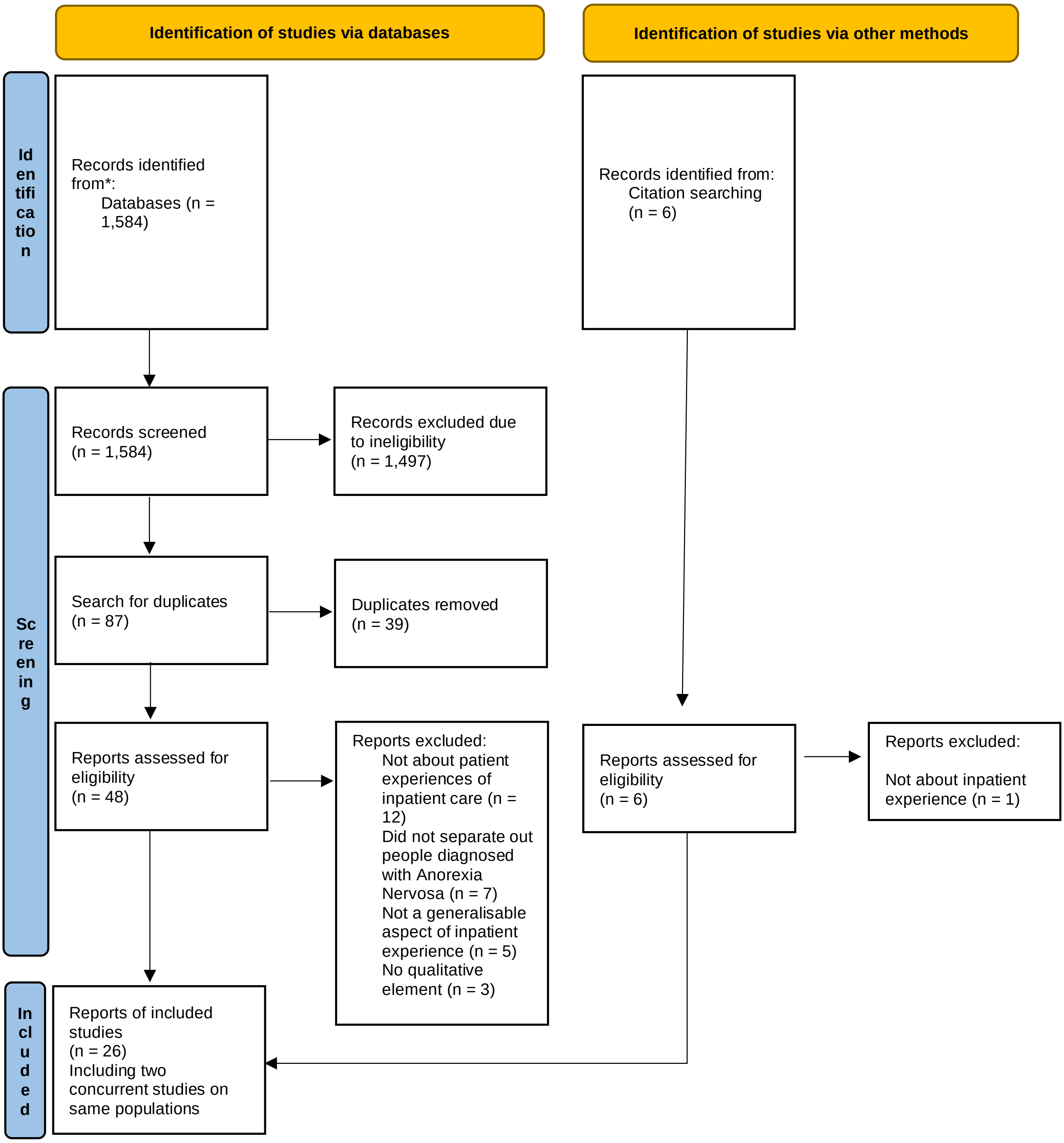
Search term	Text searched
Anorexi* OR Eating Disorder* OR Restrict* Eating OR Disordered Eating	Title/abstract

AND	
Inpatient OR Compulsory OR Acute OR Nasogastric	Title/abstract
AND	
Experience* OR Perspective* OR Perception*	Full text
AND	
Patient* OR Service user* OR Client* OR Consumer*	Full text

As shown in Figure 2, this search brought up 1,584 records across the three databases. Titles and abstracts were screened and all that clearly did not meet inclusion criteria were removed. Duplicates were eliminated, leaving 48 papers for full-text screening. Cross-checking reference lists gave a further six papers of which five met the eligibility criteria for inclusion. 26 studies were included overall, two of which had two publications each using the same data. 24 original studies were therefore included for meta-synthesis. The full text of six studies were reviewed by a second reviewer (a trainee clinical psychologist) for inclusion and exclusion criteria, yielding a 100% agreement.

Figure 2

Prisma Flowchart Showing the Process of Selecting Articles for the Review



Quality Appraisal

The Critical Appraisal Skills Programme (CASP) checklist for qualitative studies (Critical Appraisal Skills Programme, 2019) was used to assess the quality of each paper. This checklist does not have a recommended scoring criteria and items were therefore scored as follows: 0 if an item was not covered, 1 if discussed in little detail, 2 if adequately addressed and 3 if well addressed (Cesario et al., 2002). Papers were categorised as high quality if scoring above 22.5, moderate quality if scoring 15-22.4 and poor quality if scoring below 15 (see Appendix A). Three of the included studies were rated independently by a trainee clinical psychologist resulting in a linear weighted Kappa score of 0.57. Discrepancies in these scores were discussed until 100% agreement was reached across these studies.

Synthesis of Findings

A qualitative meta-synthesis of findings was conducted from the included papers following Erwin et al.'s (2011) description. Following identification of relevant papers for inclusion, information that was relevant to the research question was gathered from included papers.

As described in previous meta-syntheses (Campbell et al., 2003; Tong et al., 2008) a constant comparison method was used, with articles being read several times each and similar and contrasting findings noted. Findings and quotes from original articles were used to identify themes pertinent to the research question. Themes were grouped across papers, creating a synthesis of findings, with continual checking that these represented those in the original papers (see Appendix B).

Findings

An overview of the papers is presented in Table 3, followed by a commentary on the quality of the studies appraised and the meta-synthesis of findings.

Table 3

Studies included in the systematic review.

Author	Aim	Design	Participants	Age range (years)	Ethnicity	Current /Past Inpatient*	Specialist ED unit?	Findings	Country	CASP Rating
#1 Boughtwood & Halse (2010)	To explore how adolescent inpatients with AN construct their illness, treatment and relationships with staff.	Discourse Analysis	25 females	12-18	23 White, 2 Asian (Chinese)	Current	No	• Participants did not think that staff tried to develop an alliance or to understand them as people, this led to feeling powerless and wanting to resist the regimen of the unit. • Lack of understanding lead to either resistance to treatment or unwilling compliance.	Australia	Moderate
#2 Colton & Pistrang (2004)	To explore adolescents' views about their inpatient admission.	IPA*	19 females	12-17	18 White, 1 Black	Current	Yes	• Participants showed ambivalence about loss of control upon admission. • Positive and negative influences of peers. • Participants wished to be treated as an individual outside of their illness.	UK	Moderate
#3 Eli (2014)	To understand how hospitalisation for an eating disorder affects patients' identities.	IPA	12 female, 1 male	18-38	Unclear	Past	Yes	• Ward was seen as both oppressive and protective. • Participants felt connected to and distinct from others on the unit.	Israel	Moderate
***#4* Fox & Diab (2015)**	To explore experiences of inpatient treatment for	IPA	6 females	19-50	6 White	Current	Yes	• AN both valued and hated by participants. • Difficulties with staff who were pessimistic about recovery or not knowledgeable about AN.	UK	Moderate

	people with chronic AN.							- Relationships generally were difficult for participants and being in hospital increased detachment from family.		
#5 Holmes et al. (2021)	To investigate experiences of trust in inpatient treatment for AN.	Post-structural discourse-analytic	14 females	20-42	Unclear	Past	Mixed	- Lack of trust towards inpatients led to a lack of patient voice in treatment. - Participants described poor self-esteem, demotivation and triggering experiences of trauma.	UK	Moderate
***#6* Long et al. (2012)**	To explore patient perspectives on the experience of mealtimes during inpatient treatment for AN.	Thematic analysis	12 females	17-29	Unclear	Current	Yes	- Mealtimes were described as a battle and participants desired more choice and agency. - Consistency during mealtimes was important. - Participants were often ignored when sharing their frustration.	UK	Moderate
***#7* Nilsen et al. (2019, 2021)**	To investigate patient experiences of family-based inpatient treatment for AN.	Thematic analysis	33 female, 4 male	12-19	Unclear	Past	Yes	- Participants disliked being treated as ‘an anorexic’ and wanted to be seen as individuals. - Liked staff that enforced the rules in a respectful and compassionate way. - Activities both on and off the ward as a distraction and motivation for recovery were valued.	Norway	Moderate
#8 Offord et al. (2006)	To investigate experiences of adolescents who had received treatment for AN on general psychiatric ward.	IPA	7 females (one with experience of adult unit)	16-23	7 White	Past	No- General inpatient unit	- Wanted to be seen as an individual beyond AN - Treated differently from inpatients without AN - Feelings of worthlessness, ineffectiveness and isolation whilst receiving inpatient treatment. - Lack of psychological support until participants had gained weight was unhelpful.	UK	Moderate

#9 **Olsson & Landgren (2020)**	To explore how patients with AN experience inpatient treatment plus an acupuncture intervention.	Content analysis	25 females	18-72	Unclear	Current	Yes	• Ambivalence about being an inpatient. • Staff both helpful and oppressive • Peers provided both connection and competition.	Sweden	Moderate
#10 **Patterson et al. (2017)**	To explore patient perspectives on different aspects of inpatient treatment for AN, including relationships with staff.	Mixed methods, framework analysis	12 females.	18-50	Unclear	Past	Yes	• Staff were important to the inpatient experience. • Personalised, flexible and non-authoritarian attitudes from staff were helpful.	Australia	Moderate
#11 **Pemberton & Fox (2013)**	To explore patient experiences of emotion management whilst in inpatient treatment for AN.	IPA with grounded theory techniques	7 females, 1 male	Unclear (adults)	Unclear	Current	Yes	• Emotion management was important to recovery and affected by staff attitudes. • Good relationships with staff improved emotion management.	UK	Moderate
#12 **Ramjan & Gill (2012)**	To investigate the relationships between nurses and patients on an inpatient treatment programme for AN.	Thematic analysis	1 male, 9 females and 10 nurses.	11-18	Unclear	Current / recent	No-General medical ward	• Staff had limited understanding of psychological wellbeing. • Relationships between patients and staff were described as poor. • Patients likened treatment to prison. • Participants disliked the focus on weight and little emphasis on psychological support.	Australia	Poor

#13 Ross & Green (2011)	To explore the experiences of two women receiving inpatient care for treatment of AN.	Thematic analysis	2 females	Unclear (adults)	Unclear	Past	Unclear	• Difficulty with adjusting to being in inpatient but also to being discharged. • Feelings of isolation both on and off the ward. • Sense of safety when on the ward.	UK	Poor
#14 Seed et al. (2016)	To investigate patient experiences of detention under the MHA for treatment of AN.	Grounded theory	12 females	18-55	Unclear	Past	Unclear	• Described a battle with staff about treatment. • Some relief at having less control but also a loss of sense of self. Participants found weight gain distressing	UK	Good
***#15* Sibeoni et al. (2020)**	To understand facilitators and barriers to therapeutic alliance in inpatient treatment for AN.	Thematic analysis	15 females, 18 parents and 8 psychiatrists	13-17	Unclear	Past	Yes	• Therapeutic alliance was aided by staff respect, understanding and shared decision-making. • Parents were influential in determining relationships with staff.	France	Moderate
#16 Sly et al. (2014)	To explore the experiences of therapeutic alliance with nurses from patients receiving inpatient treatment for AN.	IPA	8 females	18-34	8 White	Current	Unclear	• Therapeutic alliance was an important part of treatment. • Nurses who were open, non-judgemental and upheld rules facilitated a therapeutic alliance. • Participants wanted to take an active role in their treatment.	UK	Poor
***#17* Smith et al. (2016)**	To explore adult females' experiences of inpatient	Thematic analysis	21 females	18-41	Unclear	Current	Yes	• Participants experienced both relief and vulnerability at loss of control. • Trusting relationships with staff and peers were helpful.	UK	Good

	treatment for AN.							- Comparison with peers was distressing.		
#18 **Spivack & Willig (2010)**	To explore the challenges and benefits of inpatient treatment for adolescents with eating disorders.	IPA	8 females	12-17	Unclear	Current	Yes	- Patients with a strong anorexic voice reported negative experiences of inpatient treatment. - Patients with a balance between anorexic and non-anorexic voices were ambivalent about inpatient experience.	UK	Moderate
#19 **Thabrew et al. (2020)**	To understand the experiences of adolescents who had recently received brief inpatient treatment for AN.	Thematic analysis	9 females	15-17	7 White, 2 Asian	Past-recent	Yes	- Positive experiences included support from staff and peers, and a feeling of safety. - Negative experiences were having little control, negative peer influences and poor staff knowledge.	New Zealand	Poor
#20 Tierney (2008)	To explore young people's experiences of treatment of AN.	Thematic analysis qualitative study	9 females, one male	11-18	10 White	Past	No	- Clinicians who challenged them empathically and treated patients as individuals rather than anorexics were valued - Patients wanted both psychological and physical needs to be attended to.	UK	Moderate
#21 **van Ommen et al. (2009)**	To investigate the aspects of nursing care that are important in recovery from the perspective of adolescent inpatients with AN.	Grounded theory	13 females	13-17	Unclear	Past	Yes	- Nurses taking initial responsibility and providing structure and normalisation was helpful. - Patients valued taking more responsibility as treatment progressed.	Netherlands	Moderate

#22 Wu & Harrison (2019)	To explore experiences inpatient treatment for AN in China.	IPA	4 females	16-19	4 Asian (Chinese)	Current	Unclear	• Participants described both positive and negative aspects of peer influence. • There was a desire for more psychological support and help to manage stigma around inpatient admission.	China	Good
#23 Zugai et al. (2013)	To investigate how nurses contribute to weight gain and inpatient experiences from the perspective of adolescent inpatients with AN.	Thematic analysis	8 females	14-16	Unclear	Past	No	• Therapeutic alliance with nurses was important to participants' motivation for recovery, experiences of inpatient care and weight gain. • Nurses that enforced rules in a flexible, understanding and non-punitive way encouraged recovery.	Australia	Moderate
#24 Zugai et al. (2018a, 2018b)	To understand the context and nature of therapeutic alliance between patients with AN and their nurses.	Thematic analysis	33 females, one male and 20 nurses.w	Over 12 (mean= 20)	Unclear	Current	No	• Participants wanted to be seen as individuals, separate from their illness. • They wanted rules to be enforced fairly, with explanation but also flexibly when needed.	Australia	Moderate

Notes: *IPA= Interpretive Phenomenological Analysis.

†= Current/past inpatient refers to whether people participated during their inpatient stay or after discharge.

Quality Appraisal Results

Aims

Eight papers aimed to investigate the therapeutic alliance in an inpatient environment (#1, #5, #12, #15, #16, #21, #23, #24), twelve looked at general inpatient experiences (#2, #4, #8, #9, #10, #13, #14, #17, #18, #19, #20, #22), and four studies aimed to explore other aspects of the inpatient experience such as mealtimes (#6), emotion management (#11), family-based admission (#7) and forming identities (#3). Therapeutic alliance, for the purposes of this review, was defined broadly as a collaboration between staff and patients to work towards helping a patient to recover and ease suffering (Bordin, 1979). Although family-based treatment is not a generalisable experience for all inpatients, this research was included because it also covered general aspects of the inpatient experience (#7).

Participants

332 participants were included, comprising of 323 females and 9 males diagnosed with Anorexia Nervosa. Estimates suggest that around 25% of cases of AN are in males (Beat, 2021), indicating that males are underrepresented across these studies. Most studies included were completed in the UK (#2, #4, #5, #6, #8, #11, #13, #14, #16, #17, #18, #20), with others conducted in New Zealand (#19), Australia (#1, #10, #12, #23, #24), Sweden (#9), Israel (#3), Netherlands (#21), Norway (#7), France (#15) and China (#22). Notably only two studies were completed in non-western countries (#3, #22). This is in line with other research into AN where non-western cultures are underrepresented (van Eeden et al., 2021), a factor that limits understanding of treatments for AN in these cultures. This is important because AN may present differently in different cultures and the requirements of inpatient units may vary (Agüera et al., 2017; Wu & Harrison, 2019). Several studies did not provide information on the ethnicities of their participants; those that did reported that participants were all white (#4, #8, #16, #20) or majority white (#1, #2, #19), except for one study conducted on a Chinese population (#22). 12 studies were in an adolescent population (#1, #2, #7,

#8, #12, #15, #18, #19, #20, #21, #22, #23), 11 on an adult population (#3, #4, #5, #6, #9, #10, #11, #13, #14, #16, #17), and one study focussed on participants over the age of 12 with no breakdown of participants' actual ages (#24). 11 studies interviewed current inpatients (#1, #2, #4, #6, #9, #11, #16, #17, #18, #22, #24), and 12 focussed on people who had been inpatients in the past (#3, #5, #7, #8, #10, #13, #14, #15, #19, #20, #21, #23), one covered both current and recently discharged inpatients (#12).

Methodology

All studies used semi-structured interviews with individuals to gather qualitative data, this may be problematic in that it relies heavily on the researchers' ability to gather meaningful data and to interpret meaning in the manner desired by the participant (Alsaawi, 2016). Some used a relatively structured guide for interview questions (#4, #12, #15), whereas others used few open-ended questions with further questions being shaped by participants' answers (#6, #7, #9, #14, #22). One study also included field notes of the researchers' observations for analysis (#1). There was variation in how well the interview questions were described with some giving explicit lists of questions and topics (#2, #4, #5, #8, #14, #15, #22) and some giving a vaguer outline of broad interests (#3, #9, #10, #13, #16, #17, #18, #20, #21, #23, #24) or in one case little information at all (#19).

Researcher Reflexivity

Although six of the studies reported that researchers kept a reflexive journal (#8, #11, #12, #14, #17, #20) and a further study reported the use of bracketing and reflection (#18), only one gave detail about the content of this and how researchers' opinions and experiences influenced their interpretation of data (#22). Reflexivity allows for enhanced credibility through increased acknowledgement of the biases of the researcher and how these affect the collection and interpretation of data (Berger, 2015). Nine studies discussed the background of the researchers (#4, #9, #10, #11, #14, #15, #16, #17, #18), and another disclosed that the researcher had experienced

AN in the past (#5) but the influence on the study was not mentioned. It is possible (particularly for those who used reflexive tools) that bias was considered but that limits imposed by journals caused this to be omitted from the published paper.

The use of techniques such as triangulation and member-checking during data analysis are employed to enhance credibility through gathering consensus opinions (Birt et al., 2016; Hill et al., 2005), however, the utility of employing such methods has been debated (Barbour, 2001). 16 papers reported using second and third raters and/or the use of member-checking and described a process of discussion and consensus-seeking in arriving at final findings (#2, #4, #5, #6, #7, #8, #9, #10, #14, #15, #16, #17, #19, #20, #21, #22).

Ethical Considerations

A minority of papers (#1, #2, #4, #19, #20) gave no mention of having obtained ethical approval for the research. Only three papers gave consideration to the full variety of ethical problems that may arise in this sort of research, including informed consent, right to withdraw and protocols for managing the distress of participants (#6, #18, #22). Given the sensitive nature of this topic, particularly for adolescent participants and those currently receiving inpatient treatment, the lack of consideration of the distress and wellbeing of participants is concerning. It is possible that this was considered but not reported due to limited journal word counts (Dodgson, 2019). The remaining papers obtained ethical approval and most reported a process of obtaining informed consent from participants (n=16).

Findings and Relevance

All studies used quotes to illustrate themes: these are important in grounding the research in the data and retaining the richness of individual experiences (Sandelowski, 1994). Some papers used quotes extensively, offering examples that both supported and contradicted themes (#2, #8 #17, #18). Extensive use of quotes, and evidence of contrasts and contradictions in the data, is helpful in enhancing credibility of the research (Huberman & Miles, 2002). Some papers used quotes sparingly, either presenting themes without quotes or using very short quotes that may not capture the intent or context of the full sentence, or failed to include contrasting data (#10, #14 #13, #18).

Meta-synthesis

The findings from the papers were grouped into four themes: ambivalence about the loss of control, relationships with staff are important, peers as helpful and unhelpful, and wellbeing and connection.

Ambivalence About the Loss of Control

Ambivalence about losing control of diet and exercise regimes and their daily lives when admitted to the inpatient unit was widely discussed, such that participants felt anger, anxiety and frustration, but also relief at the diminished responsibility (#2, #3, #4, #8, #10, #13, #14, #17, #18, #19, #20, #21, #23). For some this allowed them an “excuse for eating and not exercising” (#20). In most studies, participants described both positive and negative feelings at this loss of control, however, in three studies participants described only feeling like prisoners (#1, #5, #12). In these studies, which were not conducted in specialist eating disorder units, adult and adolescent patients were subjected to high levels of surveillance and connection with friends and family was restricted; staff were generally untrusting and saw patients as deviant.

Participants of all ages wished for all rules to have clear, well-explained rationales and for them to be applied in the least restrictive way possible (#2, #5, #7, #8, #9, #14, #18, #20). In seven studies (six in adolescent and one in adult populations) participants spoke about rules being overly punitive in inpatient units; rules were seen in this way if they were applied without any regard to the context of the situation (#2, #5, #7 #8, #12, #18, #23). Examples including limited access to the telephone (#8) or restrictions on privacy lead to feelings of rebellion, dislike of staff and a sense of lack of agency (#1, #2, #5, #8, #14, #18). In adolescent populations such rules led to feelings of anger and hopelessness (#2, #8, #12, #18, #19).

Consistency in the implementation of rules making them predictable and fair, was desired (#2, #6 #11, #12, #19, #23, #24). This contrasted with a wish amongst adolescents for rules to be flexible (#7, #18, #23, #24) and, amongst all ages, for them to be individualised (#7, #8, #9, #10, #14). Participants did not want to be treated differently from one another but disliked being forced to comply with rules that were not relevant for their specific difficulties. For example, it was deemed unfair to restrict toilet use after meals to those for whom purging was not an issue (#8).

Participants wanted to take an active role in their care and be involved in meetings, treatment plans and meal planning (#2, #6, #8, #15, #16, #17, #18, #19, #21). In one study young people in a specialist unit described how treatment programmes were implemented without any discussion or input from them, making it difficult for them to feel agency in their recovery or develop therapeutic alliances with staff (#15). This brings about a difficult issue around the need to allow patients to develop agency and understanding in their illness, whilst acknowledging that offering too much control may be accommodating of AN behaviours. There was recognition from some current inpatients that this input may be open to abuse by those strongly entrenched in their illness (#2), and there were suggestions that patients may be able to take a more active role in their treatment as they moved towards recovery (#17).

Relationships with Staff are Important

Participants described a strong desire to be treated as individuals, separate from their diagnosis and to feel genuinely listened to and cared for (#1, #2, #3, #5, #7, #8, #10, #11, #14, #15, #17, #19. #21, #23, #24). Staff who were reliable, consistent and authentic were valued (#7, #10, #15, #17, #21, #23), as were staff who introduced a sense of fun, offered distraction and spoke about normal things (#8, #9, #10, #21, #23). Some adolescent participants appreciated staff who assumed a maternal or sisterly role by enforcing rules in an understanding empathic way and valuing the individual (#15, #23, #24).

Studies with adolescents highlighted the importance of therapeutic alliance in role-modelling healthy behaviours and increasing motivation for recovery through not wanting to disappoint staff (#16, #17, #21, #23, #24). This was also true for one study in adults (#14). For all ages, staff could be helpful in providing emotional support that was valuable in managing difficult times (#5, #14, #16, #17, #19, #23).

A good relationship with staff was often dependent on bidirectional trust. Some adolescents reported having good, trusting relationships with staff where they felt like equals (#18, #23). However, many participants of all ages described experiencing distrust from staff (#1, #3, #5, #9, #11, #14, #22). At the more distressing end, this could lead to participants feeling dehumanised and retraumatised, resulting in poorer self-esteem and wellbeing (#5, #14, #22). Several studies in adults (#4, #5, #10, #11, #17) and one in adolescents (#2) reported that a lack of trust continued patterns that participants had experienced with their families, making them feel neglected. In several cases participants felt unable to feedback about different experiences or to talk about emotional difficulties without these experiences being pathologised (#2, #3, #5, #8, #14, #15, #21, #24). This potentially paves the way for abusive treatment with patients given no power to complain.

The therapeutic alliance could be damaged by staff easily believing lies they were told; patients reported that this led to them becoming more deceptive, giving more control to the eating disorder (#4, #7, #16, #20, #21). Participants praised staff who were neither too controlling nor too passive in upholding treatment rules (#16). They described a need for staff to be able to separate the individual from the illness and conceptualise challenging behaviours as a symptom of AN rather than as a personal characteristic (#4, #5, #7, #9, #10, #14, #15, #18, #21, #23). For example, a patient may have lied about exercising but this does not make them a liar (#11). This approach allowed patients to feel supported by staff and to discuss rule-breaking honestly without feeling judged or punished (#4, #5, #7, #9, #10, #14, #15, #18, #21, #23). Staff who had both expertise and experience in working with people with AN were deemed better able to understand behaviours that were characteristic of the illness and to see the individual beyond the illness (#2, #3, #5, #8, #10, #11, #14,

#15, #17, #24). This expertise was also useful in providing patients with appropriate emotional support and information about their illness (#4, #7, #8, #10, #14, #15, #19, #20, #21, #22).

Peers as Helpful and Unhelpful

Peers were reported to offer friendship and connection to others (#2, #3, #5, #8, #9, #10, #17, #18, #19, #20, #22). For some participants in a specialist unit, this sense of connection was something they had found difficult to achieve in the outside world (#10): participants reported being able to talk through their issues with people who could really understand them for the first time.

However, many participants, adolescent and adult, felt the need to compete with others on the ward to be the thinnest, take the longest time eating or to be the best at anorexia (#2, #3, #6, #7, #8, #10, #14, #17, #18, #19, #20, #22). This was especially difficult when thinner people were admitted to the ward as comparisons fuelled a desire to lose weight. Participants in both specialist and non-specialist units noted that they learnt new unhelpful behaviours from others whilst on the ward that reinforced their disordered eating (#1, #2, #3, #6, #7, #8, #10, #17, #19, #22).

Some participants noted that comparison with others could be motivating and helpful as it allowed them to see the benefits of getting better (#21), to take some responsibility for role-modelling to others (#9), and to understand the futility of ED behaviours (#3). However, people in specialist units also reported feeling frightened by seeing others in distress and were traumatised by this (#2, #9, #10, #17, #18). One study in China found that far from feeling connected, some adolescents felt alienated or bullied whilst in inpatient care and this was detrimental to their wellbeing (#22). Due to China's one-child policy participants in this study may have been living with peers for the first time, potentially influencing their experiences.

Wellbeing and Connection

Participants of all ages spoke about feeling disconnected from friends, family, school, work and their usual activities (#3, #4, #8, #12, #14, #17, #18, #19). For some, this lack of connection to the outside reduced motivation for recovery and increased anxiety about discharge (#8, #14, #18). Participants valued regular visits from friends and family in helping them to feel in touch with the outside world; they also liked getting out of the ward environment to do normal activities (#4, #7, #17). Punishments for violating rules were seen as particularly unhelpful if they increased isolation or disconnection, for example cancelling family visits or enforced bed rest (#8, #14).

Many adolescent participants felt that their psychological needs had not been fully attended to during their admission and that there was too much focus on their weight and physical wellbeing (#2, #8, #12, #19, #20, #22). This was also the case for two adult populations (#5, #10). Participants of all ages described a need for psychological treatment to be offered in tandem with physical support (#2, #8, #9, #10, #19, #22). In adults there were reports of self-esteem being negatively impacted by inpatient treatment through a lack of trust (#5) and through forced interventions such as restraint or nasogastric feeding (#14). Additionally, for adolescents a lack of psychological support to help manage shame around the illness and feelings about weight gain was described as unhelpful (#2, #8, #22).

Discussion

This review highlights clear factors that constitute good aspects of inpatient care for AN. Participants consistently valued being respected, treated as individuals rather than diagnoses and fair and relevant rules. Unhelpful aspects of inpatient care included overly punitive rules, a lack of trust from staff and being unable to have input into their own care. Other findings appear to be contradictory: participants felt both protected by the ward and trapped by it, they were comforted by peers and harmed by them, they wanted consistent regulations but also individualisation. These inconsistences were reported across adult and adolescent studies, in specialist and non-specialist eating disorder units, and in current and past inpatients. Given the widespread reporting of these issues and the fact that opinions may be influenced by the presence of ‘an anorexic voice’ (Spivack & Willig, 2010), it is likely that individuals may hold more than one view on these aspects of care. For example, they may feel both comforted and oppressed by the unit at the same time or at different times during their admission. This highlights the importance of staff that can consider the importance of patients' views and individuality, whilst also understanding the need to consistently implement rules that aid recovery.

There were few differences between adolescents and adults in what they found helpful and unhelpful from their admission. Adolescents desired a slightly different relationship with nursing staff, wanting them to be parental and deriving motivation for change through wanting to please favoured staff. Where good relationships were not achieved, adolescents reported feelings of anger and hopelessness, whereas adults tended to relate this to past experiences of feeling untrusted and this impacted their self-esteem. Adults spoke more about harmful experiences of lack of trust from staff, whereas young people focussed more on the need for greater psychological understanding and support. As adults are more likely to have had multiple admissions, this may reflect changes in perspectives following increased time spent in mental health systems and less trust in professionals following previous unsuccessful treatments.

The discussion about how much patients should be involved in their treatment plan is contentious. For patients who lack motivation to change, this may allow opportunity to influence rules in a way that maintains the eating disorder, which is of critical concern for those at a low body weight. However, motivation for change is central to recovery regardless of the culture imposed by the inpatient unit (Thaler et al., 2016) and research suggests that autonomy may precede the development of motivation (van der Kaap-Deeder et al., 2014). Furthermore, increased choice may reduce drop-out rates (Vandereycken & Vansteenkiste, 2009), and be effective over shorter-duration than standard models (Paquin Hodge et al., 2019). Promoting autonomy may also be important in allowing patients to develop a sense of self outside of their anorexic self, potentially aiding recovery (K. Williams et al., 2016; S. Williams & Reid, 2012).

Consistent with previous literature (Marzola et al., 2019; Sly et al., 2013), a good therapeutic alliance with staff was described as hugely significant to inpatient experiences and to recovery. Descriptions of staff as punitive, uncaring and invalidating, leading to patients feeling dehumanised and lacking any sense of agency, were particularly concerning. This form of treatment may lead to a ‘me against them’ mentality amongst patients who feel angry towards staff and feel incentivised to rebel against the regime or to comply solely to bring about discharge (Treasure et al., 2011). Staff that are too permissive or enabling of disordered eating behaviours were also seen as unhelpful by participants. In line with guidance given for carers by the cognitive interpersonal maintenance model (Treasure & Schmidt, 2013), staff are required to finely balance the enforcement of rules with ensuring that they are individualised, flexible and not overly punitive. To do this effectively staff need to have a good understanding of AN and be genuinely compassionate to the individual outside of the eating disorder. Guidelines state the need for staff to have expertise in treating AN, to separate out challenging behaviours as a symptom of the illness rather than as a personal characteristic, and to treat patients with compassion and respect (Royal College of Psychiatrists, 2017). This puts a high level of responsibility on staff, particularly on nursing staff who may have the most frequent contact with patients. The need to support patients physically and psychologically in the presence of challenging behaviours means that this role can be difficult and particular care is needed to ensure that staff are well supported (Davey et al., 2014; Wright & Schroeder, 2016). This is of particular concern in non-specialist units where staff may not have expertise in treating AN.

Clinical Implications

This review reaffirms the need to see people with AN as individuals outside of their illness. There is a significant emphasis on the role of staff in thoughtful enforcement of rules, providing psychological support, aiding meaningful connection for patients and motivating recovery. This requires that staff are well-trained, appropriately supervised and given time and support to carefully think through how to best help each individual. Staff are in a powerful position to influence patient experiences of inpatient treatment and as such, staff burnout should be continually assessed as a risk factor that could impact on the wellbeing and potential for recovery of inpatients. Non-specialist units particularly should assess whether staff treating people with AN have the appropriate level of knowledge, expertise and support to work with this population.

The potential negative impact of overly punitive or invasive rules should be considered and all inpatient units that treat people with AN should review their rules to ensure that they are appropriate and adaptable to individual patient needs. Where possible service users and their families should be included in this and in managing their care plans (Royal College of Psychiatrists, 2012, 2014, 2017). To reduce the risk of traumatising or abusive experiences, patients should be provided with multiple methods for feeding back on their experiences of care throughout their admission.

The findings from this review highlight the importance of encouraging people with AN to develop connections with others. When in inpatient treatment this may happen through contact with peers and/or through encouragement to maintain or rebuild connections with friends and family outside of the unit. Suitable psychological support should be available throughout the admission to help manage relationships and deal with difficulties associated with AN.

Limitations

As with any qualitative meta-synthesis, the findings of each study are heavily dependent on the context in which it was conducted, and any attempt to draw overarching conclusions is at risk of being reductionist (Bearman and Dawson 2013). In assessing patient perspectives on benefits and drawbacks of inpatient treatment for AN, I acknowledge that this is informed by my own views as a white trainee clinical psychologist with no previous experience of treatment for AN. Much of my training and experience has been focussed on a desire to provide autonomy and freedom for patients and this was challenged by the need for direct intervention against the wishes of the patient in this population. During this review I have had to balance a wish to avoid coercive treatment with an understanding that this can be lifesaving for acutely unwell patients. This potentially increases the voice I have given to those who felt oppressed by their treatment but is in keeping with an ethos of 'do no harm'.

Scoring criteria were applied to the CASP checklist, even though this contradicts the scoring guidelines suggested by the tool and may result in a reductionist evaluation of the included studies, it offers some clarity around how well each criterion was met. Some of the studies reviewed were of poor quality, with limited use of quotes to support arguments, lack of presentation of contradictory data and methodological inconsistencies. Additionally, the underrepresentation of non-female, non-western and non-white participants may limit the applicability of this review to other populations. Finally, this review neglected to include papers concerning specific aspects of inpatient treatment for AN, that whilst not general experiences may be particularly distressing for those that experience them, such as nasogastric feeding or restraint.

Further Research

Only two papers reviewed were conducted on non-Western populations and further research into patient experiences in different cultures would be valuable. One area where this would be particularly relevant is in patient experiences of peers on an inpatient unit. Future research into how to mitigate the more damaging aspects of peer relationships during admissions would be beneficial.

Finally, there is little research into staff burnout in staff who treat inpatients with AN, one recent study in Norway suggested that levels of burnout are low but further research across other healthcare systems would be beneficial to investigate this (Hage et al., 2021).

Conclusion

This systematic review focusses on patient perspectives of the positive and negative aspects of inpatient treatment for AN. Staff were very important in influencing patient experiences of inpatient treatment: positive staff relationships could be motivational and uphold treatment rules whilst providing support and understanding. More importantly, they could enable patients to have a sense of connection with others and to feel important as an individual outside of their illness. Poor relationships with staff could lead to patents feeling neglected, unimportant, and wishing to rebel against treatment. Inpatients liked to feel involved in their care where possible and for rules to be tailored to the individual, consistently enforced but not overly restrictive. Whilst treating inpatients with AN units should consider their psychological needs and promote healthy relationships and connections both inside and outside of the inpatient environment.

List of Abbreviations

AN: Anorexia nervosa
IPA: Interpretative Phenomenological Analysis

References

Agüera, Z., Brewin, N., Chen, J., Granero, R., Kang, Q., Fernandez-Aranda, F., & Arcelus, J. (2017). Eating symptomatology and general psychopathology in patients with anorexia nervosa from China, UK and Spain: A cross-cultural study examining the role of social attitudes. *PLOS ONE*, *12*(3), e0173781. https://doi.org/10.1371/journal.pone.0173781

Allison, S., Warin, M., & Bastiampillai, T. (2014). Anorexia nervosa and social contagion: Clinical implications. *Australian and New Zealand Journal of Psychiatry*, *48*(2), 116–120. https://doi.org/10.1177/0004867413502092

Alsaawi, A. (2016). A Critical Review of Qualitative Interviews. *European Journal of Business and Social Sciences*, *3*(4). https://doi.org/10.2139/ssrn.2819536

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. *Archives of General Psychiatry*, *68*(7), 724. https://doi.org/10.1001/archgenpsychiatry.2011.74

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ*, *322*(7294), 1115–1117. https://doi.org/10.1136/bmj.322.7294.1115

Beat. (2021). *How many people have an eating disorder in the UK? - Beat*. https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/how-many-people-eating-disorder-uk/

Berger, R. (2015). Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking. *Qualitative Health Research*, *26*(13), 1802–1811. https://doi.org/10.1177/1049732316654870

Bordin, E. S. (1979). The generalizability of the psychoanalytic concept of the working alliance.

Psychotherapy: Theory, Research & Practice, *16*(3), 252–260. https://doi.org/10.1037/h0085885

Boughtwood, D., & Halse, C. (2009). Other than obedient: Girls' constructions of doctors and treatment regimes for anorexia nervosa. *Journal of Community & Applied Social Psychology*, *20*(2). https://doi.org/10.1002/casp.1016

Bramer, W. M., de Jonge, G. B., Rethlefsen, M. L., Mast, F., & Kleijnen, J. (2018). A systematic approach to searching: an efficient and complete method to develop literature searches. *Journal of the Medical Library Association*, *106*(4), 531. https://doi.org/10.5195/jmla.2018.283

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*, *56*(4), 671–684. https://doi.org/10.1016/S0277-9536(02)00064-3

Cesario, S., Morin, K., & Santa-Donato, A. (2002). Evaluating the level of evidence of qualitative research. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *31*(6), 708–714. https://doi.org/10.1177/0884217502239216

Chew-Graham, C. A. (2018). Seeking the patient perspective. *Health Expectations*, *21*(3), 561–562. https://doi.org/10.1111/hex.12801

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, *12*(5), 307–316. https://doi.org/10.1002/erv.587

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435–1443. https://doi.org/10.1177/1049732312452938

Critical Appraisal Skills Programme. (2019). *CASP Qualitative Studies Checklist*. https://casp-uk.net/casp-tools-checklists/

Davey, A., Arcelus, J., & Munir, F. (2014). Work demands, social support, and job satisfaction in eating disorder inpatient settings: A qualitative study. *International Journal of Mental Health Nursing*, *23*(1), 60–68. https://doi.org/10.1111/inm.12014

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, *35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Eli, K. (2014). Between difference and belonging: configuring self and others in inpatient treatment for eating disorders. *PLoS ONE*, *9*(9), e105452. https://doi.org/10.1371/journal.pone.0105452

Erwin, E. J., Brotherson, M. J., & Summers, J. A. (2011). Understanding qualitative metasynthesis. *Journal of Early Intervention*, *33*(3), 186–200. https://doi.org/10.1177/1053815111425493

Federici, A., & Kaplan, A. S. (2008). The patient's account of relapse and recovery in anorexia nervosa: a qualitative study. *European Eating Disorders Review*, *16*(1), 1–10. https://doi.org/10.1002/erv.813

Fichter, M. M., Quadflieg, N., Crosby, R. D., & Koch, S. (2017). Long-term outcome of anorexia nervosa: Results from a large clinical longitudinal study. *International Journal of Eating Disorders*, *50*(9), 1018–1030. https://doi.org/10.1002/eat.22736

Fox, J. R. E., & Diab, P. (2015). An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an Eating Disorders Unit: An Interpretative Phenomenological Analysis (IPA) study. *Journal of Health Psychology*, *20*(1), 27–36. https://doi.org/10.1177/1359105313497526

Goddard, E., Hibbs, R., Raenker, S., Salerno, L., Arcelus, J., Boughton, N., Connan, F., Goss, K., Laszlo, B., Morgan, J., Moore, K., Robertson, D., S, S., Schreiber-Kounine, C., Sharma, S., Whitehead, L., Schmidt, U., & Treasure, J. (2013). A multi-centre cohort study of short term outcomes of hospital treatment for anorexia nervosa in the UK. *BMC Psychiatry*, *13*(1), 287. https://doi.org/10.1186/1471-244X-13-287

Gowers, S. G., An, J. W., Shore, A., Hossain, F., & Elvins, R. (2000). Impact of hospitalisation on the outcome of adolescent anorexia nervosa. *British Journal of Psychiatry*, *176*(2), 138–141. https://doi.org/10.1192/bjp.176.2.138

Gowers, S. G., Clark, A., Roberts, C., Griffiths, A., Edwards, V., Bryan, C., Smethurst, N., Byford, S., & Barrett, B. (2007). Clinical effectiveness of treatments for anorexia nervosa in adolescents. *British Journal of Psychiatry*, *191*(5), 427–435. https://doi.org/10.1192/bjp.bp.107.036764

Graham, M. R., Tierney, S., Chisholm, A., & Fox, J. R. E. (2019). Perceptions of the "anorexic voice": A qualitative study of health care professionals. *Clinical Psychology & Psychotherapy*, *26*(6), 707–716. https://doi.org/10.1002/cpp.2393

Guarda, A. S., Pinto, A. M., Coughlin, J. W., Hussain, S., Haug, N. A., & Heinberg, L. J. (2007). Perceived coercion and change in perceived need for admission in patients hospitalized for eating disorders. *American Journal of Psychiatry*, *164*(1), 108–114. https://doi.org/10.1176/ajp.2007.164.1.108

Hage, T. W., Isaksson Rø, K., & Rø, Ø. (2021). Burnout among staff on specialized eating disorder units in Norway. *Journal of Eating Disorders*, *9*(1), 138. https://doi.org/10.1186/s40337-021-00473-x

Herpertz-Dahlmann, B., Mu$ Ller, B., Herpertz, S., Heussen, N., Hebebrand, J., & Remschmidt, H. (2001). Prospective 10-year follow-up in adolescent anorexia nervosa—course, outcome, psychiatric comorbidity, and psychosocial adaptation. *Journal of Child Psychology and Psychiatry*, *42*(5), 603–612. https://doi.org/10.1111/1469-7610.00756

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology*, *52*(2), 196–205. https://doi.org/10.1037/0022-0167.52.2.196

Holmes, S., Malson, H., & Semlyen, J. (2021). Regulating "untrustworthy patients": Constructions of "trust" and "distrust" in accounts of inpatient treatment for anorexia. *Feminism & Psychology*, *31*(1), 41–61. https://doi.org/10.1177/0959353520967516

Huberman, M., & Miles, M. B. (2002). *The qualitative researcher's companion.* Sage.

Karlsson, S., Friberg, W., Rask, M., & Tuvesson, H. (2021). Patients' experiences and perceptions of recovering from anorexia nervosa while having contact with psychiatric care: A literature review and narrative synthesis of qualitative studies. *Issues in Mental Health Nursing*, *42*(8), 709–719. https://doi.org/10.1080/01612840.2020.1847222

Long, S., Wallis, D., Leung, N., & Meyer, C. (2012). "All eyes are on you": anorexia nervosa patient perspectives of in-patient mealtimes. *Journal of Health Psychology*, *17*(3), 419–428. https://doi.org/10.1177/1359105311419270

Löwe, B., Zipfel, S., Buchholz, C., Dupont, Y., Reas, D. L., & Herzog, W. (2001). Long-term outcome of anorexia nervosa in a prospective 21-year follow-up study. *Psychological Medicine*, *31*(5), 881–890. https://doi.org/10.1017/S003329170100407X

Marzola, E., Albini, E., Delsedime, N., Fassino, S., & Abbate-Daga, G. (2019). Therapeutic alliance in inpatients with severe anorexia nervosa. *European Eating Disorders Review*, *27*(6), 671–681. https://doi.org/10.1002/erv.2687

Marzola, E., Longo, P., Sardella, F., Delsedime, N., & Abbate-Daga, G. (2021). Rehospitalization and "revolving door" in anorexia nervosa: Are there any predictors of time to readmission? *Frontiers in Psychiatry*, *12*, 694223. https://doi.org/10.3389/fpsyt.2021.694223

Matusek, J. A., & Wright, M. O. D. (2010). Ethical dilemmas in treating clients with eating disorders: A review and application of an integrative ethical decision-making model. *European Eating Disorders Review*, *18*(6), 434–452. https://doi.org/10.1002/erv.1036

Meczekalski, B., Podfigurna-Stopa, A., & Katulski, K. (2013). Long-term consequences of anorexia nervosa. *Maturitas*, *75*(3), 215–220. https://doi.org/10.1016/j.maturitas.2013.04.014

Morris, J., & Twaddle, S. (2007). Anorexia nervosa. *BMJ*, *334*(7599), 894–898. https://doi.org/10.1136/bmj.39171.616840.BE

National Institute for Health and Care Excellence. (2017). *Eating disorders: recognition and treatment*. https://www.nice.org.uk/guidance/ng69/chapter/Recommendations#treating-anorexia-nervosa

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2019). Minding the adolescent in family-based inpatient treatment for anorexia nervosa: a qualitative study of former inpatients' views on treatment collaboration and staff behaviors. *BMC Psychology*, *7*(1), 72. https://doi.org/10.1186/s40359-019-0348-2

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2021). Family-based inpatient treatment for adolescent anorexia nervosa: a thematic analysis of former patients' post-treatment reflections. *Eating Disorders*, *29*(4), 390–407. https://doi.org/10.1080/10640266.2019.1656469

Offord, A., Turner, H., & Cooper, M. (2006). Adolescent inpatient treatment for anorexia nervosa: a qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review*, *14*(6), 377–387. https://doi.org/10.1002/erv.687

Olsson, A., & Landgren, K. (2020). Getting well is more than gaining weight – patients' experiences of a treatment program for anorexia nervosa including ear acupuncture. *Issues in Mental Health Nursing*, *41*(4), 328–338. https://doi.org/10.1080/01612840.2019.1663567

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. https://doi.org/10.1136/bmj.n71

Paquin Hodge, C., Gauvin, L., St-Hilaire, A., Israel, M., Azzi, M., Kahan, E., Thaler, L., Dansereau, E., & Steiger, H. (2019). A naturalistic comparison of two inpatient treatment protocols for adults with anorexia nervosa: Does reducing duration of treatment and external controls compromise outcome? *International Journal of Eating Disorders*, *52*(9), 1015–1023. https://doi.org/10.1002/eat.23150

Patterson, S., Bellair, R., Jeffrey, S., & Ward, W. (2017). Patients' perspective on inpatient treatment for eating disorders: A mixed-methods study of satisfaction, experience of care and perceived helpfulness of components of treatment. *Mental Health and Addiction Research*, *2*(5). https://doi.org/10.15761/MHAR.1000149

Pemberton, K., & Fox, J. R. E. (2013). The experience and management of emotions on an inpatient setting for people with anorexia nervosa: A qualitative study. *Clinical Psychology & Psychotherapy*, *20*(3), 226–238. https://doi.org/10.1002/cpp.794

Ramjan, L. M., & Gill, B. I. (2012). An inpatient programme for adolescents with anorexia described as a metaphorical prison. *AJN, American Journal of Nursing*, *112*(8), 24–33. https://doi.org/10.1097/01.NAJ.0000418094.31317.52

Rich, E. (2006). Anorexic dis(connection): managing anorexia as an illness and an identity. *Sociology of Health and Illness*, *28*(3), 284–305. https://doi.org/10.1111/j.1467-9566.2006.00493.x

Ross, J. A., & Green, C. (2011). Inside the experience of anorexia nervosa: A narrative thematic analysis. *Counselling and Psychotherapy Research*, *11*(2), 112–119. https://doi.org/10.1080/14733145.2010.486864

Royal College of Psychiatrists. (2012). *Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa*. http://www.rcpsych.ac.uk/publications/collegereports.aspx

Royal College of Psychiatrists. (2014). *MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa 2nd edition CR189*. http://www.rcpsych.ac.uk/

Royal College of Psychiatrists. (2017). *Standards for Adult Inpatient Eating Disorder Services Second Edition*. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/eating-disorders-qed/2nd-edition-standards-for-adult-inpatient-eating-disorder-services.pdf?sfvrsn=86374031_2

Sandelowski, M. (1994). Focus on qualitative methods. The use of quotes in qualitative research. *Research in Nursing & Health*, *17*(6), 479–482. https://doi.org/10.1002/nur.4770170611

Schlegl, S., Quadflieg, N., Löwe, B., Cuntz, U., & Voderholzer, U. (2014). Specialized inpatient treatment of adult anorexia nervosa: effectiveness and clinical significance of changes. *BMC Psychiatry*, *14*(1), 258. https://doi.org/10.1186/s12888-014-0258-z

Seed, T., Fox, J., & Berry, K. (2016). Experiences of detention under the mental health act for adults with anorexia nervosa. *Clinical Psychology & Psychotherapy*, *23*(4), 352–362. https://doi.org/10.1002/cpp.1963

Shepperd, S., Doll, H., Gowers, S., James, A., Fazel, M., Fitzpatrick, R., & Pollock, J. (2009). Alternatives to inpatient mental health care for children and young people. *Cochrane Database of Systematic Reviews*, *15*(2), CD006410. https://doi.org/10.1002/14651858.CD006410.pub2

Sibeoni, J., Verneuil, L., Poulmarc’h, L., Orri, M., Jean, E., Podlipski, M.-A., Gérardin, P., & Révah-Lévy, A. (2020). Obstacles and facilitators of therapeutic alliance among adolescents with anorexia nervosa, their parents and their psychiatrists: A qualitative study. *Clinical Child Psychology and Psychiatry*, *25*(1), 16–32. https://doi.org/10.1177/1359104519882765

Slevitch, L. (2011). Qualitative and quantitative methodologies compared: ontological and epistemological perspectives. *Journal of Quality Assurance in Hospitality & Tourism*, *12*(1), 73–81. https://doi.org/10.1080/1528008X.2011.541810

Sly, R., Morgan, J. F., Mountford, V. A., & Lacey, J. H. (2013). Predicting premature termination of hospitalised treatment for anorexia nervosa: The roles of therapeutic alliance, motivation, and behaviour change. *Eating Behaviors*, *14*(2), 119–123. https://doi.org/10.1016/j.eatbeh.2013.01.007

Sly, R., Morgan, J. F., Mountford, V. A., Sawer, F., Evans, C., & Lacey, J. H. (2014). Rules of engagement: qualitative experiences of therapeutic alliance when receiving in-patient treatment for anorexia nervosa. *Eating Disorders*, *22*(3), 233–243. https://doi.org/10.1080/10640266.2013.867742

Smith, V., Chouliara, Z., Morris, P. G., Collin, P., Power, K., Yellowlees, A., Grierson, D., Papageorgiou, E., & Cook, M. (2016). The experience of specialist inpatient treatment for anorexia nervosa: A qualitative study from adult patients' perspectives. *Journal of Health Psychology*, *21*(1), 16–27. https://doi.org/10.1177/1359105313520336

Spivack, A., & Willig, C. (2010). 'There is a battle within yourself': Exploring the experience of a split sense of self among inpatients with eating disorders. *Counselling Psychology Review*, *25*(4), 7–18.

Steinhausen, H. C., Grigoroiu-Serbanescu, M., Boyadjieva, S., Neumärker, K. J., & Metzke, C. W. (2008). Course and predictors of rehospitalization in adolescent anorexia nervosa in a multisite study. *International Journal of Eating Disorders*, *41*(1), 29–36. https://doi.org/10.1002/EAT.20414

Thabrew, H., Mairs, R., & Taylor-Davies, G. (2020). Young people's experiences of brief inpatient treatment for anorexia nervosa. *Journal of Paediatrics and Child Health*, *56*(1), 30–33. https://doi.org/10.1111/jpc.14483

Thaler, L., Israel, M., Antunes, J. M., Sarin, S., Zuroff, D. C., & Steiger, H. (2016). An examination of the role of autonomous versus controlled motivation in predicting inpatient treatment outcome for anorexia nervosa. *International Journal of Eating Disorders*, *49*(6), 626–629.

https://doi.org/10.1002/eat.22510

Tierney, S. (2008). The Individual Within a Condition: A qualitative study of young people's reflections on being treated for anorexia nervosa. *Journal of the American Psychiatric Nurses Association*, *13*(6), 368–375. https://doi.org/10.1177/1078390307309215

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*, *121*(2), 349–360. https://doi.org/10.1542/peds.2006-3470

Treasure, J., Crane, A., McKnight, R., Buchanan, E., & Wolfe, M. (2011). First do no harm: Iatrogenic maintaining factors in anorexia nervosa. *European Eating Disorders Review*, *19*(4), 296–302. https://doi.org/10.1002/ERV.1056/FORMAT/PDF

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

Treasure, J., Schmidt, U., & Hugo, P. (2005). Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry*, *187*(5), 398–400. https://doi.org/10.1192/BJP.187.5.398

Treasure, J., Willmott, D., Ambwani, S., Cardi, V., Clark Bryan, D., Rowlands, K., & Schmidt, U. (2020). Cognitive interpersonal model for anorexia nervosa revisited: the perpetuating factors that contribute to the development of the severe and enduring illness. *Journal of Clinical Medicine*, *9*(3), 630. https://doi.org/10.3390/jcm9030630

van der Kaap-Deeder, J., Vansteenkiste, M., Soenens, B., Verstuyf, J., Boone, L., & Smets, J. (2014). Fostering self-endorsed motivation to change in patients with an eating disorder: The role of perceived autonomy support and psychological need satisfaction. *International Journal of*

Eating Disorders, *47*(6), 585–600. https://doi.org/10.1002/eat.22266

van Eeden, A. E., van Hoeken, D., & Hoek, H. W. (2021). Incidence, prevalence and mortality of anorexia nervosa and bulimia nervosa. *Current Opinion in Psychiatry*, *34*(6), 515–524. https://doi.org/10.1097/YCO.0000000000000739

van Ommen, J., Meerwijk, E. L., Kars, M., van Elburg, A., & van Meijel, B. (2009). Effective nursing care of adolescents diagnosed with anorexia nervosa: the patients' perspective. *Journal of Clinical Nursing*, *18*(20), 2801–2808. https://doi.org/10.1111/j.1365-2702.2009.02821.x

Vandereycken, W. (2011). Can eating disorders become 'contagious' in group therapy and specialized inpatient care? *European Eating Disorders Review*, *19*(4), 289–295. https://doi.org/10.1002/erv.1087

Vandereycken, W., & Vansteenkiste, M. (2009). Let eating disorder patients decide: Providing choice may reduce early drop-out from inpatient treatment. *European Eating Disorders Review*, *17*(3), 177–183. https://doi.org/10.1002/erv.917

Westwood, L. M., & Kendal, S. E. (2012). Adolescent client views towards the treatment of anorexia nervosa: a review of the literature. *Journal of Psychiatric and Mental Health Nursing*, *19*(6), 500–508. https://doi.org/10.1111/j.1365-2850.2011.01819.x

Williams, K., King, J., & Fox, J. R. E. (2016). Sense of self and anorexia nervosa: A grounded theory. *Psychology and Psychotherapy: Theory, Research and Practice*, *89*(2), 211–228. https://doi.org/10.1111/PAPT.12068

Williams, S., & Reid, M. (2012). 'It's like there are two people in my head': A phenomenological exploration of anorexia nervosa and its relationship to the self. *Https://Doi.Org/10.1080/08870446.2011.595488*, *27*(7), 798–815. https://doi.org/10.1080/08870446.2011.595488

Wright, K., & Schroeder, D. (2016). Turning the Tables. *Cambridge Quarterly of Healthcare Ethics*, *25*(2), 219–227. https://doi.org/10.1017/S0963180115000523

Wu, Y., & Harrison, A. (2019). “Our daily life was mainly comprised of eating and sitting:” a qualitative analysis of adolescents’ experiences of inpatient eating disorder treatment in China. *Journal of Eating Disorders*, *7*(1), 20. https://doi.org/10.1186/s40337-019-0250-6

Zaitsoff, S., Pullmer, R., Menna, R., & Geller, J. (2016). A qualitative analysis of aspects of treatment that adolescents with anorexia identify as helpful. *Psychiatry Research*, *238*(30), 251–256. https://doi.org/10.1016/j.psychres.2016.02.045

Zipfel, S., Löwe, B., Reas, D. L., Deter, H.-C., & Herzog, W. (2000). Long-term prognosis in anorexia nervosa: lessons from a 21-year follow-up study. *The Lancet*, *355*(9205), 721–722. https://doi.org/10.1016/S0140-6736(99)05363-5

Zugai, J. S., Stein-Parbury, J., & Roche, M. (2018a). The nature of the therapeutic alliance between nurses and consumers with Anorexia Nervosa in the inpatient setting: A mixed-methods study. *Journal of Clinical Nursing*, *27*(1–2), 416–426. https://doi.org/10.1111/jocn.13944

Zugai, J. S., Stein-Parbury, J., & Roche, M. (2018b). Therapeutic alliance, anorexia nervosa and the inpatient setting: A mixed methods study. *Journal of Advanced Nursing*, *74*(2), 443–453. https://doi.org/10.1111/jan.13410

Zugai, J., Stein-Parbury, J., & Roche, M. (2013). Effective nursing care of adolescents with anorexia nervosa: a consumer perspective. *Journal of Clinical Nursing*, *22*(13–14), 2020–2029. https://doi.org/10.1111/jocn.12182

Appendix A

Critical Appraisal Skills Programme (CASP) Scores

Table A1

Scores on the CASP Qualitative Checklist Per Paper Included in the Review and a Scoring Key.

Scoring Key	
Criteria fully addressed	3
Criteria mostly addressed	2
Criteria partly addressed	1
Criteria not addressed	0

Total score	**Quality rating**
>23	Good
15.5-22.5	Moderate
<15	Poor

Authors	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Research design appropriate?	4. Recruitment strategy appropriate?	5. Data collected to address research issue?	6. Relationship between researcher and participants considered?	7. Ethical issues considered?	8. Data analysis sufficiently rigorous?	9. Clear statement of findings?	10. Will results help locally?	Total Score
Boughtwood & Halse (2010)	3	3	3	2.5	1.5	0	1	2	1.5	1	18.5

Colton & Pistrang (2004)	3	3	2	3	2	0.5	0.5	2	2	3	21
Eli (2014)	2	3	2	1	1	0	2	1	1	1	14
Fox & Diab (2015)	2	3	2	1	2	1	0	2	2.5	1.5	17
Holmes, Malson & Semlyen (2021)	2	3	2	2	2	1	2	2	1	1	18
Long et al. (2011)	2.5	3	2	2	2	0	3	1	2	2	19.5
Nilsen et al. (2019, 2021)	3	3	2	2	2	1	2	2	3	1.5	21.5
Offord, Turner & Cooper (2006)	3	2	1.5	1	1	2	2	3	3	3	21.5
Olsson & Landgren (2020)	2	3	3	2	1	1.5	2	1.5	2	1	19
Patterson et al. (2018)	3	2.5	2	2.5	2	1	2	1.5	1	1	18.5
Pemberton & Fox (2013)	3	2.5	2	2	3	1.5	2	2	2	2	22
Ramjan & Gill (2012)	1	2	1	1	2	0	2	1	1	1	12
Ross & Green (2011)	1	2	3	1.5	1	0	2.5	1	1	1.5	14.5
Seed, Fox & Berry (2016)	3	3	3	2	3	1	2	2	2	2	24
Sibeoni et al. (2020)	3	3	2	2	2.5	0.5	1	1.5	2	2.5	20
Sly et al. (2014)	1.5	2.5	2	2	2	0	1	1.5	1	1	14.5
Smith et al. (2016)	3	3	1.5	3	2	2	2	2.5	2.5	2	23.5
Spivack & Willig (2010)	1.5	2	2	2	2	2	3	2.5	2	2	21
Thabrew, Mairs & Taylor-Davies (2019)	2.5	2.5	2	2	1	0.5	0	0.5	1.5	1	13.5

Tierney (2008)	1.5	3	2	2	1.5	1.5	0.5	1	1	1	15
Van Ommen et al. (2009)	3	3	2	3	1.5	0	2	1	2	2	19.5
Wu & Harrison (2019)	2	3	2	2	2	2.5	3	2	2	3	23.5
Zugai, Stein Parbury & Roche (2013)	2.5	3	2	2	1	0	3	1	2	2	18.5
Zugai, Stein-Parbury & Roche (2018, 2018)	3	3	2	2	2	0	2	1	2	2	19

Appendix B

Example of Meta-synthesis Process

Table B1

An Example of How Findings from Papers were Extracted and Themes Identified

Paper and specifics of its population	Findings
Sibeoni et al. (2020): ***Adolescents, Past inpatients, Specialist unit***	*Ambivalence about control* • Adolescents wanted to play an active role in their own care. • Although they acknowledged that it takes time to develop a therapeutic alliance, they also said that being hospitalised for long periods of time was negative for them and was an obstacle to therapeutic alliance over time. • Adolescents thought that being excluded from decisions and forced to comply with treatment made TA impossible. *Relationships with staff* • Adolescents spoke about the importance of reliability, authenticity, being listened to and understood and being able to talk without fear of judgement. • Wanted relationships with staff that were comparable in intensity and quality to family relationships. Valued maternal-like care from staff. • Adolescents didn't like staff being overly protective or intrusive, they did not like there being a focus solely on weight gain and wanted to be considered as individuals and not diseases, liked personalised treatments. adolescents felt that often staff didn't understand their illness and saw them as hostile or aggressive or just as a list of symptoms. *Wellbeing* • Participants valued support being offered to parents and siblings independently and valued support on working to repair family relationships. They noted that separation during hospitalisation could have a calming effect on family rifts.
Smith et al. (2016): ***Adults, Current inpatients, Specialist unit.***	*Ambivalence about control* • Participants described some relief in handing over control of their illness when being admitted. However, others described this as very scary and threatening as it took away the safety and control provided by the eating disorder. • Dislike of restrictive environment but an awareness of the need for it. • Valued being able to take greater control overeating as treatment progressed. • Would like to be more involved in treatment including attending meetings. • Many found it difficult initially to adjust to inpatient treatment after home, but viewed inpatient as a safe place over time and found protection from the stresses of life. For some this led to dependence and anxiety over discharge. *Relationships with staff* • Relationships with staff were seen as key parts of the inpatient experience, good and bad. When staff were insensitive or prioritised others this was very difficult. • Valued individualised care- did not like being treated as 'anorexics' and liked it to be personalised, valued psychological support. *Influence of peers*

- Participants felt understood by peers and this was valuable. They described learning from peers in both helpful and unhelpful ways. They spoke about comparing themselves physically to others and coveting thinness- entrenching AN behaviours.
- Found it difficult to cope with the distress of others.
  Wellbeing and connection
- Participants valued being able to get out and do normal things, they worried that being in the unit was a life that was too different from reality and therefore it would be difficult to maintain recovery outside. Many worries about discharge.
- Recovery was described as physically and emotionally difficult. Development of self-identity and confidence was described during recovery.

SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

Experiences of Eating Difficulties in Siblings of People with Anorexia Nervosa: A Qualitative Study

Trainee Name: **Eleanor Scutt**

Primary Research Supervisor: **Dr. Janet Smithson**, Senior Lecturer

Secondary Research Supervisor: **Dr. Jasmin Langdon-Daly**, Clinical Psychologist

Target Journal: Journal of Eating Disorders

Word Count: 7990

Submitted in partial fulfilment of requirements for the Doctoral Degree in Clinical Psychology

Abstract

Background

Siblings of people with Anorexia Nervosa (AN) have been found to experience strong emotions, changing family roles and poorer wellbeing as a consequence of witnessing the illness. These factors, combined with genetic influences, may put siblings at an increased risk of developing eating disorder psychopathology. This research aims to explore the experiences of siblings of people with AN who have had eating difficulties themselves and investigate issues that may be important to the development and prevention of eating difficulties in this population.

Methods

This qualitative study used a reflexive thematic analysis approach. Ten adults who had witnessed a sibling with AN and experienced eating difficulties themselves participated in semi-structured interviews.

Analysis

Participants' own eating difficulties were affected by the specific experience of witnessing a sibling with AN through mealtimes becoming emotionally charged, an increased focus on body size and diet, and comparisons with their sibling. Difficult experiences, such as marital discord amongst parents were common, as was a difficulty in managing emotions. Changing family roles following their sibling's illness could have influenced the development of eating difficulties, and limited participants' ability to access support for their own difficulties. Systemic beliefs regarding the value of thinness were prevalent and influential. Possible protective factors, such as not wanting to become as unwell as a sibling with AN and an understanding of the negative consequences of AN, aided recovery.

Conclusions

Eating difficulties in siblings of people with AN may be influenced by competition for slimness, increased focus on diet and body size, and a need to manage difficult emotions. The cognitive interpersonal maintenance model of AN suggests that poor emotional regulation and disrupted social connections are influential predisposing and perpetuating factors for the illness (Treasure & Schmidt, 2013). Disruptions to connections within the family and increased emotional distress are common when a family member develops AN, and may influence the susceptibility to eating difficulties. Family therapy could address the needs of siblings and family scripts around body size and diet and aim to reduce people assuming responsibility for their sibling's health.

Key Words

Anorexia nervosa, Siblings, Eating difficulties, Experience.

Plain English Summary

This research investigates the experiences of people who have had a sibling with anorexia and had some eating difficulties themselves. Participants described difficult emotions after their sibling developed anorexia and many took on responsibility for helping their sibling. This was a stressful experience which some people managed by restricted their own eating. There was an increased focus on food and body size in the home, and this could also influence participants' diet. Getting help could be difficult as participants did not want to burden their family with their own difficulties. This research concludes that when treating people with anorexia, the impact on siblings should be considered, and support should be offered to siblings to help them to manage the difficulties that this illness presents.

Background

Anorexia Nervosa (AN) affects multiple facets of an individual's functioning, including marked changes to mood, behaviour, and relationships (Herpertz-Dahlmann, 2009). Very low body weights associated with the condition cause energy deficiencies, impaired physical and mental abilities, and an increased risk of mortality (Arcelus et al., 2011). Despite these impacts patients can show reluctance to change and concerned family members are often involved in compelling individuals into treatment and supervising eating up to six times per day (Eisler et al., 2016). The intensity of caring for someone with such an illness has been well documented (Anastasiadou et al., 2014; Coomber & King, 2008; Zabala et al., 2009), however, much of this research has focussed on parents of people with AN with far less research exploring the effects on siblings. Siblings often have their lives disrupted due to changes in family relationships and the trauma of seeing a family member acutely unwell. Recent research has started to address this gap in the literature, finding that the wellbeing of siblings is negatively affected by experiencing a sibling with AN (van Langenberg et al., 2016). A meta-analysis across eating disorder classifications suggested that siblings may experience decreased quality of life, as well as increased isolation and psychopathology (Maon et al., 2020). Such difficulties, coupled with an increased genetic susceptibility to AN in siblings, could put siblings at greater risk of eating disorder psychopathology.

Evidence surrounding the development of disordered eating in siblings of people with AN is mixed. Some research suggests that lifetime prevalence is around four times higher than the general population (Steinhausen et al., 2015; Strober, 2000). Other research suggests no increased tendency to eating disorder pathology in siblings of people with eating disorders (Amianto et al., 2011; Benninghoven et al., 2008; Wunderlich et al., 2004). Qualitative studies report that siblings describe an increased awareness of food and a tendency to compare their bodies to their unwell sibling's (Areemit et al., 2010; Callio & Gustafsson, 2016; Jungbauer et al., 2016). The impact of this on their eating habits was mixed, with some reports finding that they have developed a healthier attitude towards food (Areemit et al., 2010; Callio & Gustafsson, 2016), some that it had no effect (Benninghoven et al., 2008; Maloney & Shepard-Spiro, 1983; Wunderlich et al., 2004) and others suggesting that it was detrimental (Dimitropoulos et al., 2013; Jungbauer et al., 2016).

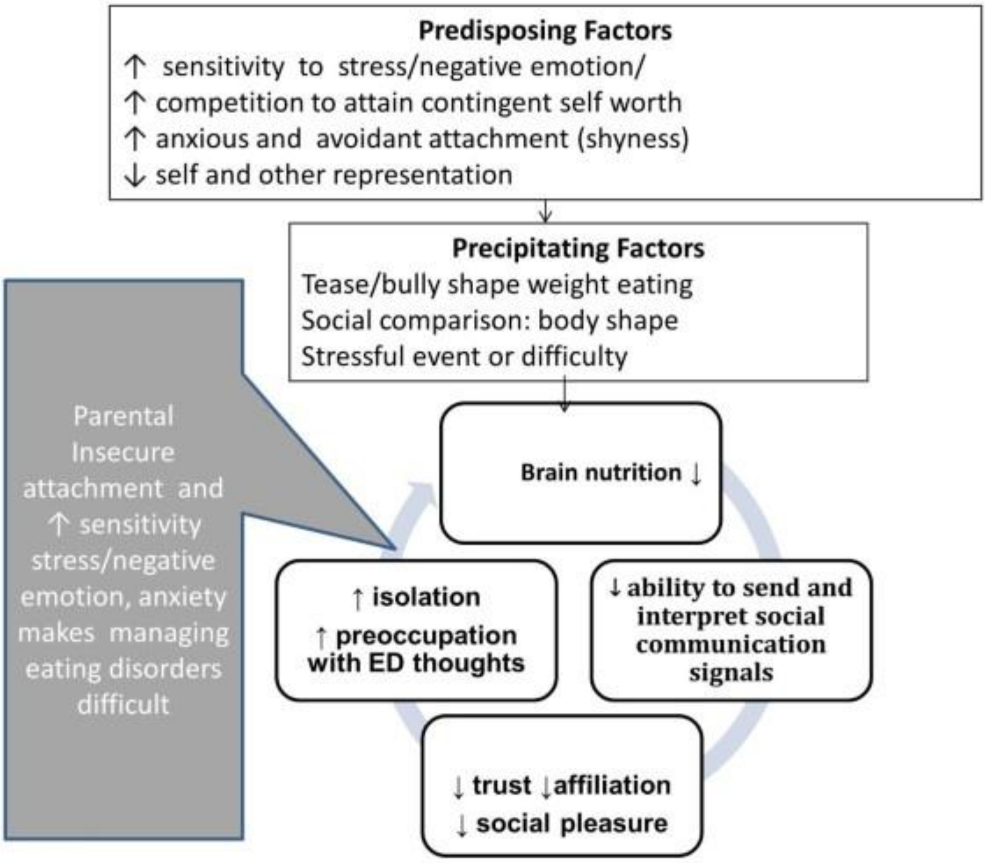
Estimates regarding the heritability of AN vary from 48-74% (Hübel et al., 2019; Thornton et al., 2011), suggesting a strong genetic contribution but not negating the impact of environmental factors. Environmental factors that increase susceptibility to AN may also be shared amongst siblings. Initial theories of the ‘psychosomatic family’ being influential in the development of AN (Minuchin et al., 1979) have been discredited with suggestion that any disturbances in family functioning may be the result of AN rather than a causal factor (Eisler, 2005). However, elements of the family or cultural environment shared by siblings may be influential in the development of eating disorders. Research suggests that restrictive diets and negative talk amongst mothers about their own or others’ body image had a detrimental effect on daughters’ eating behaviours, including the prediction of restrictive eating behaviours (Arroyo et al., 2017; Bauer et al., 2013; Zarychta et al., 2019). Family scripts around healthy eating or the need to be thin may be shared amongst siblings (Blake et al., 2008), and could contribute to a preoccupation with body image and a desire to alter eating patterns to control this. Culturally bound societal messages about the need to be thin may also contribute to this, particularly in Western societies (Izydorczyk & Sitnik-Warchulska, 2018).

Research suggests that psychopathologies such as depression and PTSD show symptom transmission amongst families, with non-genetically related relatives experiencing similar symptoms (Harold et al., 2011; Tower & Kasl, 1996; Yehuda et al., 2001). This contagion effect may also be present in eating disorders with suggestion that parents may project a desire to be thin onto their children or model unhealthy eating behaviours (Park et al., 2003; Rusell et al., 1998). Additionally, the impact of having an eating disorder may influence the ability to parent effectively and may be associated with discordant marital and family relationships that in turn increase the risk of eating disorder pathology (Park et al., 2003). Contagion effects of AN have also been reported amongst peers (Allison et al., 2014; Vandereycken, 2011), with studies finding that peer's body mass is negatively associated with the likelihood of an individual having AN (Costa-Font & Jofre-Bonet, 2013). However, little research has investigated symptom transmission or contagion between siblings. Given the competitive and comparative nature of AN and the fact that siblings are frequently in the high-risk age groups simultaneously, it is surprising that this has not been considered.

The cognitive interpersonal maintenance model of AN suggests several factors are relevant to the development and maintenance of the illness, including thinking styles, social and emotional factors, the valued nature of the condition and the reactions of others (Schmidt & Treasure, 2006; Treasure et al., 2020; Treasure & Schmidt, 2013). Trauma is a possible predisposing factor that may be shared among siblings: approximately two thirds of people diagnosed with AN report having experienced a major life event or trauma in the year leading up to the illness (Schmidt et al., 1997). Relational problems within the family or with friends are commonly cited traumatic events that may equally affect a sibling. Alternatively, the traumatic event of witnessing a sibling develop AN may constitute a non-shared factor that precedes the development of eating disorders in siblings. Figure 1 depicts how stressful life events, in combination with increased awareness of body size and social comparison, may be predisposing factors for the development of AN.

Figure 1

From the Cognitive Interpersonal Maintenance Model (Treasure & Schmidt, 2013)*: How Social Processing Difficulties Influence the Development and Maintenance of AN.*



Evidence suggests that rigid- and detail-focussed thinking styles are common in people with AN and may be both predisposing and maintaining factors of the illness (Treasure & Schmidt, 2013). These features may have genetic links, with well siblings of people with AN exhibiting weak central coherence (Kanakam et al., 2013; Roberts et al., 2013; Tenconi et al., 2010) and showing similar deficits in set-shifting (Holliday et al., 2005; Tenconi et al., 2010). A rigidity of thinking patterns amongst parents may make them more likely to respond to their child in a way that is controlling or critical (Corfield, 2014), therefore creating a stressful home environment for the whole family. Alternatively, parents may become overly permissive in an effort to reduce tension in the home, potentially enabling the continuation of disordered eating. Either of these responses may unwittingly maintain the illness (Halvorsen et al., 2013; Treasure & Schmidt, 2013), and may increase sibling’s worry or cause them to take on a new role in the family. Many siblings of people with AN report their roles in the family changing following the development of the illness: becoming carers themselves, mediators in family disputes or becoming distanced from the family (Maon et al., 2020). The combined difficulties of changing family roles, coupled with feelings of fear, guilt and sadness about their sibling's illness (Cook-Darzens et al., 2005; Dimitropoulos et al., 2009; Garley & Johnson, 1994; Jungbauer et al., 2016), make this experience very distressing. Additionally, well siblings may struggle to discuss their feelings due to a reduced availability of family members and a desire not to burden them further (Arcelus et al., 2013; Karlstad et al., 2021). These difficulties are discussed in the model as social and emotional maintaining factors.

Despite evidence of the impact of AN on siblings and the possible increased risk of eating disorder pathology, support for siblings is not routinely offered. Although they may be included in family therapy, the dominant treatment for adolescents with AN, this does not focus on their individual needs. Siblings may be reluctant to discuss their own difficulties for fear of adding extra burden to their family (Maon et al., 2020). Research is needed to investigate where to best target support and what forms of support would be beneficial. By exploring the experiences of people who have both witnessed a sibling with AN and had restricted eating themselves, this research aims to investigate what relevant factors led them to develop a similar illness, particularly considering the potential contagion of AN. I aimed to answer the following research questions:

- How did having a sibling with AN influence participants' own eating difficulties?
- What factors do participants think were relevant to the development of eating disorder symptomology in themselves and their siblings?
- What were participants' experiences of support following their sibling's difficulties?

Method

Design

A Reflexive Thematic Analysis methodology (Braun & Clarke, 2019) was used for this study, allowing for identification of themes across the data set that could give specific ideas for systemic change. Interpretive Phenomenological Analysis was also considered as an appropriate methodology but was discarded due to a wish for this research to provide clear implications for clinical practice without the need to focus intently on individual experiences and because the use of psychological models to develop the research fits better with Thematic Analysis (Braun & Clarke, 2021).

Data Collection

I developed a semi-structured interview guide based on the principles of the cognitive interpersonal maintenance model of AN with additional questions around the development of eating difficulties. It focussed on the following areas: broad experiences of eating difficulties in interviewees and their siblings, relevant factors in the development of disordered eating, management of emotion and what support would have been useful (see Appendix E). Proposed questions were reviewed by an individual with lived experience from the eating disorder support group at the University of Exeter., a pilot interview was conducted with an individual with experience of a sibling with AN but no eating difficulties herself. This individual was chosen due to the specific nature of the sample population for this study and the potential difficulty recruiting participants during the COVID-19 pandemic. The interview schedule was then revised to reduce the number of questions and make them more targeted to the research questions.

Ethics

This study received ethical approval from the University of Exeter ethics committee (see Appendix A). Participants were given an information sheet (see Appendix B) and returned a signed consent form prior to participating (see Appendix C). Due to the sensitivity of the topic, participants were offered to skip questions, pause, or stop the interview at any time and were reminded of this if showing signs of distress. At the end of the interview, I checked on the participants wellbeing and offered a debrief (see Appendix D). All participants have been given a pseudonym and identifying details have been omitted from transcripts. Demographic information about participants is aggregated rather than presented individually.

Participants were given details of my social media pages for them to access a final version of this study. I have taken care to be respectful and non-judgemental in representing the views and experiences of participants.

Participants

Participants who had witnessed a sibling with AN and then developed some restrictive eating difficulties themselves were recruited. Restrictive eating difficulties were defined as limiting food intake (with or without increased exercise and purging), with a desire to alter their body shape or weight for a period of at least three months, resulting in them rapidly losing weight or becoming underweight. Participants were required to be over the age of 16, to have been at a healthy and stable weight for a minimum of three months and not currently experiencing mental health problems. Where participants were unsure of their sibling's diagnosis or where no formal diagnosis of AN had been given, this criterion was assessed according to whether their sibling had restricted their eating for a significant period causing them to lose a significant amount of weight and resulting in them receiving a healthcare intervention for an eating disorder.

Recruitment was done through online adverts on social media sites: Twitter, Instagram and Facebook (see Appendix F). Paid-for adverts on Facebook and Instagram were targeted at people who followed prominent eating disorder accounts, such as national eating disorder charities, and those who were interested in diet, nutrition or mental health subjects. Recruitment was worldwide but targeted at English speaking countries to maximise the chances of finding eligible participants. Adverts were also posted on research platforms - MQ: Participate and Call for Participants – and on two charity websites in the UK and in the USA.

Participants who registered interest and were assessed as eligible were invited to a Zoom interview. Ten participants (nine women and one man) completed interviews lasting 40-50 minutes and were included in the study. A further male participant was interviewed but subsequently deemed ineligible due to not meeting the eating issues criteria. One participant chose a telephone interview.

Data Analysis Strategy

I conducted a Reflexive Thematic Analysis guided by the principles set out by Braun and Clarke (Braun & Clarke, 2006, 2019; Byrne, 2021). I employed an interpretivist paradigm, focussing on how the meanings made by participants of their experiences may be influenced by my own experiences and knowledge (Byrne, 2021). I used both inductive and deductive approaches (Braun & Clarke, 2019), such that theory was used to guide my interview questions and influenced my perspectives of how to interpret the data, but open coding was used to understand the meanings made by participants rather than fitting these to a theory. Cross-checking of part of one transcript by three other researchers allowed for a meaningful discussion around different perspectives of the participant's experience, and helped me to consider the impact of my knowledge and assumptions on my interpretation.

I followed the six steps for thematic analysis shown in Table 1. This was not a linear process; I moved iteratively between phases, regularly returning to the original transcripts to ensure that emerging themes were grounded in the data.

Table 1

The Six Phases of Thematic Analysis Described by Braun and Clarke (2006, 2019)

Analysis step	Process
1. Familiarisation with the data	• Listening to and transcribing interviews

	• Making initial notes of my impressions and understandings of the data
2. Generating initial codes	• Making semantic and latent codes using nVivo software • Developing codes individually for each transcript
3. Generating themes	• Moving between the transcript and codes, starting to develop initial themes • Making paper notes of ideas for emergent themes
4. Reviewing potential themes	• Going over and defining potential themes and sub-themes • Checking that themes are representative of the data
5. Defining and naming themes	• Defining boundaries for each theme • Ensuring that data extracts to support the theme are representative and compelling • Revisiting names of themes
6. Producing the report	• Reorganising themes to ensure that they are coherent in the final write up

The analysis is structured around highlighting the richness of quotes from participant’s interviews. Although this may differ from some reflexive thematic analysis approaches, Braun and Clarke have acknowledged that there are many different ways of approaching the process (Braun & Clarke, 2020). For each sub-theme I identified a list of supportive quotes, I chose quotes for the write-up based on their relevance to the theme and significance to the participant’s story.

Reflexivity

In approaching this research, I was aware that my position as a white, female, trainee clinical psychologist would influence my questioning during the interviews and my interpretation of the data. Throughout the interview process I kept a reflexive diary (see Appendix G) to record my feelings and assumptions, and how participants' accounts fitted with my prior knowledge (Tobin et al., 2004). To increase validity, I documented decisions I made during my analysis and rationales for these (Nowell et al., 2017).

Analysis

Participants were aged between 21-33 years of age (mean= 26.7), all identified themselves as white. Seven were resident in the UK, with the remaining three from New Zealand, South Africa and Ireland. Two participants had received a formal diagnosis of AN, eight had received no eating disorder diagnosis. Four reported previous episodes of depression, one had previously received a bipolar type 2 diagnoses and one an obsessive-compulsive disorder diagnosis.

All participants reported having a sister with AN; in one case this was undiagnosed and in a further case the participant was unsure of formal diagnosis. Participants had between one and six full siblings (mean=2.1), four reported that their sibling with AN was older, five younger and one was a twin. Three had been involved in family therapy for their sibling's illness. Nine participants developed eating difficulties after their sibling's diagnosis, one developed AN before their sibling but relapsed when their sibling was diagnosed.

The themes and sub-themes developed from the data are shown in Table 2.

Table 2

Superordinate and Subordinate Themes Developed During the Analysis

Superordinate theme	**Subordinate theme**
Eating difficulties were influenced by sibling's AN	*Emotionally charged mealtimes at home*

	Comparison and competition *Increased focus on body image and diet*
Changing eating patterns to manage difficult emotions	*Feeling responsible for a sibling with AN* *Restricting eating to manage emotions* *Traumatic experiences increasing the need for control*
Systemic pressure to be thin	*Family beliefs about diet and body size* *The thin ideal*
Finding appropriate support was difficult for participants	*Being the well sibling* *Difficulties getting support* *Types of support that may have helped*

Eating Difficulties were Influenced by Sibling's AN

Emotionally Charged Mealtimes at Home

Mealtime supervision, a key part of treatment for AN, is often very difficult for people with AN who feel fearful and stressed at the prospect of having to eat, and for their families who are tasked with enforcing meal plans. Several participants spoke of how this caused them to associate mealtimes with stress.

Sophie: *"There was a lot of stress a lot of crying and shouting and throwing food and things, which doesn't really help when you have your own digestive issues."*

Participants also discussed the difficulties of having to follow controlled eating plans and show a good example.

Holly: *"I felt sort of trapped by it, it was always like 'you have to eat enough to show her a good example, you have to'."*

Losing control of their eating patterns and diet appeared to be a trigger for some participants to restrict their eating as a way of feeling in control as soon as they could. Four participants spoke of restricting their eating once they left home and were no longer being pressured to eat.

Sophie: *"When I went away to university I just kind of saw it as like an opportunity that like they can't worry about me now, I'm not at home anymore so I saw it as free rein to sort of restrict a lot more dramatically."*

In contrast, Andrea stopped restricting her diet when at university as she learnt more healthy patterns of eating from those around her.

Andrea: *"I think it was just kind of seeing people having like three meals a day and like having snacks in between and not worrying about like the fat content and certain foods."*

The pressure to eat a lot when at home was also a means of reassuring parents that they were well. However, Heather found that this led to her restricting before and after a visit home, despite having a mostly healthy eating pattern now.

Heather: *"I was always very conscious that when I would go home I'd be eating loads and so I'd have to be careful the week after, in my head I'm always like 'you're going home, you're going to be eating loads make sure you don't eat too much in the week after or week before'."*

Comparison and Competition

Body shape comparisons were discussed by all female participants but appeared to be particularly important for participants who had only one female sibling.

Sophie: *"She was 13 at the first diagnosis and I was 16 so it wouldn't have made sense any way to compare our bodies, but I definitely did, and I definitely felt very jealous of her in a sick sense."*

Sophie's account suggests an awareness that wanting to be as thin as her sister was unhealthy but that there was a part of her that still aspired to be that way. For Andrea, this comparison was an imagined sense that others, including her sister, were expecting her to look a certain way, underpinned by a societal norm of thinness as an aspiration.

Andrea: *"The feelings of just like she's older than me like, quite substantially older than me and she's wearing smaller dress sizes than I am, like what does what must she think of me, or what does that mean about me."*

A desire for thinness was not the only basis for comparison; Holly spoke about restricting her eating to appear strong and perfectly healthy rather than thin, but also spoke of feeling competitive with her sister.

Holly: *"I'm naturally quite competitive as well, so as soon as her eating disorder started comparing then I'd naturally compare back you know, want to be better."*

This sense of competition could lead to a cycle of siblings triggering one another to restrict their eating. This was described by Chloe who developed AN first and struggled whenever she noticed her sister becoming thinner.

Chloe: *"We went shopping and she was tiny, and I remember that made me feel rubbish again and I started to restrict my eating, I don't know what it is, is it a fear of she's going to be thinner than me?"*

In some cases, comparisons between siblings were explicit. Rachel described her sister becoming violent towards her out of jealousy when she became thinner.

Rachel: *"She'd had to gain weight and she was a healthy weight, and I went in quite underweight which she didn't like so she used to beat me up."*

Rachel did not have a desire to be thinner than her sister but stated that experiences like this brought up difficult emotions that perpetuated her mental health struggles and restrictive eating.

Increased Focus on Body Image and Diet

Even for those who did not directly compare their bodies to their sibling's, the increased focus in the home on diet, exercise and body image could be contagious.

Paul: *"The constant conversations about food have definitely made me think about food and I'd mirror that behaviour and check what's in food and obsess a bit more."*

Paul did not have eating difficulties before his sister became unwell but had experienced anxiety; an increased awareness of food became something for him to worry about and want to have control over.

The focus on diet and weight within the home when someone has AN can be inescapable and for participants this could make recovery difficult. Rachel discussed the need to have space from her sister and to prepare mentally for visiting her as she is aware that visits can be a challenge in her recovery.

Rachel: *"In my recovery I haven't been able to forget about having an eating disorder because my sister speaks to me every day about it, and I have to visit her every week when she weighs five stone and has a tube up her nose so it's just really difficult to ever move on from."*

Changing Eating Patterns to Manage Difficult Emotions

Feeling Responsible for a Sibling With AN

Participants took on responsibility and guilt for their sisters eating disorder for a range of reasons including not noticing it early enough, thinking that they caused it and being unable to save them.

Andrea: *"I've felt like I could be the one to like save her, like if I was as thin as she was or just maybe not as thin as her, but maybe like an acceptable level of thinness to her and she saw me eating, then she might think it wasn't so bad to eat."*

For many this assumed responsibility resulted in failed attempts to help their sibling, bringing about complex emotions.

Rachel: *"I just had too much hatred to myself, I think I blame myself for (sister) as well. I told myself if anyone can get her better I will, so I think mine was more a hatred towards myself."*

Over several years of witnessing a sibling with an eating disorder, through cycles of relapse and remission, emotions and attitudes towards a sibling may change. Andrea explained her changing emotions following her sister's relapse after having tried many times to help her.

Andrea: *"I think at the start I was kind of like her champion, 'I'm there for you, I will do anything for you', and it was after a few years of her consistently lying to me about it all that it just I just felt quite betrayed."*

Others took on responsibility for their sibling as a way of helping their parents.

Sophie: *"I wouldn't say I parented as such, but I definitely felt very responsible, felt very guilty, I felt like it was my job to help and stuff which you know I didn't mind helping, but I do think the stress again played a big part in later mental health issues."*

Hannah felt that her attempts did help her sister recover, however, this placed a high responsibility on her to help.

Hannah: *"I think it actually brought us closer together because she sort of, not listened to me, but I could reason with her more than what my mum could."*

Restricting Eating to Manage Emotions

All participants described having strong emotions towards their sibling when they were unwell with AN. For some, the intensity of emotions and difficulty knowing how to manage them led to increased anxiety, depression and restrictive eating patterns as a way to cope.

Sarah: *"I think a lot of it would just be in times of stress when I felt like I needed to control something."*

Stress was often borne out of fear and uncertainty of what might happen. Many participants feared for their siblings' lives when they were unwell and struggled to know how to cope with this feeling.

Bobbi: *"I found it incredibly scary at the time, it felt like an overload of fear all the time that something was going to happen long-term and that she was essentially just killing herself slowly."*

For many participants emotions were complex, changing and difficult to discuss.

Sophie: *"I definitely think that anger is a difficult emotion to process, especially because I can feel very guilty over anger, like the anger that I felt towards my sister, I still feel very, very guilty over that and I haven't forgiven myself for the way that I treated her."*

Although participants described restricting their eating to feel more in control and to manage emotions, they were also aware that this compounded the guilt they felt for acting in a similar way.

Paul: *"I am such a hypocrite because I'm just endorsing this behaviour but then on the other hand trying to stop this behaviour."*

Traumatic Experiences Increasing the Need for Control

Bobbi and Rachel spoke about emotional and physical abuse from their parents which they thought may have influenced their illnesses. No other participants mentioned any forms of abuse. However, several mentioned other difficult childhood experiences, such as marital discord and divorce in parents shortly before or after the development of an eating disorder. Several participants cited this as a factor in triggering difficult emotions and wanting a sense of control that could be achieved through restricting their eating.

Chloe: *"I think the trigger was when I turned 14 my mum had an affair, and I think the shock of it was just you know really devastating as a teenager and I think my immediate reaction was, you know that's something I can control like I'm going to stop eating."*

Experiences of health issues either for participants or for their parents were also mentioned as factors increasing emotional distress and a wish to have more control.

Heather: *"My dad had a heart attack when I was about nine and my sister was six, I remember my mum fully going on a health kick then… my mum was like we need to be healthier as a family."*

Systemic Pressure to be Thin

Family Beliefs About Diet and Body Size

Family scripts around a need to be thin and modelling from parents around eating was discussed by many participants as a possible antecedent to their eating difficulties. These included observations of parent's approaches to their own diets.

Heather: *"Mum does that thing, where she'll also punish herself, she'll be like 'Oh well, I shouldn't have that piece of cake, because I didn't go for walks today."*

There were also accounts of parents giving explicit instructions to their children to be thin.

Bobbi: *"(My father) would very often restrict what we ate and how much of it we were allowed to eat, and there were a lot of different rules for everybody in our house because we looked different."*

Bobbi thought that instructions from her father on what she and her sisters could eat was a causative factor in all her sisters developing eating disorders.

Thinness as an aspiration is so ubiquitous in Western society that some parents may try to help their children with staying slim without realising the potential negative consequences of this.

Sophie: *"(My mother) sort of said to me 'Oh, you know you can try this diet that I tried when I was your age and that'll help' and obviously she regrets that now, but at the time she just thought that was normal, like teenagers go on diets."*

This was not consistent across all participants; Holly remembers no unhealthy attitudes from her parents towards food whilst growing up.

Holly: *"We'd never been restrictive at all at home, and I'd never seen my parents diet or anything like that."*

The Thin Ideal

Messages around the thin ideal were seen to be widespread in the media, schools and in general society. Viewpoints on thinness were often dissonant, with participants acknowledging that AN was an awful illness that they would not wish on anyone, whilst also holding aspirations towards thinness. Several were aware of this contradiction and spoke of the difficulty of wanting to manage their weight but not become unwell.

Hannah: *"I didn't like what I'd seen on her, I don't think she looked good, she looked ill, I remember thinking I would never want that to happen to me sort of thing. But kind of very similar did."*

There were different ways of managing this dissonance: Sophie has learnt that it can be difficult for her to diet without it becoming unhealthy for her.

Sophie: *"I always felt like you should straddle the line between being just you know just thin enough and go no thinner than that, and that was what I was like my sister is gone too much that way she let it get out of control, but I have it in control, I can just do it just enough."*

Other participants managed dissonance by distancing themselves from their sisters' illness and minimising their difficulties.

Sarah: *"You don't have anorexia because you know what that looks like so what are you doing, like feeling like you're kind of making a fuss."*

This initially increased Sarah's wish to restrict her eating but this passed over time.

Sarah: *"There were periods where I would have like imposter syndrome and I would be like well I've just got to like double down on this and I've gotta really restrict because then it will justify what I'm doing. But then, on the other side of that, probably towards the end of the periods, I would be like well I just need to stop, because this is ridiculous and I'm better than this"*

An awareness of the possible dangers of trying to be thin and a worry about becoming as unwell as their sibling was protective in preventing further eating difficulties.

Heather: *"I think I worry that if I was to get into the same habit as my sister like I'm very conscious of it, like I don't calorie count now, I don't weigh myself, I don't do any of that because I almost worry that I would end up like her."*

Finding Appropriate Support was Difficult for Participants

Being The Well Sibling

Talking about emotions in the family could be difficult as participants did not want to burden their unwell sibling with their problems or make their illness worse. However, for some participants, siblings could also provide a source of support, particularly when both had recovered from similar illnesses as this fostered a sense of shared understanding.

Bobbi: *"We confided in each other a lot, we found a lot of support and love with each other."*

Participants sometimes found it difficult to speak with their parents about their difficulties and this could make it difficult for parents to be aware of the struggles of their other children.

Heather: *"I thought, they've got one unwell child they don't need another one, so I've just never really spoken to them about it."*

There was an awareness that parents may be struggling to cope themselves and participants did not wish to burden them with their feelings. Sarah articulated her role in trying not to put extra pressure on her parents.

Sarah: *“Everyone's like rallying around to look after this person and you feel like you kind of have to be the mature one and, like not get into much trouble and just make sure that you're looking after things because you don't want to put extra stress on what is already going on.”*

This led to increased difficulties with eating as an alternative way to cope.

Sarah: *“It's like you don't know how to open up to these people around you so here's something that you can do to control everything that's overwhelming.”*

A difficulty in discussing issues with parents may also have been due to a lack of time spent together as parents were busy supporting their child with AN. Andrea felt upset and angry that her needs are still never prioritised.

Andrea: *“They always put her needs like in front of mine at my expense, like not just even like when it doesn't affect me, like when things you know would kind of harm me, it would be her needs first”.*

However, other participants stated that their siblings’ illness brought them closer together as a family.

Sophie: *“I think I actually became more dependent on my mum because of the whole thing and possibly her on me as well a little bit like we became close.”*

The intense and continuous nature of AN means that carers are often subject to burnout and often siblings take on the role of offering support. Heather spoke about the isolation she felt when supporting her sister to allow her parent’s respite.

Heather: *"It was just me and her and I couldn't really leave her in the house alone, so I was just trapped for a month with her the only time I went out was either to walk the dog or go to the shops it was just a bit of a hermit life."*

Speaking up about feeling overwhelmed could also conflict with a sense of duty and the values of participants, making it difficult for them to seek help.

Sophie: *"I wouldn't have felt like I could say you know that it's a bit too much or whatever, because I did grow up in a Christian household as well, so it was very much like, you know, you should self-sacrifice."*

Although participants expressed a desire to support their family, at times this could feel overwhelming. Paul felt intense pressure at the need to be the one to support his sister as he worried that his family did not take her illness seriously. This has led to pressure within the family and a difficulty communicating his needs for fear of hypocrisy.

Paul: *"I am the one person that she hates, because I am the one person who tries to interfere with the eating disorder and help. My mum says 'just be her brother' and I'm like, 'well I could be her brother if you were helping her, and then I could stay out of it'."*

Difficulties Getting Support

Possible barriers to seeking support are numerous and several participants alluded to worries about being stigmatised, being unsure how to seek help or their needs not being great enough to need professional intervention. Andrea said that she struggled to ask for support because her parents were busy, and she was worried about being assumed crazy or being put in hospital.

Andrea: *"I just thought I'd be in trouble I didn't know what was okay, and what wasn't okay, in terms of the mental health spectrum."*

Despite therapeutic interventions being widely offered to siblings with AN and some participants attending family therapy sessions with their sibling, no participants in this study were offered individual support from a professional because of their sibling's illness.

Most participants who had sought support pursued this themselves and either had private therapy or six sessions of individual therapy. Others participated in their sibling's family therapy but found that this did not help in supporting them and could add to the difficulty of their sibling's illness.

Sophie: *"I would have liked it if I'd had one-on-one, but they didn't offer that, it was just as the whole group, and I think my sister found it really embarrassing as well, and I remember the counsellor was asking me about how I felt about my parent's divorce in front of my parents. I remember thinking 'How is this helpful for me?'."*

Types of Support that may have Helped

There was a desire amongst all participants for more support when their sibling became unwell. They suggested that individual support, education in schools and support groups might have helped them to understand and manage their emotions around the situation at home.

Andrea: *"Just having someone to say 'It's okay if you're feeling xyz, it's normal to feel xyz even though it's like a scary feeling to have but it's normal and that's like in the normal experience, how can we help support you through that?'"*

Support for parents to help them cope better with difficulties was also suggested as potentially being beneficial and may allow them to better support other siblings in the house.

Holly: *"If my parents had some of the load taken off them, I feel like I don't know if my problems were serious enough to need serious psychological help, it was more I just needed the support of my parents."*

Despite a struggle for support, all participants in this study had learnt to manage their eating difficulties. For some this was due to having space from their unwell sibling or their sibling also being in recovery.

Holly: *"I think the main thing was, that helped was just distancing in me being away at Uni and then that kind of allowed (sister) to shut me off, as part of the disorder and resolved all those issues."*

This signifies both a desire for a range of different supports to be put in place but also an acknowledgement that even with extensive support, sometimes getting distance from an unwell sibling and space to recover may be essential.

Discussion

This research aimed to investigate the perspectives of siblings of people with AN on factors they deemed to be relevant to the development of their own eating difficulties and how they navigated their sibling's illness and their own recovery. Having a sibling with AN had a huge impact on the lives of all participants, most of whom were adolescents when their sister's illness began. Feelings of responsibility for their sibling, changed roles within the family and a need to present as healthy were consequences of their sibling becoming unwell and impacted on participants' wellbeing. In addition, traumatic experiences and a want to gain control of difficult and uncertain situations were a catalyst for eating difficulties. Direct effects of witnessing a sibling's illness and treatment, such as an increased focus on food and body weight, comparisons between siblings and having to role-model eating were all pertinent factors in participants' own struggles with eating. Societal idealisation of thinness and difficulties in accessing appropriate support presented barriers for participants in getting well.

Consistent with some previous findings, participants in this research described their body image being influenced by their sister's (Jungbauer et al., 2016); this effect was stronger for younger siblings (Tsiantas & King, 2001). In this study, participants appeared particularly susceptible to comparison with one another if they were both sisters with no other siblings, but age order did not appear to be relevant. Comparisons both encouraged restrictive eating and motivated participants to eat to avoid becoming as unwell as their sister. Several participants held both views concurrently and discussed a previous desire to find a perfect level of thinness. These aspirations were underpinned by systemic messages around thinness being desirable, notably all participants were white and came from Western cultures where slimness is idealised. An idealisation of thinness was pervasive amongst several of the participants' families, with all but two talking about their parents' own restriction of certain foods, encouragement of compensatory eating behaviours or general negative attitudes towards fatness. This may evidence a contagion effect in families where parental beliefs about the value of thinness and an expressed desire for their children to be slim translated into restrictive eating patterns in participants and their siblings (Park et al., 2003). For participants in this study, all of whom had recovered, this had at some point been outweighed by an understanding of the risks of the illness and the detrimental impact it has on lives.

The cognitive interpersonal maintenance model states that poor social connections may be linked with the maintenance of AN and that establishing connections with others is an important part of treatment (Schmidt & Treasure, 2006; Treasure et al., 2020; Treasure & Schmidt, 2013). Interviewees described changed family relationships following the onset of AN in a sibling and for many this resulted in increased distance from their family. Furthermore, several participants spoke of traumatic events in the family that immediately preceded the development of AN within the family and led to strained relationships. This may have increased susceptibility to eating difficulties in participants. Reconnecting with family whilst a sibling still has AN may make recovery difficult; participants only felt able to recover when their sibling recovered or when they were able to distance themselves from their family and make connections with others.

Feelings of sadness, fear and responsibility have been well documented in well siblings of people with AN (Areemit et al., 2010; Dimitropoulos et al., 2009; Fjermestad et al., 2020; Garley & Johnson, 1994; Maon et al., 2020). Consistent with the cognitive interpersonal maintenance model (Schmidt & Treasure, 2006; Treasure et al., 2020; Treasure & Schmidt, 2013), some participants said that their eating difficulties arose as a consequence of the stress of managing intense emotions following their sibling's illness. This link between stress and eating difficulties is consistent with other research (Ball & Lee, 2000; Costarelli & Patsai, 2012; Kupeli et al., 2017). Sources of stress included: relational tensions within the family, major life changes and taking on responsibility for their sibling's health. Several participants found it difficult to discuss their emotions due to not wanting to burden parents, parental availability, and shame around the content of these emotions. Minimisation of their difficulties and feeling that these were not sufficiently bad to seek support were also barriers for participants in getting help.

My construction of themes was heavily influenced by systemic theory. I developed the 'systemic pressure to be thin' theme based on the idea that participant's views on the value of thinness had been formed by the scripts around this from the family and the wider world (Byng-Hall, 1985). In some cases learnt scripts around body size had been challenged by their sibling's illness, this is reflected in ideas that there might be an ideal level of thinness. In addition, the onset of AN in the family appeared to disrupt scripts around family roles and in some cases cause participants to take on a role that may be inconsistent with their idea of the family life cycle (McGoldrick & et al., 2011). This is evident throughout the themes but particularly in descriptions of participants adjusting their relationships with family members and in taking on caring roles. Additionally, roles within the family may be directly affected by a sibling's body size, both through the illness eliciting care giving behaviours from family members and through how body size might position someone in the family order.

Strengths and Limitations

The integration of multiple perspectives and experiences in this research is beneficial in that it has allowed me to develop overarching themes, combining my interpretation of participants' stories and previous research. However, the need to synthesise all the complex and contradictory accounts mean that the analysis may be reductionist, losing some of the rich detail contained in individual interviews.

The population was relatively homogenous in that all participants came from Western cultures and identified as white and cis-gendered. In common with much research in the field of AN, only one participant was male (Scutt et al., 2022). Although this research presents the narratives of specific individuals and therefore may not be generalisable to the wider population, increasing diversity among participants may have allowed for a broader range of participant experiences and interpretations. This may have allowed for a richer exploration of nuances and contradictions in my interpretation and analysis of the data.

One participant developed AN before her sibling and relapsed after her sibling became unwell. I chose to include this participant in recognition that the development of eating disorders is often not linear, meaning that although most participants developed eating difficulties after their sibling, many also described unhealthy relationships with food or their bodies prior to this. The experiences of this participant may have differed from others in the study, for example she did not feel the same pressure to change her behaviour to look after her sister. For such instances where this experiences of this participant were judged to be because of the order in which the illness affected each sibling, contradictions from the main data set were noted but not remarked upon in the write up of the research.

The reflexive thematic analysis may differ from other practices and as a novice researcher there are things that I would do differently if I were to repeat this analysis such as linking my interpretations of the data more clearly with theory and including a more in-depth analysis. My analysis could have been improved by using Yardley's evaluative criteria, this may have allowed me to consider more carefully the context of the interviews and to present my own exposure to theory and how this influenced my interpretation of the data (Yardley, 2000).

Reflexivity

As a white female with no history of an eating disorder and limited experience of working with people with eating disorders, I am aware that many of my preconceived ideas regarding eating disorders were based in my reading and in cultural narratives around the illness. For example, in my reflexive journal I noted that I held an assumption that all participants would subscribe to an idealisation of thinness and that seeing a sister become thinner would bring about some ideas of desirability of the illness for participants. Whilst the thin ideal was present in my interpretation of the data, I also recognised contradictions to this and that for many emaciation was not seen as aspirational.

Throughout this process, it was difficult to separate my dual roles of researcher and clinician; this was particularly difficult when speaking to participants who had had negative experiences of the health system. In these instances, I found myself becoming critical of the system and wanting to support participants rather than engaging with the content and meaning that interviewees were providing.

Staying engaged with participants' experiences both during interviews and analysis was also challenged by the dominant positivist narrative present in Clinical Psychology (Breen & Darlaston-Jones, 2010). At times I felt myself being steered towards positivist narratives to develop generalisable implications. This was influenced by a sense of duty to participants to maximise the possible impact of their stories, however, this approach would have done these participants a disservice by ignoring the complexities and nuances of their experiences.

Clinical Implications

Consistent with the findings of previous research (Jungbauer et al., 2016; Maon et al., 2020), siblings of people with AN wanted individualised support when their sibling became unwell. As a potentially high-risk group, individual support should be routinely considered as a preventative measure to help manage the stresses of living with someone with an eating disorder and attend to other risk factors. Multiple sources of information about eating disorders from mental health services and schools would also help in allowing siblings to understand AN and to prevent eating disorder psychopathology.

Advice for parents on how best to support siblings through not pressuring them to eat and avoiding comparisons between siblings should be incorporated into treatment for AN. Family therapy should address the potentially changed roles within the family and help to ensure that siblings are not taking on parental roles or assuming responsibility for their unwell sibling’s health. Work around family scripts and beliefs about body size and diet may also be helpful in reducing unhelpful narratives that could put siblings at an increased risk of eating difficulties.

Consideration should be given to the involvement of siblings in structured eating plans and whether this may be detrimental to them. For siblings that develop eating difficulties, thought should be given to how to allow them sufficient space from unwell siblings to encourage recovery.

Further Research

This research has identified some areas that may be associated with an increased risk of eating difficulties in siblings of people with AN. Further evidence is needed into the impact of particular risks, such as traumatic family events and obvious comparisons between siblings. Future studies may also consider how best to treat cases where more than one individual has AN concurrently.

Further research is needed into the impact of anti-obesity messaging within families and institutions on eating disorder pathology, particularly in siblings and peers of people with AN, given the possible contagion in these groups (Allison et al., 2014; Vandereycken, 2011).

Finally, research into the efficacy of preventative interventions for siblings of people with AN would be valuable. Some evidence suggests that a support group for siblings of people with AN may be helpful but is it unclear whether this is protective against the development of eating disorder pathology (Persico et al., 2021).

Conclusion

Siblings of people with AN have an increased genetic and environmental risk for disordered eating. This research suggests that the experience of witnessing a sibling with AN can impact on family structures and bring up difficult emotions and may affect wellbeing and restrictive eating. Additionally, an increased focus on food and body size at home, comparisons between siblings and emotionally charged mealtimes could influence eating patterns. Barriers to seeking support such as not wanting to burden family members and not seeing their difficulties as deserving of intervention were present. However, a desire to avoid the negative consequences of AN and a wish not to become as unwell as their sibling provided motivation for participants to eat healthily. Increased offers of support for siblings of people with AN to help identify those at risk of developing an eating disorder and to offer preventative treatments or early intervention would be beneficial.

List of Abbreviations

AN: Anorexia nervosa

References

Allison, S., Warin, M., & Bastiampillai, T. (2014). Anorexia nervosa and social contagion: Clinical implications. *Australian and New Zealand Journal of Psychiatry*, *48*(2), 116–120. https://doi.org/10.1177/0004867413502092

Amianto, F., Abbate-Daga, G., Morando, S., Sobrero, C., & Fassino, S. (2011). Personality development characteristics of women with anorexia nervosa, their healthy siblings and healthy controls: What prevents and what relates to psychopathology? *Psychiatry Research*, *187*(3), 401–408. https://doi.org/10.1016/j.psychres.2010.10.028

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*(3), 464–477. https://doi.org/10.1016/j.eatbeh.2014.06.001

Arcelus, J., Haslam, M., Farrow, C., & Meyer, C. (2013). The role of interpersonal functioning in the maintenance of eating psychopathology: A systematic review and testable model. *Clinical Psychology Review*, *33*(1), 156–167. https://doi.org/10.1016/j.cpr.2012.10.009

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. *Archives of General Psychiatry*, *68*(7), 724. https://doi.org/10.1001/archgenpsychiatry.2011.74

Areemit, R. S., Katzman, D. K., Pinhas, L., & Kaufman, M. E. (2010). The experience of siblings of adolescents with eating disorders. *Journal of Adolescent Health*, *46*(6), 569–576. https://doi.org/10.1016/j.jadohealth.2009.12.011

Arroyo, A., Segrin, C., & Andersen, K. K. (2017). Intergenerational transmission of disordered eating: Direct and indirect maternal communication among grandmothers, mothers, and daughters. *Body Image*, *20*, 107–115. https://doi.org/10.1016/j.bodyim.2017.01.001

Ball, K., & Lee, C. (2000). Relationships between psychological stress, coping and disordered eating: A review. *Psychology & Health*, *14*(6), 1007–1035. https://doi.org/10.1080/08870440008407364

Bauer, K. W., Bucchianeri, M. M., & Neumark-Sztainer, D. (2013). Mother-reported parental weight talk and adolescent girls' emotional health, weight control attempts, and disordered eating behaviors. *Journal of Eating Disorders*, *1*(1), 45. https://doi.org/10.1186/2050-2974-1-45

Benninghoven, D., Tetsch, N., & Jantschek, G. (2008). Patients with eating disorders and their siblings: An investigation of body image perceptions. *European Child and Adolescent Psychiatry*, *17*(2), 118–126. https://doi.org/10.1007/s00787-007-0645-9

Blake, C. E., Bisogni, C. A., Sobal, J., Jastran, M., & Devine, C. M. (2008). How adults construct evening meals. Scripts for food choice. *Appetite*, *51*(3), 654–662. https://doi.org/10.1016/j.appet.2008.05.062

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. In *Qualitative Research in Sport, Exercise and Health*. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology, 18*(3), 328-352. https://doi.org/10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Breen, L. J., & Darlaston-Jones, D. (2010). Moving beyond the enduring dominance of positivism in psychological research: Implications for psychology in Australia. *Australian Psychologist*, *45*(1), 67–76. https://doi.org/10.1080/00050060903127481

Byrne, D. (2021). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity*, 1–22. https://doi.org/10.1007/s11135-021-01182-y

Callio, C., & Gustafsson, S. (2016). Living with a sibling who suffers from an eating disorder: a pilot interview study. *Journal of Multidisciplinary Healthcare*, *Volume 9*, 615–622. https://doi.org/10.2147/JMDH.S115934

Cook-Darzens, S., Doyen, C., Falissard, B., & Mouren, M.-C. (2005). Self-perceived family functioning in 40 French families of anorexic adolescents: implications for therapy. *European Eating Disorders Review*, *13*(4), 223–236. https://doi.org/10.1002/erv.628

Coomber, K., & King, R. M. (2008). The role of sisters in body image dissatisfaction and disordered eating. *Sex Roles*, *59*(1–2), 81–93. https://doi.org/10.1007/s11199-008-9413-7

Corfield, F. (2014). *Attachment, affect and social processing in eating disorders*. https://kclpure.kcl.ac.uk/portal/files/45170797/2014_Corfield_Freya_1030299_ethesis.pdf

Costa-Font, J., & Jofre-Bonet, M. (2013). Anorexia, body image and peer effects: Evidence from a sample of European women. *Economica*, *80*(317), 44–64. https://doi.org/10.1111/J.1468-0335.2011.00912.X

Costarelli, V., & Patsai, A. (2012). Academic examination stress increases disordered eating symptomatology in female university students. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity*, *17*(3), 164–169. https://doi.org/10.1007/BF03325343

Dimitropoulos, G., Freeman, V. E., Bellai, K., & Olmsted, M. (2013). Inpatients with severe anorexia nervosa and their siblings: Non-shared experiences and family functioning. *European Eating Disorders Review*, *21*(4), 284–293. https://doi.org/10.1002/erv.2230

Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review*, *17*(5), 350–365. https://doi.org/10.1002/erv.937

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*, *27*(2), 104–131. https://doi.org/10.1111/j.1467-6427.2005.00303.x

Eisler, I., Simic, M., Blessitt, E., & Dodge, L. (2016). *Maudsley service manual for child and adolescent eating disorders*. South London and Maudsley NHS Foundation Trust King's Health Partners. Maudsley-Service-Manual-for-Child-and-Adolescent-Eating-Disorders-July-2016.pdf

Fjermestad, K. W., Rø, A. E., Espeland, K. E., Halvorsen, M. S., & Halvorsen, I. M. (2020). "Do I exist in this world, really, or is it just her?" Youths' perspectives of living with a sibling with anorexia nervosa. *Eating Disorders*, *28*(1), 80–95. https://doi.org/10.1080/10640266.2019.1573046

Garley, D., & Johnson, B. (1994). Siblings and eating disorders: a phenomenological perspective. *Journal of Psychiatric and Mental Health Nursing*, *1*(3), 157–164. https://doi.org/10.1111/j.1365-2850.1994.tb00039.x

Halvorsen, I., Rø, Ø., & Heyerdahl, S. (2013). Nine-Year Follow-up of girls with anorexia nervosa and their siblings: Retrospective perceptions of parental bonding and the influence of illness on their everyday life. *European Eating Disorders Review*, *21*(1), 20–27. https://doi.org/10.1002/erv.2191

Harold, G. T., Rice, F., Hay, D. F., Boivin, J., Van Den Bree, M., & Thapar, A. (2011). Familial transmission of depression and antisocial behavior symptoms: disentangling the contribution of inherited and environmental factors and testing the mediating role of parenting. *Psychological Medicine*, *41*(6), 1175–1185. https://doi.org/10.1017/S0033291710001753

Herpertz-Dahlmann, B. (2009). Adolescent Eating Disorders: Definitions, symptomatology, epidemiology and comorbidity. *Child and Adolescent Psychiatric Clinics of North America*, *18*(1), 31–47. https://doi.org/10.1016/j.chc.2008.07.005

Holliday, J., Tchanturia, K., Landau, S., Collier, D., & Treasure, J. (2005). Is impaired set-shifting an endophenotype of anorexia nervosa? *American Journal of Psychiatry*, *162*(12), 2269–2275. https://doi.org/10.1176/appi.ajp.162.12.2269

Hübel, C., Marzi, S. J., Breen, G., & Bulik, C. M. (2019). Epigenetics in eating disorders: a systematic review. *Molecular Psychiatry*, *24*(6), 901–915. https://doi.org/10.1038/s41380-018-0254-7

Izydorczyk, B., & Sitnik-Warchulska, K. (2018). Sociocultural appearance standards and risk factors for eating disorders in adolescents and women of various ages. *Frontiers in Psychology*, *9*(MAR). https://doi.org/10.3389/fpsyg.2018.00429

Jungbauer, J., Heibach, J., & Urban, K. (2016). Experiences, burdens, and support needs in siblings of girls and women with anorexia nervosa: Results from a qualitative interview study. *Clinical Social Work Journal*, *44*(1), 78–86. https://doi.org/10.1007/s10615-015-0569-7

Kanakam, N., Raoult, C., Collier, D., & Treasure, J. (2013). Set shifting and central coherence as neurocognitive endophenotypes in eating disorders: A preliminary investigation in twins. *The World Journal of Biological Psychiatry*, *14*(6), 464–475. https://doi.org/10.3109/15622975.2012.665478

Karlstad, J., Moe, C. F., Wattum, M., Adelsten Stokland, R., & Brinchmann, B. S. (2021). “Putting your own oxygen mask on first”: a qualitative study of siblings of adults with anorexia or bulimia. *Journal of Eating Disorders*, *9*(1), 83. https://doi.org/10.1186/s40337-021-00440-6

Kupeli, N., Norton, S., Chilcot, J., Campbell, I. C., Schmidt, U. H., & Troop, N. A. (2017). Affect systems, changes in body mass index, disordered eating and stress: an 18-month longitudinal study in women. *Health Psychology and Behavioral Medicine*, *5*(1), 214–228. https://doi.org/10.1080/21642850.2017.1316667

Maloney, M. J., & Shepard-Spiro, P. (1983). Eating attitudes and behaviors of anorexia nervosa patients and their sisters. *General Hospital Psychiatry*, *5*(4), 285–288. https://doi.org/10.1016/0163-8343(83)90008-7

Maon, I., Horesh, D., & Gvion, Y. (2020). Siblings of individuals with eating disorders: A Review of the Literature. *Frontiers in Psychiatry*, *11*, 604. https://doi.org/10.3389/fpsyt.2020.00604

McGoldrick, M., Carter, B., & Garcia-Preto, N. (Eds.) (2011). The expanded family life cycle. Individual, family, and social perspectives (4th Ed.). Boston: Allyn & Bacon.

Minuchin, S., Rosman, B. L., & Baker, L. (1979). Psychosomatic families: Anorexia nervosa in context. *Social Service Review*, *53*(1), 147–151. https://doi.org/10.1086/643716

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis. *International Journal of Qualitative Methods*, *16*(1), 160940691773384. https://doi.org/10.1177/1609406917733847

Park, R. J., Senior, R., & Stein, A. (2003). The offspring of mothers with eating disorders. *European Child & Adolescent Psychiatry*, *12*(1), 1–1. https://doi.org/10.1007/s00787-003-1114-8

Persico, A., Grandclerc, S., Giraud, C., Moro, M. R., & Blanchet, C. (2021). “We thought we were alone”:Tthe subjective experience of the siblings of anorexic adolescent patients. *Frontiers in Psychiatry*, *12*. https://doi.org/10.3389/fpsyt.2021.664517

Roberts, M. E., Tchanturia, K., & Treasure, J. L. (2013). Is attention to detail a similarly strong candidate endophenotype for anorexia nervosa and bulimia nervosa? *The World Journal of Biological Psychiatry*, *14*(6), 452–463. https://doi.org/10.3109/15622975.2011.639804

Rusell, G. F. M., Treasure, J., & Eisler, I. (1998). Mothers with anorexia nervosa who underfeed their children: their recognition and management. *Psychological Medicine*, *28*(1), 93–108. https://doi.org/10.1017/S003329179700603X

Schmidt, U., Tiller, J., Blanchard, M., Andrews, B., & Treasure, J. (1997). Is there a specific trauma precipitating anorexia nervosa? *Psychological Medicine*, *27*(3), S0033291796004369. https://doi.org/10.1017/S0033291796004369

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, *45*(3), 343–366. https://doi.org/10.1348/014466505X53902

Scutt, E., Langdon-Daly, J., & Smithson, J. (2022). *Patient perspectives of the positive and negative aspects of inpatient treatment for anorexia nervosa: A systematic review*.

Steinhausen, H.-C., Jakobsen, H., Helenius, D., Munk-Jørgensen, P., & Strober, M. (2015). A nation-wide study of the family aggregation and risk factors in anorexia nervosa over three generations. *International Journal of Eating Disorders*, *48*(1), 1–8. https://doi.org/10.1002/eat.22293

Strober, M. (2000). Controlled family study of anorexia nervosa and bulimia nervosa: Evidence of shared liability and transmission of partial syndromes. *American Journal of Psychiatry*, *157*(3), 393–401. https://doi.org/10.1176/appi.ajp.157.3.393

Tenconi, E., Santonastaso, P., Degortes, D., Bosello, R., Titton, F., Mapelli, D., & Favaro, A. (2010). Set-shifting abilities, central coherence, and handedness in anorexia nervosa patients, their unaffected siblings and healthy controls: Exploring putative endophenotypes. *The World Journal of Biological Psychiatry*, *11*(6), 813–823. https://doi.org/10.3109/15622975.2010.483250

Thornton, L. M., Mazzeo, S. E., & Bulik, C. M. (2011). The heritability of eating disorders: Methods and current findings. *Current Topics in Behavioral Neurosciences*, *6*(1), 141. https://doi.org/10.1007/7854_2010_91

Tobin, G. A., Rmn, R., Rnt, R., Begley, C. M., Rm, R., Ffnrcsi, R., & Tobin, G. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388–396. https://doi.org/10.1111/J.1365-2648.2004.03207.X

Tower, R. B., & Kasl, S. V. (1996). Depressive symptoms across older spouses: Longitudinal influences. *Psychology and Aging*, *11*(4), 683–697. https://doi.org/10.1037/0882-7974.11.4.683

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

Treasure, J., Willmott, D., Ambwani, S., Cardi, V., Clark Bryan, D., Rowlands, K., & Schmidt, U. (2020). Cognitive interpersonal model for anorexia nervosa revisited: The perpetuating factors that contribute to the development of the severe and enduring illness. *Journal of Clinical Medicine*, *9*(3), 630. https://doi.org/10.3390/jcm9030630

Tsiantas, G., & King, R. M. (2001). Similarities in body image in sisters: The role of sociocultural internalization and social comparison. *Eating Disorders*, *9*(2), 141–158. https://doi.org/10.1080/10640260127717

van Langenberg, T., Sawyer, S. M., Le Grange, D., & Hughes, E. K. (2016). Psychosocial well-being of siblings of adolescents with anorexia nervosa. *European Eating Disorders Review*, *24*(6), 438–445. https://doi.org/10.1002/erv.2469

Vandereycken, W. (2011). Can eating disorders become ‘contagious’ in group therapy and specialized inpatient care? *European Eating Disorders Review*, *19*(4), 289–295. https://doi.org/10.1002/erv.1087

Wunderlich, U., Gerlinghoff, M., & Backmund, H. (2004). Eating disturbances in siblings of patients with eating disorders. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and*

Obesity, *9*(4), 258–263. https://doi.org/10.1007/BF03325079

Yehuda, R., Halligan, S. L., & Bierer, L. M. (2001). Relationship of parental trauma exposure and PTSD to PTSD, depressive and anxiety disorders in offspring. *Journal of Psychiatric Research*, *35*(5), 261–270. https://doi.org/10.1016/S0022-3956(01)00032-2

Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, *17*(5), 338–349. https://doi.org/10.1002/erv.925

Zarychta, K., Kulis, E., Gan, Y., Chan, C. K. Y., Horodyska, K., & Luszczynska, A. (2019). Why are you eating, mom? Maternal emotional, restrained, and external eating explaining children's eating styles. *Appetite*, *141*, 104335. https://doi.org/10.1016/j.appet.2019.104335

Appendix A

Statement of Ethical Approval

CLES – Psychology
Psychology
College of Life and Environmental Sciences
University of Exeter
Washington Singer Building
Perry Road
Exeter
EX4 4QG
Web: www.exeter.ac.uk

CLES – Psychology Ethics Committee

Dear Eleanor Scutt

Ethics application - eCLESPsy001999
An Investigation into the Impact of Anorexia Nervosa on Disordered Eating in Subsequent Siblings

Your project has been reviewed by the CLES – Psychology Ethics Committee and has received a Favourable opinion.

The Committee has made the following comments about your application:
Nick Moberly commented, ES: 'Yes that's fine, I can do that. My supervisor is contactable if things come up so can ask her for assistance if needed. I am also asking participants if they are generally healthy and mentally well when they consent to the interview and anyone that is not will be excluded. '

- Please view your application at https://eethics.exeter.ac.uk/CLESPsy/ to see comments in full.
If you have received a Favourable with conditions, Provisional or unfavourable outcome you are required to re-submit for full review and/or confirm that committee comments have been addressed before you begin your research.

If you have any further queries, please contact your Ethics Officer.

Yours sincerely

Date: 16/03/2021

Appendix B

Participant Information Sheet

Participant Information Sheet

Title of Project: An Investigation into the Impact of Anorexia Nervosa on Disordered Eating in Siblings

Researcher name: Ellie Scutt

Invitation and brief summary:

My name is Ellie and I am inviting you to take part in this research project investigating the experiences of siblings of people with Anorexia Nervosa. I am specifically interested in interviewing people who have had eating difficulties after experiencing their sibling's Anorexia.
Please take some time to read through the information in this document and make sure that you understand this and are happy with it. If you have any questions or if anything is unclear, please contact me using the contact details at the bottom of this document. You may take time to think through the study, talk it through with friends or family and consider whether you would like to take part. If you choose to participate, I will go through this information with you before you take part and ask you to give your consent.

Purpose of the research:
This research aims to investigate how the experience of living with a sibling with Anorexia Nervosa impacts on people's mental health and on their own relationship with eating. Past research has shown that living with a sibling with Anorexia can have a big impact on the whole family. There is evidence that the emotional wellbeing of siblings and parents may affected by the experience of helping someone to manage a diagnosis of Anorexia. This study will investigate how the experience of living with someone with anorexia influenced participant's own difficulties with eating. In particular we want to find out whether there were any things about this experience that may have increased the risk of eating difficulties developing. We also want to think about what things might have helped you during this time and may have prevented you from becoming unwell.

We hope that the results of this research will be helpful in increasing our understanding of how to protect siblings of people with anorexia from becoming unwell themselves.

Why have I been approached?
You will have seen this research project advertised and have contacted us to show your interest in participating. If you have witnessed a sibling managing a restrictive eating disorder (such as anorexia) and have experienced difficulties with eating yourself then you are welcome to take part.

What would taking part involve?
The first step of taking part in this research is a short (10-15 minute) telephone call with me (Ellie). This call is to make sure that you understand the study, that you are eligible to participate and that you are happy to discuss sensitive information about your eating difficulties and your experiences of your sibling's eating disorder (the interview will focus on your experiences and not the details of your sibling's illness).

Following this call, if you choose to participate you will be invited to take part in a skype interview about your experiences. The interview will last around 30-45 minutes and you can choose not to answer any questions that make you feel uncomfortable. You may choose to have your webcam on or off during this interview. I will make sure that I am in a quiet space for this interview where I cannot be overheard.

At the end of the interview you will be asked to take part in a debrief with me to ensure that you are unaffected by your participation.

What are the possible benefits of taking part?
The main benefit to taking part in this research is that it may help to increase understanding about how eating disorders develop and how they are maintained. It may also help us to think more about how siblings of people with anorexia can be supported and possibly prevent future siblings from developing similar eating difficulties.

You will also be offered entry into a prize draw where one participant from this study will be given £50 worth of Amazon vouchers.

What are the possible disadvantages and risks of taking part?
This study involves an in-depth interview about your experiences of eating difficulties and of living with a sibling with an eating disorder. It is possible that the questions may bring up some difficult memories or may ask about things that are upsetting to talk about. You can choose not to answer a question at any point if you wish. The researcher is a Trainee Clinical Psychologist and has experience in supporting people with mental health difficulties and in talking about difficult issues. Throughout the interview the researcher will check in with how you are feeling and check whether you are happy to continue. You may take a break from or end the interview at any time.

If you are in need of further support not related to taking part in the interview, then the researcher will direct you to the following support services:

- BEAT helpline: 08088010677, https://www.beateatingdisorders.org.uk/
- Samaritans: 116123, https://www.samaritans.org/
- Childline: 08001111
- For immediate support you will be directed to your local NHS A&E service.

What will happen if I don't want to carry on with the study?
You are free to stop taking part in the study at any point until the end of the interview. After you have completed the interview your data will be anonymised with all identifying information kept separately and securely. If you wish to remove your data from the study, you will be able to do so at any point up to September 2021. After this all identifying information about you will be deleted and the information given by you during your interview will be analysed.

How will my information be kept confidential?
The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

You will be asked to give your address, GP details, email and phone number to take part in the study. The information you give about yourself will only be accessible to me (as the researcher). The only exception to this will be if you disclose immediate risk to yourself or to others, then confidentiality may need to be broken. This may involve passing your details to the police or to your GP, but this will only be done in situations where the researcher believes that you are at immediate risk of harm to yourself or others.

Skype interviews will be recorded and will be saved anonymously in a confidential location on the university's system. This will only be accessible by the researcher. Any personal information about you, such as your name or contact details, will be saved confidentially on the university secure system and separately to this recording. Recordings will be listened to and transcribed by the researcher. In some cases, recordings with no identifiable information from the participant may be transcribed by a professional at a Transcription Service who provide confidential transcriptions for the purposes of research. Once all data has been transcribed and analysed all personal information about participants will be deleted (by September 2021) and it will not be possible to withdraw your data. Anonymised quotes and sections of text from interviews will appear in the final write up.

Anonymised transcripts from the interviews will only be accessible to me as the researcher and my supervisors. Transcripts will be kept for one year after my thesis is accepted (expected to be in 2022) and will not be kept beyond September 2024. After this date all transcripts will be deleted.

If you are interested in the outcomes of this study, a summary of the results of this research will be published on a twitter page that is made for this research following the final submission of the write up.

Will I receive any payment for taking part?

All participants will be offered entry into a prize draw with the potential to win £50 worth of Amazon vouchers. Participants who withdraw from the study will still be entered into the draw unless they ask to be withdrawn from this.
The prize draw will take part after all the interviews for this study have been completed (around October 2021) and the winner will be notified by email and sent an e-voucher.

What will happen to the results of this study?
The results will be written up and will be submitted as a thesis for assessment as part of the Doctorate in Clinical Psychology programme at the University of Exeter. It is hoped that the findings will also be published in a relevant journal. Participants will be able to contact the researcher to request a copy of the completed thesis once it has been completed and passed by the university.

Who is organising and funding this study?
This study is being funded by the University of Exeter.

Who has reviewed this study?
This project has been reviewed by the Research Ethics Committee at the University of Exeter (Reference Number….),

Further information and contact details
For further information please contact:

Ellie Scutt, Trainee Clinical Psychologist and researcher for this study
07875751682, es716@exeter.ac.uk

Dr Janet Smithson, Research Supervisor and Senior Lecturer in Psychology
j.smithson@exeter.ac.uk

Gail Seymour, Research Ethics and Governance Manager
g.m.seymour@exeter.ac.uk, 01392 726621

Thank you for your interest in this project

Appendix C

Consent Form

UNIVERSITY OF EXETER

Participant Identification Number:

CONSENT FORM

Title of Project: An Investigation into the Impact of Anorexia Nervosa on Disordered Eating in Siblings

Name of Researcher: Ellie Scutt

1. I confirm that I have read the information sheet dated.................... (version no............) for the above project. 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 without giving any reason and without my legal rights being affected. ☐

3. I understand that relevant sections of the data collected during the study, may be looked at by members of the research team, a transcription service and individuals from the University of Exeter, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I understand that taking part involves anonymised interview transcripts to be used for the purposes of reports published in an academic publication ☐

5. I agree to take part in the above project. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of researcher taking consent	Date	Signature

Appendix D

Debrief Sheet

Debrief

Thank you for taking part in this research interview. The purpose of this research was to explore your experiences of eating difficulties for both yourself and your sibling. We hope that the interview was not distressing and that you found the experience worthwhile. If you have found the experience difficult and you would like to speak to one of the researchers about this please contact:

Ellie Scutt- es716@exeter.ac.uk, (insert telephone number)

Dr Jasmin Langdon-Daly- jasmin.langdon-daly@somersetft.nhs.uk, (insert telephone number)

If you have any questions or complaints about this research please contact:

Gail Seymour, Research Ethics and Governance Manager
g.m.seymour@exeter.ac.uk, 01392 726621

If you need further support around your difficulties eating or with feelings of continuing low mood or thoughts of harming yourself please contact one of the following:

- BEAT eating disorders helpline: 0808 801 0711, https://www.beateatingdisorders.org.uk/
- The Samaritans: 116 123 (24 hours helpline), https://www.samaritans.org/

Alternatively you may wish to contact your local GP or for urgent enquiries call NHS 111 or go to your local A&E department.

Information regarding the results of this research will be made available on the researcher's twitter page: (insert page). You may also contact the researcher for information on the findings of this research.

Appendix E

Semi-structured Interview Questions

Thank you for agreeing to participate in this research, as you are aware participation is voluntary and you may choose to end the interview or to skip a question at any time. This research is interested in your experiences as someone who has witnessed a sibling with Anorexia and who has experienced eating difficulties yourself. The questions I will ask are designed to find out more about your experiences, some of them may be difficult to answer or sensitive and you may ask to pause at any time. At times I may ask for further information on a question or for a bit more detail, this is to make sure that I have understood your experience and can accurately summarise this for the research. There are no correct or expected answers, you are the expert on your experiences so please share as much as you feel comfortable to.

General Experiences

1. Please could you give me an overview of your experiences of having eating difficulties
2. What were your experiences of living with a sibling with Anorexia nervosa/an eating disorder?
3. What support would you have liked when your sibling was first experiencing eating difficulties?
4. What, if anything, do you think could have been done to prevent you from developing eating difficulties?
5. Do you recall any significant events from your childhood that may have impacted on your eating difficulties?

Family Functioning

6. What were your family relationships like before your sibling became unwell?
7. How did you sibling’s anorexia nervosa affect your relationship with your family members?
8. How did your relationship with your sibling change after they became unwell?
9. How have your own eating difficulties affected your family relationships?
10. Did you have any other significant relationships that helped or hindered your wellbeing?
11. What was the effect of your sibling’s difficulties on your own body image?

Emotional Regulation/Experience of Trauma

12. What emotions did you experience in relation to your sibling’s illness?

13. How did you manage these emotions?

14. What support would you have liked to help you manage emotions and difficulties following your sibling's illness?

15. Did your sibling's health have any influence on your illness or recovery?

16. What strengths do you have that have helped you to overcome these difficulties?

Appendix F

Advert for Participants

Have you had a Sibling who Experienced Anorexia?

Have you Restricted your Eating with a Desire to Change your Body?

I would like to invite you to take part in a research study investigating the experiences of siblings of people with Anorexia.

If you:

- Are over the age of 16
- Have lived with a sibling with Anorexia (with or without diagnosis)
- And then gone on to have difficulties with your eating (restricting eating, binging or purging)
- Have now recovered/are in recovery from eating difficulties

Please contact me and I will arrange a short telephone call to explain the research and answer questions. If you are eligible you will be invited to complete a Zoom interview about your experiences lasting up to an hour.

All participants will be entered into a prize draw to win £50 worth of Amazon vouchers

This research is part of my Doctorate in Clinical Psychology

Contact Details:

Ellie Scutt, Trainee Clinical Psychologist, email:
es716@exeter.ac.uk

Appendix G

Reflexive Diary Extract

Experiences as an interviewer

Feeling nervous as an interviewer- the interview felt familiar in some senses are some similarities with a clinical interview, but I am aware that the purpose is very different. I am still aiming to help people ultimately but this is unlikely to have any direct benefit to the participant I am talking to. I am being trusted with their stories and feel a strong responsibility to them to represent what they are saying accurately. I am also aware of the need to look for themes across the data set and I do not want to lose the nuances of each participant's story when doing this…

Beliefs affecting questions

Listening back to this interview I realise that I am assuming that this participant has a desire to be thin or would have envied aspects of her sister's illness when she is clearly telling me otherwise. I have grown up in a culture where it is assumed that being thin is better, this participant comes from a similar culture and perhaps I am assuming that they have the same experiences as I do on the value of being thin. I have not had a sister with AN and therefore my experiences have been different. This participant's motivation for restricting their eating is not what I initially expected but makes sense in the context of feeling uniquely placed to take on responsibility for their sibling. This fits with my reading around the topic but I am conscious that this experience has been different for everyone I have spoken to and that responsibility for a sibling is not one thing. An understanding of what an eating disorder is may also not be one thing. I am aware that many participants have been given different bits of information on what an eating disorder is and this may conflict with my concept (which is based on reading, research and some clinical experience). The sense they make of what has happened appears to influence their emotions around this and the meaning they have made of the experience.

Attitudes towards food

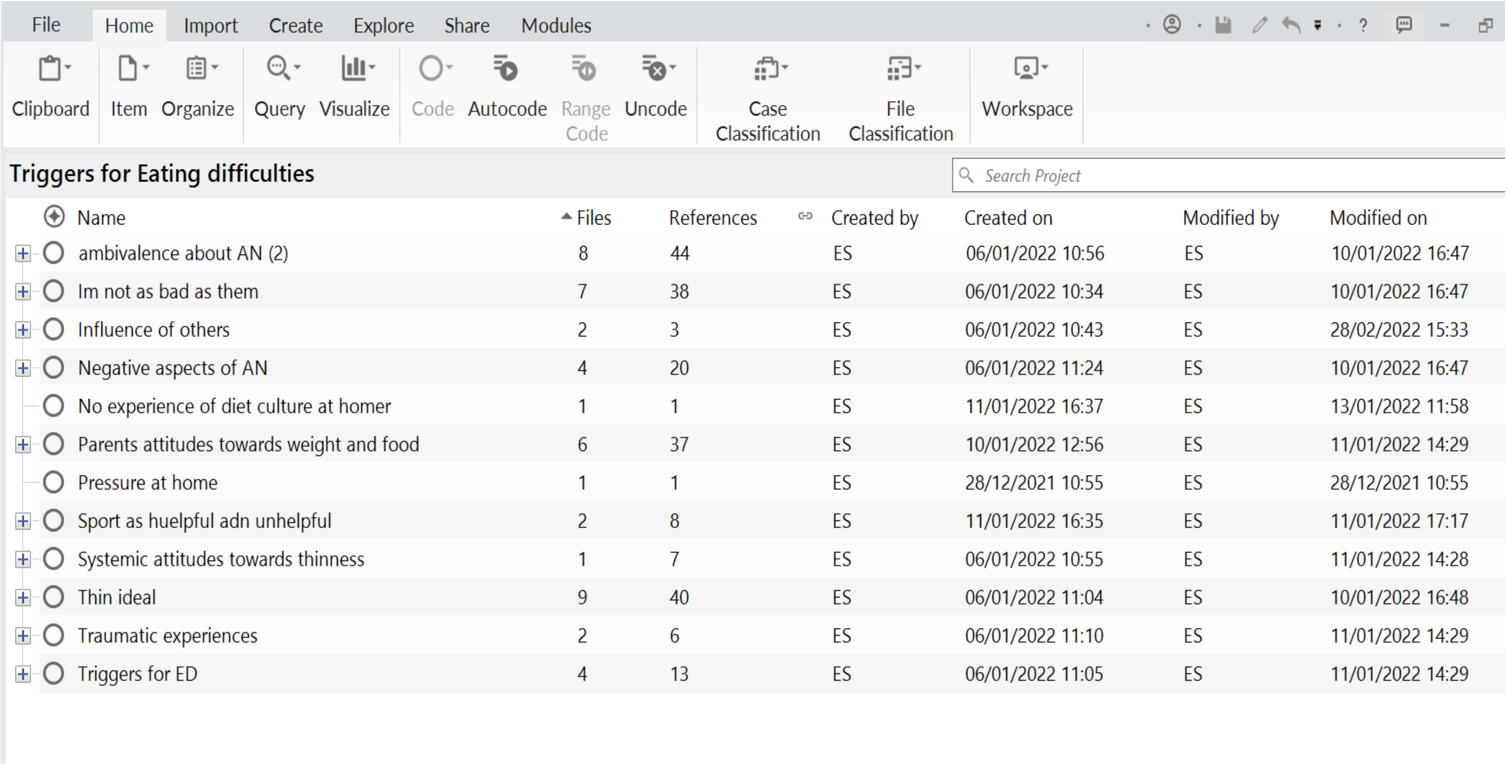
Many narratives around eating disorder in the past have looked for someone to blame and historically this has focussed on parents. I am aware that AN is a very complex illness and there is no one factor that leads to its development. I therefore want to be careful that this research is not blaming of people. This has been challenged when participants speak of abuse from care systems, as a professional within a care system it feels easier to blame this as I feel a part of it. I am also aware that my role here is as a researcher and therefore I cannot be apologetic on behalf of care system failings. I am also aware that there is a narrative throughout training of 'do no harm' accompanied by examples of harm being done in the past. So when I hear of failings it easily taps into that narrative. It is possible that where failing occurred this was not necessarily the 'fault' of anyone but that there was a lack of knowledge about how best to support people with AN. I should take care not to put too much weight on this factor.

Appendix H

An Example of How Themes were Built

Figure G1

Example of How Coding Extracts for Themes were Collected



Triggers for Eating difficulties

Name	Files	References	Created by	Created on	Modified by	Modified on
ambivalence about AN (2)	8	44	ES	06/01/2022 10:56	ES	10/01/2022 16:47
Im not as bad as them	7	38	ES	06/01/2022 10:34	ES	10/01/2022 16:47
Influence of others	2	3	ES	06/01/2022 10:43	ES	28/02/2022 15:33
Negative aspects of AN	4	20	ES	06/01/2022 11:24	ES	10/01/2022 16:47
No experience of diet culture at homer	1	1	ES	11/01/2022 16:37	ES	13/01/2022 11:58
Parents attitudes towards weight and food	6	37	ES	10/01/2022 12:56	ES	11/01/2022 14:29
Pressure at home	1	1	ES	28/12/2021 10:55	ES	28/12/2021 10:55
Sport as huelpful adn unhelpful	2	8	ES	11/01/2022 16:35	ES	11/01/2022 17:17
Systemic attitudes towards thinness	1	7	ES	06/01/2022 10:55	ES	11/01/2022 14:28
Thin ideal	9	40	ES	06/01/2022 11:04	ES	10/01/2022 16:48
Traumatic experiences	2	6	ES	06/01/2022 11:10	ES	11/01/2022 14:29
Triggers for ED	4	13	ES	06/01/2022 11:05	ES	11/01/2022 14:29

Table G1

Process of Defining Themes for the Analysis

Potential theme	**Changing relationships with family**	**Influence on Eating behaviours**	**Factors influencing development of AN**	**Wellbeing**
Subjects covered	Being the well sibling Not wanting to burden others Changed relationship with sibling and parents It's all about her Our relationship revolves around food Taking on responsibility Parental role Frustration towards parents Admiration for parents I need to get sister better	Motivation to get better I don't want to be like her I want to be like her Comparison and competition Focus on weight and shape Eating being controlled Sisters influencing each other Pressure to role model	Abuse Attitudes of parents towards food/diet Comments from school/outside world Comments from family Loss Family management of emotion Thin Ideal	Emotion management Understanding of AN Guilt and anger towards sibling Ambivalence towards AN I am not like her Imposter syndrome Reluctance to admit positives Emotion management Let down by system Sport Need for more support

Appendix I

Dissemination Statement

I intend to submit this research for publication in the Journal of Eating Disorders. I plan to post the final version to my Twitter, Instagram and Facebook pages for participants to access. In conjunction with my second supervisor for this work I plan to disseminate the findings to local eating disorder services through presentations and email summaries of the findings.

Appendix J

Link to Instructions for Submissions to the Journal of Eating Disorders

https://jeatdisord.biomedcentral.com/submission-guidelines/preparing-your-manuscript/research-article