LYNSEY DAVIES BSc (Hons) MSc PG Cert

REFINING PSYCHOLOGICAL INTERVENTIONS FOR ANOREXIA NERVOSA

Section A: Key features of the therapeutic relationship in psychological therapy for anorexia nervosa: A systematic review and thematic synthesis

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Summary of the Major Research Project

Section A provides a systematic review of the literature exploring what people with anorexia nervosa, who have received psychological therapy, identify as key features of the therapeutic relationship in treatment. The review critically appraises and synthesises nine qualitative papers and identifies four over-arching themes: universal features of the therapeutic relationship, needing other supportive relationships, clinical features of anorexia impact the establishment of the therapeutic relationship and distance from the identity of anorexia. Key findings are discussed in relation to existing theoretical and empirical literature. The review suggests recommendations for clinical practice and future research, including focusing on relational approaches in developing treatments for anorexia nervosa.

Section B explored the experiences of people with anorexia, carers and therapists on engaging with emotion and inside and outside of therapy, and their perspectives on what facilitates or hinders emotional change in anorexia nervosa. This was in order to refine and consolidate a new emotion focused treatment for anorexia nervosa. Thematic analysis of existing data was used to identify four over-arching themes; early experiences of engaging with emotion, how to achieve emotional change through the therapeutic relationship, factors impacting emotional change and accessing appropriate support. The findings are presented in relation to existing literature and theory. The results offered preliminary support for the new model and treatment. Clinical and research implications are discussed.

Table of Contents

Section A: Literature Review

Abstract	9
Introduction	10
An Introduction to Anorexia Nervosa	10
Treatment for Anorexia Nervosa	10
Predictors of Treatment Response	12
The Therapeutic Relationship	12
Defining and Measuring the Therapeutic Relationship	13
Qualitative Literature	14
Rationale and Aims of the Current Review	14
Method	15
Literature Search	15
Inclusion and Exclusion Criteria	16
Structure of this Review	19
Quality Appraisal	19
Overview of Studies	19
Approach to Quality Appraisal	23
Research Aims, Questions and Study Design	27
Participants and Recruitment	27
Data Collection and Rigour of Analysis	29
Ethics and Researcher Reflexivity	29
Findings	30
Conclusion	30
Thematic Synthesis	31
Universal Features of the Therapeutic Relationship	34
Needing Other Supportive Relationships	35
Clinical Features of Anorexia Impact the Establishment of the Therapeutic	36
Relationship	
Distance from the Identity of Anorexia	38
Discussion	38
Review Findings	39
Clinical and Research Implications	43
Strengths and Limitations	45
Conclusion	47
References	48

Section B: Empirical Paper

A Lordon and	5 0
Abstract	58
Introduction Decrease in Assessment Names and	59 50
Recovery in Anorexia Nervosa	59 50
Impact Page 1 and Transfer 1 and Tr	59
Recommended Treatments	60
New Developments	61
The SPEAKS Programme SPEAKS Theoretical Model	62
	63
SPEAKS Integrative Model of Change	64
Rationale for the Current Study	65
Aims	68
Method	68
Design	68
Positioning	69
Participants	69
Procedure	71
Recruitment	71
Focus Groups and Interviews	71
Data Protection and Confidentiality	72
Ethical Considerations	72
Data Analysis	73
Reflexivity and Quality Assurance	77
Results	77
Early Experiences of Engaging with Emotion	78
How to Achieve Emotional Change Through the Therapeutic Relationship	80
Factors Impacting Emotional Change	82
Accessing Appropriate Support	85
Discussion	88
What are Stakeholders' Experiences of Exploring Emotion in and Outside of	88
Therapy?	
The Emotions of People with Anorexia	88
Caregivers' Emotions	89
What do Stakeholders Perceive Facilitates and Hinders Engaging with Emotion or	90
Emotional Change?	
Expressing Emotion and Addressing Core Issues in Therapy	90
Developing the Self	91
Developing the Healthy Adult	92
Caregiver and Service Factors	92
Strengths and Limitations	93
Implications	94
Conclusion	95
References	97

Section A List of Table and Figures

List of Tables

	sion and Exclusion Criteria	17					
	view of Studies Included in the Review	20					
	eal Appraisal of Qualitative Studies using the CASP	25 26					
Table 4. Critical Appraisal of the Mixed Method Study using the MMAT							
Table 5. Them	natic Synthesis of Findings	33					
	List of Figures						
Figure 1. Flow	Diagram of Literature Search	18					
	Section B List of Table and Figures						
	List of Tables						
Table 1. Emot	ion Focused Maintenance Models of AN	62					
Table 2. The S	SPEAKS Model of Change and Intervention for AN	65					
Table 3. Demo	ographic Information for PwAN Participants	70					
	ographic Information for Therapist Participants	70					
	Collection Methods Across Participants	71					
Table 6. Identi	fied Themes	78					
	List of Figures						
Figure 1. Phas	es of SPEAKS	66					
Figure 2. Data	Analysis Process	76					
	Section C: Appendices of Supporting Materials						
Annondiy A.	Health Desearch Authority Letter of Approval for Terminated Project	105					
Appendix A: Appendix B:	Health Research Authority Letter of Approval for Terminated Project Email for Research Ethics Committee Confirming end of Major	100					
Appendix B.	Research Project	100					
Appendix C:	Quality Appraisal of Qualitative Studies Using the Critical Appraisal	107					
	Skills Checklist for Qualitative Research						
Appendix D:	Appraisal of Mixed Methods Study Using the Mixed Methods	109					
	Appraisal Tool						
Appendix E:	Extract of Coded Data	110					
Appendix F:	Thematic Synthesis	111					

Appendix G:	Flowchart of the SPEAKS Model of Change	113
Appendix H:	Information Sheet for People with Anorexia	114
Appendix I:	Information Sheet for Carers	118
Appendix J:	Information Sheet for Therapists	122
Appendix K:	Consent Form for People with Anorexia	126
Appendix L:	Consent Form for Carers	128
Appendix M:	Consent Form for Therapists	130
Appendix N:	Topic Guide for Interviews with People with Anorexia	132
Appendix O:	Topic Guide for Interviews with Carers	134
Appendix P:	Topic Guide for Interviews with Therapists	136
Appendix Q:	Health Research Authority Letter of Approval	138
Appendix R:	Confirmation of Ethical Approval from Canterbury Christ Church	139
	University	
Appendix S:	Summary Letter to Participants	140
Appendix T:	Summary Letter to Research Ethics Committee	143
Appendix U:	Deductive Analysis Codebook	147
Appendix V:	Extract of Inductive Analysis Codes	149
Appendix W:	Example Coded Transcript of Therapist Focus Group	150
Appendix X:	Example Thematic Maps	151
Appendix Y:	Abridged Research Diary	153
Appendix Z:	Journal of Eating Disorders Author Guidelines	156

8	
Section A: Key features of the therapeutic relationship in psychological therapy for anorexia	
nervosa: A systematic review and thematic synthesis	
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SECTION A: LITERATURE REVIEW

9

Abstract

The therapeutic relationship has been linked to outcomes in psychological therapy for anorexia nervosa, though there is little research in this topic area and research is yet to determine the key features of this relationship from the client's perspective. This review explored what people with anorexia, who have experience of psychological therapy, perceive to be key features of the therapeutic relationship. A systematic literature search and quality appraisal yielded nine published studies for inclusion in this review. A thematic synthesis of the papers identified four themes; universal features of the therapeutic relationship, needing other supportive relationships, clinical features of anorexia impact the establishment of the therapeutic relationship and distance from the identity of anorexia. Results indicate that there are nuanced aspects to the therapeutic relationship that are specific to this population. These factors in the development and maintenance of the therapeutic relationship should be considered by clinicians, and future research should focus on how relational treatment approaches could improve outcomes and engagement in psychological therapy for anorexia nervosa.

Keywords: anorexia nervosa; therapeutic relationship; therapeutic alliance; psychological therapy; qualitative methods

Introduction

An Introduction to Anorexia Nervosa

Anorexia nervosa (AN) is an eating disorder characterised by restriction of food intake with the intent to reach a low weight, a fear of weight gain and body image difficulties which impact on self-evaluation (American Psychiatric Association, 2013). The estimated lifetime prevalence of AN in females is 1.2 to 2.2% with a-typical or subthreshold estimates reaching 4.3% (Bulik et al., 2006; Keski-Rahkonen, 2007; Wade et al., 2006). However, estimates using newer diagnostic and statistical manual of mental disorders (DSM) criteria indicate that prevalence rates may be higher (Mustelin et al., 2016). Prevalence rates in males are estimated to be 0.29% (Bulik et al., 2006) however AN in males may be under identified (Keski-Rahkonen et al., 2008). The onset of AN usually begins in adolescence to early adulthood (Volpe et al., 2016; Wentz et al., 2009) and is associated with high psychiatric comorbidity, higher rates of suicidal thoughts and self-harm compared to other mental health difficulties, and elevated mortality rates (Doll et al., 2005; Smink et al., 2012; Swinbourne & Touyz, 2007). It is associated with a reduced quality of life (Jenkins et al., 2011) including significant negative impact on family and social relationships (Gilbert et al., 2000; Westwood et al., 2016) and on education or employment opportunities (Maxwell et al., 2011; Robinson et al., 2015).

Treatment for Anorexia Nervosa

In the United Kingdom (UK) the recommended treatment pathway for AN is through specialist eating disorder (ED) services which are outpatient or day patient services, or inpatient care for people with AN (PwAN) with the highest physical risks (National Institute for Health Care Excellence [NICE], 2017). Along with dietary support and physical monitoring, evidence based psychological treatments are recommended for PwAN including

ED focused cognitive behavioural therapy (CBT-E) (Fairburn et al., 2008) and the Maudsley anorexia nervosa treatment for adults (MANTRA) (Schmidt et al., 2014). ED focused focal psychodynamic therapy is recommended where previous treatments are ineffective (NICE, 2017). For children and young people (CYP) family focused therapy for AN (FT-AN) (Lock & Le Grange 2015) is recommended, which emphasises the role of the family in recovery (NICE, 2017). There is an emerging evidence base for the efficacy of FT-AN for CYP (Hay et al., 2014), however the adult literature emphasises a lack of evidence for treatment superiority when comparing the available therapies (Bryne et al., 2017; van den Berg et al., 2019; Hay et al., 2015; Schmidt et al., 2013), and a recent large scale meta-analytic study found the same when considering treatment of adolescents (van den Berg et al., 2019).

Although recovery from AN is difficult to define, outcome measures in randomised control trials (RCTs) usually include measures of weight gain, body mass index (BMI), eating pathology (restriction, binge/purge frequency, shape/weight concern), quality of life and social impairment (van den Berg et al., 2019).

Studies indicate that current treatments may not be acceptable to clients, as only 60% of PwAN who access NICE recommended interventions complete treatment; only 50% of those achieve a healthy weight post-treatment, and a further 28.3% experience remission at 12 months follow up (Bryne et al., 2017). Reports of achieving a healthy weight is lower in other literature investigating CBT-E (Fairburn et al., 2013) though marginally higher for MANTRA (Schmidt et al., 2015). Taken together, this indicates the poor outcomes after treatment and highlights the need to improve engagement in treatment for AN, identify predictors and moderators of treatment outcome and consider the mechanisms of change in interventions.

Predictors of Treatment Response

Research has focused on personal characteristics, traits or symptoms of PwAN as predictors of response to treatment, with evidence from a meta-analytic study suggesting that lower levels of ED pathology predict better outcomes, however this effect was not significant at follow up (Vall & Wade, 2015). Low psychiatric comorbidity, weight and shape concern, onset of AN, and better interpersonal functioning also predict more favourable outcomes (Vall & Wade, 2015). The scope of this review does not allow for a full discussion of predictor variables however there are further personal and interpersonal factors noted in the literature, including shame and self-compassion (Kelly et al., 2014). Interestingly, the majority of these large scale RCTs only focus on the characteristics of PwAN in relation to outcomes, which may not be reflective of the wider picture in psychological treatment, where the interpersonal factors between the therapist and the client inevitably influence the experience of treatment.

The Therapeutic Relationship

The therapeutic relationship (TR), also termed the therapeutic alliance, has been empirically associated with treatment outcome in both individual and family therapy across mental health difficulties (Friedlander et al., 2011; Martin et al., 2000) and is considered both a therapeutic tool and important process in psychotherapy. In FT-AN, the TR has been linked to weight gain and lower treatment dropout (Ellison et al., 2012; Isserlin & Couturier, 2012; Pereira et al., 2006) and in psychotherapy for AN, the TR is associated with treatment outcome (Zeeck & Hartmann, 2005). One recent systematic review collated evidence from quantitative studies that investigated the TR in therapy for EDs, where at least one measure of the therapeutic alliance was collected, in addition to one measure of treatment outcome (remission, drop out or ED symptoms). All seven studies focusing on AN found a positive effect of the TR on

treatment outcomes (Werz et al., 2021). Furthermore, the therapeutic alliance has been found to have positive associations with motivation to change in AN (Marzola et al., 2019). Research suggests that a better understanding of the key factors in the TR for AN could help inform future treatments (Marzola et al., 2019). This is of potential significance considering the relatively poor efficacy and completion rates of AN treatments and further justified due to the ambivalence in treatment for AN (Gregersten et al., 2017).

Defining and Measuring the Therapeutic Relationship

The TR is often discussed both clinically and in the empirical literature, though can refer to a range of qualities or processes and benefits from definition. Bordin (1979) offered the first definition of the TR which still captures the present-day understanding. Bordin's (1979) conceptualisation included three elements: agreement of the therapy goals, agreement on the tasks of therapy and the quality of the bond between the client and the therapist. One of the most common measures of the TR is the Working Alliance Questionnaire (WAQ) (Horvath & Greenberg, 1989) which was developed based on Bordin's (1979) theory and has been utilised in measuring the TR in ED research. Different versions are available to capture the client, therapist and observer views.

Although the WAQ has been widely used in ED research, its applicability to AN may be limited. Both the tasks and goals of therapy may not be easily agreed in therapy due to differing clinician and client views and specifically in AN due to the ambivalence and resistance to treatment early in therapy (Gregersten et al., 2017). This is particularly pertinent for adolescents, who are often brought to treatment by their parents (Forsberg et al., 2012). Furthermore, attachment style has been associated with the TR, with an anxious attachment style predicting the most difficulty in establishing this relationship (Slade, 2008).

PwAN are reported to have higher levels of insecure attachment compared to people with bulimia nervosa (BN) and other EDs (Tereno et al., 2008; Troisi et al., 2005) and therefore establishing the TR may pose unique difficulties for this client group. Considering the above factors, other aspects of the TR may be important in addition to Bordin's (1979) model. The qualitative literature in this area is able to pose unique insights, which may help to provide a more accurate reflection of the process of establishing the TR in treatment for AN.

Qualitative Literature

Qualitative studies investigating the experiences of treatment for AN have highlighted the importance of a positive TR with staff in both adolescent and adult populations (Rance et al., 2017; Ross et al., 2011; Sly et al., 2014; Smith et al., 2016; Zaitsoff et al., 2016). Some studies have identified what factors are considered to be key to the TR in treatment for AN, including externalising the ED, maintaining hope, a strengths-based approach and being treated as a person rather than a diagnosis, whereas unhelpful factors included a lack of therapist confidence or knowledge (Oyer et al., 2016; Ramjam, 2004; Wright & Hacking, 2011). However, due to the multi-disciplinary involvement in treatment for EDs, research tends to focus on relationships with all professionals or focuses on relationships with nursing staff in inpatient care. Furthermore, the experience of the TR is often embedded in research investigating the experience of treatment in general, often has a small section of the results and is difficult to find through literature searching.

Rationale and Aims of the Current Review

Previous reviews in this area have focused on the impact of the TR in AN (Ordon, 2012), experiences of treatment (Sibeoni et al., 2017) and nurses' establishment of health promoting relationships (Salzmann-Erikson & Dahlen, 2017). To the author's knowledge there are no

systematic qualitative reviews investigating what PwAN identify as the key features of a TR in therapy for AN. Considering the level of dropout and poor outcomes in therapy for AN and the high predictive validity of the TR on both outcomes and dropout rates, it is important to consider what PwAN identify as key factors in the TR specifically during psychological therapy for AN, as this may differ depending on the nature of the clinician's involvement in treatment. Geller et al. (2001) also highlight the need for clinicians to understand how the TR is established and maintained for PwAN. Despite this being recommended in the literature 20 years ago, this has yet to be identified in the empirical research. Therefore, this study aims to explore the TR in therapy for AN, from the perspective of PwAN through the qualitative literature. Specifically, this paper asks, what do PwAN, who have experience of psychological therapy, identify as key features in the development of the TR?

Method

Literature Search

An electronic search of the databases ASSIA, PubMed, PsychINFO and Web of Science was conducted in September 2021. Titles, abstracts and keywords were searched using the search terms (Anorexia Nervosa AND therapeutic alliance OR therapeutic relationship OR helping alliance). Search terms were based on common names for the TR in existing qualitative literature. No limits were imposed on the date of publication. Additional searches using Google Scholar did not identify any further papers meeting inclusion criteria. The search was not limited to published studies, but did not yield any grey literature that met inclusion criteria. No previous reviews were identified through Google Scholar, the Cochrane Library or PROSPERO databases.

SECTION A: LITERATURE REVIEW

16

Titles and abstracts of the papers were screened to determine if the study was appropriate to the current review. Reference lists were hand searched during the abstract screen to identify further relevant papers. Full texts were screened to identify papers that met inclusion criteria. Result of the literature search are displayed in Figure 1. The search yielded nine papers for inclusion in this review, all of which were published articles in peer reviewed journals.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria are detailed in Table 1. Studies were included that presented detail of the TR in the results section of the paper as there are few papers exclusively investigating the TR. Qualitative or mixed methods papers were included, where there was qualitative information on the TR. This was in order to understand the individual experience of PwAN. Translated research was excluded in case the original quotes of participants could not be directly translated.

The papers must have stated that all participants had received psychological therapy in order to provide a more accurate insight into the TR with therapists, as opposed to other clinicians. The decision to include subthreshold AN, or an other specified feeding or eating disorder (OSFED) with restrictive type symptomology, was made due to the DSM-5 widening the criteria for AN, with some older papers typically using a diagnosis of AN and subthreshold AN according to the fourth edition DSM criteria. This was also due to the likelihood that people who marginally do not meet criteria for AN are likely to present similarly clinically.

 Table 1

 Inclusion and Exclusion Criteria

- Published in English
- Qualitative design or mixed method design with clear reporting of qualitative data

Inclusion Criteria

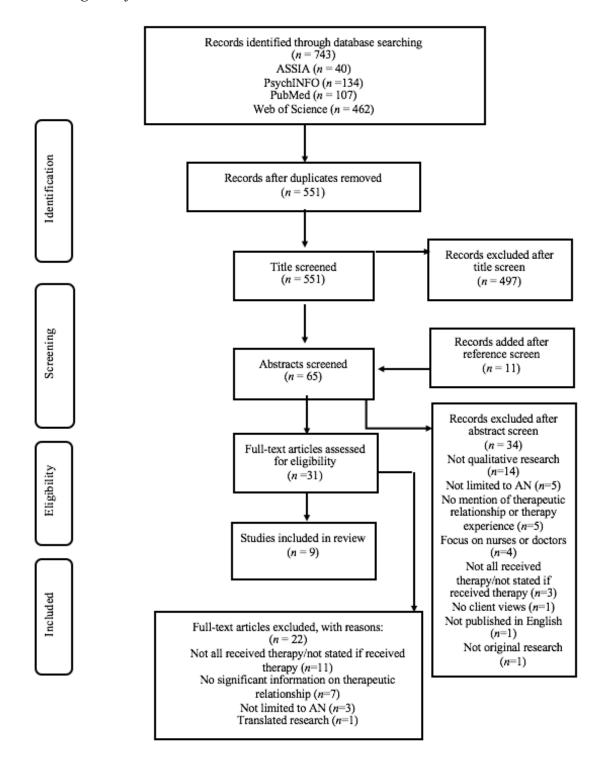
- Research regarding TR or results largely including description of the TR
- Views from PwAN identified separately to other respondents if multiple stakeholder groups are included in the study
- All participants to have received psychological therapy
- Clear focus on anorexia nervosa, subthreshold AN or OSFED restrictive type only

- Not available in English
- Quantitative only design
- No qualitative results focusing on TR

Exclusion Criteria

- Translated research
- None or very limited description of the TR in results section of the paper
- Participants had not received psychological therapy
- Not stated if participants had received psychological therapy
- Focus on all EDs with no clear distinction by diagnosis in the results sections

Figure 1
Flow Diagram of Literature Search



Structure of this Review

This review will present a critical appraisal of the studies before detailing a thematic synthesis of results. Following this, clinical and research implications, and strengths and limitations of this review will be discussed.

Quality Appraisal

Overview of Studies

The literature search identified nine published studies meeting inclusion criteria for this review published between 2001 and 2020. Eight of the studies used a qualitative approach whereas one paper opted for a mixed method design (Button & Warren, 2001). One study was completed from each of Sweden, the United States of America, France and Ireland and the remaining five studies took place in the UK. Participant numbers ranged from six to 36 participants. An overview of the studies is presented in Table 2.

Table 2

Overview of Studies Included in the Review

Authors	Country	Design	Recruitment	Sample	Study Aims	Data Analysis	Findings about the Therapeutic Relationship
Blackburn et al., 2020	Ireland	Qualitative research design using a psychoanalytically informed interview technique.	Online advert on a national eating disorder website.	6 White Irish Women (aged 22-44) Formally diagnosed with AN.	To explore the interpersonal and intrapsychic experiences of individuals with long standing AN and consider the impact on recovery.	Thematic analysis. Informed by a psychoanalytic approach considering interviewer's feelings and reflections.	Participants disliked a one size fits all approach. Trust and showing genuine care are important. Holding onto hope was an important factor. Diagnostic labels used by therapist perceived as pessimism. Therapists must encourage clients to meet their own needs rather than doing it for them.
Button and Warren, 2001	UK	Mixed method design using semi structured interview and outcome measures.	Recruited from specialised ED service by the Consultant Psychiatrist.	36 adults with AN interviewed. Demographic details not provided.	To explore how people with AN view AN, the effects on their lives and their view of treatment.	Not stated. Appears to be thematic analysis.	The TR is an important factor in treatment satisfaction. A lack of interest by the therapist hindered the relationship as did a lack of trust. Treating the client as a person was important. Being viewed as a diagnostic label appeared to hinder the TR.
Fox and Diab, 2015	UK	Qualitative research design using semi-structured interviews.	Recruited from inpatient ED services.	6 White British women with AN (aged 19-50) Diagnosis of AN with duration of 6+ years.	To explore the people with AN perceived experience of living with and being treated in an ED unit for AN.	Interpretative Phenomenological Analysis.	Trust and belief in practitioner's expertise is a key factor of the TR. Setting appropriate and meaningful goals is important. Lack of skill by the therapist was unhelpful. Therapist absence was unhelpful. Separating the person from the eating disorder was a helpful tool by the therapist.

SECTION A: LITERATURE REVIEW

Lindstedt et al., 2015	Sweden	Qualitative research design using a hermeneutic phenomenological approach.	Recruited by clinicians at specialised eating disorder services.	15 Participants (aged 13-19). AN of EDNOS Restrictive type symptomatology.	To investigate how young people experienced their time in treatment for their ED.	Thematic analysis.	Therapists' confidence and trust are important factors. Letting the therapist take control of the treatment was preferred initially. Having a choice in decisions and their own wishes considered was also important. View of the TR like a complementary addition to existing relationships. Genuinely caring and a focus on well managed endings was also deemed to be important.
Oyer et al., 2016	United States of America	Qualitative research design utilizing a psychoanalytically informed interview technique.	Recruited by therapists working with clients with AN, through two eating disorder association websites.	8 people diagnosed with AN (aged 20 – 63). 7 therapists.	To investigate the experiences of clients and therapists regarding which factors aided and challenged the therapeutic alliance in individual psychotherapy.	Phenomenological analysis.	Important factors were strong basic counselling skills, therapist self-disclosure, expertise in eating disorders, collaboration with external support systems and individualised treatment. Lack of attunement and being judgemental were unhelpful factors.
Rance et al., 2017	UK	Qualitative research design using semi-structured interviews.	Internet-based advertisements on 'beat' website and notices in waiting room of ED services and support groups.	12 women (aged 18 – 50). 11 formally diagnosed with AN. 1 not formally diagnosed but had a long history of restriction.	To explore client's views about their treatment for their ED.	Thematic analysis.	Being seen as a whole person is important. Removing hope was unhelpful. Labelling all clients as experiencing similar difficulties was unhelpful. Feeling judged and dismissed by therapist was unhelpful. Experienced therapist was preferred. Desire for therapist self-disclosure was mixed.
Sibeoni et al., 2020	France	Qualitative research design using semi-structured interviews.	Identified from specialised ED services. Recruited using purposeful sampling by clinicians. Participants were selected based on who they thought would provide the most information.	15 adolescent girls with anorexia (aged 13 – 17). 18 parents. 8 psychiatrists.	To identify barriers and facilitators of the therapeutic alliance during inpatient treatment.	Thematic analysis.	Facilitators of alliance included human qualities, good relational skills, playing an active role in treatment, time and taking care of the family. Barriers to the alliance included being too close or too distant, focusing on weight, control and power imbalance and focusing on diagnostic labels.

SECTION A: LITERATURE REVIEW

Smith et al., 2016	UK	Qualitative research design using semi- structured interviews.	Recruited from inpatient ED services.	21 adult women with a diagnosis of AN (aged 18 – 41).	To explore women's experiences of specialist inpatient treatment for AN.	Thematic analysis.	Participants highlighted the importance of trust and understanding, being seen as a whole person and addressing psychological issues.
Tierney, 2008	UK	Qualitative research design using semi- structured interviews.	Recruitment by ward manager on adolescent inpatient unit and self-help network.	10 White adolescents treated for AN (aged 11 to 18).	To provide a perspective on how it feels to be treated for AN.	Thematic analysis.	Therapist's leaving can impact on trust. Being challenged by therapists was helpful. Clinicians require special training to work with this client group. Unhelpful that therapists are perceived to believe everything they are told.

Approach to Quality Appraisal

The Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (CASP, 2018) was used to appraise the qualitative papers in this review (Table 3 and Appendix C). This checklist was chosen as it is recommended by NICE (2014) to assess the quality of qualitative studies for development of their guidelines. NICE (2014) does not recommend a framework for mixed methods studies. The mixed method study in this review was appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) (Table 4 and Appendix D) which has been demonstrated to be a reliable tool.

A scoring system is not recommended by the authors of the CASP checklist or MMAT, and the Cochrane guidelines advises against using overall scores to categorise studies (Noyes et al., 2018). Therefore, cut off scores to determine quality are not available in the published literature. Consequently, researcher judgement along with a discussion of the papers was used to determine the quality of the papers, as is acknowledged that quality appraisal tools may only assess quality of reporting (Carroll et al., 2012). Guidance on quality appraisal for qualitative research was used to determine whether papers were included in the thematic synthesis.

According to the overall quality scores alone, all papers addressed the majority of the quality criteria. Four papers met all criteria, which may indicate the highest quality papers (Blackburn et al., 2020; Lindstedt et al., 2015; Rance et al., 2017; Smith et al., 2016). The MMAT indicated that rigour of analysis in one paper was not sufficiently addressed, which may indicate the poorest quality study (Button & Warren, 2001) as Long et al. (2020) suggest this a key criterion in determining quality. The CASP checklist for the remaining papers (Fox & Diab, 2015; Oyer et al., 2016; Sibeoni et al., 2020; Tierney, 2008) indicated the majority of

criteria were met though had areas for improvement, which may suggest these papers are of moderate quality. Researcher reflexivity was assessed using guidance from the CASP and considered whether researcher's previous experience, relationships to participants and influence of data analysis were all reflected upon and whether suggestions were made on how this could impact results.

 Table 3

 Critical Appraisal of Qualitative Studies using the CASP

CASP Question	Blackburn et al., 2020	Fox and Diab, 2015	Lindstedt et al., 2015	Oyer et al., 2016	Rance et al., 2017	Sibeoni et al., 2020	Smith et al., 2016	Tierney, 2008
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	Yes	Can't tell	Yes	Can't tell	Yes	Can't tell	Yes	Yes
Have ethical issues been taken into consideration?	Yes	No	Yes	Can't tell	Yes	Yes	Yes	Can't tell
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the research valuable?								
 	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Number of quality criteria met	10	8	10	8	10	9	10	9

Table 4Critical Appraisal of Mixed Method Study using the MMAT

_	Methodological Quality Criteria	Button & Warren (2001)
Screening Questions	Are there clear research questions?	Yes
C	Do the collected data allow to address the research questions?	Yes
Qualitative Studies	Is the qualitative approach appropriate to answer the research question?	Yes
	Are the qualitative data collection methods adequate to address the research question?	Yes
	Are the findings adequately derived from the data?	Can't tell
	Is the interpretation of results sufficiently substantiated by data?	Yes
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes
Quantitative Descriptive	Is the sampling strategy relevant to address the research question?	Yes
Studies	Is the sample representative of the target population?	Yes
	Are the measurements appropriate?	Yes
	Is the statistical analysis appropriate to answer the research question?	Yes
Mixed Methods Studies	Is there an adequate rationale for using a mixed method design to address the research question?	Yes
	Are the different components of the study effectively integrated to answer the research question?	Yes
	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes
Number of Quality criteria Met		16

Research Aims, Questions and Study Design

Seven of the papers aimed to broadly investigate the experience of PwAN, with one focusing on recovery (Blackburn et al., 2020), six on the experience of treatment (Button & Warren, 2001; Fox & Diab, 2015; Lindstedt et al; 2015; Rance et al., 2017; Smith et al., 2016; Tierney, 2008) and two focusing the facilitators and barriers to the TR (Oyer et al., 2016; Sibeoni et al., 2020). All papers stated their aims and chose appropriate methodology to answer the research questions. Two papers used a psychoanalytically informed interview technique (Blackburn et al., 2020; Oyer et al., 2016). Six papers used thematic analysis to address their aims (Blackburn et al., 2020; Lindstedt et al., 2015; Rance et al., 2017; Sibeoni et al, 2020; Smith et al., 2016; Tierney, 2008) which does allow for participants' subjective experience to be captured, however the aims of exploring unique experiences may have been better captured by a more in-depth design. Two studies used phenomenological analysis (Fox and Diab, 2015; Oyer et al., 2016) which provides a rich description of participants' experiences. Button and Warren (2001) did not state their type of analysis used to address the research aims, which represents poor quality, however the analysis appears to be a form of thematic analysis.

Participants and Recruitment

The studies used purposeful sampling techniques in order to address the aims of the research questions. Three of the studies recruited participants from inpatient settings (Fox & Diab 2015; Sibeoni et al., 2020; Smith et al., 2016). Four studies used participants in the community, who were not necessarily involved in current ED treatment at the time of interview (Blackburn et al., 2020; Button & Warren, 2001; Oyer et al., 2016; Rance et al. 2017) whilst the remaining studies recruited participants from both groups. Across studies participants had mixed and multiple experience of services and therefore overall, the

literature could be considered applicable to a wide range of PwAN. However, only three studies provided detail as to why some participants who were contacted chose not to take part in the study (Button & Warren, 2001; Lindstedt et al., 2015; Smith et al., 2016) which does not indicate whether there was a selection bias in recruitment or whether people who declined to take part had a particularly negative experience during treatment for AN, which may cause a bias in results. Sibeoni et al. (2020) selected participants by clinicians stating who they thought would have most to contribute to the findings, which represents a selection bias.

Six studies used an adult population (Blackburn et al., 2020; Button & Warren 2001; Fox & Diab, 2015; Over et al., 2016; Rance et al., 2017; Smith et al., 2016) while the remaining three studies focused on adolescents' experiences. All but two papers chose to focus exclusively on client views (Oyer et al., 2016; Sibeoni et al., 2020) though this was justified in their rationales and results from different stakeholder groups could be identified independently in the results section of the papers. Age ranges were included in most of the studies, with the exception of Button and Warren (2001) who instead gave the average age, which could be skewed by outliers. However, they did focus on experiences seven years after treatment with an ED service, so it could be argued this inclusion criterion provided sufficient detail in relation to their study aims. Two studies only recruited female participants (Rance et al., 2017; Smith et al., 2016) in line with their study aims, whereas one study was only able to recruit female participants (Sibeoni et al., 2020). The remaining studies used a mixture of genders however significantly fewer males took part. Although more females typically present with AN (Bulik et al., 2006) only three studies referenced the lack of male participants in their limitations section (Linstedt et al., 2015; Sibenoi et al., 2020; Tierney, 2008). The ethnicity of participants was stated in four studies, where all participants included in the studies were White (Blackburn et al., 2020; Fox & Diab, 2015; Oyer et al., 2016;

Tierney, 2008). This is problematic and represents an overall weakness of the literature as the results may not be generalisable to other races, particularly where different values or approaches may be appreciated from different cultural backgrounds.

Data Collection and Rigour of Analysis

All studies sufficiently described their data collection process except one study where information was lacking (Fox & Diab, 2015). Three studies provided the full interview schedule (Fox & Diab, 2015; Lindstedt et al., 2015; Sibenoi et al., 2020) whereas one gave a sample of the questions (Oyer et al., 2016) and one advised this was available on request (Button & Warren, 2001). This means that two studies were fully replicable (Lindstedt et al., 2015; Sibenoi et al., 2020), except for the use of follow up questions due to the nature of semi-structured interviews. One study failed to provide a description of their chosen method of data analysis (Button & Warren, 2001) and although it appears to be a form of thematic analysis, this limits the rigour of analysis for this particular study. One further study provided limited information on their data analysis process (Tierney, 2008). Most papers did describe inter-rater reliability or checking of the coding process except for Fox and Diab (2015), however there are differing opinions in whether this is appropriate or necessary in thematic analysis and therefore does not necessarily mean the study lacks methodological rigour. Three papers provided exemplary outlines of their data analysis process with step-by-step guides (Blackburn et al., 2020; Lindstedt et al., 2015; Sibeoni et al., 2020).

Ethics and Researcher Reflexivity

Four studies provided a description of their ethical approval and ethical processes that were in place in the study (Lindstedt et al., 2015; Rance et al., 2017; Sibeoni et al., 2020; Smith et al., 2016) and Blackburn et al. (2020) stated their ethical approval only. None of the other studies

provided sufficient description of their ethical approval or considerations for the studies, which is limitation of the research. Researcher reflexivity was well described by three studies (Blackburn et al., 2020; Rance et al., 2017; Smith et al., 2016). None of the other studies addressed researcher reflexivity which is problematic in qualitative research. Fox and Diab (2015) made some attempt at this by describing the previous experience of the researchers but do little to explain how this could influence the data.

Findings

Most studies presented their findings to a high standard with all studies providing quotes in the discussion sections, though one study may have benefitted from providing richer quotes (Oyer et al., 2016). All papers made reference to relevant existing literature and provided clinical implications, whilst most papers made reference to future research except for two papers (Lindstedt et al., 2015; Tierney, 2008).

Conclusion

The quality checklists and discussion of quality appraisal found that the studies included in this review mostly satisfied quality criteria. There are areas for improvement in terms of widening the participant pool, adding the reasons for deciding not to take part and reporting ethical processes, however this is not sufficiently concerning to exclude papers in the thematic synthesis. Button and Warren's (2001) failure to include the method of analysis calls into question the quality of this paper, however they did provide rich descriptions of themes and included numerous quotes. Overall the study designs, data collection quality and rigour of analysis was satisfactory across studies.

Papers were not excluded from the thematic synthesis on the basis of quality as Thomas and Harden (2008) recommend including all studies, as there is no widely accepted method of excluding studies based on a quality appraisal. All literature was also included to ensure the review captured all available views from PwAN given there is little research into this topic. Furthermore, some researchers suggest that appraisal tools for qualitative research may not be appropriate or representative for this type of research (Hannes et al., 2010). However, due to Button and Warren (2001) failing to state their method of analysis and this paper being the poorest quality paper according to the critical appraisal tools, only direct quotes from participants were included in the synthesis, following guidance from Long et al. (2020).

Thematic Synthesis

Following the critical appraisal, the qualitative results of the studies were analysed using a thematic synthesis, following guidance from Thomas and Harden (2008). The thematic synthesis involved three key stages beginning with entering the results of all studies into NVivo coding software and using line-by-line coding for the findings of the papers (Appendix E). The codes were not applied to results that specifically referred to healthcare professionals other than therapists or information unrelated to the TR. Following this, initial codes were organised into descriptive themes which remained close to the original text. Finally, interpretive themes in relation the research question of this review were identified (Appendix F). The final stage is completed in order to move beyond the findings of the original papers and was cyclical in process until all the interpretive themes could describe the initial descriptive themes and answer the research questions (Thomas & Harden, 2008). This also follows guidance from Braun and Clark's (2006) approach in refining and reviewing the themes, whilst maintaining researcher reflexivity, whereby the researcher questions their own assumptions during the coding and theme development process. Four over-arching themes

and six subthemes were identified from the papers in relation to the research question; what do people with anorexia who have experience of psychological therapy identify as key features in the development of the TR? Results are presented in Table 5.

Table 5 *Thematic Synthesis of Findings*

	~ 4.4	
Theme	Subthemes	Contributing Studies
Universal features of the therapeutic relationship	Ability to help	Blackburn et al. 2020; Button & Warren 2001; Fox & Diab, 2015; Lindstedt et al. 2015; Oyer et al. 2016; Rance et al. 2017; Sibeoni et al. 2020; Tierney, 2008
	Holding onto hope and goals	Blackburn et al. 2020; Fox & Diab, 2015; Lindstedt et al., 2015; Oyer et al., 2016; Rance et al. 2017
	Connecting as people	Blackburn et al. 2020; Button & Warren, 2001; Fox & Diab, 2015; Lindstedt et al., 2015; Oyer et al., 2016; Rance et al. 2017; Sibeoni et al. 2020; Smith et al. 2016; Tierney, 2008
Needing other supportive relationships		Lindstedt et al. 2015; Oyer et al. 2016; Sibeoni et al. 2020
Clinical features of anorexia impact the establishment of the therapeutic relationship	Anorexia blocks the development of the therapeutic relationship	Fox & Diab, 2015; Lindstedt et al. 2015
	Beliefs about being in relationships as a barrier	Blackburn et al., 2020; Button & Warren, 2001; Rance et al., 2017
	The therapist's approach needs to shift over time	Blackburn et al. 2020; Lindstedt et al. 2015; Oyer et al. 2016; Sibeoni et al. 2020; Smith et al. 2016
Distance from the identity of anorexia		Blackburn et al. 2020; Button & Warren 2001; Fox & Diab, 2015; Lindstedt et al., 2015; Oyer et al. 2016; Rance et al. 2017; Sibeoni et al. 2020; Smith et al. 2016; Tierney, 2008

SECTION A: LITERATURE REVIEW

34

Universal Features of the Therapeutic Relationship

This theme refers to the typical features of the TR relating to personal and professional qualities and therapy considerations.

Ability to help: Highest, moderate and poorest quality papers contributed to this theme. The theme appears to map onto Bourdin's (1979) conceptualisation of 'therapeutic tasks' and considers the expertise of practitioners, ability to help, being challenged in therapy. PwAN reported the therapists' expertise in the area of EDs was a useful factor in developing the TR, as it seemed to give them confidence that they knew how to help. Conversely, a lack of expertise or confidence seemed to hinder faith in the therapists' ability to support or understand their experience. Part of therapists' perceived expertise seemed to stem from being appropriately challenged in therapy, appeared to create trust and the view that they were safe and supported.

'Over half of client participants explained that having their therapist be direct with a "no fooling around" attitude instilled a feeling of trust and safety.' (Oyer et al., 2016, p.129).

Holding onto hope and goals: Highest and moderate quality papers contributed to this theme. The theme seemed to map onto the 'goals of therapy' in Bourdin's (1979) conceptualisation of the TR and considers the importance of achievement, progress and goals. Interestingly, although participants appeared to see setting goals as a helpful factor, holding onto hope for recovery and recognising achievements seemed to be more pertinent than goal setting in establishing the TR, though they are related topics. Having the therapists' faith seemed to directly impact the PwAN having faith in themselves.

'Holding hope also seemed especially important for these participants. Sarah highlighted that "a team has to provide a really... strong sense of we've got this. We know what we are doing. And we will support you through it." (Blackburn et al., 2020, p.9).

Connecting as people: Highest, moderate and poorest quality papers contributed to this theme. All studies reported human qualities that strengthen a relational bond as key factors in the TR, mapping onto the third component of the TR identified by Bordin (1979) as 'bonds.' When people felt understood, respected, listened to using an empathetic and sincerely caring approach, this appeared to strengthen trust in the TR which led to positive experiences, feeling at ease and contributed to a genuine bond being established. Conversely, feeling misunderstood, ignored, criticised or judged impaired the development of the TR.

'I mean I didn't like her, I didn't trust her enough to open up to her. I didn't want to tell her my problems because I felt she was dissecting everything I said and it was all wrong what she was saying.' (Button & Warren, 2001, p.84).

Needing Other Supportive Relationships

Highest and moderate quality papers contributed to this theme. A key factor in establishing the TR seemed to be that it worked well alongside other supportive relationships. This was complicated for adolescents where the therapy relationship seemed to be impacted by the views and actions of their parents, possibly because they were another adult in a caring role. People seemed to establish a TR relatively well if it complemented other relationships and worked effectively with existing support systems.

'I talked a lot with my best friend too, and then I felt that it was nice to have someone who was close to me. [...] But on the other hand she [the therapist] at the eating disorder unit was also a great support. [...] Where my pal provided friendship support, she had something else to offer me.' (Lindstedt et al., 2015, p.5).

Clinical Features of Anorexia Impact the Establishment of the Therapeutic Relationship

This theme describes how factors unique to this population have an impact on forming a relationship with a therapist.

Anorexia blocks the development of the therapeutic relationship: Moderate quality papers contributed to this theme. Some PwAN spoke about how initially during treatment, the symptoms of AN initially seemed to get in the way of the establishment of a TR. The blocks to the TR at this stage largely seemed to fall in line with typical clinical characteristics of this population and ambivalence towards recovery, rather than personality factors of either the PwAN or therapists. For example, participants talked about intentionally deceiving therapists or being in denial of their difficulties, in line with the goals of their ED, which blocked a true connection forming with their therapist. The goal of weight loss and desire to stay close to anorexia seemed to pull the person further away from committing to developing a relationship with their therapist.

'It was as if there were two different sides within me, one saying "Oh God, this is great, I'm going to get help now, I'll get out of this shit", but at the same time it was also like this, "No, now they're going to destroy what you have achieved, and you who have come this far [...]

Do you really want that?" This kept going on; it was like a battleground all the time.' (Lindstedt et al., 2015, p.4).

Beliefs about being in relationships as a barrier: Highest and poorest quality papers contributed to this theme. PwAN appeared to talk about negative beliefs about being vulnerable or cared for in relationships, or causing disagreements, as blocking the TR. This was despite people longing to form a connection and have someone take care of them.

'She felt "unable to get closer or dependent on anyone. Or to be vulnerable with people. Or to let them in. When anyone gets in any way close, because I'm terrified of becoming too...

I'm terrified of just being completely betrayed by people," and she described this as a "huge barrier." (Blackburn et al., 2020, p.9).

The therapist's approach needs to shift over time: Highest and moderate quality papers contributed to this theme. Some PwAN appeared to report that during the acute phases of AN, the TR with therapist took away their own perceived need to control their food intake and environment and seemed to replace their need to engage in perfectionist behaviours. It appeared to be a relief for people to hand over control to the therapist despite this being a difficult task. People seemed to indicate this was a key part of the relationship in the early stages, which appeared to relieve additional stress on and allow the person to settle into the therapy. In contrast, one paper reported that a perceived lack of control hindered the development of the TR. People appeared to highlight that this factor of the TR needs to change over time, where the therapist gives back control over treatment choices to PwAN when they are in later stages of recovery. This highlighted how therapists may need to reposition themselves as the client moves towards recovery.

SECTION A: LITERATURE REVIEW

38

'You don't have to control it anymore and you can give over that control ... it feels as if you are in that stage where you can't make any decisions ... so it is nice to have other people take over.' (Smith et al., 2016, p.20).

Distance from the Identity of Anorexia

Highest, moderate and poorest quality papers contributed to this theme. It seemed despite their own preoccupations with food, weight or shape, PwAN needed the TR to be a place free of these topics almost completely. This seemed to help PwAN know that their therapist viewed them as a person aside from their ED and represented a desire and attempt to be seen as separate to their diagnosis.

'Focusing or organizing treatment for the sole purpose of regaining weight was perceived by the adolescents as an obstacle to the therapeutic alliance.' (Sibenoi et al., 2016, p.27).

Discussion

This review explored qualitative literature concerning the TR in AN. This review asked:
'What do people with anorexia who have experience of psychological therapy identify as key
features in the development of the TR?' The thematic synthesis of papers highlighted four
themes; universal features of the therapeutic relationship, needing other supportive
relationships, clinical features of anorexia impact the establishment of the therapeutic
relationship and distance from the identity of anorexia. The themes are discussed with
reference to existing literature, and clinical and research implications.

Review Findings

The review identified the theme universal features of the therapeutic relationship that broadly maps onto Bordin's (1979) theory of the components of the TR. The subtheme connecting as people seemed similar to the 'bonds' construct in the model which relates to the 'human relationship between therapist and patient' (Boudin, 1979, p.254). This reinforces the idea that basic counselling skills are applicable to working with this client group, similar to research across mental health and eating disorder research outlining these factors as key features of the TR (Ackerman & Hilsenroth, 2003; Antoniou & Cooper, 2013). The theme of ability to help appeared to highlight that the perceived expertise and appropriate use of therapeutic techniques to challenge PwAN in recovery was a key feature of the TR. People reported wanting to be challenged, which seems to suggest that despite their own ambivalence to recover (Serpell et al., 1999; Williams & Reid, 2012) challenge seemed to be interpreted as care towards the client. The achievement of both of these aspects highlight the complexity in establishing a TR, by needing to remain sensitive and caring towards a client's experience, whilst challenging them appropriately in their recovery, which may be further complicated by the severity of the AN.

The theme **holding onto hope and goals** appeared to map onto Bordin's (1970) goals of therapy construct which considers working towards mutual goals, and perceiving the therapist to be invested in these, as a key feature of the TR. Across studies, although goal setting was mentioned, holding onto hope for recovery seemed to be a more pertinent factor than setting concrete goals. This corresponds to anorexia being ego-syntonic in nature, where maintaining anorexia is valued by PwAN and they are ambivalent towards recovery (Serpell et al., 1999; Williams & Reid, 2012). Previous research suggests that goals of PwAN usually lack alignment with that of typical treatments, which include weight restoration and increasing

energy intake (Darcy et al., 2010). Furthermore, goals of PwAN are reported often not to align with those of their family members (Darcy et al., 2010) or therapists, when comparing quantitative measures of the WAQ goals subscale between adolescent PwAN and their therapists (Pereira et al., 2006). This supports the findings of this review as goal setting did not appear to be as prominent a feature in the TR as Bordin (1979) proposes. The importance of hope also supports research that suggests it may be important for clinicians to maintain hopefulness for recovery in AN (Dawson et al., 2014), which has a relationship with treatment outcome by strengthening the TR. This is particularly important as it may be difficult for therapists to hold onto hope, with previous research suggesting that some nursing staff experience negative attitudes towards PwAN and pessimism towards their ability to make a full recovery (Crisafulli et al., 2008; Ramjan, 2004).

A key feature of the TR was that PwAN reported **needing other supportive relationships**, which appeared to indicate that alliance formation is influenced by complementing other key relationships in a person's life. This may highlight the need for PwAN to have other stable relationships to ensure the relationship with the therapist goes well. Bordin (1979) does not reference other relationships in his conceptualisation of the TR, which contrasts the results of this study. This seems particularly important for AN, considering that family-based treatment is the treatment of choice for adolescents. Adults with AN in this review also recognised involving significant others, including family members. It is possible that involving key relations works to improve the TR by increasing understanding of the client's life.

PwAN identified a complex interplay of the clinical features of AN and the impact on TR, by identifying this common barrier to its development. In the theme **anorexia blocks the development of the therapeutic relationship**, PwAN appeared to highlight how the TR

could become an arena which the goals of their ED could feed into, by either furthering AN or using therapist reactions as a measure of success of AN. This may highlight a particularly difficult nuance in the TR with PwAN which differs to the alliance in comparison to other mental health difficulties, and may mean that Bordin's (1979) conceptualisation misses something important about the key features of the alliance and its complexities in this population.

Furthermore, PwAN appeared to report beliefs about relationships, such as beliefs about being cared for or fears of abandonment, as key features of the TR, by acting as a barrier to its formation. This can be interpreted with reference to literature on attachment as PwAN are reported to have greater insecure attachment styles compared to people with BN and non-clinical control groups (Tereno et al., 2008; Troisi et al., 2005; Ward et al., 2000). The participants seemed to suggest they feared previous attachment traumas being played out with the therapist, such as the therapist leaving or abandoning them, or fears around being vulnerable, which is common of the interpersonal difficulties in AN. This finding is important as neither CBT-E nor MANTRA practically highlight using the TR in relation to attachment difficulties and are used cross-diagnostically for AN and BN. However, this is a key feature of focal dynamic psychotherapy, despite this typically being offered only when the initial treatments are ineffective. Due to the significance of this finding, a key feature or task of the TR could be to provide a corrective relational experience for clients, which can aid exploration of AN and lead to recovery (Holmes, 1999).

Furthermore, PwAN appeared to highlight that a key factor in the development of the TR was that the therapist's approach needs to shift over time. It seemed that PwAN who had been controlling their eating behaviours or other aspects of their life, which is reflected in the

literature on clinical perfectionism in this population (Cockell et al., 2002), seemed almost desperate to hand responsibility over to someone else, which seemed to give them permission to be able to recover. It seemed that the role of the therapist acts by taking the internalised pressure or need to control away from PwAN, which was a relief for people despite it being a difficult task, though one paper reported that a perceived lack of control hindered the TR. This finding seems to contrast previous findings on the TR with nurses and PwAN, where a struggle for control was reported by nursing staff; nurses felt both themselves and PwAN wanted to control the treatment, that PwAN reacted poorly to a perceived lack of control which was specifically identified as a barrier to the TR (Ramjan, 2004). This could highlight a potential difference in key factors in TRs with therapists compared to nurses, where nurse relationships may be viewed differently due to their role in providing invasive physical interventions. Furthermore, this highlight how therapists might need to re-position themselves over time as the client moves towards recovery, which in developmental terms, is consistent with the idea of a reparenting experience.

Distance from the identity of anorexia appeared to be a key feature of the TR. PwAN explained that a strong TR was achieved through focusing on the person, which consisted of not using diagnostic labels or focusing conversations around food, weight and shape. In addition to this indicating a strong alliance, it seems possible that this part of the relationship is used as a therapeutic tool, by encouraging the development of an identity aside from anorexia. Literature has identified how anorexia is intrinsically linked with identity (Lamoureux & Bottorff, 2005; Rich, 2006) with the treatment MANTRA focusing on the development of an identity. The results of this review seemed to indicate a key feature of the TR is that it may be partly maintained by focusing on other aspects of a person's identity,

whilst also being a tool to move away from the anorexic identity and contribute to the development of a new healthier one.

Clinical and Research Implications

This review appears to highlight the need for clinicians to consider traditional factors of the TR in AN and specific factors that are unique to this population. Clinicians should continue to practice with their traditional understanding of what clients want from the TR, despite this potentially seeming in conflict with a client's ambivalence about recovery. Therapists may need to be aware that people with AN might have particular difficulty in establishing the TR initially, whereby anorexia seems to exert its effects through the reaction or by facilitating a block to the development of the relationship. Some therapeutic approaches may consider this a useful tool in therapy, in relational or psychotherapy-based approaches, which could be a potential therapeutic tool to explore. As previous research has identified negative views towards PwAN from professionals (Crisafulli et al., 2008) this information could be important across groups of healthcare professionals, where behaviour is viewed as a result of AN, rather than personality features of this population. Furthermore, due to therapists' expertise being identified as building the TR, it could be useful for therapists to demonstrate their expertise and knowledge to support this relationship early in the therapy process. This could involve verbally expressing experience of working with EDs or AN, which anecdotally does not appear to be commonplace in therapy across UK mental health services. As clients seemed to identify the importance of holding onto hope for recovery in the development of the TR, it may also be useful to explicitly state this early in the therapy process.

This review identified that a key feature of the TR was that it may be difficult to establish due to worries arising from other relationships, potentially indicating attachment difficulties in

this client group, which is supported by the empirical literature (Tereno et al., 2008; Troisi et al., 2005; Ward et al., 2000). Attachment is important for clinicians to hold in mind when treating AN. It has been suggested that CBT approaches should be used with caution with clients with an avoidant attachment style (Purnell, 2010) which is commonplace in AN. Purnell (2010) proposed this is because CBT approaches may reinforce the need for self-control rather than feeling difficult emotions. Furthermore, Holmes (2001) argues that people with anxious attachment styles would benefit from developing a theory about their emotions in therapy, rather than solely focusing on the present, as a CBT approach recommends. This may suggest that emotion focused therapies could be useful for clinicians to draw upon and is an important area for future research.

The usefulness of goals may not be as important for PwAN, in contrast to a CBT approach which emphasises goal setting and monitoring. Furthermore, talking about food, weight and shape may also be a barrier to the development of the TR in therapy, as PwAN try to distance themselves from the identity of AN. Close monitoring of food and weight are key features of both CBT-E (Fairburn et al., 2008) and MANTRA (Schmidt et al., 2014), the treatments recommended by NICE. Although this has benefits for risk management and weight increase, it is possible that it could be a contributing factor to the difficulties of engagement early in therapy. Future interventions may benefit from focusing less on these aspects and focus more on developing an identity and sense of self away from AN, which is consistent with previous research suggesting that creating a new identity and discovering the self is important in recovery (Williams et al., 2016), and a new emotion focused model of AN (Oldershaw et al., 2019). Furthermore, a new emotion focused intervention by the Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex programme (SPEAKS) is currently in development and promotes the importance of not focusing on food, weight or shape concerns

in treatment (Oldershaw & Startup, 2020). This approach aligns with the results of this study and may be a promising area for future research.

The TR was not only identified conceptually by this review but appeared to be a therapeutic tool. Therefore, future research is needed into how interventions can incorporate relational treatment approaches in treatment for AN. The new SPEAKS intervention is a relational treatment and may be an important step in shifting to using a relational approach in treatment for AN. Furthermore, a key feature of this treatment is that the therapist provides a reparenting experience. This may be important as clients recognised this review highlighted that PwAN thought that their therapists approach needs to shift over time, which is consistent with a reparenting approach.

Research into the TR in therapy for AN is limited and many of the included papers focused on experiences of treatment more widely. Further qualitative research into this area is needed to clarify key features of the TR in AN, and for different groups of people with AN, for example those who have been unwell for a short time, compared with enduring AN or those acutely unwell in inpatient settings, and those who have fully recovered. According to this view, quantitative research using the measures based on Bordin's (1979) conceptualisation is valid but may not capture further features of the TR in AN, namely the involvement of family or clinical features of AN that influence the development of the TR. It would also be useful to explore therapists' views of the TR in AN, as has been done with literature on nurses.

Strengths and Limitations

To the author's knowledge, this is the first systematic review and thematic synthesis of what PwAN, with experience of psychological therapy, identify as key features of the TR. It

provides a useful starting point in considering what factors might be important in the establishment and maintenance of the TR, which has been identified as a key factor in treatment outcomes (Werz et al., 2021). This review considers salient points in relation to clinical and research implications and could contribute towards refining and developing new interventions for AN.

All of the studies included were considered to meet an acceptable standard of quality. However, there are a number of limitations arising from this review. Firstly, the nature of a thematic synthesis involves re-interpreting the original authors' findings. Specifically, for this review, few of the papers adequately considered researcher reflexivity in their papers and some failed to state why participants chose not to take part in the studies, which means this review could be re-producing an unknown bias in results. Furthermore, participants who did take part may have a particular view on their treatment for AN or the TRs, which may neglect the views of a sub-section of PwAN.

Furthermore, many papers failed to state the ethnicity of participants. This, coupled with the fact most of the participants were female provide little insight as to how PwAN from diverse backgrounds, or males, experience the TR. Many papers focused on the experience of treatment, and due to the limit on word count on published papers, may have omitted information that could have expanded the results of the thematic synthesis. Additionally, although all participants had experience of therapy for AN, they may not have been referring to therapists in their account of the TR due to multi-disciplinary interventions offered by ED teams, though it is hoped participants would have a unique insight in having experienced psychological interventions. This review attempted to account for this by not coding material that specifically referenced professionals other than therapists.

Finally, it has been reported that quality appraisal tools do not sufficiently allow for appraisal of papers using different methodologies (Williams et al., 2021) and some items of checklists may be more or less appropriate to different study designs (Tod et al., 2021). Despite using the CASP which is considered high quality (NICE, 2014) and has been identified as a good measure of transparency (Dixon-Woods et al., 2007) using appraisal tools designed specifically for the differing methodologies may have provided higher quality insights.

Conclusion

This review aimed to explore what PwAN perceive to be key factors in development of the TR having had experience of psychological therapy. A systematic literature search identified nine papers which explored experiences of treatment and views of PwAN on the TR. A thematic synthesis of results indicated traditional factors associated with the TR and further nuances that are important to consider for this client group. This paper highlighted important factors for clinicians to consider whilst delivering therapy for AN and further research is needed into how the TR can be used as a therapeutic tool.

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	57
Section B: Experiences of engaging with emotion and emotional change in recovery from	om
anorexia nervosa: Supporting the refinement of a new emotion focused intervention	
Word Count: 8000 (375)	

SECTION B: EMPIRICAL PAPER

Abstract

Effective psychological therapies are yet to be established for anorexia nervosa. Emotion focused therapies are a promising new area and treatments that focus on one underlying mechanism of change are proposed to be beneficial. This study aimed to refine and consolidate a new emotion focused treatment for anorexia nervosa using existing interview data from 28 participants, comprising of people with anorexia, carers and therapists.

Thematic analysis was used to identify four over-arching themes; early experiences of engaging with emotion, how to achieve emotional change through the therapeutic relationship, factors impacting emotional change and accessing appropriate support. The findings provided initial support for the new emotion focused model and treatment whilst highlighting factors to focus on in the refinement of the therapy. The results highlighted the needs of carers and therapists, which are discussed with implications for clinical practice and future research.

Keywords: anorexia nervosa; psychological therapy; emotion; SPEAKS; qualitative methods

Introduction

Recovery in Anorexia Nervosa

Anorexia nervosa (AN) is an eating disorder (ED) characterised by restriction of energy intake to achieve a significantly low weight, an intense fear of gaining weight and body image disturbance (American Psychiatric Association, 2013). On average, 46.9% of people with AN recover, 33.5% improve and 20.8% remain unwell (Steinhausen, 2002), though differing outcome measures used post-treatment contribute to different recovery rates being reported. The low recovery rates are concerning and sit within a context of a considerable lack of research attempting to identify underlying mechanisms of change in the recovery process (Wollburg et al., 2013).

Impact

People with anorexia nervosa (PwAN) have high rates of comorbid mental health difficulties and report negative impacts of AN on physical health, daily living skills and emotional wellbeing (Herpertz-Dahlmann et al., 2001; Arkell & Robinson, 2008). Furthermore, PwAN report high levels of shame and frustration in relation to AN, which contributes to social isolation and loneliness (Skårderud et al., 2007; Rance et al., 2017). PwAN highlight the destructive impact AN has on their relationships, with reports of lost friendships and family difficulties (Button & Warren, 2001).

AN has a significant impact on carers, who report negative emotions in response to their family member's AN, including feeling confused and guilty, inadequate in their ability to cope, and helpless or pessimistic regarding their family member's recovery (McCormark & McCann, 2015; Whitney et al., 2005). Carers report their own social support systems do not

understand the complexities of living with someone with AN, which can include difficulties in family relationships (McCormark & McCann, 2015; Whitney et al., 2005). Family members' response styles to PwAN have been reported to be highly anxious, over-protective and at times critical (Whitney et al., 2005) which fits with the concept of high familial expressed emotion and is associated with negative treatment outcomes (Schmidt & Treasure, 2006). These interpersonal strains contribute to high rates of clinical anxiety and depression in carers (Kyriacou et al., 2008).

Recommended Treatments

The National Institute for Health and Care Excellence (NICE) (2017) recommends enhanced cognitive behavioural therapy (CBT-E) (Fairburn, 2008) and the Maudsley model of anorexia treatment (MANTRA) (Schmidt et al., 2014) as first line psychological treatments for adults with AN, or focal psychodynamic therapy (Zipfel et al., 2014) where these are not effective. The models informing recommended treatments highlight cognitive and interpersonal factors in the development and maintenance of AN. NICE (2017) also recommends specialist supportive clinical management (SSCM) (McIntosh et al., 2006) which was developed as a control intervention for clinical trials. Research suggests that cognitive-behavioural strategies may be ineffective at targeting the mechanisms that maintain AN (Solmi et al., 2021; Juarascio et al., 2013) and consistently demonstrates that no one established treatment is superior to any other, or to treatment as usual (Schmidt et al., 2012; Watson & Bulik, 2013; Fairburn et al., 2015). The lack of effective interventions is disappointing and calls for innovative interventions to be developed for AN.

Treatment for AN is further complicated by the difficulties that therapists may experience, with some reporting their own negative emotions such as anger, fear and incompetence when

working with EDs and AN (Hamburg & Herzog, 1990; Jarman et al., 1997). Furthermore, research on attitudes of healthcare staff indicates some feel manipulated by PwAN and have difficulty trusting clients (Ramjan, 2004; King & Turner, 2000). King and Turner (2000) found that nurses distanced themselves from clients in response to their own difficult emotions which made it difficult to sustain a positive therapeutic relationship.

New Developments

Working with emotion is a promising area in the treatment of AN (Sala et al., 2016) and there is a wealth of literature centring on difficulties in emotion regulation (ER) in AN. (Lavender et al., 2015). Gross (1998) defines ER as the way in which people influence their emotions and how they experience them and his theory suggests that ER can strengthen, reduce or maintain the experience of emotion depending on one's needs. A systematic review using Gross's (1998) theory found that PwAN exhibit difficulties in emotion generation, emotional processing and ER, and that recovery is associated with an improvement in these areas (Oldershaw et al., 2015).

Emotion focused (EF) models of AN (Table 1) and associated interventions have become a focus of new research. Sala et al. (2016) conducted a review of EF interventions which seek to decrease emotional avoidance, increase emotional awareness and distress tolerance and improve interpersonal relationships. They found EF interventions were associated with remission from AN, improved weight and reduced ER difficulties, though further studies are needed before conclusions can be drawn. They also highlight a need to identify the mechanisms of change in EF interventions, as the models underpinning these interventions focus on maintenance factors.

Table 1Emotion Focused Maintenance Models of AN

Model	Key features	
Wildes et al. (2010)	Increased emotional avoidance in PwAN leads to eating psychopathology to	
Functional Model of Emotional	regulate aversive emotion. Emotional avoidance mediates the relationship	
Avoidance	between depression and anxiety in AN.	
Wildes and Marcus (2011)	PwAN experience emotions as aversive and uncontrollable, leading to	
Emotion Acceptance Behavioural	emotional avoidance through AN symptoms. AN symptoms may increase the	
Therapy Model (2011)	frequency and intensity of aversive emotional reactions and cause other areas	
	of life to be neglected.	
Haynos and Fruzzetti (2011)	PwAN have a history of invalidating responses regarding inner experiences.	
Transactional model for emotion	These contribute to emotional dysregulation in response to ordinary events	
dysregulation as applied to anorexia	leading to increased emotion which further increases emotion dysregulation	
nervosa (AN).	and inaccurate expression. ED behaviours lead to invalidating responses to	
	valid emotions and validating responses to problematic behaviours. Starvation	
	increases emotional vulnerability.	

The SPEAKS Programme

The Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex programme (SPEAKS) is aiming to develop and test an EF intervention for adults with AN (Oldershaw & Startup, 2020). Although existing therapies make some attempt to work with emotion, they all highlight multiple factors in the maintenance of AN, so numerous factors are targeted in treatment which contributes to treatment overlap across models. This makes it difficult to identify mechanisms of change and what factors of the interventions are associated with outcomes. Oldershaw et al. (2019) highlighted a need to develop an explanatory model that differentiates between risk and maintenance factors, which focuses on the role of emotion as a central maintenance factor of AN.

SPEAKS Theoretical Model

A new EF explanatory framework for AN was developed in 2019 by Oldershaw and colleagues which SPEAKS use as their theoretical model. The model is evidence based and highlights early influences on development of the self in AN, utilising research including attachment, gender, family and peer relationships. PwAN are reported to have higher levels of maladaptive schemata related to guilt, shame and social isolation related to early experiences, which influence the interpretation of, and responses to situations. They suggest that early experiences, including feeling emotionally overwhelmed, may contribute to difficulties in attuning to and expressing emotion, due attempts to cope in early life. This may lead to emotional suppression, negative beliefs about emotional expression and negative coping styles (Startup et al., 2013) which can reinforce negative schemata.

Emotional suppression leaves people with greater negative emotion to regulate (Gross & Levenson, 1997), which reinforces ER strategies in AN. It may influence others' responses to emotion, perpetuate attunement difficulties and further invalidate the sense of self (Oldershaw et al., 2019). Poor interoceptive awareness due to the effects of starvation may further impair the sense of self, through disrupting the integration of self-awareness and one's internal experiences.

The model proposes that coping strategies in AN move someone away from a strong sense of a 'core emotional self', favouring the view of others and maladaptive schemas. The self is defined as the organization and integration of one's many identities (Haworth-Hoeppner & Manies, 2005). This 'lost sense of emotional self' leaves people without emotions to guide them. The model suggests that if 'bottom up' emotional experiences cannot be accessed one will experience difficulties in the self and relationships, in line with EFT (Greenberg, 2004).

Therefore, this model identifies 'the lost sense of emotional self' as the core variable that underpins and perpetuates AN.

SPEAKS Integrative Model of Change

The SPEAKS integrative model of change draws influence from schema therapy and EFT. The schema mode model was identified by Young et al. (2003) and suggests that when a schema is activated, the coping response associated with a schema mode is also activated. Dysfunctional coping modes are strategies that were adaptive for survival in childhood but are excessive and unhelpful in adulthood by blocking access to emotion or relationships. Young et al. (2003) also highlight healthy modes, including a 'healthy adult' function, which serves as an executive mode to moderate a person's needs. It can make decisions in accordance with goals even if it results in emotional distress. A strong 'healthy adult' mode can lead to the awareness of one's feelings and the ability to respond to oneself in a nurturing and balanced way.

Oldershaw et al. (2019) argue that other interventions do not sufficiently address difficulties with emotion and identify the main goal of therapy as establishing a core sense of an emotional self, which can be used to direct one's needs and relationships. The change process is demonstrated in Table 2 and Appendix G. It identifies the need to focus on primary and 'bottom up' emotional experience, integrating this with the self to a sense of identity and self-efficacy, in line with an EFT approach (Greenberg, 2004). Coping modes are named and worked through and 'healthy adult' is developed. The intervention is relational and recognises the importance of the therapeutic relationship.

Table 2The SPEAKS Model of Change and Intervention for AN

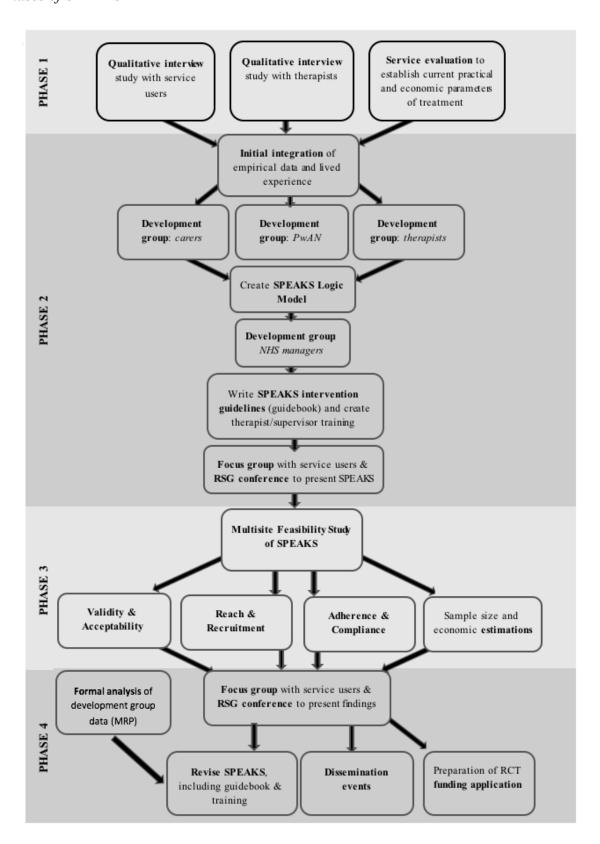
Phase	Key features of treatment
1	Focus on building the therapeutic relationship so feared emotions can safely emerge; building a narrative away
	from eating, weight and shape concerns as the core issue; guiding the PwAN to unsaid emotions; naming coping
	modes or anxiety as blocking access to emotion
2	Working with anxiety; working with guilt, shame around food, ED behaviours and the self; supporting
	connection with emotional experience and avoiding a purely cognitive experience; noticing coping modes in
	daily life; working to bypass coping modes blocking access to emotion
3	Revealing core issues and unmet needs (identity concerns, abandonment, attachment concerns, loneliness);
	Expressing assertive anger; expressing sadness and grief
4	Connecting emotional experience to new ways of intrapersonal responding; developing self-compassion;
	connecting emotional experience to new ways of interpersonal responding (asserting own needs, boundary
	setting); Working towards acceptance of own emotional experience
5	Developing relationships, independence, an identity, self-efficacy and self-agency; reflecting on the therapeutic
	relationship; working towards a balance in coping modes

Rationale for the Current Study

The SPEAKS project has four phases: (1) reviewing current approaches, (2) developing the intervention, (3) trialling the intervention and (4) revising the intervention and developing the protocol for a randomised controlled trial study (RCT) if deemed appropriate. This project feeds into phase four by informing the intervention prior to applying for RCT funding (Figure 1).

Figure 1

Phases of SPEAKS



The project used existing interview data from clients who had experience of an intervention for AN (not SPEAKS), carers and ED therapists. Formal analysis of this data has not been completed and as the intervention is still in development, this is required to inform SPEAKS and gain new insights to working with emotion. Thematic analysis was chosen to analyse the data as it was the author's intention to gain new insights to develop a newly proposed intervention rather than to build a new theory.

Guidance for complex interventions from the Medical Research Council (MRC) highlights the importance of understanding change processes in the development of interventions (Craig et al., 2008). MRC guidance suggests this process is not always linear in order to account for alternative possibilities throughout the development process so that future evaluations do not fail, or the intervention is not implemented in practice (O'Cathain et al., 2019). This fits with the rationale to analyse data at this stage of SPEAKS development.

NICE and the MRC highlight the importance of integrating the view of all stakeholder groups in developing interventions (O'Cathain et al., 2019), which supports using data from PwAN, therapists and carers in this project. It is necessary to explore views of PwAN to ensure that their experiences are accounted for in developing SPEAKS, considering the poor outcomes and high dropout rates in therapy. Due to the difficult emotional experiences that both carers and therapists report it is important to investigate their experience of exploring emotions with PwAN. Carers are also experts in managing their loved one's AN and SPEAKS recognise the importance of learning from their experiences. This will help to inform how SPEAKS can be tailored to the needs of all stakeholders. This project is consistent with NHS values of 'commitment to quality of care' and 'improving lives' by seeking to improve interventions for PwAN.

Aims

The aim of the current study was to explore experiences of engaging with emotion inside and outside therapy for AN, across key stakeholder groups, to refine and consolidate the SPEAKS model. This study sought to address the following questions:

- a) What are stakeholders' experiences of exploring emotions in and outside of therapy?
- b) What experiences or interactions, including those within therapy, are perceived to facilitate or hinder engaging with emotion and/or emotional change?

Method

Design

This study used a qualitative design. Existing data was used which had been collected through guided focus groups and semi-structured interviews. The data was analysed using a hybrid form of thematic analysis which utilised a deductive and inductive approach (Fereday & Muir-Cochrane, 2006; Braun & Clark, 2006). A deductive approach was used initially to ground the data in the existing evidence-based literature, followed by an inductive approach to make room for new perspectives. The deductive approach was important to utilise the evidence that has been identified thus far, whilst remaining in line with the goal of SPEAKS which aims to develop an intervention using a bottom-up approach.

Thematic analysis was utilised due to the systematic yet flexible nature of the approach and allows for intricacy to be conveyed to enhance the meaning of results (Alhojailan, 2012). The approach is also useful in identifying common themes in diverse data whilst leaving room to highlight differences of opinion (Alhojailan, 2012; Crawford et al., 2008; Blacker, 2009).

This is important in identifying specific experiences across stakeholder groups. The sample size for this project was similar to other studies using thematic analysis in ED research (Reid et al., 2008; Tierney & Fox, 2010).

Positioning

A critical realist epistemological position was adopted throughout this research. Critical realism suggests that there is a real social world that we can attempt to understand through the sciences (Danermark et al., 2002), arguing that we can gain knowledge 'in terms of theories which can be more or less truthlike' (Danermark et al., 2002, pg. 10). Using this approach supports using a deductive approach to provide an initial grounding to the analysis, whilst leaving room for the reality of others to be identified in the data, through an inductive analysis (Roberts et al., 2019).

Participants

Data was used from 28 participants who were 12 adults with AN, seven carers (all female, mothers) and nine therapists who worked with PwAN. Available participant characteristics are reported in Tables 3 and 4, which were gathered verbally prior to interviews. Participants were included if they had a current or past diagnosis of AN, were a family member of somebody with current or past diagnosis or were a therapist with at least one year's experience in AN. Participants were aged over 18 and had capacity to consent to take part. Participants were excluded if they were acutely unwell with AN and receiving inpatient treatment or were therapists from the SPEAKS team.

Table 3Demographic Information for PwAN Participants

ID	Age	Gender	Ethnicity
1	20-30	F	White British
2	20-30	F	White European
3	20-30	F	White British
4	20-30	F	White British
5	20-30	F	White British
6	20-30	F	White British
7	20-30	F	White British
8	20-30	F	White British
9	20-30	F	White British
10	20-30	F	White British
11	30-40	F	White British
12	30-40	F	White Other

 Table 4

 Demographic Information for Therapist Participants

Participant ID	Gender	Profession
1	F	Clinical psychologist
2	F	Clinical psychologist
3	F	Counselling psychologist
4	F	Counselling psychologist
5	F	Family therapist
6	M	Nurse therapist
7	F	Nurse therapist
8	M	Nurse therapist
9	F	Psychotherapist

Procedure

Recruitment

Participants were recruited via website advertisements (Trusts' websites, Beat charity), posters in ED service waiting rooms or through adverts to ED support groups, ED staff groups, or databases of previous patients who consented to be contacted. Therapists were recruited from two Trusts in England. Participants were invited to contact a member of the SPEAKS team by email or telephone, with no obligation to take part. During the initial contact, participants were provided with an information sheet about the project (Appendices H - J). Participants who agreed to take part were invited to take part in a focus group or an individual interview depending on their preference. Participants provided written informed consent (Appendix K - M) prior to interview. They were informed that they could withdraw at any time.

Focus Groups and Interviews

The focus groups/interviews took place at a Trust's site. The focus groups lasted approximately two hours and interviews around one hour. Table 5 shows how data was collected.

Table 5

Data Collection Methods Across Participants

Data collection method	Participant group	Interviewer
Focus groups	2 therapist groups 2 PwAN groups 2 carer groups	SPEAKS lead researcher and one other member of the local SPEAKS research team
Individual interviews	3 PwAN 3 carers	Member of SPEAKS research team

The focus groups/interviews were informed by a topic guide (Appendix N - P). All participants were asked about their experiences of talking about emotions inside or outside of therapy, helpful and unhelpful techniques in talking about emotion, and the impact of talking about emotion on recovery. PwAN were asked about their experiences in therapy and advice for therapists. Carer's were asked about challenges and benefits of being a carer and advice for families. Therapists were asked about experiences of providing therapy and advice for therapists. Interviewees were invited to add to the agenda throughout and explicitly at the end of each interview.

The interviews were audio recorded and were transcribed prior to the commencement of this study, by the SPEAKS team and external transcription services. The author aimed to listen to all recordings to become familiar with the data and check the transcripts, however due to damage to the files, only three were accessible.

Data Protection and Confidentiality

Transcripts were anonymised to ensure confidentiality of participants and were stored on a password protected computer. The author was sent the transcripts and audio files securely via encrypted NHS email; all documents were password protected. The audio files and transcripts were accessed on one participating Trust's computer server. Paper-based documents were filed securely in the respective Trusts' filing cabinets on site.

Ethical Considerations

Favourable NHS ethical approval and Health Research Authority (HRA) approval (Appendices Q) was granted for this project through the SPEAKS programme. Favourable

ethical approval for this stage of the study was subsequently granted through Canterbury Christ Church University (Appendix R). The two NHS Trusts provided research approval. A summary of the project findings was provided to the SPEAKS team and will be disseminated to the participants who had requested a copy of the findings (Appendix S) and the research ethics committee (Appendix T).

In order to ensure participant wellbeing, they were invited to take part in either a focus group or interview and were offered a debrief with a member of the research team. Participants were informed that they could pause the interview, with only one interviewee taking this option to take a telephone call. If participants had become distressed during the interview the research team would have paused or terminated the interview and followed local guidance, however this did not occur. Participants were provided with information of local support services.

Data Analysis

Transcripts were imported into Nvivo computer software, a qualitative data analysis tool which has been highlighted as compatible with thematic analysis (Zamawe, 2015).

A hybrid approach to thematic analysis is described by Fereday and Muir-Cochrane (2006) and the deductive stage of their analysis was used to guide the current project. Their deductive stage of thematic analysis identifies four stages. The first stage of deductive analysis is to create a priori codebook, from existing theory or research, to apply to the dataset. The codebook was identified in relation to the research questions and included key features of SPEAKS, which were reviewed by the supervisor involved in SPEAKS to ensure the codes captured the model. The second stage involves testing the reliability of the

codebook to ensure its applicability to the dataset, therefore the codebook was initially applied to two transcripts. This highlighted that some codes were too broad and therefore were refined. The final codebook is available in Appendix U. The third stage involves reading, listening to and summarising the raw data, so the author listened to the audio recordings, read over the transcripts and made initial points relating to the data. The fourth stage involved coding the whole dataset, so the deductive codebook was applied to all of the transcripts. The final stage of the hybrid analysis described by Fereday and Muir-Cochrane (2006) is the inductive analysis, where new codes are identified within the dataset. The author, from this point on, followed guidance from Braun and Clark (2006) as they more clearly describe the analysis process and hold onto the importance of reflexivity.

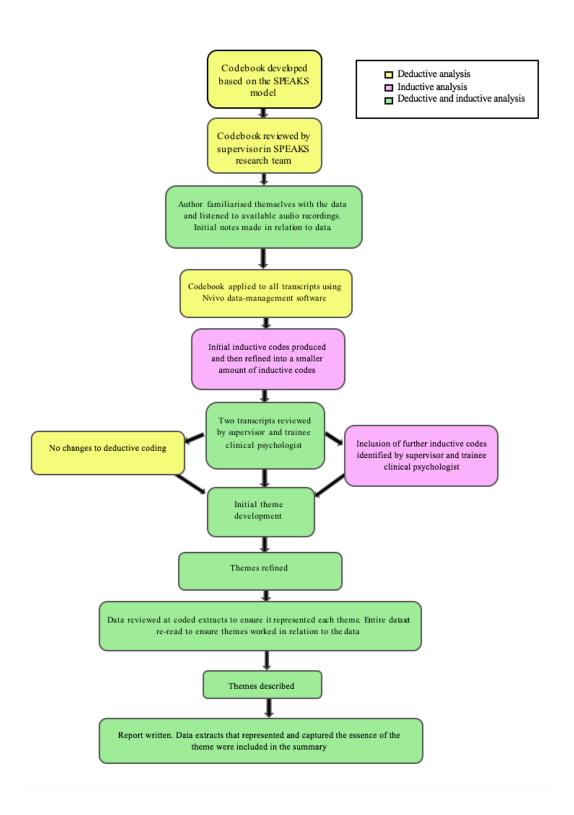
The inductive analysis followed the six phases of thematic analysis as identified by Braun and Clark (2006). The first stage involves the author familiarising themselves with the data, which had been completed in the deductive analysis. The second stage involved initial coding of the dataset. The inductive codes were initially more semantic and developed to be interpretive through the process of revising and reviewing the codes, to promote qualitative rigour, the researcher's engagement with the data and to reduce the impact of pre-existing assumptions on the final themes (Appendix V). Final coded transcripts were sent to the supervisor not involved in SPEAKS and another trainee psychologist. Some further inductive codes were identified through this process and were applied to the dataset (Appendix W). Although the use of a second coder is not always recommended for thematic analysis, a critical realist perspective argues that various realities are possible and in order to apply the findings to a wider population, some reliability between researchers is necessary (Roberts et al., 2019).

The third stage involved searching for initial themes from the codes. Both the deductive and inductive codes were brought into the analysis to identify initial themes (as Fereday & Muir-Cochrane (2006) recommend). The fourth stage involved reviewing and refining the themes at a higher level of abstraction This process was aided by the use of thematic maps (Appendix X). This also involved discussions with the supervisor for the project not involved in SPEAKS. The themes were then reviewed across the coded data extracts to make sure the data represented each theme and the author re-read the entire dataset to ensure the themes worked in relation to the data. The second supervisor reviewed the themes on one occasion. The fifth stage involved describing the themes to capture what each theme was referring to. The final stage involved writing up the results, including data extracts that captured the nature of each theme.

Although the theme development is presented as linear process, they were created over time and involved a process of refining and revisiting the themes. The stages of the inductive and deductive analysis overlapped and were integrated (Figure 2).

Figure 2

Data Analysis Process



Reflexivity and Quality Assurance

Braun and Clark (2019) highlight the importance of reflexivity in thematic analysis. This means that the researcher is required to reflect on their assumptions that influence the analysis, and the process is active and reflective rather than themes being identified in a linear process. To aid reflexivity, the author queried the assumptions being made in the coding process and revisited the transcripts to ensure all relevant data was coded. The author employed the use of one supervisor and trainee psychologist in the coding process to include further insights. The author took regular breaks from the process of developing themes to create distance from the data, which is proposed to increase researcher sensitivity and reduce the chance of an incomplete analysis (Vaismoradi et al., 2016). The supervisor involved in the SPEAKS programme provided reflections on the themes at a later point in the process to reduce the possibility of pre-existing assumptions being reported in the themes, whilst following recommendations to include an expert in the topic area during the last stages of theme development, to expose areas the author may have missed (Lincoln & Guba, 1985).

The author approached this project having had some experience working in an ED inpatient setting and an ED research team prior to clinical training. The author kept a research diary (Appendix Y) to highlight how ideas evolved and to notice pre-existing assumptions (Cutcliffe & McKenna, 1999). As the data had already been collected, bias was reduced in the data collection process.

Results

Four over-arching themes and 14 subthemes were found in relation to the research questions, which are described with anonymised quotes from the data.

Table 6

Identified Themes

Theme	Subtheme	Participant Group	
Early experiences of engaging with emotion	The process of connecting to emotion	All groups	
	Differing views of emotional distress between caregivers and people with anorexia	All groups	
	The carer's struggle in navigating their own role	Carers and therapists	
How to achieve emotional change through the therapeutic relationship	Learning to express emotion	All groups	
	Addressing core issues	All groups	
	Establishing and maintaining boundaries in relationships	All groups	
Factors impacting emotional change	Interpersonal factors	All groups	
	Intrapersonal factors	All groups	
	Goal setting	All groups	
	Therapist factors	Therapists	
	Carer factors	PwAN and carers	
Accessing appropriate support	The need for high quality professional support	Pwan and carers	
	Timely support	Carers and therapists	
	The usefulness of group work	PwAN and carers	

Early Experiences of Engaging with Emotion

This theme demonstrates the process and key features of engaging with emotion during the acute phase of AN.

The process of connecting to emotion: PwAN appeared to describe that initially they found it extremely difficult to connect with, or intentionally avoided, their emotional experience and

struggled to express the emotions they did recognise to other people. Carers and therapists also identified this in PwAN. PwAN seemed to report that beginning to express emotions took time and that it was a relational process, only possible through connecting with other people. There were, however, carers who described PwAN being unable to move past the initial stage of a sense of disconnection with their emotions, which appeared to be in reference to family members described as acutely unwell. Learning about emotion and emotional expression seemed to be a new experience for PwAN, in which therapists became teachers in developing an emotional vocabulary. This seemed surprising to PwAN who had no prior experience of using a complex language for emotion and its expression. Although this was difficult, people appeared to find the process of beginning to express emotions helpful.

'I blocked feelings and emotions for so long and when I learned to start acknowledging them and identifying them, well, it gave me a little bit of a platform to start working on, and it gave me, like, a starting point to speak to someone like yourself.' (Person with AN).

Differing views of emotional distress between caregivers and people with anorexia:

Across stakeholder groups high levels of anxiety were reported across all stages of AN. However, therapists and carers reported noticing displays of intense anger in PwAN during the acute phases of AN. This seemed to contrast reports from PwAN, who described anger but much less often and to a milder degree. Carers tended to report that this anger was expressed in harmful ways, such as violence, self-harming behaviours or arguments. Therapists however, tended to report that the anger was often masked during therapy interactions, though seemed significant.

SECTION B: EMPIRICAL PAPER

'they are really good girls, good, well-behaved citizens, and behind all that compliance, the flip side is rage.' (Therapist)

The carer's struggle in navigating their own role: Carers reported difficulties in navigating their new role as a carer, and seemed to believe they needed to be both a parent and therapist. Though they appeared to feel positioned in the role of a professional, they reported feeling ill prepared to manage their family member's emotional difficulties and believed they were not doing enough to help. Therapists shared these views and reported feeling incompetent. When carers did make attempts to help, it appeared the response from the family member was unpredictable, which seemed to cause the carer to believe their attempts were not good enough or made the situation worse. This seemed to lead some carers to avoid emotional topics to prevent the situation escalating.

'It seems like anything you say is the wrong thing, you know. There are times when anything you seem to say is the wrong thing, and you think, well, shall I just say nothing about it?' (Carer)

'we're parents, we're not psychologists or, you know, we've got no training in it. And what do you do?' (Carer)

How to Achieve Emotional Change Through the Therapeutic Relationship

This theme highlighted how emotional change seemed possible through using the therapeutic relationship, which then extended to other relationships.

Learning how to express emotion: PwAN appeared to describe behaviours to avoid emotion and emotional pain or interpersonal difficulties and privileging of the perceived needs of others over their own needs. PwAN seemed to overcome these behaviours by slowly learning how to identify, label and understand emotion, consider the origins of beliefs around emotion and to understand how these to linked to their ED behaviours. This seemed to precede successfully expressing emotion. In addition to verbal expression of emotion, emotional expression was described through modelling, images, the arts and letter writing. Across stakeholder groups, the expression of assertive anger seemed particularly important and was highlighted at being successful in helping to achieve emotional change.

'So when I came to feel more free in saying when I'm angry because I was so used to being quiet and submissive and just trying to like disappear from everyone's life than my own that I actually to have a kind of presence to actually say what I feel has been a real battle. Erm and until I could address that, yeah I couldn't even think about food. Or think about food in a positive way.' (Person with AN)

Addressing core issues: Addressing core issues appeared possible in therapy by beginning to explore emotions and shifting the conversations away from eating and weight concerns.

Across stakeholder groups, people appeared to recognise that it was necessary to be able to access core emotions, other than anxiety around food, to achieve significant change.

However, some participants, who reflected on a time when they were acutely unwell, reported that during the acute phases of AN, talking about food concerns was a helpful starting point. Exploring core issues appeared to highlight working with complex factors such as guilt and shame, difficulties linked to family histories, loneliness, attachment and abandonment worries.

'They might think that the perfectionism is self-driven, but when we actually got down to the core, it was about winning approval, wasn't it? and being liked and accepted.'

(Therapist)

Establishing and maintaining boundaries in relationships: It appeared that the boundaries within the therapeutic relationship had to be well maintained to lead to emotional change. Poorly maintained boundaries seemed to hinder engaging with emotion by causing confusion around the relationship. Therapists and PwAN seemed to recognise the importance of building supportive boundaried relationships outside of the therapeutic relationship to achieve emotional change. This appeared possible by asserting one's own needs and seemed to occur after some time in therapy.

'I think being able to not forget what your relationship is and who they are and I think sometimes if you've been with that person [therapist] for a really long time that can get a bit kind of misleading' (Person with AN)

Factors Impacting Emotional Change

This theme highlights factors that can either facilitate or hinder the process of engaging with emotion or achieving emotional change.

Interpersonal factors: Caregiver qualities and actions were identified as helpful both inside and outside of therapy to ensure PwAN feel comfortable to express emotions, including accepting and validating emotional experience, displaying genuine care, listening skills, trust

and empathy. PwAN appeared to dislike feeling like a diagnosis, which therapists and carers also recognised as beneficial in exploring emotion. PwAN and their carers reported that feeling judged or not listened to hindered engaging with emotion.

'if you are speaking to the emotion, you have a conversation at all times, and that is very, very helpful, because that word again, it shows compassion and it shows respect, and just that understanding, I can understand you feel like that, I understand where you might be coming from, it's awful to feel fat.' (Carer)

Learning new ways of intrapersonal responding: All stakeholders appeared to refer to the development of self-efficacy, self-agency, independence, belief in one's own ability to recover and the rediscovery of interests as facilitating emotional change. A lack of identity appeared to hinder emotional change by decreasing motivation. PwAN and carers seemed to identify that developing and experiencing self-compassion can facilitate emotional change and reported that this extended to becoming more compassionate towards others.

'I'm kind of living with more self-compassion, which is important, because I can blame myself ... I think it would be important to learn to treat myself kindly and almost to see it as kind of a survival story rather than a failure.'

(Person with AN)

Goal setting: Goal setting appeared important by PwAN and carers to achieve emotional change. Carers and therapists thought celebrating achievement of goals was important in facilitating change. However, some PwAN reported this enhanced guilt, but other PwAN found it motivating.

'So there were goal setting type of therapeutic sessions on a Monday and Friday ...

you know, that's just being given your goals and then reporting back on it... And I

found that was good because ... it actually set your mind thinking about more than

just yourself during the week and trying to achieve something.' (Person with AN)

Carer factors: Carers reported feeling difficult emotions including helplessness, anxiety and anger. They appeared to talk about how managing their own emotional responses and taking time out, self-care and maintaining their own identity, were helpful in engaging with their family member's emotion. Carers appeared to intentionally hide their emotions from PwAN, which PwAN seemed to also report as necessary. Carers reported that planning their responses in advance rather than being led by their feelings, modelling expression of emotion, and taking breaks at times of high emotion seemed helpful to ensure emotions remained manageable in the family. Communicating at times of heightened emotion hindered engagement with emotion.

'you've got to find time to go for a walk, meet a friend, put headphones on and just shut yourself away sort of thing, because if you don't calm yourself down and you're not in a good place, you can't support anybody else then anyway' (Carer)

'I'm happy to talk sometimes, but if it's deteriorating, I say, "it doesn't look as if you're getting out of it what you wanted. Maybe I got it wrong, what do you think? Do you think we should take a break or do you wish to pursue this?" (Carer)

Therapist factors: Similarly to carers, therapists reported feeling their own difficult emotions, however these appeared less intense than carers' emotions. Therapists also highlighted the importance of self-care to effectively engage with emotion. Interestingly, therapists appeared to report mirroring the emotional expression of their clients, where emotive conversation could become avoided at times of high anxiety. Anxiety in the therapist appeared to be created by feeling incompetent, seeing clients deteriorate, having to manage the physical risks and by having large numbers of clients. They often felt that risk issues took up a lot of therapy time which led to emotions being discussed less. There seemed to be a parallel process in supervision, where risk issues were discussed more frequently than emotion.

'I find myself having such highs and lows, in a way I didn't when I spent more of my time in adult mental health, and swinging, so the impact on me as a person who is a clinician, it's kind of the swing from feeling very incompetent, and like the worst therapist in the world, to feeling, actually, no, I can do this' (Therapist)

'They start to sort of start to deteriorate physically and the conversation moves away from the kind of the emotions we manage, that's the anxiety bit, again both within the team and, emotions kind of get lost in that.' (Therapist)

Accessing Appropriate Support

This theme refers to how PwAN and carers reported needing to access professional support to engage with emotion and achieve emotional change.

The need for high quality professional support: PwAN and carers highlighted the need for high quality support, with references to multi-disciplinary interventions, continuity of care, individualised support and a well-managed ending in therapy. PwAN and carers reported that previous negative experience with services contributed to a difficulty in engaging with emotion when further support was received, with fragmentation of services contributing to a lack of engagement. PwAN and therapists reported therapists needed a range of skills and models to successfully facilitate change. PwAN highlighted the need for continuity in session content, and a lack of continuity or rationale for therapy interventions appeared to hinder engaging with emotion.

'Or if we'd do exercises together, and I'd just think, "Well, I don't know why you asked me to do that. I don't know what the outcome is, and I don't why ... will we ever go back and look at that again?" And that's less helpful.' (Person with AN)

'I would like to see that middle therapy in place between admission and the home'
(Carer)

'I think what's helped is having the right person and having someone who can use a range of skills, rather than someone use one particular model' (Person with AN)

Timely support: Carers stressed the importance of receiving their own support early on. Therapists suggested therapy for PwAN was of more benefit after some weight restoration, as engaging with a range of emotion was easier when PwAN were at a higher weight, whereas working with anxiety was common at a lower weight. Carers appeared to hold an alternative view and reported a need for their family member to access therapy early.

'And the other thing that I think ... because we were told very early on when her BMI is too low, there's no point doing therapy. That's been the message all the way down the line and, actually, I know the cognitive function is seriously impaired, but I disagree. I think it should have been much... much earlier, and less focus on the eating and more on the thought.' (Carer)

'working with people on the severe pathway, I think it is mainly anxiety that we are talking about, and how to manage that, so exactly what you're expressing. And it's more in the moderate pathway that the range of emotions are beginning to be thought about' (Therapist)

The usefulness of group work: Carers highlighted that group work was useful as they could learn new skills and talk to others in a similar situation. There were mixed views of group work with PwAN, with some people finding it hard to be around other people in distress.

However, many PwAN seemed to find group work helpful for emotional change by learning from others, processing emotions together and feeling less alone.

'Talking all the time with people that you can relate to and the group together acts very much as a mirror, I think. I might get annoyed with you, seriously annoyed with you, but what's actually happening is I'm looking in a mirror and then actually something about ... I don't even know if it's something about myself I don't like and I've seen it in you, but that's where facilitation comes in.' (Person with AN)

Discussion

This research provides a thematic understanding of the experiences of PwAN, carers and therapists and results will be discussed in relation to the research questions.

What are Stakeholders' Experiences of Exploring Emotion in and Outside of Therapy?

The Emotions of People with Anorexia

All participant groups seemed to identify that PwAN initially had difficulty connecting with and expressing emotion and that the **process of connecting to emotions** was a new, challenging experience. This lends support to literature identifying ER difficulties in PwAN (Oldershaw et al., 2015, Lavender et al., 2015), EF models of AN (Wildes et al., 2010; Haynos & Fruzzetti, 2011) and the SPEAKS model. The initial difficulty in connecting with emotions could also be considered a 'detached protector' coping mode (Young, 2003) where a person cuts off from their own negative emotions or needs. This schema mode has been demonstrated to be significantly higher in AN compared to healthy controls (Talbot et al., 2015). This aligns with Gross' (1998) theory of ER as PwAN suppressed emotions according to their needs, which were reported to be to avoid emotional pain or interpersonal conflict.

It was reported that although PwAN initially had difficulty in expressing their emotional experience, carers and therapists appeared to recognise high levels of distress in PwAN, which may appear contradictory. It is possible that these initial high levels of distress - reported here particularly as anxiety and anger – might represent secondary emotions blocking access to core emotion, such as 'feeling angry in response to feeling hurt' (Greenberg, 2004 p.8). EFT and SPEAKS propose that these need to be explored in order to access deeper emotions and facilitate emotional change. PwAN reported that learning simple

knowledge around emotion was a new and helpful experience. This finding may support techniques used in MANTRA and EF interventions which use psychoeducation around emotion. It is important to recognise aspects of existing therapies that are useful.

Participants appeared to report a shift in their ability to explore emotion after accessing support and as PwAN moved towards recovery. PwAN seemed to report that as they worked towards recovery, they found became better at exploring emotion inside and outside of therapy, which may support existing literature suggesting an improvement in emotion generation, identification and improved beliefs about emotion in recovered PwAN (Oldershaw et al., 2015). The finding that connecting with emotion seemed to be a relational process supports SPEAKS being a relational model. This could be seen as akin to emotion coaching in EFT which is described as a highly collaborative process between the client and therapist (Linehan, 1993).

Caregivers' Emotions

The results highlighted carers' needs who initially reported a **struggle in navigating their own role** as a carer and felt unskilled in exploring emotion, which appeared to contribute to their own emotional difficulties. Therapist's also highlighted their own difficult emotions and noticed avoiding discussions around emotion with PwAN. This supports previous research that suggests family members find it difficult during the time their family member is unwell with AN (Whitney et al., 2005) and that therapists experience difficult emotions (Jarman et al., 1997). Similarities in PwAN and carers' emotional distress and communication about emotion seemed apparent. It is tentatively suggested that carers may experience difficulties in communication of emotion linked to their own schemas. Support for this comes from the idea

that schemas are similar within families due to what the parents bring to the relationship (Dattilio, 2005).

What do Stakeholders Perceive Facilitates and Hinders Engaging with Emotion or Emotional Change in Treatment for AN?

Expressing Emotion and Addressing Core Issues in Therapy

This study references how emotional change seemed to be facilitated through the therapeutic relationship, which links to evidence suggesting that it is a predictor of treatment response (Werz et al., 2021). A number of **interpersonal qualities** in the therapist appeared important in facilitating and hindering engaging with emotion which show the importance of remembering basic therapeutic techniques.

Emotional change seemed to be achieved through PwAN developing a deeper understanding of emotions, how emotions relate to ED behaviours and learning to express emotions. This seemed to give PwAN a starting point to build a narrative to explain their experience, as EFT approaches suggest (Whelton & Greenberg, 2000), and respond differently to emotional triggers or difficult interpersonal situations. Although some of these factors have been identified as helpful by other treatments for AN it is possible that the SPEAKS model may provide an explanation how it facilitates emotional change. This is because the themes of identifying and expressing emotion could be interpreted as PwAN noticing and working through coping modes, which typically block emotion to manage emotional pain (Young, 2003) and lead to an improved sense of self. This is in line with EFT which suggests it is not necessarily helpful to simply express all emotions to achieve emotional change (Greenberg, 2002).

Participants appeared to report that it was useful for PwAN to express assertive anger, which is proposed to help establish boundaries in relationships (Greenberg, 2004). Expressing anger seemed to be particularly important in facilitating emotional change and may be an important focus for SPEAKS. This is supported by previous research that has highlighted a link between anger and AN (Truglia et al., 2006) and suggestions that accessing anger in response to unjust treatment promotes positive emotional change (Greenberg, 2004).

Learning to express emotion seemed to facilitate the process of addressing core issues where PwAN felt more able to share difficult feelings such as shame, guilt, loneliness or to address difficulties within their relationships. This supports research that suggests PwAN experience high levels of guilt and shame (Skårderud, 2007) and this finding may demonstrate the process of addressing unmet needs in the SPEAKS model. Mixed opinions were provided with regard to focusing on eating, weight and shape concerns in therapy. Some stakeholders found it hindered engaging with emotion, which support research suggesting eating and body image related concerns rarely underlie the main issues in AN (Sternheim et al., 2012). However other people appeared to see the usefulness retaining some form of communication around these concerns. It would be useful to further investigate when these conversations are likely to be helpful.

Developing the Self

Participants described **learning new ways of intrapersonal responding,** such as the development of self-compassion, an identity, self-efficacy and self-agency as facilitating emotional change, which appeared to occur after **learning how to express emotions** and **addressing core issues** in line with the SPEAKS model. This lends support to the theory of

the 'lost-emotional self' whereby accessing emotions in a felt sense rather than cognitive way leads to a stronger sense of self and improvement from AN (Oldershaw et al., 2019) and a dialectical-constructivist view of human experience suggesting feeling experiencing emotions in a felt sense leads to self-organisation (Watson & Greenberg, 1996).

Developing the Healthy Adult

Establishing and maintaining boundaries in relationships, goal setting and the development of self-compassion seemed important in facilitating and hindering engaging with emotion and emotional change, which could be interpreted as fostering change through PwAN developing a strong 'healthy adult' function. The healthy adult focuses on working towards goals even if they cause distress, for example eating and weight gain in recovery, asserting one's needs and the ability to respond to one's self in a nurturing way (Young, 2003).

Caregiver and Service Factors

Both carers and therapists appeared to recognise the importance of self-care to ensure they can effectively engage with PwAN, with self-care reported to lead to positive emotional change within themselves and PwAN. PwAN also highlighted that it was important to manage responses as the caregiver so PwAN could express their emotions freely without prioritising others' feelings. This supports previous evidence that reports carers moderation of their emotional responses promotes emotional change for PwAN (Goddard et al., 2010).

PwAN and carers appeared to report that it was necessary to access **high quality professional support** to achieve emotional change. A lack of professional support or poorquality support seemed to hinder emotional change. Therapists and carers seemed to differ in

their views of what was considered **timely support**. Therapists reported engaging with emotion was difficult when PwAN were at a lower weight as the focus was mainly around anxiety, which may represent a primary emotion blocking access to secondary emotions (Greenberg, 2004). This may also indicate that progress of emotional change process is slower at a lower weight, requiring a greater number of sessions and lends support to research highlighting the role of starvation in maintaining AN (Oldershaw et al., 2019; Haynos & Fruzzetti, 2011). Carers appeared to want therapy to begin when PwAN were at low weight, which may reflect their own feelings of helplessness, or because they see further possibilities for change by being around the family member more often.

Strengths and Limitations

This study's strengths come from interviewing three key stakeholder groups. This was useful as different themes were identified from different groups and contributed to the data being rich in content. A further strength was using both an inductive and deductive approach to the analysis. This allowed for existing aspects of the SPEAKS model and new insights to be identified. Although the analysis was reflexive in nature, this does not eliminate the risk of bias completely.

One limitation of this study is that all of the PwAN were female and white, and all carers were female, which may mean that results do not extend to other demographic groups. Although the main purpose of qualitative research is not to generalise results to the wider population (Myers, 2000), it is possible that the homogeneity of the sample could make the practical application of results more difficult. Furthermore, the themes identified tended to focus more on what facilitated emotional change, which may have been due to participants in

the study having a more positive experience of services. People who were being treated as an inpatient for AN were excluded from participating in the study. Whilst this was done for ethical reasons, it is possible that people who are acutely unwell hold different views.

As the author did not collect the data, this may have changed the results as the author may have used different follow up questions based on the research questions. Finally, listening to all audio recordings is a part of familiarisation with the data in thematic analysis and this was not possible for the project. This may mean that important nuances in participants' accounts have potentially been missed.

Implications

This project appeared to provide preliminary support for the SPEAKS models, which may be an important development in improving treatment options for AN. The results may have identified key factors important to stakeholder groups, including potential examples of how to work with emotion, developing intrapersonal responding and highlighted the needs of caregivers. Future research could examine how self-compassion is developed in therapy for AN as this was highlighted as important by PwAN and carers. Self-compassion has been viewed by PwAN as insincere and unfamiliar but having potential to improve one's ability to cope (Kelly et al., 2021). It is a complex concept to work with and warrants further research.

It may be useful to develop a SPEAKS carers' programme that could be delivered concurrently to the intervention for PwAN. This fits with carers' self-reported desire for professional support and how impactful they appeared to find support groups. Future research is needed to determine the acceptability and efficacy of the SPEAKS intervention to stakeholder groups. Future research may also be necessary to determine which group of

PwAN SPEAKS is most appropriate for based on the finding that significantly low weight is a hindrance to emotional change and the project's exclusion criteria.

Therapy seemed to be mostly reported as a helpful factor in achieving emotional change. This is reassuring for clinicians to recognise to maintain hope for recovery, considering the ambivalence seen in PwAN (Gregersten et al., 2017). PwAN appeared to highlight **the usefulness of group work.** Should future research determine that SPEAKS is effective, a group therapy or combined approach may help to improve access to services and cost-effective interventions. Risk issues and busy services seemed to hinder engaging with emotion which suggest that having a smaller caseload may help therapists to work more effectively. Results highlighted the importance of supervision to manage therapists' own emotions, which appeared to sometimes mirror those of PwAN.

Conclusion

The study aimed to explore views of PwAN, therapists and carers on engaging with emotion inside and outside of therapy to refine and consolidate SPEAKS. Specifically, this study sought to understand; what are stakeholders' experiences of exploring emotions in and outside of therapy and what experiences or interactions, including those within therapy, are perceived to facilitate or hinder engaging with emotion and/or emotional change. A thematic analysis of existing data indicated the that the experience of exploring of emotion was new and difficult but gradually improved over time. The results also highlighted ways of achieving emotional change through both interpersonal and intrapersonal methods and highlighted the needs of therapists and carers. The results offer support for the SPEAKS

model and possible directions for its future, such as creating a carers' programme and group therapy approach. Further research is needed into the efficacy of the intervention.

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	104
Section C: Appendices of Supporting Materials	

Appendix A Health Research Authority Letter of Approval for Terminated Project

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Appendix B Email for Research Ethics Committee Confirming end of Major Research Project

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Appendix C Quality Appraisal of Qualitative Studies Using the Critical Appraisal Skills Checklist for Qualitative Research

CASP Question	Blackburn et al., 2020	Fox and Diab, 2015	Lindstedt et al., 2015	Oyer et al,. 2016	Rance et al., 2017	Sibeoni et al., 2020	Smith et al., 2016	Tierney, 2008
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes, but more could have been provided.	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes – but no discussion around if some participants declined to take part.	Yes – but no discussion around if some participants declined to take part.	Yes	Yes – but no discussion around if some participants declined to take part.	Yes – but no discussion around if some participants declined to take part.	Yes – but participants selected by clinicians on their opinions of who would have most to talk about, which could cause bias.	Yes	Yes – but no discussion around if some participants declined to take part.
Was the data collected in a way that addressed the research issue?	Yes	Yes, but does not stated if audio recorded interviews.	Yes	Yes	Yes – but topic guide is not provided in full.	Yes	Yes	Yes – although topic guides were not provided.
Has the relationship between researcher and participants been adequately considered?	Yes	Some researcher reflexivity was described.	Yes	Can't tell – no description of this.	Yes	Can't tell– researchers not reflected on potential bias to research question and data collection.	Yes	Yes, changes to topic guide were stated. No reflexivity in researcher's analysis of the data.
Have ethical issues been taken into consideration?	Yes	No	Yes – but not stated if a debrief was offered to participants.	Can't tell – Consent procedure is not adequately described. No discussion around debrief process. No	Yes	Yes – but not stated if a debrief was offered to participants.	Yes	analysis of the data. Consent is discussed but other ethical issues or approval is not stated.

Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	comment on ethical approval. Yes – but own bias could have been discussed to a greater degree.	Yes	Yes. There could be more discussion of researchers own bias as it is a psychoanalytically informed study.	Yes – but own bias could have been discussed to a greater degree.	Yes, reflexive journal and discussions were provided.
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing literature, clinical implications and areas for future research.	The research is discussed in relation to existing research and clinical implications. Areas for future research are not identified.

Appendix D Appraisal of Mixed Methods Study Using the Mixed Methods Appraisal Tool

	Methodological Quality Criteria	Button & Warren, 2001
Screening	Are there clear research questions?	Yes
Questions	Do the collected data allow to address the research questions?	Yes
Qualitative Studies	Is the qualitative approach appropriate to answer the research question?	Yes
	Are the qualitative data collection methods adequate to address the research question?	Yes
	Are the findings adequately derived from the data?	Partially—sufficient data is provided in the paper. The method of analysis is not described but it appears to be a form of thematic analysis.
	Is the interpretation of results sufficiently substantiated by data?	Yes – majority views and inconsistencies are described.
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes
Quantitative Descriptive Studies	Is the sampling strategy relevant to address the research question?	Yes
Studies	Is the sample representative of the target population?	Yes
	Are the measurements appropriate?	Yes
	Is the statistical analysis appropriate to answer the research question?	Yes
Mixed Methods Studies	Is there an adequate rationale for using a mixed method design to address the research question?	Yes. They focus on separate aspects.
	Are the different components of the study effectively integrated to answer the research question?	Yes – The components of the study investigate different aspects. The interview complemented the quantitative measure.
	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes

Appendix E Extract of coded data

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Appendix F Thematic Synthesis

Theme	Subtheme	Example Codes	Quotes
Universal features of the therapeutic relationship	Ability to help	Expertness	Quotes have been removed from the electronic copy
		Lack of specialised knowledge	
		Being challenged	
	Holding onto hope and goals	Hope for recovery	
		Staff pessimism towards treatment	
		Weight goals were unhelpful	
	Connecting as people	Basic counselling skills	
		Understanding	
		Trust	
Needing other supportive relationships		Having family involved	
		Working with support systems	

		Complementing other relationships
Clinical features of anorexia impact the establishment of the therapeutic relationship	AN blocking to the establishment of the therapeutic relationship	AN exerting influence
		Feeling conflicted
		Not wanting help initially
	Beliefs about being relationships as a barrier	Inability to be vulnerable
		It's selfish to be cared for
		Selfish to talk about myself
	The 41	The issue of food is removed
	The therapist's approach needs to shift over time	
		Handing over control was a relief
		Regaining control over time
Distance from the identity of anorexia		Externalising the eating disorder
		Being seen as a whole person
		Focus on food and weight was unhelpful

Appendix G

Appendix H Information Sheet for People with Anorexia



FOCUS GROUPS for PEOPLE WITH ANOREXIA

Participant Information Sheet

You are being invited to take part in a research focus group. It is important for you to understand why the research is being done and what it will involve. Please take time to read and listen to the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why is this research being done?

This research forms part of a research programme called SPEAKS (Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex) which aims to develop a new emotion focussed therapy for adults with anorexia. It is important to us and to the success of the project that we learn as much as we can from people with lived experience of anorexia while developing SPEAKS. We feel that it is only by better understanding the experience from your perspective that we can develop a useful therapy.

We will be holding focus groups with different groups of people in different locations to give us an opportunity to hear as many views as possible. The focus group will enable us to ask you questions about your experiences and what did or did not help you. It will also be a space for us to put to you some of our initial hypotheses and ideas for SPEAKS to get your thoughts and comments. As well as running groups with people who have personal experience of anorexia, we will also be running groups with carers/family members, therapists and NHS managers. The groups will not be mixed and will only include other people with experience of anorexia.

Who is organising the research?

The research is being organised by researchers at the Eating Disorder Service in [Trust name], the Salomons Centre for Applied Psychology at Canterbury Christ Church University, and [Trust name]. It is led by Dr Anna Oldershaw who is a clinical psychologist working for [Trust name]. The research is being funded by the National Institute of Health Research.

Why have I been asked to take part?

You have been invited to take part in this study as **you are somebody aged over 18** with current or past experience of having a diagnosis of anorexia who may be willing to share their views.

What will happen to me if I take part?

If you are interested in participating in the research you will be contacted by Dr Anna Oldershaw. She will answer any questions you may have and collect some demographic details and information about your experience of anorexia, such as when you first became ill and how long you were/have been ill for. This can be done over the phone or in person depending on what you prefer. This information will be used purely for study purposes and will not be seen by anyone outside of the research team. During this contact, your nearest focus group will be identified and you will be invited to come along. Alternatively, if you would like to contribute to the research and prefer to have a one-to-one interview, this will be arranged.

Focus groups will be small groups of a maximum of eight people who have experience of a diagnosis of anorexia. The groups will be co-facilitated by Anna, with one or two co-facilitators from the research team also present. The focus groups will last a maximum of two hours and will include several short breaks. The facilitators will present an agenda at the start of the group outlining a plan for the time. Group members will be invited to add to the agenda if they wish.

The focus groups (or interview) will be recorded by audio-tape using a Dictaphone and this will be transcribed (typed up) word for word. This is to help us better remember everything that has been talked about. During the transcription process any identifying information will be removed and the audiotapes will be destroyed after transcription.

Expenses and payments

You will be reimbursed for up to £10 in travel costs incurred during your participation. You will also be given a £25 voucher to say thank you for taking the time to participate in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will get this information sheet to keep and you will be asked to sign a consent form.

If you decide to take part, you can still withdraw at any time without giving a reason. If you decide to not take part, or to withdraw at any stage, it will not affect your current or future care in any way. Unfortunately, it will not be possible to exclude your data after the focus groups. This is because it will be difficult to identify and distinguish your contribution from that made by others on tapes or in transcripts.

What are the possible benefits from taking part?

You will receive no direct benefit from taking part in the study, but your participation will contribute to the development of the SPEAKS therapy which may mean that we can better help those with anorexia in the future.

What are the possible disadvantages and risks of taking part?

Some people may find it hard to talk about their experiences or to hear those of others. The focus groups will have scheduled breaks. The facilitators will be available during breaks if you

need to let them know that you are finding it difficult or wish to talk privately on any matter. If you are finding the focus group difficult you are not obliged to stay and are free to leave at any point without giving a reason.

Will my taking part in the study be kept confidential?

- Any information you have provided about yourself will be anonymised and will be stored in a locked cabinet on [Trust name] property.
- Your consent form (which you signed) will be kept in a locked cabinet on [Trust name] property. This will be kept separate from your data and focus group transcripts.
- Your identity will not be recorded within written transcripts of the groups/interviews, and
 will not be revealed in any publication that may result from this study. Data will be
 collected with only a participant number and pseudonym to identify it. All information
 you provide will be kept confidential, except as governed by law (i.e. if there is a legal
 obligation on the researcher to disclose this information to authorities). If the researcher
 needs to contact a third party due to concerns about risk, they would always try to speak
 with you about this first.
- The data collected in this study will be used only for the purpose described in this form, and will be available only to the research team. Therefore, your identity and the fact that you have participated will be known only to the clinicians from [Trust name] and [Trust name] present at the focus groups and members of the research team.
- Data gathered from this study will be retained as long as required by regulations, which is
 up to five years following the publication of empirical articles or communications
 describing the results of the study.

What if I have a concern about the research?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact in writing, providing a detailed description of your concerns:

- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]
- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]

What will happen to the results of the research study?

It is intended that we will use the views provided at the focus groups to inform the development of the SPEAKS therapy. Short extracts from the focus groups may appear in reports or publications. This may include publication in a scientific journal, presentations at professional conferences,

research reports to the ethics committee/NIHR or other SPEAKS documents (e.g. in a description of the resulting therapy intervention). However, these extracts will always be anonymised and will not be linked to any identifying information. It will not be possible for anyone to tell that you took part in this study or to know which views were yours.

What if I want to have some further information?

If you have any specific questions regarding this research study or would like further information about the focus groups or the SPEAKS project, please ask Dr Anna Oldershaw (Lead Researcher) who will be happy to answer any questions (contact details below).

You will be asked if you would like to receive further information about the outcomes of the focus groups and of the wider SPEAKS project. If you would like to be kept updated, your name will be added to our list of contacts and we will share regular updates and newsletters with you. You can choose to be removed from this list at any time by contacting Anna Oldershaw.

If you would like any further information about participating in research generally or of other projects which are currently running in [Trust name] then you can arrange an appointment to speak to a research officer at [Trust name] Research & Development Office by emailing [Trust details] To find out more about research in [Trust name] email [Trust details]

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, known as the Research Ethics Committee. This study has been reviewed in accordance with the guidelines for Canterbury Christ Church University research and has been approved by the **London – Dulwich Research Ethics Committee (Reference 17/LO/0606).**

Thank you for taking the time to hear about our research. We hope that you will consider taking part in it.

Dr Anna Oldershaw

Clinical Psychologist
NIHR Clinical Academic Fellow (Clinical Lectureship)
[Trust name]
[Trust Address]

Tel: [Trust telephone number] Email: SPEAKS@canterbury.ac.uk

Appendix I Information Sheet for Carers



FOCUS GROUPS for FAMILY MEMBERS/CARERS OF PEOPLE WITH ANOREXIA

Participant Information Sheet

You are being invited to take part in a research focus group. It is important for you to understand why the research is being done and what it will involve. Please take time to read and listen to the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why is this research being done?

This research forms part of a research programme called SPEAKS (Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex) which aims to develop a new emotion focussed therapy for adults with anorexia. It is important to us and to the success of the project that we learn as much as we can from people with lived experience of anorexia while developing SPEAKS. We feel that it is only by better understanding the experience from your perspective that we can develop a useful therapy.

We will be holding focus groups with different groups of people in different locations to give us an opportunity to hear as many views as possible. The focus group will enable us to ask you questions about your experiences and what did or did not help you and/or your family member with anorexia. It will also be a space for us to put to you some of our initial hypotheses and ideas for SPEAKS to get your thoughts and comments. As well as running groups with people who are carers/family members of people with anorexia, we will also be running groups with people who have personal experience of anorexia, therapists and NHS managers. The groups will not be mixed and will only include other carers and family members of people with anorexia.

Who is organising the research?

The research is being organised by researchers at the Eating Disorder Service in [Trust name], the Salomons Centre for Applied Psychology at Canterbury Christ Church University, and [Trust name]. It is led by Dr Anna Oldershaw who is a clinical psychologist working for [Trust name]. The research is being funded by the National Institute of Health Research.

Why have I been asked to take part?

You have been invited to take part in this study as you are somebody **aged over 18** who has experience of a close family member having a diagnosis of anorexia who may be willing to share their views.

What will happen to me if I take part?

If you are interested in participating in the research you will be contacted by Dr Anna Oldershaw. She will answer any questions you may have and collect some demographic details and information about who in your family has or had anorexia, when they first became ill and how long they were/have been ill for. This can be done over the phone or in person depending on what you prefer. This information will be used purely for study purposes and will not be seen by anyone outside of the research team. During this contact, your nearest focus group will be identified and you will be invited to come along. Alternatively, if you would like to contribute to the research and prefer to have a one-to-one interview, this will be arranged.

Focus groups will be small groups of a maximum of eight people who have a family member with experience of a diagnosis of anorexia. The groups will be co-facilitated by Anna, with one or two co-facilitators from the research team also present. The focus groups will last a maximum of two hours and will include several short breaks. The facilitators will present an agenda at the start of the group outlining a plan for the time. Group members will be invited to add to the agenda if they wish.

The focus groups (or interviews) will be recorded by audio-tape using a Dictaphone and this will be transcribed (typed up) word for word. This is to help us better remember everything that has been talked about. During the transcription process any identifying information will be removed and the audiotapes will be destroyed after transcription.

Expenses and payments

You will be reimbursed for up to £10 in travel costs incurred during your participation. You will also be given a £25 voucher to say thank you for taking the time to participate in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will get this information sheet to keep and you will be asked to sign a consent form.

If you decide to take part, you can still withdraw at any time without giving a reason. If you decide to not take part, or to withdraw at any stage, it will not affect your current or future care in any way. Unfortunately, it will not be possible to exclude your data after the focus groups/analysis. This is because it will be difficult to identify and distinguish your contribution from that made by others on tapes/transcripts or to analysed themes.

What are the possible benefits from taking part?

You will receive no direct benefit from taking part in the study, but your participation will contribute to the development of the SPEAKS therapy which may mean that we can better help those with anorexia in the future.

What are the possible disadvantages and risks of taking part?

Some people may find it hard to talk about their experiences or to hear those of others. The focus groups will have scheduled breaks. The facilitators will be available during breaks if you need to let them know that you are finding it difficult or wish to talk privately on any matter. If you are finding the focus group difficult you are not obliged to stay and are free to leave at any point without giving a reason.

Will my taking part in the study be kept confidential?

- Any information you have provided about yourself will be anonymised and will be stored in a locked cabinet on [Trust name] property.
- Your consent form (which you signed) will be kept in a locked cabinet on [Trust name] property. This will be kept separate from your data and focus group transcripts.
- Your identity will not be recorded as part of your data, and will not be revealed in any
 publication that may result from this study. Data will be collected with only a participation
 number to identify it. All information you provide will be kept confidential, except as
 governed by law (i.e. if there is a legal obligation on the researcher to disclose this
 information to authorities due to risk). If the researcher needs to contact a third party due
 to concerns about risk, they would always try to speak with you about this first.
- The data collected in this study will be used only for the purpose described in this form, and will be available only to the research team. Therefore, your identity and the fact that you have participated will be known only to the clinicians from [Trust name] and [Trust name] present at the focus groups and members of the research team.
- Data gathered from this study will be retained as long as required by regulations, which is
 up to five years following the publication of empirical articles or communications
 describing the results of the study.

What if I have a concern about the research?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact in writing, providing a detailed description of your concerns:

- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]
- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]

What will happen to the results of the research study?

It is intended that we will use the views provided at the focus groups to inform the development of the SPEAKS therapy. Short extracts from the focus groups may appear in reports or publications. This may include publication in a scientific journal, presentations at professional conferences,

research reports to the ethics committee/NIHR or other SPEAKS documents (e.g. in a description of the resulting therapy intervention). However, these extracts will always be anonymised and will not be linked to any identifying information. It will not be possible for anyone to tell that you took part in this study or to know which views were yours.

What if I want to have some further information?

If you have any specific questions regarding this research study or would like further information about the focus groups or the SPEAKS project, please ask Dr Anna Oldershaw (Lead Researcher) who will be happy to answer any questions (contact details below).

You will be asked if you would like to receive further information about the outcomes of the focus groups and of the wider SPEAKS project. If you would like to be kept updated, your name will be added to our list of contacts and we will share regular updates and newsletters with you. You can choose to be removed from this list at any time by contacting Anna Oldershaw.

If you would like any further information about participating in research generally or of other projects which are currently running in [Trust name] then you can arrange an appointment to speak to a research officer at [Trust name] Research & Development Office by emailing [Trust details] To find out more about research in [Trust name] email [Trust details]

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, known as the Research Ethics Committee. This study has been reviewed in accordance with the guidelines for Canterbury Christ Church University research and has been approved by the **London – Dulwich Research Ethics Committee (Reference 17/LO/0606).**

Thank you for taking the time to hear about our research. We hope that you will consider taking part in it.

Dr Anna Oldershaw

Clinical Psychologist
NIHR Clinical Academic Fellow (Clinical Lectureship)
[Trust name]
[Trust Address]

Tel: [Trust telephone number] Email: SPEAKS@canterbury.ac.uk

Appendix J Information Sheet for Therapists



FOCUS GROUPS for STAFF WORKING WITH PEOPLE WITH ANOREXIA

Participant Information Sheet

You are being invited to take part in a research focus group. It is important for you to understand why the research is being done and what it will involve. Please take time to read and listen to the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why is this research being done?

This research forms part of a research programme called SPEAKS (Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex) which aims to develop a new emotion focussed therapy for adults with anorexia. It is important to us and to the success of the project that we learn as much as we can from people with lived experience of anorexia while developing SPEAKS. We feel that it is only by better understanding the experience from your perspective that we can develop a useful therapy.

We will be holding focus groups with different groups of people in different locations to give us an opportunity to hear as many views as possible. The focus group will enable us to ask you questions about your experiences and what you think does or does not help people with anorexia in their recovery. We will also be interested in management or service issues that arise in relation to treating people with anorexia. It will also be a space for us to put to you some of our initial hypotheses and ideas for SPEAKS to get your thoughts and comments.

As well as running groups with staff, we will also be running groups with people who have personal experience of anorexia and people who are carers/family members of people with anorexia. The groups will not be mixed and the staff groups will only include staff members. Furthermore, staff groups will also be divided into separate groups of therapists and managers.

Who is organising the research?

The research is being organised by researchers at the Eating Disorder Service in [Trust name], the Salomons Centre for Applied Psychology at Canterbury Christ Church University, and [Trust name]. It is led by Dr Anna Oldershaw who is a clinical psychologist working for [Trust name]. The research is being funded by the National Institute of Health Research.

Why have I been asked to take part?

You have been invited to take part in this study as you are somebody who is experienced in working with people with anorexia who may be willing to share their views.

What will happen to me if I take part?

If you are interested in participating in the research you will be contacted by Dr Anna Oldershaw. She will answer any questions you may have and collect some demographic details and information about your professional background and training and how long you have been working with people with anorexia. This can be done over the phone or in person depending on what you prefer. This information will be used purely for study purposes and will not be seen by anyone outside of the research team. During this contact, your nearest focus group will be identified and you will be invited to come along. Alternatively, if you would like to contribute to the research and prefer to have a one-to-one interview, this will be arranged.

Focus groups will be small groups of a maximum of eight people who have experience of a diagnosis of anorexia. The groups will be co-facilitated by Anna, with one or two co-facilitators from the research team also present. The focus groups will last a maximum of two hours and will include several short breaks. The facilitators will present an agenda at the start of the group outlining a plan for the time. Group members will be invited to add to the agenda if they wish.

The focus groups (or interviews) will be recorded by audio-tape using a Dictaphone and this will be transcribed (typed up) word for word. This is to help us better remember everything that has been talked about. During the transcription process any identifying information will be removed and the audiotapes will be destroyed after transcription.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will get this information sheet to keep and you will be asked to sign a consent form.

If you decide to take part, you can still withdraw at any time without giving a reason. If you decide to not take part, or to withdraw at any stage, it will not affect your current or future care in any way. Unfortunately, it will not be possible to exclude your data after the focus groups/analysis. This is because it will be difficult to identify and distinguish your contribution from that made by others on tapes/transcripts or to analysed themes.

What are the possible benefits from taking part?

You will receive no direct benefit from taking part in the study, but your participation will contribute to the development of the SPEAKS therapy which may mean that we can better help those with anorexia in the future.

What are the possible disadvantages and risks of taking part?

Some people may find it hard to talk about their experiences or to hear those of others. The focus groups will have scheduled breaks. The facilitators will be available during breaks if you need to let them know that you are finding it difficult or wish to talk privately on any matter.

If you are finding the focus group difficult you are not obliged to stay and are free to leave at any point without giving a reason.

Will my taking part in the study be kept confidential?

- Any information you have provided about yourself will be anonymised and will be stored in a locked cabinet on [Trust name] property.
- Your consent form (which you signed) will be kept in a locked cabinet on Trust name] property. This will be kept separate from your data and focus group transcripts.
- Your identity will not be recorded as part of your data, and will not be revealed in any
 publication that may result from this study. Data will be collected with only a participation
 number to identify it. All information you provide will be kept confidential, except as
 governed by law (i.e. if there is a legal obligation on the researcher to disclose this
 information to authorities due to risk). If the researcher needs to contact a third party due
 to concerns about risk, they would always try to speak with you about this first.
- The data collected in this study will be used only for the purpose described in this form, and will be available only to the research team.
- Data gathered from this study will be retained as long as required by regulations, which is
 up to five years following the publication of empirical articles or communications
 describing the results of the study.

What if I have a concern about the research?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact in writing, providing a detailed description of your concerns:

- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]
- The [Trust name] Team at [Trust email address] if you are participating in [Trust name]

What will happen to the results of the research study?

It is intended that we will use the views provided at the focus groups to inform the development of the SPEAKS therapy. Short extracts from the focus groups may appear in reports or publications. This may include publication in a scientific journal, presentations at professional conferences,

research reports to the ethics committee/NIHR or other SPEAKS documents (e.g. in a description of the resulting therapy intervention). However, these extracts will always be anonymised and will not be linked to any identifying information. It will not be possible for anyone to tell that you took part in this study or to know which views were yours.

What if I want to have some further information?

If you have any specific questions regarding this research study or would like further information about the focus groups or the SPEAKS project, please ask Dr Anna Oldershaw (Lead Researcher) who will be happy to answer any questions.

You will be asked if you would like to receive further information about the outcomes of the focus groups and of the wider SPEAKS project. If you would like to be kept updated, your name will be added to our list of contacts and we will share regular updates and newsletters with you. You can choose to be removed from this list at any time by contacting Anna Oldershaw.

If you would like any further information about participating in research generally or of other projects which are currently running in [Trust name] then you can arrange an appointment to speak to a research officer at [Trust name] Research & Development Office by emailing [Trust details] To find out more about research in [Trust name] email [Trust details]

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, known as the Research Ethics Committee. This study has been reviewed in accordance with the guidelines for Canterbury Christ Church University research and has been approved by the **London – Dulwich Research Ethics Committee** (Reference 17/LO/0606).

Thank you for taking the time to hear about our research. We hope that you will consider taking part in it.

Dr Anna Oldershaw

Clinical Psychologist
NIHR Clinical Academic Fellow (Clinical Lectureship)
[Trust name]
[Trust Address]

Tel: [Trust telephone number] Email: SPEAKS@canterbury.ac.uk

Appendix K Consent Form for People with Anorexia

Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex



FOCUS GROUPS for PEOPLE WITH ANOREXIA

Participant Consent Form

Locatio	on:			
Partici	pant Identificat	ion Number:		
			Please initial the relev	ant boxes
1)	sheet for the a	I have read/had read to me an above study (dated 20/03/201 en given the opportunity to co and have had these answered	onsider the information,	
2)	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and that my current and future care will be unaffected.			
3)	I understand that any information collected about me will not have my name on it.			
4)	I agree to the focus groups being recorded and transcribed and anonymised extracts being used in reports or publications.			
5)	I agree to part	icipate in the above study		
Name	of Participant	Date	Signature	
Name	of Person	Date	Signature	

Taking Consent
I would like to be kept updated with outcomes:
Of the focus groups
And/or of the wider SPEAKS project
If you would like to be kept updated, initial box above and provide your preferred contact address:
Email:
OR
Postal address:

Appendix L Consent Form for Carers

Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex



FOCUS GROUPS for FAMILY MEMBERS/CARERS OF PEOPLE WITH ANOREXIA

Participant Consent Form

Locatio	on:			
Partici	pant Identificati	on Number:		
			Please initial the relev	vant boxes
1)	sheet for the al	bove study. I have also been g	nd understood the information given the opportunity to consider d these answered satisfactorily.	
2)	2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and that my current and future care will be unaffected.			
3)	I understand the my name on it.	at any information collected	about me will not have	
4)		ocus groups being recorded a eports or publications.	and transcribed and anonymised extracts	
5)	I agree to parti	cipate in the above study		
Name	of Participant	 Date	Signature	
Name	of Person	Date	Signature	
	Englis Groupsi En	mily 8 Carors Varsian 1.1 20/0:	2/2017 PEC Poft 17/10/0606 (London - Dubuich)	

Taking Consent
I would like to be kept updated with outcomes of the focus groups and of the wider SPEAKS project.
If you would like to be kept updated, initial box above and provide your preferred contact address:
Email:
OR
Postal address:

Appendix M Consent Form for Therapists

Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex



FOCUS GROUPS for STAFF WORKING WITH PEOPLE WITH ANOREXIA

Participant Consent Form

Location:			
Participant Identification Nu	ımber:		
		Please initial the relev	ant boxes
sheet for the above :	study. I have also been	nd understood the information given the opportunity to consider d these answered satisfactorily.	
 I understand that my am free to withdraw and future care will l 	at any time, without g	ary and that I iving a reason, and that my current	
I understand that an my name on it.	y information collected	l about me will not have	
4) lagree to the focus go being used in reports		and transcribed and anonymised extracts	
5) I agree to participate	e in the above study		
Name of Participant	Date	Signature	
Name of Person Taking Consent	Date	Signature	
Focus Groups: Staff Groups	1 Version 1.1 20/03/2017	REC Ref: REC Ref: 17/LO/0606 (London – Dulwich)	

I would like to be kept updated with outcomes:
Of the focus groups And/or of the wider SPEAKS project
If you would like to be kept updated, initial box above and provide your preferred contact address:
Email:
OR
Postal address:

Appendix N Topic Guide for Interviews with People with Anorexia

Agenda & Topic Guide

People with Experience of Anorexia

All focus groups will follow a similar agenda with questions of similar themes, but adapted to each participant group. The agenda and topic guide for people with experience of anorexia are outlined below.

Introductions (approx. 10 minutes)

- The group facilitators will introduce themselves and remind participants of the purpose of the group.
- Facilitators will briefly outline this agenda and advise participants of the breakout rooms
- Participants will be invited to introduce themselves and if they feel comfortable to say a
 little about why they have come today and what interested them about the study.

Group Rules (approx. 5 minutes)

- Facilitators will introduce some common group rules such as respect, allowing everybody
 the chance to speak, everybody being allowed their own opinion including when it differs
 from our own.
- Participants will be invited to add to the rules or to question them.
- · Facilitators will seek agreement from the group of the rules
- · Agreed rules will be written on a flip chart visible throughout the session

Q1 Experience of therapy (approx. 15 minutes)

What has been your experience of therapy?

Q1 Follow up Questions

What has been positive about therapy for you?

What has been more difficult in therapy?

What has stayed with you most from your time in therapy?

Break (5 minutes)

Q2 Emotions in Therapy (approx. 15 minutes)

Do you think talking about emotions is an important part of therapy?

What has been your experience of talking about emotions in therapy?

Q2 Follow up questions

Agenda & Topic Guide – People with Experience of Anorexia | Version 1.1 | 17/05/17 | REC Ref: 17/LO/0606 (London – Dulwich)

What were the most helpful approaches or techniques for thinking about emotions/moving towards recovery?

What has been unhelpful/didn't help you make any change?

How has this impacted your experience of your eating disorder/recovery?

Q3 Advice for therapists (approx. 10 minutes)

If you were going to give advice to a therapist about how to tackle difficulties with emotions in therapy with somebody who currently has anorexia, what would you want them to know?

Q4 Check in/Anything remaining/debrief (approx. 5 mins)

Is there anything on this topic that you have not had a chance yet to say that you would like for us to know?

Are there any further questions that you have for us?

Facilitators will remain available after the session and will be available to speak with participants one to one, including in private in one of the breakout rooms if required.

Appendix O Topic Guide for Interviews with Carers

Agenda & Topic Guide

Carers & Families of People with Anorexia

All focus groups will follow a similar agenda with questions of similar themes, but adapted to each participant group.

Introductions (approx. 10 minutes)

- The group facilitators will introduce themselves and remind participants of the purpose of the group.
- · Facilitators will briefly outline this agenda and advise participants of the breakout rooms
- Participants will be invited to introduce themselves and if they feel comfortable to say a
 little about why they have come today and what interested them about the study.

Group Rules (approx. 5 minutes)

- Facilitators will introduce some common group rules such as respect, allowing everybody
 the chance to speak, everybody being allowed their own opinion including when it differs
 from our own.
- Participants will be invited to add to the rules or to question them.
- · Facilitators will seek agreement from the group of the rules
- · Agreed rules will be written on a flip chart visible throughout the session

Q1 Experience of caring (approx. 15 minutes)

What has been your experience of caring for somebody with anorexia?

Q1 Follow up Questions

What have been the challenges to you personally? And in your relationship with the person with anorexia?

What, if any, have been the benefits?

Break (5 minutes)

Q2 Talking about Emotions (approx. 15 minutes)

What has been your experience of talking about emotions with your family member with anorexia?

Q2 Follow up questions

What has helped you/you as a family to discuss emotions and enhance positive emotional communication?

What was unhelpful/didn't seem to help emotional communication with your family member?

Agenda & Topic Guide - Carers & Families | Version 1.1 | 17/05/17 | REC Ref: 17/LO/0606 (London - Dulwich)

Do you think emotional communication and your family member's experience of emotions has impacted their eating disorder/recovery?

Q3 Advice for other families (approx. 10 minutes)

If you were going to give advice to another family about how to improve emotional communication with somebody who currently has anorexia, what would you want them to know?

Q4 Check in/Anything remaining/debrief (approx. 5 mins)

Is there anything on this topic that you have not had a chance yet to say that you would like for us to know?

Are there any further questions that you have for us?

Facilitators will remain available after the session and will be available to speak with participants one to one, including in private in one of the breakout rooms if required.

Appendix P Topic Guide for Interviews with Therapists

Agenda & Topic Guide

Therapists Working with People with Anorexia

All focus groups will follow a similar agenda with questions of similar themes, but adapted to each participant group.

Introductions (approx. 10 minutes)

- The group facilitators will introduce themselves and remind participants of the purpose of the group.
- · Facilitators will briefly outline this agenda and advise participants of the breakout rooms
- Participants will be invited to introduce themselves and if they feel comfortable to say a
 little about why they have come today and what interested them about the study.

Group Rules (approx. 5 minutes)

- Facilitators will introduce some common group rules such as respect, allowing everybody
 the chance to speak, everybody being allowed their own opinion including when it differs
 from our own.
- · Participants will be invited to add to the rules or to question them.
- · Facilitators will seek agreement from the group of the rules
- · Agreed rules will be written on a flip chart visible throughout the session

Q1 Experience of Therapy (approx. 15 minutes)

What has been your experience of providing therapy to people with anorexia?

Q1 Follow up Questions

What has been positive about this therapeutic work for you?

What has been more difficult?

What stays with you most from your time in therapy?

Break (5 minutes)

Q2 Talking about Emotions (approx. 15 minutes)

What has been your experience of talking about emotions when working in therapy with people with anorexia?

Q2 Follow up questions

What was a helpful approach or technique for thinking about emotions in the therapy room/helping clients move towards recovery?

What was unhelpful/didn't seem to help clients move towards/make change?

Agenda & Topic Guide - Therapists | Version 1.1 | 17/05/17 | REC Ref: 17/LO/0606 (London - Dulwich)

How has this impacted your experience of your eating disorder/recovery?

Q3 Advice for other therapists (approx. 10 minutes)

If you were going to give advice to another therapist about how to tackle difficulties with emotions in therapy with somebody who currently has anorexia, what would you want them to know?

Q3 Follow up question

How would you say working with emotions with people with anorexia is similar or different to other client groups, if at all?

Q4 Check in/Anything remaining/debrief (approx. 5 mins)

Is there anything on this topic that you have not had a chance yet to say that you would like for us to know?

Are there any further questions that you have for us?

Facilitators will remain available after the session and will be available to speak with participants one to one, including in private in one of the breakout rooms if required.

Appendix Q Health Research Authority Letter of Approval

This has been removed from the electronic copy

Appendix R Confirmation of Ethical Approval from Canterbury Christ Church University

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SECTION C: APPENDICES OF SUPPORTING MATERIALS

140

Appendix S Summary Letter to Participants

Dear participant

Thank you so much for taking part in the research about your experiences of engaging with emotion during the recovery process from anorexia nervosa. Your participation in the project has been invaluable to the SPEAKS team, who are aiming to develop a and test a new emotion focused psychological intervention for anorexia. We are truly grateful for your time taken to participate in this project and hope that we can contribute to developing more effective interventions for people with anorexia.

The research aimed to explore the views of people with anorexia, carers and therapists on engaging with emotion during recovery from anorexia, and what is perceived to facilitate or hinder emotional change in recovery. In total, 28 participants took part in this part of the SPEAKS project. The interviews and transcripts went through a process of data analysis that looked at common themes identified participants. We found the follow results

- People with anorexia found it really difficult to connect to or express emotions whilst they were very unwell.
- Expressing emotions took time and was often only possible with the support of therapists and carers.
- Learning about emotion was often a new experience for people with anorexia and was generally found to be a helpful process.
- Therapists and carers recognised high levels of anxiety and anger in those that they care for.

- Carers found it difficult to navigate their ways through two different caring roles, often feeling as if they needed to be a carer and therapist at the same time. They highlighted that they needed to manage their own emotions and access carers support groups to be able to effectively engage with emotion with their family member.
- People with anorexia identifies ways of coping with distress that usually involved their suppression their emotions to protect themselves from emotional pain or to protect other people's feelings. This could be overcome by learning to express how they felt in therapy and to their family members.
- People with anorexia felt it was important to take responsibility for their own recovery and set goals.
- People with anorexia needed their therapists to listen to them, understand them and display genuine care.
- It was important to develop self-compassion, independence and an identity away from anorexia in recovery.
- Therapists highlighted that they could work more effectively with clients if they had more time and had quality supervision and support from their colleagues.
- Poor experiences of services hindered engagement with emotion for people with anorexia and carers.
- Carers requested that people with anorexia can access therapy early, even if they are at a low weight.
- Carers and people with anorexia tended to find group work challenging but helpful.

The results from this study provided us with support that the new SPEAKS intervention may be suitable as a treatment for anorexia. Participants have provided us with important areas to focus on in informing this intervention and some ideas for future research.

SECTION C: APPENDICES OF SUPPORTING MATERIALS

142

Thank you again for taking part. Your participation will help to inform more effective treatments to support people with anorexia and their families.

If you have any questions, please feel free to contact me or the SPEAKS research team.

Best wishes,

Lynsey Davies

Trainee Clinical Psychologist

Ld458@canterbury.ac.uk

Appendix T Summary Letter to Research Ethics Committee

To whom it may concern,

I am writing to inform you of the completion of the major research project titled:

Experiences of engaging with emotion and emotional change in recovery from anorexia nervosa: Supporting the refinement of a new emotion focused intervention. This study was sponsored by the National Institute for Health Research and Canterbury Christ Church University. This project was granted favourable ethical opinion from Canterbury Christ Church University and the London Dulwich Research Ethics Committee and approved by the Health Research Authority. Please find a summary of the project below.

Background

Anorexia nervosa is associated with high psychiatric comorbidity and significant negative effects on physical health and emotional and social wellbeing. Recovery rates for anorexia nervosa are suboptimal and effective psychological therapies are yet to be established.

Treatment is further complicated by difficulties that therapists experience in relation to their clients and the significant difficulties carers have in managing their own responses to their family members.

Emotion focused therapies are a promising new area and treatments that focus on one underlying mechanism of change are required. Although existing treatments make some attempt to work with emotion, they all highlight multiple factors in the maintenance of anorexia nervosa, so numerous factors are targeted in treatment which contributes to treatment overlap across models. This makes it difficult to identify mechanisms of change and identify what factors of the intervention are associated with outcomes.

A new emotion focused explanatory model has been developed that differentiates between risk and maintenance factors of anorexia nervosa. This focuses on one key underlying factor that contributes to perpetuates anorexia nervosa. The model proposes that maladaptive coping strategies in anorexia nervosa, used to survive in early life, move a person away from a strong sense of a 'core emotional self'. This leaves people without emotions to guide them and therefore people with anorexia experience difficulties in the self and relationships. The Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex programme (SPEAKS) is aiming to develop and test an emotion focused intervention for adults with AN based on this new model.

Rationale

The SPEAKS project has four phases: reviewing current approaches, developing the intervention, trialling the programme and developing the protocol for a randomised controlled trial study (RCT). This project feeds into phase four by informing the intervention prior to applying for RCT funding. The project uses existing data from clients who had experience of an intervention for anorexia (not SPEAKS), carers and ED therapists. Formal analysis of this data has not been completed and as the intervention is still in development, this is required to inform refinement of SPEAKS and emerging new insights to working with emotion. Using three stakeholder groups was key in determining how the SPEAKS intervention can be tailored to the needs of all stakeholders.

<u>Aims</u>

The aim of the current study was to explore experiences of engaging with emotion inside and outside of therapy for AN across key stakeholder groups to refine and consolidate the SPEAKS model. This study sought to address the following questions:

SECTION C: APPENDICES OF SUPPORTING MATERIALS

145

- c) What are stakeholders' experiences of exploring emotions in and outside of therapy?
- d) What experiences or interactions, including those within therapy, are perceived to facilitate or hinder engaging with emotion and/or emotional change?

Method

This study used a qualitative design. Existing data was used for the project which had collected through guided focus groups and semi-structured interviews. Data was used from 28 participants who were 12 adults with anorexia nervosa, seven carers, and nine therapists who worked with PwAN. The data was analysed using a hybrid form of thematic analysis which utilised a deductive and inductive approach.

Results

Four over-arching themes were found in relation to the research questions: early experience of engaging with emotion, how to achieve emotional change through the therapeutic relationship, factors impacting emotional change and accessing appropriate support.

Results indicated that people with anorexia found it difficult to connection with their emotional experience, though carers and therapists report witnessing high levels of distress in the people they cared for. Carers found it particularly difficult to navigate their new role as a carer and highlighted the need for their own individual support to effectively engage with emotion with their family member. Therapists also highlighted that they needed to manage their own emotions, which was hindered by having to managing physical risks associated with the client group and working within busy services. The results indicated that working with emotion was key in facilitating emotional change and provided preliminary support for

SECTION C: APPENDICES OF SUPPORTING MATERIALS

146

key aspects that the SPEAKS model. Interpersonal qualities and intrapersonal factors were

found to impact emotional change, including self-compassion and developing an identity

other than anorexia nervosa. Group work was particularly useful for participants. The results

offer recommendations for refinement of the SPEAKS intervention and possible directions

for its future, such as creating a carer's programme and group therapy approach. Further

research is needed into the efficacy of the intervention.

Feedback to participants

A summary of the project's findings has been provided to the SPEAKS research team who

will disseminate this to participants.

Please feel free to contact me if you have any queries or would like to further discuss the

research.

Yours sincerely,

Lynsey Davies

Trainee Clinical Psychologist

Ld458@canterbury.ac.uk

Appendix U Deductive Analysis Codebook

SPEAKS model of AN

Avoidance of emotional triggers

Suppression of emotions

Suppression of emotion to avoid interpersonal conflict

Early life experiences contribute to emotion being overwhelming or confusing

Unable to access own emotions

Avoiding emotional experience

Privileges the emotional experience of others

Experiencing distress

Inability to see the world other than AN

SPEAKS phase 1

Building the therapeutic relationship so feared emotions can safely emerge

Building a narrative away from eating, weight and shape concerns

Addressing core issues and associated emotions

Following the pain to uncover emotional experience

Deepening the person's ability to connect with emotion

Naming coping modes blocking access to emotion

Naming anxiety as blocking other forms of emotional processes

Mapping out parts of the emotional self through

Building trust

Validating emotional experience

Connecting with emotions takes time

SPEAKS phase 2

Exploring shame and guilt around body/ED behaviours

Exploring shame, guilt and worthlessness of self

Working with anxiety

Working with anxiety to access core emotions

Noticing coping modes in daily life

Working to bypass coping modes blocking access to emotion

SPEAKS phase 3

Learning to be guided by emotional experience

Expressing assertive anger

Expressing attachment and/or abandonment fears

Expressing grief

Expressing sadness

Identifying and/or reflecting on unmet needs

Therapist connecting with the vulnerable side of the self

Reflecting on identity concerns

SPEAKS phase 4

Developing boundaries in relationships
Healthy assertion of own needs
Developing and experiencing self-compassion
Accepting own emotional experience
The therapeutic relationship as a reparenting experience

SPEAKS phase 5

Developing self-efficacy
Developing self-agency
Developing independence
Reflecting on the therapeutic relationship
Consolidating boundaries in relationships

Appendix V Extract of inductive analysis codes

A focus on food, weight or shape is not helpful

A lack of identity

A way out and hopefulness

Accepting emotional experience of client

Accepting mistakes will be made

Adapting strategies

Addressing core issues and associated emotions

Admitting there was a problem

Anger decreased communication

Anger expressed in harmful ways

Animal analogy

Appropriate expression of emotions

Asking questions

Balancing talking about food and other issues

Being compassionate

Believing in ability to recover

Boundaries about emotional expression

Boundaries at home

Boundaries in therapeutic relationship

Carer feeling painful emotions

Carer managing own emotions

Carer managing own responses

Carer needs support

Celebrating achievements

Communicate early

Communicate with skills rather than emotion

Communicating emotion

Communicating needs

Communication has improved aggression

Communication improves eating distress

Communication improves honesty

Competing demands

Continuity between sessions

Continuity of care

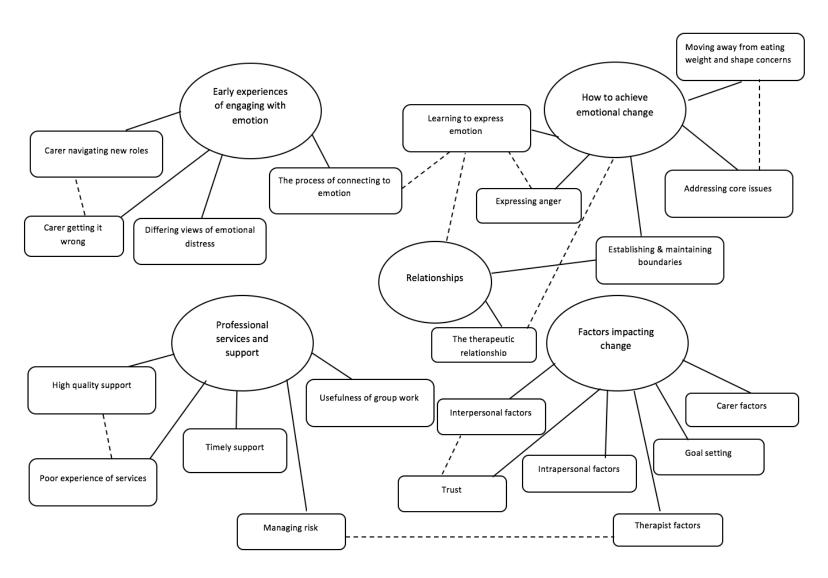
Dependency on carer

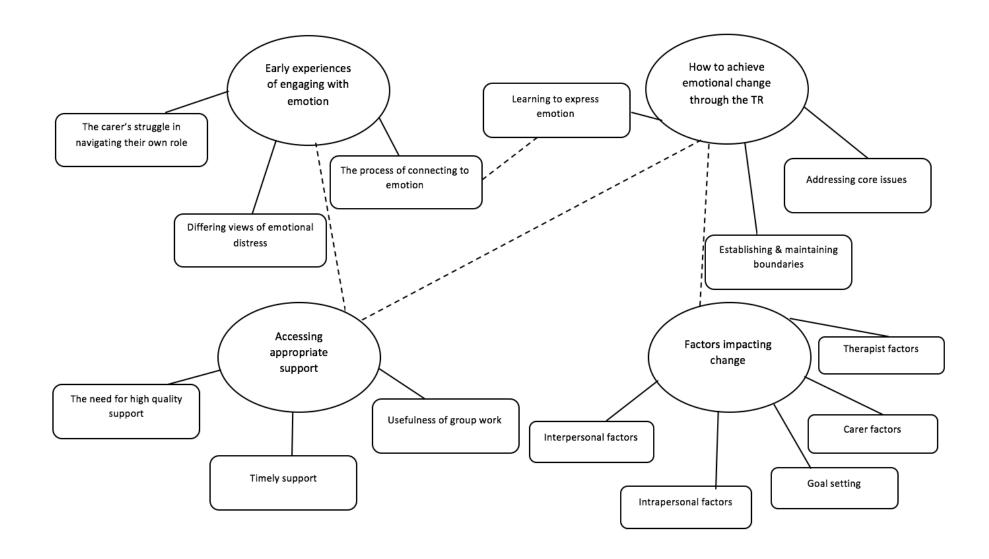
Developing an understanding of other people

Appendix W Example Coded Transcript of Therapist Focus Group

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Appendix X
Example Thematic Maps





Appendix Y Abridged Research Diary

9th March

I'm extremely grateful that Maria has identified a new project for me, and that Anna has allowed me to come on board such an important project at this point in my training. I've bought the book outlining the SPEAKS model through amazon as it's not available online yet. I'm nervous to try to get to grips with a new topic area and evidence base in such a short space of time, but as I already have an interest in the area, I think should be the easiest task of the project. I'm finding my placement quite difficult at the moment and it's nearly two hours' drive each way, so I am nervous about how I am going to finish the project in time. I have discussed with Maria about the possibility of a July hand-in, but we have agreed this is probably too optimistic.

I'm finding that I have had to do a lot more background reading than anticipated on both emotion focused therapies and schema therapy to get to grips with the theory behind the model. Although I had some understanding of the topic area, the model is very different to current treatment approaches, and trying to understand anorexia for a new perspective has been academically challenging at times. I'm currently working on the proposal whilst trying to contact clinicians across multiple teams that had been trying to help me recruit for my old project, so I feel like I'm juggling both the new and old MRP at the moment. I'll be glad when I can focus all of my energy on this project.

23rd March

I've submitted my first proposal. I'm hoping for a quick turnaround so I can begin with the project.

30th March

Some final amendments need to be made to the transcript. Following a meeting with the supervisors it seems we can easily address all the changes.

6th May

Final proposal submitted.

8th June

The project has been approved – feeling very relieved.

1st July

I've taken some time out of section B to focus on section A, as I started a search for a new topic so both parts would be related. It's helping me develop new understandings to the difficulties of working with this client group which I think will be helpful when writing the clinical and research implications for section B.

17th July

I've found out that most of the audio files have been damaged. Despite contacting IT support within the participating NHS trust to try and find a solution to the problem but have been informed there is no way of retrieving the files. This is really disappointing as the audio files

I was able to listen to were really insightful and helped bring the data to life. I need to ensure that I am really familiar with the topic area

2nd August

I've been blown away at how emotive the transcripts are and having looked into the research area more thoroughly now, have a much better understanding of how much new interventions for anorexia are needed. I notice a tendency that I'm already hoping that SPEAKS is a success so need to be aware of this when analysing the data so not to bias the results. I've had a discussion with a fellow trainee about this which is something they found whilst doing there research too. They found it helped to have bit of distance from the evidence base before coding the data and so I have allowed myself a short break before beginning the data analysis.

6th August

I'm noticing I'm really feeling for some of the carer participants in the project, who seem to have had a really difficult time. I'm wondering if this is why they have chosen to take part in the research, as they haven't had the best experience and want things to change for themselves and for others. I'm also left wondering about the carer's voices that weren't heard in this project. It seems like support for carers is just as essential when working with this client group, and I'm left thinking about how much money would be needed to fund service that could meet this client's groups need. This links to my own experience in CAMHS and thinking about how parents can sometimes need as much support as young people, and how truly vital this is to achieve long lasting change within some families.

17th August

The coding process is taking much longer than expected. I noticed at first that I was tending to code for the parts of the model and codes I found easier to hold in mind, so I have revisited the transcripts a number of times to ensure I have coded all relevant data. Following a discussion with my supervisor, we revised the importance of including all stakeholders' views and how I could present the results to ensure I capture everyone's viewpoint. I'm therefore ensuring that I code aspects of the dataset that even if it does not feel relevant to the research question at this stage, to ensure no important data is lost in the process.

15th September

I'm struck by a number of things at this stage – there appears to be a number of similarities between how clinician's find themselves avoiding discussion emotions due to the provision of the services they work in, and the avoidance of emotions in people with anorexia. I was wondering whether clinicians might have been likely to talk about this with the hope that new research could potentially influence their working environments eventually. I wondered what I would talk about if I was being interviewed in a participant group of trainee clinical psychologists. I think I would be more likely to highlight what is working well, especially if it was in front of other clinicians I did not know, or how hard it might be to voice everything I wanted to highlight in a relatively short space of time. This might be useful to bear in mind later when considering the limitations of the study.

I have also noticed that carers and therapist seemed to identify high levels of anger in the people they care for, which is not something I had associated with anorexia before. This is highlighting to me the usefulness of including all stakeholders in this research as the results may have been less diverse if only using the data from people with anorexia.

19th October

I'm at the point of developing themes and feeling slightly overwhelmed at how much data there is to account for. I'm noticing so much potential for themes involving emotion and I'm surprised at how this area of the literature is still developing when it seems so prevalent in this dataset. I'm noticing the need to hold in mind where new insights can be identified. Even if they seem like obvious viewpoints it is important the results capture the essence of what has been talked about by participants.

2nd November

It has been really useful reflecting on the development of the themes with Maria and Anna and thinking about how these can clearly be coded at a higher level of interpretation. After having a break from looking at the themes, this now appears obvious in a way I couldn't see before. It is so useful to have had a bit of space and come back to the analysis, which has allowed me to develop a much richer explanation of the findings.

13th November

Time is tight now – still feeling like I have a lot more to do before submission but about to send off my final draft. It's strange how personal the analysis feels at this point of the project and I can see how much the researcher has the potential influence the results in qualitative analysis.

Appendix Z Journal of Eating Disorders Author Guidelines

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