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Family-based Treatment for Young People's Eating Disorders: An Interpretative Phenomenological Analysis of Parental Perspectives.

And

Clinical Research Portfolio

Rachel Hanson

MRes in Psychology

MA in Cognitive Behavioural Therapy

BSc Honours in Psychology

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Institute of Health and Wellbeing College of Medical, Veterinary and Life Sciences

University of Glasgow

July 2019

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CHAPTER 1: SYSTEMATIC REVIEW

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Prepared in accordance with guidelines for submission to the European Eating Disorders Review (See Appendix 1 in Chapter 2)

Abstract

Background

Few randomised controlled trials (RCTs) investigating effectiveness of treatment of anorexia nervosa (AN) in young people exist. Most existing research incorporates both adults and adolescents with varying diagnoses of restrictive eating disorders including bulimia nervosa, binge eating disorder as well as anorexia.

Aim

To systematically review the quality of RCTs of psychological interventions for AN in young people published from 2012-2019 inclusive and synthesise the included studies' findings.

Method

Four databases were systematically searched. Eight RCTs investigating the effectiveness of psychological therapies for youth with AN, were identified. The Cochrane Risk of Bias (CRoB) tool was used to quality appraise each study.

Results

Seven eligible studies were included. A variety of outcome measures for AN symptomology were used to assess a range of mostly, family therapies for AN in youth. Results indicated varying rates of remission, ranging between 33-80%. Follow up data was limited and methodological limitations are highlighted. Studies varied in their performance across the CRoB's domains of bias. Performance and other bias (response bias) were identified as domains with the highest risk of bias. Selection, attrition and reporting bias were low risk across all the studies.

Conclusions

While efforts are being made to further develop the evidence base, recovery rates are modest and methodological limitations further restrict findings. Risk of performance bias should be interpreted with caution as blinding participants and personnel in ED research can be impractical. Variation of outcome measures employed limits comparability of findings. Furthermore, over-reliance on self-report measures warrants further attention.

Keywords; anorexia nervosa, adolescent, systematic review, RCT

Introduction

Anorexia Nervosa and Young People

Anorexia nervosa (AN) is characterised by a persistent restriction of food intake resulting in severely low body weight, intense fear of weight gain and a distorted body image (The Diagnostic and Statistical Manual of Mental Disorders 5th ed.; DSM–5; American Psychiatric Association, 2013). AN is a complex disorder associated with poor quality of life, functional impairment and high rates of psychiatric and physical comorbidity (Lindvall Dahlgren and Ro, 2014). AN has an increased risk of chronicity, poor outcomes and increased risk of death (Nagl *et al.* 2016) often due to malnutrition and suicide. In terms of typical onset, Baily *et al.* (2014) estimate that 75% of AN cases onset at 22 years of age or younger, while Nagl *et al.* (2016) argue that typical age of onset is during early adolescence. Nagl *et al.* (2016) propose that onset during this important developmental stage accounts for the significant functional impairment, disability and impact on education, employment and earnings which often persists into adulthood. Given the early onset of AN, it's increased risk of mortality and comorbidity and its long-term impact on patients' lives, effective treatment is crucial.

Evidence Base for Psychological Interventions for AN in Young People

According to the Matrix (2015) and NICE guidelines (2017), the recommended psychological interventions proposed for treating AN in young people are Family-based Treatment (FBT), Cognitive Behavioural Therapy (CBT) and Adolescent-focused therapy (AFT). Despite these being the first line treatments for AN in young people, few systematic reviews investigating effectiveness and efficacy of psychological therapies for AN in adolescents exist. Challenges associated with AN research such as heterogeneity of age and illness factors, differing views on best treatment and complexity between medical and psychiatric aspects of AN (Bulik *et al.*, 2007) are likely to account for this. The systematic reviews that do exist often synthesise studies which employ mixed samples including both adolescents and adults and various diagnoses of restrictive eating disorders rather than focusing specifically on AN in adolescents. Additionally, they tend to synthesise studies with a wide range of designs such as clinical trials, mixed trials or cohort studies. Consequently, systematic reviews of RCTs on psychological treatments of adolescent AN are rare. The results of three of the most relevant systematic reviews are presented below and discussed in relation to the rationale for the present systematic review.

Bulik *et al.* (2007) conducted a systematic review of 32 RCTs published from 1980-2005 which investigated the efficacy of medical and psychological treatments. However, the studies had mixed samples consisting of both adolescents and adults with AN. Bulik *et al.* (2007) reported that the 32

studies involved only medication, only behavioural interventions or a combination of both. They found that the evidence base for medical and behavioural treatments of AN is limited except for family therapy for adolescent AN which was moderately strong (Bulik *et al.* 2007). They highlighted methodological issues within AN literature such as insufficient sample sizes, high attrition rates, unclear randomization processes and a need for standardization of outcome measures.

A more recent systematic review conducted by Lock (2015) appraised studies investigating psychosocial interventions for restrictive eating disorders including AN, bulimia nervosa (BN), binge eating disorder (BED) and avoidant/restrictive food intake disorder (ARFID), specifically in children and young people. While Lock handsearched articles from 2012-2014, database searches were conducted for studies published between 1985-2011 inclusive. Lock (2015) appraised 98 publications investigating family therapy, individual therapy, cognitive behavioural therapy, interpersonal psychotherapy, cognitive training, and dialectical behavior therapy. Lock (2015) reported that family therapy with a behavioural focus (FT-B) is the only "well-established" treatment for adolescent AN. He reported family therapy with a systemic focus and adolescent-focused psychotherapy (AFT) are "probably efficacious" treatments for adolescents with AN. Enhanced cognitive behavioural therapy, dialectical behavioural therapy, cognitive training, and interpersonal psychotherapy were classed as experimental treatments for adolescent eating disorders. Lock (2015) concluded that further research focusing on treatments for eating disorders in young people is needed.

Since Lock's (2015) review, Alckmin-Carvalho *et al.* (2018) have published a systematic review of evidence-based psychotherapy for treatment of AN in children and adolescents. Like Lock (2015), the review included studies of various designs including RCTs, open trials and mixed methods. Fourteen studies published between 1990-2015 were included. Nine psychotherapeutic treatments were investigated, with 7 studies on various forms of family-based treatment (FBT). The appraisal of these studies was based on the studies' characteristics such as design, outcome measures, results at end of treatment and follow-up and methodological limitations. While Alckmin-Carvalho *et al.'s* (2018) review provides a more recent update of the evidence, a significant limitation of this review is that no established quality appraisal tool appears to have been used to quality appraise the included studies. Consequently, it is felt that a review of studies from 2012 to date is worthwhile.

Rationale

Previous systematic reviews have highlighted that AN research is challenging to conduct and previous studies have been characterised by methodological limitations. In comparison with other mental health disorders, the evidence base for effective treatments for AN in adolescents is sparse in terms of RCTs investigating the effectiveness of psychological treatments. The few existing

systematic reviews of RCTs investigating AN tend to employ heterogeneous samples in terms of age such as Bulik et al.'s (2007) and often data are not stratified for adolescents with AN. Those that focus on adolescents such as Lock's (2015) review employ transdiagnostic samples rather than focusing on AN. The present systematic review aims to provide an update of the evidence base for adolescent AN since Bulik *et al.* (2007), Lock (2015) and Alckmin-Caravalho *et al.'s* (2018) systematic reviews were published. While research on eating disorders appears to be increasing, there is value in ascertaining whether the quality of this evidence is increasing. Unlike previous systematic reviews in this area, this review focuses on synthesising RCTs evaluating psychological treatments specifically for AN in adolescents and utilises a well-established quality appraisal tool to evaluate the quality of recently published RCTs. RCTs will be focused on as this design is considered to be the gold standard for assessing effectiveness of healthcare treatments.

Aim

- To provide an update of the evidence base by systematically reviewing the findings of RCTs for psychological interventions for anorexia nervosa in children and adolescents published from 2012-2019 inclusive.
- Evaluate the quality of this research, highlighting methodological strengths and limitations.
- To provide recommendations for future research on psychological interventions for anorexia nervosa in children and young people.

Methods

Initial Literature Scoping Exercise

An initial literature search on the Prospero archive was conducted in February 2019. This search indicated that no listed systematic reviews investigating the effectiveness of psychological interventions for anorexia nervosa specifically in young people appeared to have been conducted since Lock's (2015) review which employed a trans-diagnostic sample.

A literature scoping exercise was undertaken on MEDLINE and PsycINFO to ascertain the utility of undertaking a review in this area. These search results indicated that there is a relatively limited research base investigating the effectiveness of psychological interventions for AN and often adult and child/adolescent samples are combined in the existing research. Similarly, existing systematic reviews tend to include participants with bulimia nervosa, atypical anorexia, binge eating disorders and eating disorders otherwise not specified as well as AN.

Search Strategy

In line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher *et al.,* 2009) a PICOS model was developed when considering the search terms for this systematic review. *Participants* were children and adolescents aged 6-20; *Intervention* related to psychological treatments for anorexia nervosa; *Comparison* related to appropriate control groups including treatment as usual and waitlist controls*; Outcome* referred to BMI, weight for height and attitudinal measures*; Study Design* included randomised controlled trials (RCTs), controlled trials and clinical trials initially, at the database search stage as it was unclear if there were enough RCTs on this topic to warrant a systematic review. However, at the screening stage when it was established that there were sufficient numbers of RCTs to review, RCTs were the study design this review focused on.

Electronic Databases

The following databases were systematically searched on the advice of the supervisory team; MEDLINE, EMBASE, CINAHL, and PsycINFO. Search terms were identified by exploring the literature and other systematic reviews in the area. Combinations of these terms were developed and tested between March and June 2019. Finalised searches were conducted from 13th-16th June 2019. SIGN (Scottish Intercollegiate Guidelines Network) Search Filters guidelines (SIGN, 2019) were adhered to in order to use sensitive and specific search terms for randomised controlled trials for MEDLINE, EMBASE and CINAHL databases. Lock's (2015) search terms and the guidance provided by Cochrane

Work (2019) informed the use of search terms for randomised controlled trials within the PsycINFO database. Details of the final search terms are outlined below.

Other Sources

A decision was taken not to hand search journals given that the most relevant journals (*International Journal or Eating Disorders; European Eating Disorders Review; Eating Disorders Journal of Treatment and Prevention*) are indexed by the electronic databases searched. However, the references within the Matrix Evidence Tables for Children and Young People (2015) related to anorexia nervosa were hand searched and a forward text citation of Lock's (2015) and Alckmin-Carvalho *et al.'s* (2018) systematic reviews were conducted using Google Scholar. This did not yield any further studies included in the review.

Final Search Terms

1. Anorexia Nervosa/ OR Anorexia/ OR anorexia.mp.
2. Adolescent/ OR Child/ OR (Adolescent* OR Teenager* OR Youth*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3. Randomized Controlled Trials as Topic/ OR randomized controlled trial/ OR Random Allocation/ OR Double Blind Method/ OR Single Blind Method/ OR clinical trial/ OR clinical trial, phase i.pt. OR clinical trial, phase ii.pt. OR clinical trial, phase iii.pt. OR clinical trial, phase iv.pt. OR controlled clinical trial.pt. OR randomized controlled trial.pt. OR multicenter study.pt. OR clinical trial.pt. OR exp Clinical Trials as topic/ OR (clinical adj trial$).tw. OR ((singl$ OR doubl$ OR treb$ OR tripl$) adj (blind$3 OR mask$3)).tw. OR PLACEBOS/or placebo$.tw. OR randomly allocated.tw OR (allocated adj2 random$).tw.
4. Not case report.tw. OR letter/ OR historical article/
5. 1 AND 2 AND 3 NOT 4

Given that Lock's (2015) electronic database searches were from 1985-2011, search results were limited by years 2012-2019. Results were also limited by English language.

Search Results

Table 1 depicts the databases, number of results, interfaces used and the dates the searches were completed on.

Table 1 Database Search Results

Database	Results	Interface	Dates Searched
MEDLINE	227	Ovid	13/6/19
EMBASE	831	Ovid	13/6/19
CINAHL	532	EBSCO	14/6/19
PsycINFO	194	EBSCO	13/6/19

The 1784 results generated through from the above database searches were exported to EndNote. Following the removal of duplicates, 1546 records were systematically evaluated according to the inclusion criteria listed below.

Inclusion criteria were as follows:

- Studies written in English, published from 2012-2019, in a peer reviewed journal.
- Randomised controlled trials (RCTs) that focus on investigating the effectiveness of outpatient, psychological interventions for AN with young people aged up to 20 years old.
- Studies with treatment outcomes reported including weight-related outcomes and/or validated measures of eating disorder symptoms (including cognitions, behaviours or attitudes).
- Studies which employ a mixed sample of young people aged up to 20 and adults above this age were included if the data for those aged up to 20 were stratified.
- Studies which employ a mixed sample of young people diagnosed with AN, atypical AN and otherwise not specified (EDNOS) are included given the overlap in symptomology.

Figure 1 provides a summary of the process of article selection in line with PRISMA guidelines (Moher *et al.* 2009). Database searches, screening of articles and data extraction were completed by the primary researcher.

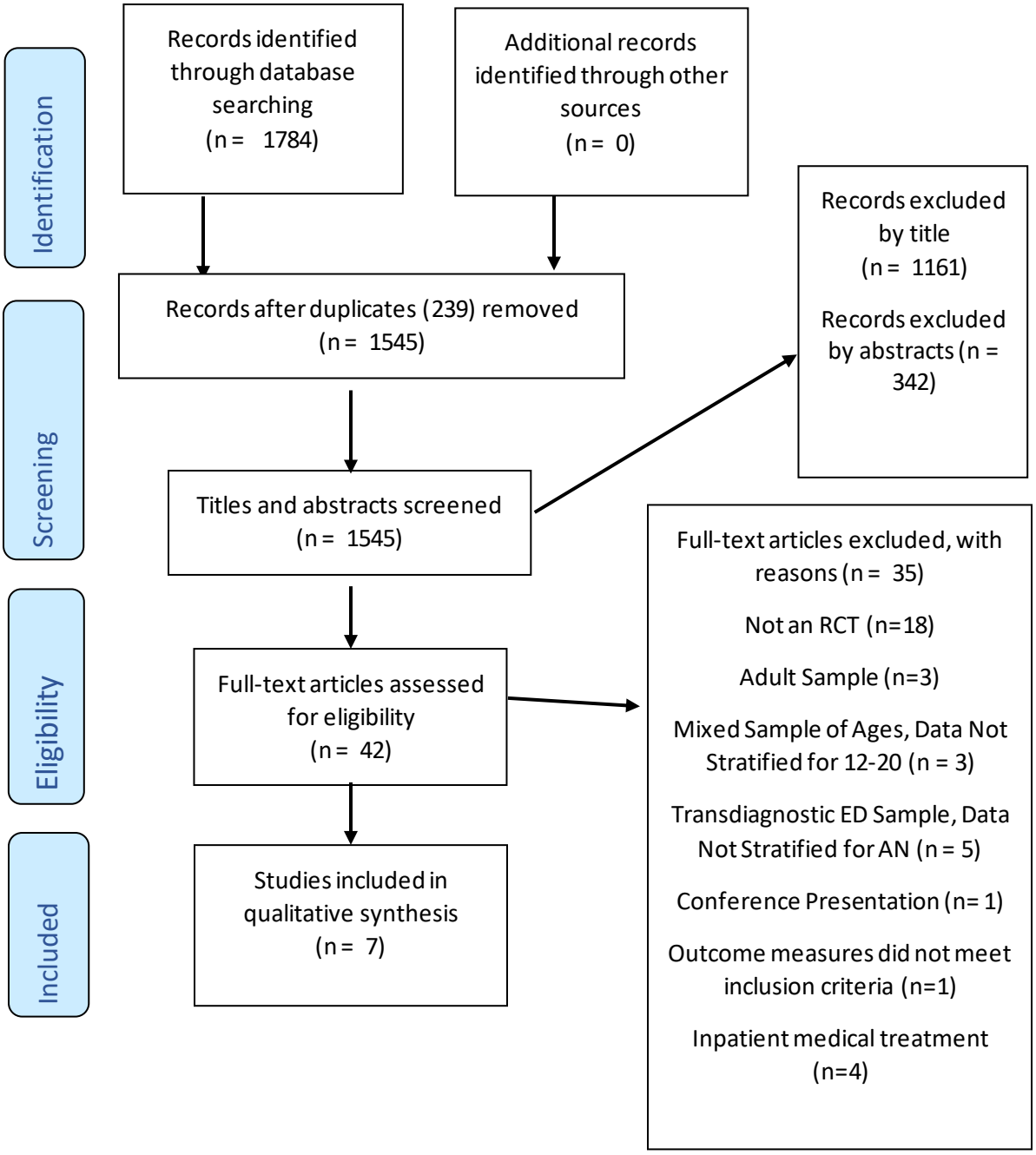
Quality Appraisal

The Cochrane Risk of Bias (CRoB) tool is a widely used tool utilised in systematic reviews of RCTs (Jørgensen *et al.* 2016). Unlike other appraisal tools such as scales or checklists, the CRoB is a component-based approach for assessing risk of bias within RCTs based on domains established through empirical evidence (PRISMA, 2009). Bias is evaluated as a judgment of risk (high, low, or unclear) within seven domains of potential bias; 1) random sequence generation (selection bias) 2) allocation concealment (allocation bias), 3) blinding of participants and personnel (performance bias),

4) blinding of outcome assessment (detection bias), 5) incomplete outcome data (attrition bias), 6) selective reporting (reporting bias) and 7) other bias (Jørgensen *et al.* 2016). Evidence to support each judgement of bias within these domains is documented (Appendix 1).

The 7 included studies were quality appraised by the primary author, a trainee clinical psychologist. Three of these studies were randomly selected and appraised independently by another trainee clinical psychologist who is experienced in eating disorders research. It was decided that three studies was a sufficient number to be inter-rated within the time restraints of this project. Inter-rater agreement was initially 81%. Inter-rater reliability was achieved through comparing the separate appraisals of these three studies. One hundred percent inter-rater reliability was achieved through discussion and negotiation of the separate appraisals. Following this, the primary researcher appraised the remainder of the studies included in this systematic review.

Figure 1 PRISMA Flowchart Diagram



Results

Study Characteristics

The relevant data from the 7 included studies were extracted and are presented in Table 2. Studies were published from 2012-2017 and were all conducted in high income countries apart from Herscovici *et al.* (2017) which was conducted in Argentina. Samples were predominantly white and female and sample sizes ranged from 23-172. Age of participants ranged from 9-20 inclusive. One study was a pilot RCT study (Hodsoll *et al*., 2017). Six studies took place in outpatient settings, while Herpetz-Dahlmann *et al.'s.* (2014) study compared outpatient treatment with continued inpatient treatment.

Interventions included in the studies were primarily variations on family therapy (FT); family-based treatment (FBT) multi-family therapy (MFT) and single-family therapy (SFT), conjoint family treatment, separated parent-focused family therapy andFBT with and without a family meal. Other interventions included multimodal multidisciplinary treatment (inpatient and day-patient versions) and multidimensional outpatient treatment with and without FT.

Outcomes were weight measures including median BMI and percentage of expected body weight and various measures of eating disorder psychopathology (see Table 2). Additionally, studies included outcomes on self-esteem and wider mental health psychopathology. These tended to be secondary measures. Studies investigating family-based therapies included parent/carer measures also.

Table 2 Baseline Characteristics of included studies

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
Agras *et al.* (2014) USA	Comparison of effectiveness of two family therapies for adolescent AN.	RCT	N = 158 Diagnosis: AN Gender: 141 females, 17 males Age Range: 12-18, M=15.3, SD = 1.8	Multi-site trial of outpatient family treatments.	Family-based treatment vs. Systemic family therapy - 16 one hour sessions over a 9-month period	Period: baseline, EOT, 12 month FUs Primary: %IBW K-SADS: (parent and child versions) - baseline Secondary: EDE interview BDI STAI State-Trait Anxiety Inventory, CY-BOCS RSES, YBC-EDS YBC-OCD QLES-Q: Quality of Life Enjoyment and Satisfaction Questionnaire	Period: EOT (36 weeks) No significant differences between treatments for weight gain (d = 0.13), eating disorder symptoms (d= 0.18) or comorbid psychiatric disorders (d = 0.075) found at EOT. Remission rates for FBT = 33.1% and for SyFT =25.3% at EOT, d= 0.08).	Period: 12 months No significant differences between treatments for weight gain (d = 0.14), eating disorder symptoms (d= -0.20) or comorbid psychiatric disorders (d= 0.095) at the FU. Remission rates for FBT = 40.7%, for SyFT = 39% at FU (d = 0.02).

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
Eisler *et al.* (2016) UK	Investigating effectiveness of multi-family therapy vs. single family therapy in outpatient setting	RCT	167 (n=82 in FT-AN Group, n= 85 in MFT-AN Group) Gender: 91% female, 9% male Diagnosis: AN (76%) EDNOS (restricting type) (34%) Age Range: 13-20 M =15.7, SD=1.7	Multi-site outpatient specialist eating disorders services in the NHS.	FT-AN vs. MFT-AN (consisting of single family therapy in addition to multi-family sessions)	Periods: Various. EOT = 12 months post randomisation, FU = 18 months post randomisation Primary Measures: MR-GOS – baseline, EOT and FU %mBMI – baseline, EOT and FU Other measures: EDE Interview – baseline, EOT and FU BDI - baseline, 3 months post baseline, EOT and FU	Both groups showed clinically significant differences in MR-GOS at EOT (FT-AN = nearly 60% and MFT-AN > 75%), favouring MFT-AN (OR=2.55 95% CI =1.17-5.52; p=0.019). No statistically significant differences between the two treatments for %mBMI, eating disorder psychopathology, depression or self-esteem found at EOT.	Differences for MR-GOS favouring MFT was not significant at FU (OR= 2.01 95% CI= 0.91 - 4.45; p=0.086). Clinically significant improvements were found at FU for %mBMI (d=0.68), mood (d=0.15) and eating disorder psychopathology (d=0.26) for both treatment groups. No significant differences in treatments on any of the other measures..

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
						RSES- baseline, 3 months, EOT and FU Client Satisfaction Questionnaire - EOT Experience of Caregiving Inventory - at baseline and EOT (carer measure)		
Godart *et al.* (2012) France	To compare two multidimensional outpatient treatments, TAU vs. TAU and family therapy.	RCT	N=60 Diagnosis: AN Gender: All female Age Range: 13-19, M = 16.6, SD=1.6	Outpatient setting	TAU vs TAU and FT TAU included sessions individual patient sessions and psychiatry sessions with patient and parents. TAU+FT program was identical to	Period: baseline and 18 months post randomization Primary: MR-GOS Secondary: MINI GOAS EDI WSAS BMI	Not included in the study.	18 months Significant improvement in all outcome measures in both treatment groups. A significant effect for the MR-GOS in favour of TAU+FT was found (OR= 3.2, intention to

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
					TAU and included family therapy sessions targeting intra-familial dynamics, but not eating disorder symptoms	Menstrual status Contraceptive use No. of hospitalisations		treat analysis: p=0.054).Similar group effects found for achievement of a healthy weight, i.e. BMI>10th%ile (OR=3, 95%CI, 1.0, 9.9; p=0.44), EDI scores (d=0.8) and menstrual status (d=0.3).
Herpetz-Dahlmann *et al.* (2014) Germany	To investigate safety and efficacy of day-patient (DP) treatment after short inpatient care compared with continued inpatient (IP).	RCT	172 (85 inpatients, 87 day-patient) <u>Diagnosis:</u> AN <u>Gender:</u> 172 female <u>Age Range:</u> 11-18,	Day-patient treatment vs. continued inpatient treatment.	Multimodal MDT treatment, based on weight restoration, nutritional counselling, CBT and FT.	Period: Baseline at admission and 12 month FU Primary: Difference in BMI between time of admission and the 12-month FU / timepoint of an ED-	Period: EOT Approx. 80% in both groups had a BMI >10th %ile with patients gaining approx. 3 BMI units during treatment. Mean BMI much the same for both groups at EOT.	DP non-inferior to IP in terms of BMI at FU, (d= 0.16). No between-group difference in MRGOS or readmissions found. Greater loss to FU in inpatient group.

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
			M = 15.2 , SD = 1.5 (inpatient group) M = 15.3, SD=1.5 (day-patient group)			related readmission Secondary: MRGOS SIAB-EX EDI-2 and Brief Symptom Inventory total scores No. of ED-related readmissions, Difference in health insurance costs between IP and DP until the date of discharge. No. of patients lost to follow-up.		Mean BMI was much the same between groups at FU, with larger variations than at EOT. Approx 25% in both groups still fulfilled criteria for AN at FU and 5 DP patients developed BN, 1 developed BED. No. of treatment-related serious adverse events similar in both groups (IP = 8, Dp = 7), 3 events in IP group and 2 in DP group were related to suicidal ideation; Approx. 20% mean insurance cost savings for DP.

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
Herscovici *et al.* (2017) Argentina	To evaluate if the family meal intervention had a positive effect on increasing weight gain or on improving other general outcome measures .	RCT	N = 23 Diagnosis: AN Gender: 1 male, 22 females Age Range: 12–20 M = 17.1 SD = 2.3	Outpatients receiving 6 months of treatment M no. of sessions: FT = 14 FTFM = 18	Family therapy with family meal intervention (FTFM) vs. family therapy with no FMI (FT) Treatment = 6 months duration	Periods: Baseline, EOT and FU at 6 months post EOT Primary: Weight gain, %EBW Secondary: MRHAS (AOS and GOS) EDI-2 SCL-90-R GSI Resumption of menses (ROM)	All 5 outcome measures improved with time (p values all ≤0.005). No significant differences between FT and FTFM found in weight, % (ES=-2.13, 95% CI, -9.74-4.21, p =.501), %EBW (ES=0.05, 95%CI, -0.03-0.12, p=0.235), or MRAOS score (ES=-0.50, 95%CI, -1.89-0.88, p=.469). Significant treatment effects found for EDI-2 (ES=2.73, 95%CI, 0.34-5.12, p=.026) and SCL90-R-GSI scores (ES=10.61, 95%CI, 2.51-18.71, p=.012). A significant	n = 21, assessed at 6 month post-treatment FU. 2 in FTFM group lost at follow up. The following outcomes continued to improve over time: %EBW (ES=0,06, 95%CI: 0.04-0.07, p<.0001), MRAOS (ES=.95, 95%CI, 0.60-1.30, p<.001), EDI-2 (ES=-0.78, 95%CI, -1.3- -0.25, p<.005) and SCL-90-R GSI (ES=-4.83, 95%CI, -6.61- -3.05, p<.0001) and no significant differences between FT and

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
							difference in EDI-2 was found between treatment groups and was explained as a different levels of psychological distress at baseline. ROM for FTFM = 80% ROM for FT = 27%	FTFM groups were found. ROM for FTFM = 78% ROM for FT = 36%
Hodsoll et al. (2017) UK	To investigate acceptability, feasibility and the effect size of adding a carer intervention to treatment as usual (TAU).	Pilot RCT	N = 149 Diagnosis: AN Gender: 137 female, 12 male Age Range: 13–20 M=16.9, SD not reported	Outpatient family treatments.	TAU (outpatient FT) vs TAU plus Experienced Caregivers Helping Others (ECHO) telephone guidance vs TAU ECHO alone	Period: Baseline, EOT, FU Patient Measures: SEED, DAWBA, SDQ, CIA, DAAS 21, CSRI: Carer Measures: DASS-21 - baseline, 1 year	Period: 6 months post randomization ECHO group showed a reduction in accommodating and enabling behaviour at 6 months (ES = 0.17, where ES was a regression coefficient standardised by baseline standard deviations of measure).	Period: 12 months after randomization ECHO group showed a moderate increase in carer skills (ES = 0.4) at FU. Carers in ECHO group spent less time care giving (ES = 0.40,) at FU and patients had a minor advantage

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
						FQ - baseline, 6 months AES-ED - baseline, 6 months CASK - baseline, 6 months and 1 year. Family eating patterns – baseline	The addition of telephone guidance to ECHO produced little additional benefit.	in body mass index (ES = 0.17), fewer admissions, decreased peer problems (ES = -0.36) and more pro-social behaviours (ES = 0.53)
LeGrange *et al.* (2016) Australia and USA	To compare efficacy of conjoint FBT and separated parent-focused treatment (PFT).	RCT	N = 106 Diagnosis: AN Gender: 93 female, 13 male Age Range: 12-18 M=15.5, SD=1.5	Multi-site study of outpatients	FBT vs. PFT 18 sessions over 6 months	Periods: Baseline, EOT, and at 6 and 12 months post treatment. Primary measures: %mBMI EDE Interview, Secondary Measures: demographic variables,	Higher remission rates were higher for PFT (42%) versus FBT (22%) at EOT where OR=3.03, 95% CI: 1.23-7.46. No proposed baseline variables significantly moderated outcome at EOT.	Period: 6 and 12 months post EOT. Differences in remission rates between PFT (39%) and FBT (22%) were insignificant at 6 month FU (OR=2.48, CI 0.989-6.22) and at 12 month FU (PFT =37%, FBT 29%, OR=1.39,

Author, Year and Country	Objective	Design	Sample Characteristics	Context & Setting	Interventions	Outcome Measures	Results Outcome at End of Treatment (EOT)	Results Outcome at Follow Up (FU)
						CDI, RSES, CY-BOCS, YBC-EDS, MINI-Kid, SCL-90-R, FMSS, TSPE, HRQ, PVA, PANAS-X, BPQ, FES		95% CI: 0.60-3.21). EDE and YBC-EDS scores moderated outcomes at 6 month and 12-month FU. No differences between in terms of secondary outcome measures were found at FU.

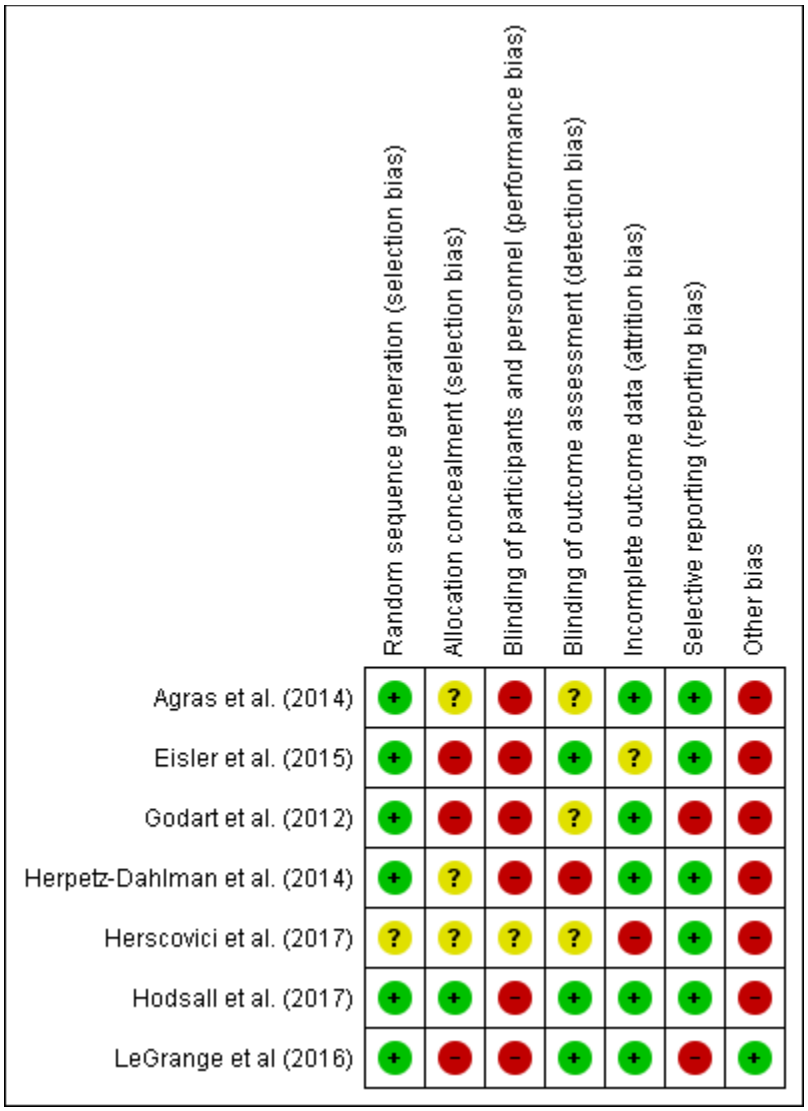
%EBW: Percentage of Expected Body Weight, %mBMI: Weight data % median BMI for young people, AES-ED: Accommodation and Enabling Scale for Eating Disorders, BDI: Beck Depression Inventory, BPQ: Borderline Personality Questionnaire, CASK: Caregiver Skills (CASK) scale, CBT: Cognitive behavioural therapy, CDI: Child Depression Inventory, CHQ: Child Health Questionnaire, CIA: Clinical Impairment Assessment, CSRI: Client Service Receipt Inventory, CY-BOCS: Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS), d: Cohen's d, DAAS 21: Depression, Stress and Anxiety Scale, DAWBA: Development and Wellbeing Assessment, EDE Interview – Eating Disorder Examination (Clinical Interview), EDI: Eating Disorder Inventory – 2, FAD: Family Assessment Device, FT: Family therapy, FBT-AN: Manualized family-based treatment for AN, FES: Family Environment Scale, FMSS: Five Minute Speech Sample, FQ: Family Questionnaire, GOAS: Global Outcome Assessment Scale, IPPA: Inventory of Parent and Peer Attachment, HRQ: Helping Relationship Questionnaire, K-SADS: Kiddie–Schedule for Affective Disorders and Schizophrenia–Present and Lifetime Version, MDT: multidisciplinary, MFT-AN: Multi-family therapy for

AN, MINI: mini-neuropsychiatric interview, MINI-Kid: Mini International Neuropsychiatric Interview for Children and Adolescents, MRHAS: The Morgan-Russell Assessment Schedule (MRHAS), MR GOS: Morgan/Russell Global outcome scale, OR: Odds Ratio, PANAS-X: Positive and Negative Affect Scale–Expanded, PVA: Parents Versus Anorexia, QLES-Q: Quality of Life Enjoyment and Satisfaction Questionnaire, SCL-90-R: SCL-90-R: Symptom Check List-90-Revised, SEED: Short Evaluation of Eating Disorders, SIAB-EX: Structured Interview for Anorexia and Bulimia Nervosa, STAI State-Trait Anxiety Inventory, SDQ: Strengths and Difficulties Questionnaire, RSES: Rosenberg Self Esteem Scale, TAU: treatment as usual, TSPE: Therapy Suitability and Patient Expectancy, WSAS: Weissman's social adjustment scale, YBC-EDS: Yale-Brown-Cornell Eating Disorder Scale, YBC-OCD: Child Yale-Brown Obsessive Compulsive Scale

Quality Appraisal - Risk of Bias

A summary of the risk of bias for each domain of the CRoB within the included studies is presented in Figure 2. A narrative synthesis of the results of the quality appraisal of the included studies is presented below. Further details on information supporting judgements of risk of bias is provided in Appendix 1.

Figure 2 Summary of risk of bias across the included studies.



Random sequence generation (selection bias)

Six studies (Agras *et al.*, 2014; Eisler *et al.* 2016; Herpetz-Dahlmann *et al.*,2014; LeGrange *et al.* 2016; Godart *et al.* 2012; Hodsoll *et al.* 2017) were assigned a low risk of bias judgement due to clear

descriptions of the randomization methods employed which were likely to produce comparable groups. Methods included computer-generated randomization and randomization databases. Herscovici *et al.*'s (2017) study was assigned an unclear judgement of risk due to limited information regarding randomisation.

Allocation concealment (allocation bias)

Three studies were assigned as having a high risk of bias (Eisler *et al.* 2016; LeGrange *et al.* 2016 and Godart *et al.* 2012) due to allocation sequence concealment being reported for researchers but not for participants. Three studies (Agras *et al.*, 2014; Herpetz-Dahlmann *et al.*,2014; Herscovici *et al.*2017) were judged as unclear due to insufficient information to make a judgement on risk of allocation bias. One study was judged as low risk (Hodsoll *et al.* 2017) as it provided adequate information about methods of concealment of allocation for participants and personnel.

Blinding of participants and personnel (performance bias)

Six of seven studies were judged as having a high risk of performance bias. Herscovici *et al.*'s (2017) study was rated as unclear due to not having sufficient information in the study relating to blinding of participants or personnel to make a judgment on this domain of bias. High risk appraisals for six of the included studies were due to participants or personnel appearing to have knowledge of which intervention participants received. This finding suggests that the feasibility of blinding of participants and clinicians in psychological interventions for AN may be impractical. This is likely for those that are offering an adjunctive intervention such as Hodsoll *et.al* (2017) or those offering treatments where the differences between experimental treatment and control are obvious to participants e.g. multi-family therapy and single family therapy. This argument is supported by Cochrane Handbook for Systematic Reviews of Interventions (Higgins & Green, 2011) which argues that double blinding to group allocation is often impractical.

Blinding of outcome assessment (detection bias)

Three studies were rated as having low risk of bias (Hodsoll *et al.* 2017; LeGrange *et al.*, 2016; and Eisler *et al.* 2016) as the process of blinding for outcome assessment was clearly outlined. One study were rated as having high risk of detection bias (Herpetz-Dahlmann, 2014) as blinding was not maintained. Three studies were rated as having an unclear risk of bias due to insufficient detail on methods of how assessors were blinded (Herscovici *et al.* 2017; Godart *et al.* 2012; and Agras *et al.* 2014).

Incomplete outcome data (attrition bias)

Five of the seven included studies (Agras *et al.*, 2014; LeGrange *et al.*, 2016; Goardart *et al.*, 2012; Herpetz-Dahlmann *et al.* 2014 and Hodsoll *et.al*. 2017) were rated as having a low risk of attrition bias due to clearly reporting the amount of missing data, reasons why it was missing and reporting that missing or excluded data were adequately handled through intention to treat analysis. Herscovici *et al.* (2017) was rated as high risk as no intention to treat analysis was reported for missing data. Eisler *et al.'*s (2016) study was given an unclear judgement of bias.

Selective reporting (reporting bias)

Two studies (LeGrange *et al.* 2016; Godart *et al.* 2012) were rated as having a high risk of reporting bias due to some outcome measures not being reported in the paper for each assessment timepoint (further details in appendix 1). The remainder of the sample (Agras *et al.* 2014; Eisler *et al.* 2016; Herscovici *et al.*, 2017; Herpetz-Dahlmann *et al.* 2014; Hodsoll *et.al*. 2017) were rated as low risk for reporting bias as these studies reported outcomes for both primary and secondary outcome measures and consequently reporting bias was deemed to be unlikely.

Other bias

Six studies were rated as high risk of other bias. Agras *et al. (*2014) paper was rated high risk due to sample size calculations not being conducted and five were deemed to be high risk due to no informant measures used to measure ED symptomology (Eisler *et al.* 2016; Godart *et al.* 2012; Hodsoll *et.al*. 2017; Herpetz-Dahlmann *et al.* 2014; Herscovici *et al.* 2017). LeGrange *et al.* (2016) was rated as low risk for other bias due to explicit reporting of a sample size calculation and the inclusion of informant measures in addition to weight and self-report measures.

Discussion

Summary of main findings

This review highlights that the evidence base for anorexia nervosa is developing, albeit slowly. Three studies compared effectiveness of family-based treatment (FBT) with other interventions or variations on FBT including FBT with a family meal versus FBT without a family meal (Herscovici *et al.* 2017), FBT versus systemic family therapy (Agras *et al.* 2014) and FBT versus parent-focused treatment (Le Grange *et al.* 2016). Other studies focused on alternative family therapies (FT); multi-family therapy versus single family therapy (Eisler *et al.* 2016) and multi-dimensional treatment as usual (TAU) versus TAU combined with family therapy (Godart *et al.* 2012). Hodsoll *et al.* (2017) compared outpatient FT (TAU) with TAU plus carer telephone guidance vs TAU carer support groups alone. In contrast, Hepetz-Dahlman *et al.* (2014) compared effectiveness of day patient multimodal MDT treatment with inpatient MDT treatment.

While NICE (2017) and Lock (2015) report that FT has the strongest evidence base supporting effectiveness in treating AN in young people, this may be due to FTs receiving increased attention in the recent literature as opposed to these treatments achieving impressive sustained remission rates. Surprisingly, given that CBT and AFT are recommended by NICE (2017) and the Matrix (2015), few recent RCTs investigating the effectiveness of CBT or AFT or those comparing the efficacy of these treatments to family therapy, were found.

Overall, the findings of the included studies highlight mixed results, with remission rates varying from 33% (Agras *et al.* 2014) for FBT to 80% (Herpetz-Dahlmann *et al.* 2014) for inpatient and outpatient multimodal treatments at end of treatment. While six of the seven included studies indicate increases in weight, primarily indicated by BMI, the highest proportion of participants showing an increase in BMI is emphasised by the research by Herpetz-Dahlmann *et al.* (2014). While Herpetz-Dahlmann *et al.* (2014) report that participants gained 3 BMI units in each treatment group by end of treatment, they define remission as having a BMI which falls above the 10th percentile. While this finding may sound promising, a BMI above the 10th percentile does not necessarily bring participants' BMIs into the normal range. Furthermore, almost 25% in both inpatient and outpatient treatment groups still fulfilled criteria for AN at follow up and 5 patients developed BN, 1 developed BED at follow up. Therefore, of all eight included studies, the study which reports the best outcome should be interpreted with caution.

Furthermore, the sources of bias found in the included studies call into question the quality of the evidence. Looking at the risk of bias profiles across the included studies in Figure 1, these rates vary

from high to relatively low across the included studies, with just two studies demonstrating a reasonable risk of bias profile, those by LeGrange *et al.* (2016) and Hodsoll *et al.* (2017). Taking these two studies with the strongest quality ratings, findings remain unremarkable. Hodsoll *et al.*'s (2017) findings suggest that at follow up, the addition of the ECHO carers group has a minor advantage on BMI and fewer hospital admissions compared to treatment as usual. However, the effect size for BMI increase is small and most outcome measures focused on carer wellbeing rather than the patients' ED symptoms. Similarly, findings from LeGrange *et al.* (2016) indicate that parent-focused therapy was more efficacious than FBT in remitting adolescents with AN, with a 3-fold increase in the odds of remission for those who received PFT. However, differences in remission rates were insignificant at follow up and patients appear to be almost back to where they started regardless of whether they received parent-focused therapy or FBT interventions at 12 months post-treatment. Consequently, while these papers demonstrate moderate quality in terms of risk of bias, the results at follow up are unremarkable.

The combination of varying remission rates, unremarkable results at follow up and the varying risk of bias profiles across the included studies, reinforces Lock's (2015) assertion that the psychological treatments of adolescent anorexia requires further study with more rigorous research methods employed. In conclusion while it appears that there has been an increase in research into psychological treatment of adolescent AN, the quality of the research continues to require further attention.

Methodological Limitations and Quality Issues

The findings of the included studies are further limited by methodological issues. Firstly, the studies varied significantly in sample size with some samples employing as few as 23 participants.

Furthermore, few studies reported a sample size calculation or effect sizes. Samples were predominantly white females living in high income countries. Therefore, generalizability of results is limited. Further research is required with larger samples and the inclusion of male participants and varied ethnicities to identify if these demographic factors impact on findings. Additionally, given the differences in healthcare systems across these countries such as public versus private models of care in the UK and US respectively, popularity of the medical versus psychological treatments across these countries, accessibility to and cultural beliefs about psychological treatment and eating disorders, it is important that the potential impact of these factors on the results of the included studies is considered. For example, given family-based treatment consists of 15-20 sessions, it may be difficult to recruit participants and patients for such a treatment within a fee-for-service health system due to significant financial cost to patients and families. This may increase the likelihood of

primarily middle-class families engaging in this treatment and in RCTs within countries such as the USA. Consequently, samples may not be representative of the wider public and results must be interpreted with caution. Furthermore, families from a diversity of classes and income brackets may be more likely to engage in FBT in the UK and France where medical treatment does not involve a cost to the patient or is subsidised by government funds. Therefore, drawing overall comparisons between studies conducted across a diversity of healthcare systems is challenging.

While some studies' objectives were to directly compare effectiveness of two psychological treatments, others compared treatment settings and formats of delivery. Variation was also observed in attrition rates, inclusion criteria and follow up data. Consequently, drawing comparisons across the included studies findings was not straightforward.

Significant variation in outcome measures was observed. This finding is in line with Alckmin-Carvalho *et al.* (2018) who found similar diversity in outcome measures across RCTs and proposes that standardization of measures between research sites would facilitate easier comparison of results. This review supports strongly this proposal. A further issue with outcome measures was the focus on self-report measures. Anorexia is an illness which is characterised by secrecy and concealment. Consequently the findings based primarily on self-report measures are subject to response bias and may not reflect accurate results. Incorporating informant measures to corroborate self-reports is suggested. This is likely to be more straightforward for adolescent samples given parents are often involved in treatment.

Furthermore, the results of these studies should be interpreted in light of their quality as appraised by the CRoB. Quality appraisal of these studies highlighted variation in bias across the CRoB's seven domains. Six studies were rated as having a high risk of performance bias and other bias (primarily response bias). Three studies were rated as having a high risk of allocation bias while another three studies were rated as having an unclear risk of bias. These findings should be interpreted with caution considering the practicalities of blinding patients and therapists engaging in interventions for AN. It is impractical to blind participants and therapists to whether patients are receiving family-based treatment versus individual treatment, or to blind them to multi-family versus single family treatment. Regarding response bias, this was due to the use of self-report measures as outlined above.

Six studied were rated as having low risk of selection bias. Five studies were rated as having a low risk of attrition and reporting bias. Although attrition rates varied across studies, data was handled adequately through intention to treat analysis.

Relevant Implications

While family therapy appears to have received more attention in the literature on adolescent AN, it is not appropriate for all patients. Consequently, it is recommended that future research focus on effectiveness of AFT and CBT interventions, which are also recommended by NICE (2017) and the Matrix (2015), or efficacy of family therapy in comparison with these treatments.

Considering the varied family interventions investigated in the included studies, there is value in further investigation into the psychological mechanisms of change that reduce ED symptoms such as exposure, self-efficacy, reducing perfectionism, improving interpersonal relationships, development of adaptive coping strategies and reducing body over-evaluation. With further focus on this, effective mechanisms of change could potentially be incorporated into different formats of family therapy and tailored to family and patient need.

Lastly, wherever possible, future research investigating AN treatment should clearly outline methods used to blind participants and personnel before and after treatment allocation and report how blinding is maintained. If double blinding is impractical within future research this should be highlighted and the likelihood of this influencing the results of the RCT should be discussed.

Limitations

As this review focused on RCTs, clinical trials and non-randomised controlled trials which may contribute to the evidence base for psychological treatments of AN in young people were excluded.

Although a well-established quality appraisal tool was employed to evaluate the quality of the included studies the CRoB features its own limitations. Jørgensen *et al.* (2016) highlights its choice of domains as a limitation as it excludes a domain related to conflict of interest. Additionally, Jørgensen *et al.* (2016) highlight that at least one risk of bias domain is judged as "unclear" by almost 90% of researchers using this tool. This suggests that criteria for judging risk of bias may need to be revised.

Inter-rater reliability was achieved for three papers due to time constraints encountered in this project. It is preferable that two coders are used when using the CRoB tool. While the CRoB is considered a transparent quality appraisal tool, it's ratings could be viewed as subjective. Consequently, a limitation to this review is that two coders were not used for appraising the entire sample. A final limitation was that the database searching, screening of articles and data extraction were conducted by one person. The addition of a second researcher at these stages of the research process would further increase reliability.

Conclusions

This review emphasises that while the evidence base for psychological treatments of adolescent AN continues to develop, it remains limited in comparison with other mental health issues. While family-based interventions appear to be relatively effective, remission rates are variable, follow up data is limited, and sample sizes vary greatly. Measures of ED symptomology are primarily self-reports. Furthermore, heterogeneity in outcome measures and limited results on remission at follow up points across the studies made drawing meaningful conclusions challenging.

Quality appraisal of these studies highlighted variation in bias across the CRoB's seven domains. Domains of high risk and low risk were discussed in reference to eating disorders literature. Further RCTs on treatment effectiveness and efficacy are required to strengthen the existing evidence base. Pilot and feasibility studies are needed to assess effectiveness of emerging treatments for AN. Additionally, prioritisation of an agreed subset of outcome measures would increase comparability across future RCTs and inclusion of informant measures may limit response bias.

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Appendix A:

COCHRANE RISK OF BIAS TABLE

Study	Domain of bias	Risk Level	Support for Judgement
Agras *et al.* (2014)	Random sequence generation	Low	Reference to computer-generated program to randomize participants.
	Allocation concealment	Unclear	Not enough information to permit judgement. No mention of how allocation was concealed or maintained.
	Blinding of participants and personnel	High	Assessors blinded to treatment allocation. No mention of participants and research staff being blinded to intervention allocation or how blinding of assessors was maintained. Blinding viewed as incomplete by review author.
	Blinding of outcome assessment	Unclear	Explicit statement that assessors were blinded to treatment outcomes. Not enough information to judge if blinding was likely effective or not.
	Incomplete outcome data addressed	Low	26% withdrew from FBT (n = 20) and 25% (n = 20) withdrew from SyFT. Reasons clearly outlined. Handling of incomplete data was sufficient and unlikely to have produced bias. Reasons for missing data provided and unlikely to be related to true outcome.
	Selective reporting	Low	Results clearly reported for all outcome measures.
	Other bias	High	Effect sizes reported for all measures, exclusion criteria identified, objective clearly reported. Inclusion of informant measure as well as self-report measures. No report of sample size calculation.
Eisler *et.al.* (2016)	Random sequence generation	Low	Blocked randomisation of patients to two treatment arms was conducted using a computer random number generator.
	Allocation concealment	High	Patients were allocated to treatment groups using a randomisation database. The paper explicitly states that research workers carrying out the assessments were blind to the allocation but does not state if

			participants were blinded suggesting study was a single blind study.
	Blinding of participants and personnel	High	Explicit statement that the trial co-ordinator informed each therapist assigned to cases about allocation of treatment. Likely to result in performance bias.
	Blinding of outcome assessment	Low	The article explicitly states that independent assessors who completed assessment measures at were blinded to the allocation of treatment groups.
	Incomplete outcome data addressed	Unclear	Paper reports little attrition regarding the primary outcomes at EOT and FU. Loss to follow-up was considerably higher than expected attrition rate of 10% for secondary outcome measures (53% missing) and baseline characteristics predicted missingness. As attrition rate varied significantly for primary and outcome measures, risk of attrition bias is unclear.
	Selective reporting	Low	Results were reported for all measures that were outlined in the paper.
	Other bias	Low	Objective, inclusion criteria, primary outcome measures specified, sample size calculated, main effects reported. Sample mostly female. Primary measure is weight gain and self-report and informant measure of psychopathology symptoms.
Godart *et al.* (2012)	Random sequence generation	Low	Block randomisation performed using SPSS randomisation program.
	Allocation concealment	High	Allocation issued to participants in a sealed envelope by the psychiatrists who then enrolled patients and assigned them to the intervention group. Allocation concealed for participants, not research staff.
	Blinding of participants and personnel	High	Neither therapists nor participants were blinded.
	Blinding of outcome assessment	Unclear	Paper reports evaluators were blinded, unclear as the whether blinding was likely effective or not.
	Incomplete outcome data addressed	Low	Missing data appropriately handled using intention to treat and per-protocol analysis.

	Selective reporting	High	No outcome data reported for MINI measure.
	Other bias	High	Aims clear, inclusion criteria clear, sample size calculation completed a priori. No outcome measures for EOT. Primary measures weight measure and self-report measure of ED symptoms.
Herpetz-Dahlmann *et al.* (2014)	Random sequence generation	Low	Computer-generated randomized sequence used for randomising participants to groups.
	Allocation concealment	Unclear	Not sufficient information to identify method of allocation sequence concealment.
	Blinding of participants and personnel	High	Paper reported that patients and therapists were not masked to treatment allocation.
	Blinding of outcome assessment	High	Independent assessors took all outcome assessments. Assessors were initially masked to treatment allocation however, this was not maintained. Masking was maintained for the primary measure, BMI.
	Incomplete outcome data addressed	Low	Attrition rate at EOT was relatively low (6%). Adverse events reported for each group (8 in inpatient, 7 in day-patient group). Missing data appropriately handled with intention to treat analysis which indicated that the study was not biased by non-adherence.
	Selective reporting	Low	All primary and secondary outcomes measures reported on.
	Other bias	High	Clear inclusion criteria, objective, sample size calculation based on 30% attrition, power calculation also calculated. No informant measures used to assess ED symptomology.
Herscovici *et al.* (2017)	Random sequence generation	Unclear	No mention of how participants were randomised. Insufficient detail reported regarding random sequence generation to make judgment.
	Allocation concealment	Unclear	Methods of allocation concealment not outlined in article.
	Blinding of participants and personnel	Unclear	Unclear if participants and personnel were blinded.
	Blinding of outcome assessment	Unclear	No mention of who assessor was or if they were blinded.

	Incomplete outcome data addressed	High	2 participants' data missing at FU. Given the sample size is so limited, this is likely to introduce bias.
	Selective reporting	Low	Results for each outcome measure provided at EOT and FU.
	Other bias	High	Refers reader to supporting information section for further information on method and results but this is not available in published paper. Outcome measures are weight gain measure and self-report measures, likely to incorporate bias.
Holdsoll et. al. (2017)	Random sequence generation	Low	Stratified randomization by study site, illness severity and type of service. Randomisation was conducted using the King's Clinical Trials Unit's independent web-based system.
	Allocation concealment	Low	Separately published protocol states the two lead researchers were responsible for managing the randomisation of a selection of the participating sites. Each researcher was blind to the group allocation of those managed by the other. Participants blinded also. Unlikely to result in selection bias.
	Blinding of participants and personnel	High	Protocol states this was a single blind study. Researchers blinded to allocation. Participants not blinded. Awareness of which treatment group is likely to contribute to performance bias.
	Blinding of outcome assessment	Low	Study protocol states that outcome measures assessed so that researchers will only conduct interviews with those for whom they are blind to treatment allocation.
	Incomplete outcome data addressed	Low	Significant level of missing data and clearly reported. Missing data appear to be handled appropriately. Predictors of missingness were included in multiple imputation, which allowed for a missing data generating process whereby identified baseline variables and treatment completion could drive missingness.
	Selective reporting	Low	All outcome measures reported on for each timepoint.

	Other bias	High	Inclusion and aims clearly outlined. No report of sample size calculation, however as this was a pilot RCT it did not seek to detect statistically significant differences between groups. Outcome measures were weight measure, self report and carer measures. Carer measures focused on carer wellbeing not informant measures for ED symptoms.
LeGrange *et al.* (2016)	Random sequence generation	Low	Participants were randomized to treatment groups using a randomization schedule developed by off-site statistician stratifying ED by severity.
	Allocation concealment	High	Researchers emailed participant info number and severity category to independent personnel managing randomization schedule. Researchers received allocation by email and therefore not blinded.
	Blinding of participants and personnel	High	Staff independent of the study allocated participants to treatment groups using randomization schedule prior to treatment. However, researchers, treating clinicians and patients were aware group allocation.
	Blinding of outcome assessment	Low	Independent assessors not involved in treatment administered all outcome measures.
	Incomplete outcome data addressed	Low	84.9% completed treatment. Rates of assessment completion for primary outcomes, were 88.7% at EOT, 69.8% at 6 month follow up and 58.5% at 12 month follow up. Adequate investigation and handling of dropouts was reported. Missing data addressed through multiple imputation analysis based on fully Markov chain Monte Carlo. Handling of data unlikely to have produced bias.
	Selective reporting	High	Results not reported for following secondary measures; Mini-Kid, SCl-90-R, HRQ, PVA, PANAS X, BPQ, FES.
	Other bias	Low	Objective, inclusion criteria, primary outcome measures all clearly specified and sample size calculated.

			Inclusion of informant measures and self-report measures.

CHAPTER 2: MAJOR RESEARCH PROJECT

Family-based Treatment for Young People's Eating Disorders: An Interpretative Phenomenological Analysis of Parental Perspectives.

Word count: 9,726 (including quotes and references)

Prepared in accordance with guidelines for submission to the European Eating Disorders Review (Appendix 1)

Plain English Summary

Title

Family-based Treatment for Young People's Eating Disorders: An Interpretative Phenomenological Analysis of Parental Perspectives.

Background

Family-based treatment (FBT) is community-based intervention for anorexia and bulimia nervosa. It offers an alternative to hospitalisation that is less disruptive to the young person's life. FBT involves parents playing an active role in refeeding their child to restore them to a healthy weight. Few studies have explored parental perspectives of FBT and how they cope with the responsibility this treatment places on them. Similarly, there is little research into the challenges that parents face and their support needs while engaging in FBT. Given parents play such an active role in this treatment and that few studies have explored their perspectives, it was felt that an exploration into parental experiences of FBT was worthy of investigation.

Aims & Questions

The overarching aim of this study was to explore the experience of parents engaging in FBT for their child's eating disorder. A further aim was to explore the psychological and social impact this has on parents' identities, wellbeing, relationships and their engagement in treatment.

Methods

This study was a qualitative, interview study and therefore focuses on non-numeric data. Participants were parents (n = 9) who engaged in FBT for their child's eating disorder. Participants were initially approached by clinicians who were known to them. Two fathers and seven mothers of eight children took part in semi-structured interviews that were audio recorded, transcribed and analysed verbatim.

Analysis

Interview transcripts were analysed using interpretative phenomenological analysis (IPA). IPA is a qualitative research method which aims to gain insight into how a person makes sense of a given experience in a context. IPA involves the participants making sense of their experiences and the researcher interpreting their account of their experiences. This involves reading and rereading the interview transcripts, taking initial notes, developing emergent themes, moving to the next case and looking for patterns across cases.

Results

Four main themes were identified across the nine parents' accounts: 1) Parenting Challenges; this theme explored difficulties that parents experienced when engaging with FBT, 2) Impact on Family Life; this theme focused on how life was at home for family members when the young person was receiving FBT, 3) Coping explored the different strategies and mechanisms parents drew on to survive the demanding task of intervening with their child's eating disorder, 4) Support explored parents views of the FBT support available to them and their recommendations for service improvements.

Conclusions

The results of this study helped increase understandings of the lived experiences of parents who engaged in FBT for their son/daughters' eating disorder. Recommendations to improve clinical practice and increase supports for other families engaging in this treatment are discussed.

ABSTRACT

Objective

Family Based Treatment (FBT) is an effective, evidence-based treatment for adolescent anorexia and bulimia nervosa. However, it relies heavily on parents taking a very active intervention role. Few studies have explored the psychosocial impact FBT has on parents, the challenges they face, and their support needs.

Aims

1. To gain a rich understanding into the lived experience of parents engaging in FBT for adolescent anorexia or bulimia nervosa.
2. To explore the psychosocial impact on parents and to identify their support needs.
3. To tentatively inform clinical practice on how support for parents could be improved.

Methods

This was a qualitative, interview study. Participants were approached by clinicians known to them and took part in a predominantly one-to-one, semi-structured interviews. Interviews transcripts were analysed using interpretative phenomenological analysis.

Results

Four superordinate themes were identified: Parenting Challenges, Impact on Family Life, Coping and Support. Findings suggest that views on empowerment varied significantly and that FBTs agnostic stance exacerbates parental guilt and anxiety. The financial cost of re-feeding was strongly felt by parents and psychoeducation resources could be tailored to individual families' needs.

Conclusion

Participants' accounts were dominated by experiences of needing reassurance and practical advice from clinicians to empower them in taking control of their child's eating. Implications for clinical practice and future research are discussed.

Keywords; Family-based therapy; FBT; interpretative phenomenological analysis; IPA; parental perspective

INTRODUCTION

Overview of Family-based Treatment for Adolescent Eating Disorders

Family-based treatment (FBT) for anorexia nervosa (AN) offers a less disruptive community-based, alternative intervention to hospital admissions for young people. It is an intensive treatment which views parents as key agents of change (Rienecke, 2017).

FBT is characterised by fewer in-patient hospital admissions, faster rates of remission and weight restoration and lower rates of relapse in comparison to treatment as usual controls (LeGrange & Lock, 2011). These outcomes are largely maintained at a five year follow up. Consequently, both the Matrix (2015) and NICE (2017) recommend FBT as a first line treatment for young people with AN or BN of three years duration or less.

FBT usually consists of 15-20 sessions over the course of one year (LeGrange & Lock, 2011). It comprises three distinct phases outlined in Table 1.

Table 1 Phases of FBT

Phase	Characteristics
1. Refeeding/Weight Restoration	• Parents actively re-feed child to rapidly restore them to a healthy weight (LeGrange & Lock, 2011). • Parents take control over child's eating, temporarily removing choice over food, monitoring food intake and exercise levels (Rienecke, 2017).
2. Returning control over eating to adolescent	• Control of eating gradually returned to young person (Lock and LeGrange, 2013) when they accept parental views on increased food intake and weight re-gain (Rienecke, 2017). • Continued focus on eating disorder (ED) symptoms. • Discussion of family relationship and parenting issues also incorporated into therapy sessions (Rienecke, 2017).
3. Establsihing healthy adolescent identity	• Begins when the young person can independently maintain a weight above 95% of ideal weight (Lock and LeGrange, 2013).

	• Focus is on impact of ED on young person's identity (LeGrange and Lock, 2011), ensuring normal family life has returned and relalpse prevention (Rienecke, 2017).

Key principles of the FBT approach

FBT takes an agnostic and non-blaming view of the ED. Focus is on treatment and weight restoration rather than identifying the aetiology (Lock & LeGrange, 2013). A family meal where the family brings a meal to the therapists' clinic is a feature of FBT. FBT views the family meal as empowering for parents as it demonstrates to parents that with support, they can encourage their child to eat more than they would otherwise (Rienecke, 2017). A further principle is that the ED is externalised from the child. Parents are tasked with fighting the illness rather than fighting against their child (Lock and LeGrange, 2013).

FBT requires clinicians to take a non-authoritarian stance (Rienecke, 2017) and serve as an expert consultant to families. While they take an active role in guiding families towards recovery (Rienecke, 2017), FBT recognises that parents are experts on their family. Although responsibility for refeeding lies with parents, most decisions are left up to parents and no definitive plan for how to refeed the young person is provided (Rienecke, 2017). Empowerment is an important feature of this approach. Parents are viewed as a strong resource for bringing about recovery and are thought to possess the necessary skills to refeed their child to a healthy weight. The therapist's role is to enhance these parental skills. Parental confidence in responding to their child and the ED is needed for this intervention to be successful (Rienecke, 2017). Lastly, FBT is a pragmatic approach. It's emphasis is on symptom reduction and restoring the child to a healthy weight (Lock and LeGrange, 2013). Comorbidities such as anxiety and depression are not discussed within phase one as it is proposed that when the child returns to a healthy weight some of these associated difficulties will be alleviated (Rienecke, 2017).

Literature on Parental Perspectives

Fox, Dean and Whittlesea's (2017) meta-analysis on the impact of ED on family carers highlighted a major negative impact on family members and that family caregiver needs are often unmet. While the research into caring for a loved one with an ED is still developing, there appears to be a lack of qualitative research exploring the experience of families engaging specifically in FBT.

A randomised control trial by Allan, LeGrange, Sawyer *et al.* (2017) found that adolescents of mothers who remained high in expressed emotion (EE), were less likely to remit compared with adolescents for whom EE decreased or remained low. These results emphasise the importance of considering EE and family dynamics when implementing FBT for adolescents with anorexia nervosa.

These studies indicate that family dynamics and communication styles are likely to impact on outcomes of treatment. Despite this, most qualitative FBT research focuses on clinicians' experiences of and perceptions of FBT. For example, Dimitropoulos, Freeman, Lock and LeGrange (2017) explored clinicians' views of what principles of FBT are most effective. Parental empowerment was cited as the most effective and clinicians highlighted that adolescent, parental and family factors could hinder or enhance parental empowerment. Dimitropoulos *et al.* (2017) propose that future research should focus on addressing barriers to parental empowerment.

Conti *et al.'s* (2017) in-depth case study focused on a family who disengaged from FBT. Results suggest that initially the patient found it comforting to pass the responsibility for eating to her family and that this restored a sense of control within the family (Conti *et al.* 2017). However, these results were not maintained and the family reported feeling disabled by the FBT approach. This study highlights the importance of identifying barriers to FBT treatment and progression within treatment.

Justification for the Research

While previous research demonstrates that FBT is an effective intervention for AN and BN in adolescents, it has highlighted a need to explore parental perspectives to address barriers to engagement, treatment adherence and parental support needs. Furthermore, the lived experience of parents engaging in FBT is worthy of investigation given the negative impact of the caregiver role on family members and the very active role that parents play in this intervention.

Given that the nature of parents' experiences of FBT is poorly understood, complex and sensitive an interpretative phenomenological analysis was used. No IPA study has previously explored the psycho-social impact FBT has on parents, the impact on wider intrafamily dynamics, parents' support needs and the challenges and barriers that families face.

Applications

Given the key role of parents in FBT refeeding (LeGrange, 2005) there is value in gaining a better understanding of intrafamily dynamics and the psychosocial impact of FBT on parents.

Aims and Hypotheses

The overarching research question was:

"What are parental experiences of engaging in FBT for adolescent EDs?"

Aims:

1. To gain a rich and detailed understanding of parents' lived experiences of engaging in FBT for their child's ED.
2. To explore the psychosocial impact of the parental role in engaging in FBT for a young person's ED.
3. To draw conclusions from the research which may highlight some tentative implications for support services for families engaged in this treatment.

METHODS

Design

This study employed a qualitative design with semi-structured interviews, analysed using interpretative phenomenological analysis (IPA).

IPA aims to explore participants' experiences of their social and personal world and the meanings that they attach to these experiences (Smith 2004). IPA recognises the chain of connections between what people say, think and their emotional state and acknowledges the influence that the researcher has on the analysis of the data due to his/her own conceptions (Smith & Osborn, 2008). Data analysis is a two-stage process with the participant making sense of their reality while the researcher makes sense of the participant making sense of their reality.

While other qualitative approaches were considered for this study, it was felt that an IPA methodology best fit with the research question and the aims of this study. Given parents' lived experiences of engaging in FBT is an under-researched and poorly understood concept, an inductive approach was required to acquire depth of information on participants' perspectives (Smith 1996; Smith & Osborn 2008). As this study aimed to generate a rich insight into parents' idiographic experiences of engaging in FBT rather than to develop theory, IPA was a more suitable approach than grounded theory. Finally, it was felt that IPA could add more to the research base by exploring the idiographic experience of parents who have engaged in FBT, gaining a rich insight from participants themselves and linking cognition and language to explore how participants make sense of this experience.

Ethical Approval

Ethical approval was obtained through the West of Scotland Ethics Committee (REC) (Appendix 3) and NHS Lanarkshire (ref: L18063) and NHS Greater Glasgow and Clyde Research and Development Departments (ref: GN18MH589).

Recruitment Procedures and Sampling

Recruitment

FBT clinicians were approached in June 2018 via the West of Scotland FBT Working Group and briefed on the research and inclusion criteria (see Table 2).

Table 2 Inclusion and exclusion criteria for the present study

Inclusion Criteria	Exclusion Criteria
Aged 16 or over	Non-English speaking
Parental figure or primary caregiver to a young person referred for FBT with anorexia (AN) or bulimia nervosa (BN).	Parental figures identified by clinicians as unsuitable due to medium to high levels of suicide risk or adult/child protection concerns.
Engaged in a minimum of 5 sessions of FBT for young persons' AN or BN or, previously engaged in FBT for AN or BN within 18 months of participating in the study.	Siblings and extended family members who do not take a parental role in the life of the young person engaged in FBT.

Once ethical approval was granted in February 2019, FBT clinicians across two West of Scotland health boards were supplied with information packs and asked to identify potential participants who met the inclusion criteria from their current and previous caseloads. These included:

- A letter of introduction from the FBT clinician
- Participant information sheet (Appendix 4)
- An opt in/out form (Appendix 6)
- Stamped, addressed envelope
- Information on GDPR and information storage

Clinicians who were providing or previously provided FBT to potential participants were asked to post information packs to families who were identified as meeting the inclusion criteria. Parents/carers were asked to complete the opt in/out slip and return to the researcher by post, stating whether they wished to take part in the study. Participants who opted in were telephoned by the researcher to arrange a research interview.

Sampling

In line with the IPA methodology, a purposive sampling method was employed. The focus on the IPA methodology is on depth of data rather than breadth. As large amounts of data are generated for

each participant, fewer participants are required to examine the commonalities and idiographic differences between participants' accounts. Smith *et al*. (2009) recommend a sample size of 6-10 participants for IPA research. Consequently, the target sample was 8-10 and the study recruited to target (n=9).

Sample Characteristics

Fifty information packs were sent to potential participants and 9 participants (two fathers and seven mothers) of young people with AN or BN completed research interviews. Seven participants were interviewed individually, and one couple were interviewed together. Further demographic information about each participant and the young person with an ED is presented in Table 3 to contextualise the lived experiences of each participant.

Table 3 Participants' demographic information and the young person with an ED.

Pseudonym	Melissa	Emer	Jason	Pauline	Anna	Tracy	Joanna	Simon	Christine
Gender	Female	Female	Male	Female	Female	Female	Female	Male	Female
Ethnicity	White Scottish	British	White British	Scottish	White British	White Scottish	Scottish	White Scottish	White Scottish
Age	40	46	61	52	53	44	56	54	48
Marital Status	Married	Divorced	Separated	Married	Married	Single	Married	Married	Married
Relationship to Young Person with ED*	Mother	Mother	Father	Mother	Mother	Mother	Mother	Father	Mother
Phase of FBT when interview was conducted	Completed Treatment	Completed Phase 1, (moving into phase 2)	Phase 3	Completed Treatment	Phase 3	Phase 3	Phase 3	Completed phase 2	
Age of Young person at outset of FBT	9	12	17	18	17	14	15	16	
Young Persons' Diagnosis	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	Anorexia Nervosa	

*Eating Disorder

Procedure and Interview

Interview Schedule

The interview schedule (Appendix 7) was developed from a review of the literature on parental experiences of EDs and FBT in line with the aims of this study. A draft schedule was initially developed with the supervisory team. Questions focused on participants' feelings, thoughts and their behaviour in response to FBT treatment, the challenges they encountered, support needs and how FBT impacted parents' lives, plans for the future and, sense of self. This draft was disseminated to the West of Scotland FBT Working Group and Dr Charlotte Oakley, an expert in the EDs field. The interview schedule was subsequently revised based on their feedback and recommendations.

Interview Protocol

Interviews were conducted in person, by the primary researcher at NHS health centres between March and May 2019. The researcher briefed participants on the aims of the research and what participation would entail. Written consent (Appendix 5) was obtained from each participant and they were given the opportunity to ask questions before taking part. Participants were assured that participation was confidential and voluntary. Participants were reminded that they could withdraw from the study at any time, that they could pause the interview at any time and that they could decline to answer any questions within the interview.

Each semi-structured interview was audio-recorded and transcribed verbatim by the researcher. Each participant and their child were assigned a pseudonym during the transcription process to protect their anonymity. Participants were provided with debriefing sheets (Appendix 9) which provided the email address of the primary researcher and included contact details for helplines in case they felt upset after discussing their child's ED within the interview.

Data Analysis

Interview transcripts were analysed using IPA. Analysis adhered to the steps outlined by Smith, Flowers and Larkin (2009): 1. reading and rereading the interview transcripts; 2. taking initial notes; 3. developing emergent themes, moving to the next case and then looking for patterns across cases (Smith, Flowers and Larkin, 2009). Throughout the transcribed text, comments such as summaries, associations and preliminary interpretations were written in the left-hand margin of each transcript (Appendix 8). On rereading the transcript, emerging themes were inserted on the right-hand margin. An initial list of themes within each transcript was compiled and similar themes were clustered to develop a coding tree. Superordinate themes and subthemes were the result of the interaction

between the researcher's interpretation of the interviewee's experiences and the interviewee's personal experiences described in their own words (Eatough, Smith & Shaw, 2008).

Researcher Reflexivity and Credibility

This study was conducted and subsequently reported in line with the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong & Craig, 2007). In line with these principles, reflexivity was engaged in throughout the research process. Reflexivity is defined as the process where a researcher "engages in self-aware meta-analysis" (Finaly, 2002, p.209) to ensure integrity and trustworthiness of research. Consequently, characteristics about the researcher and her own preconceptions and biases regarding the phenomenon of interest are outlined.

The primary researcher is a female, trainee clinical psychologist, experienced in the use of the IPA methodology. Prior to contacting potential participants who had opted in to the study, she had no relationship with them. Throughout engagement with the extant literature, data collection and interpretation, the researcher maintained a reflexive diary. This allowed for identification of her own motivations, values and biases as new understandings emerged, through ongoing introspection. The researcher acknowledges that prior to commencing this research, she felt positively about FBT's use of the family as a strong resource and how it offers an alternative to hospitalisation. The researcher's awareness of the responsibility FBT places on parents increased throughout the data collection and analysis process.

Furthermore, credibility checks were employed to ensure credibility of the primary researcher's themes. Both the primary researcher and a member of the supervisory team with expertise in qualitative methods, analysed and coded 3 interview transcripts separately. Inter-rater reliability was gained through comparing these separate analyses and resulting themes and subsequent negotiation between the two researchers through discussion.

RESULTS

Four super-ordinate themes were identified: 1) *Parenting Challenges,* 2) *Impact on Family Life,* 3) *Coping* and 4) *Support*. Table 3 depicts an overview of the distribution of these superordinate themes and related sub-themes. These themes outline in detail with quotations to provide depth to the participants lived experiences.

Within the *Coping* superordinate theme, two further subthemes were identified; *Suppressing own needs* and *Respite*. As these themes are consistent with well-established findings in the wider caregiver literature they are outlined in Appendix 10.

Table 4 Superordinate themes and related subthemes

Superordinate Theme	Subthemes
1. Parenting Challenges	Self-blame
	Regression and parenting style
	Mixed feelings on empowerment
2. Impact on Family Life	An all-consuming task
	Impact on family relationships
	Financial cost
3. Coping	Externalizing eating disorder from young person
	Increasing understanding of eating disorders
4. Views on Support	Experiences of FBT
	Recommendations for support services

PARENTING CHALLENGES

Self-blame: *"wow, why have we missed this?"*:

Most parents reported a strong sense of guilt and reported that they blamed themselves for not identifying that their child had developed an ED earlier. This was best captured by Pauline:

> *"I did feel really guilty and I still feel guilty that I missed it. Not that I missed it, 'cos I knew there was wee things, but I thought, why didn't I catch it earlier? Especially when I caught him weighing his food. I thought, that's a sign for me to have intervened with him."* (Pauline)

For Melissa and Christine the lack of emphasis FBT places on identifying the underlying cause of the ED exacerbated their sense of self-blame:

> *"Yeah I mean even if it's because of us, you know, I'd like to know that we-- 'Cause I've blamed myself. I thought if I had done this to my child. You know?.. I think it's about if it was down to me, if it was my fault, then I could change the way I was you know uh huh."* (Christine)

For Melissa whose daughter was aged nine when she began treatment, not establishing the cause exacerbated anxiety and maintained concerns that she would be unable to prevent a relapse particularly in her daughter's adolescence:

> *"I really expected them to try and find the cause of the problem. And I was really told time and time again that you know, that that wasn't their focus and that they really wanted to just that the weight gain was important thing… I think there is a point in looking into them"* (Melissa)

Parenting Style and Regression: *"it's like when you've got a new baby"*

Parents reported feeling that they were responding to the needs of a much younger child:

> *"I mean it was like actually going back to this supervision you need with a newborn baby."* (Melissa)

Anna, Emer and Melissa found this experience comparable to when they had newborns, toddlers and young children. Similarly, Emer and Christine described the high level of care their teenage daughters required during this period:

> ***"****Her hands were literally shaking and you having to actually grab her hand and sort of help her to eat. That was a very, very, very tough thing to do."* (Emer)

Styles of parenting were also impacted by FBT. While Emer reported FBT required a firmer style of parenting:

> *"it just made you harder as a parent..you've got to be.."* (Emer)

Simon reported that ensuring his daughter ate required him to change his style of parenting significantly:

> *"And you need to treat your child like a two-year-old, like that, for months until you break the anorexia…it's like you have re-discipline your child to make sure she eats. And if she refuses it, then you have to be- you have to be a bit like a prison warder- warden, you have to be so strict."* (Simon)

While it was felt that this parenting style was necessary for effective treatment of the ED he stated that this was a significant change from Simon's previous parenting style:

> *"from being a loving, comforting father and mother to somebody who she hates"* (Simon)

A strong sense of commitment to restoring the child to good health was evident across all accounts, despite the challenges parents experienced along the way. Christine's quote below best demonstrates this:

> *"She couldn't bathe herself, so I had to bathe her again, so 15, 16.. It's not something that you think you're gonna do, but it's your child, you do it, you know? What-what other option is there?"* (Christine)

Mixed Feelings on Empowerment: *"I don't know that I'd ever felt empowered"*

Parents seemed to vary in their views of FBT providing a sense of empowerment in taking control of their child's eating. Emer, Pauline and Jason denied feeling that FBT felt empowering:

> *"No, it didn't feel it was empowering. You know, it was difficult, but not empowering. I just thought it was like a job that you had to do. When I say a job, I don't mean it was like any kind of burden or task, it was just something that had to be done. It's just taking the advice of the ED service."* (Jason)

> *"Em no, not really [empowering]. I didn't feel it should all be down to the parents, you know that parents should have to do that, and do this."* (Pauline)

Tracy reported that FBT leaves parents with a combined sense of pressure and empowerment:

"I think it's a mixture of both. I think you always feel a sense of responsibility because it's your kid so I don't think it matters what age they are or where they have to be…I think what we did was, it was easier just to try and plan everything all out." (Tracy)

Having a meal plan appeared to increase Tracy's confidence and sense of empowerment in tackling the ED. Meanwhile, both Jason and Emer reported that reassurance and practical advice from the FBT clinician helped them to feel more confident and empowered in taking control of refeeding:

"Yes, and more comfortable, yes confident as well and you knew what you had to actually do for that whole week… And actually, wakening me up to things as well. Like with anorexic voice and stuff." (Emer)

It appears the knowledge of eating disorders and directive, practical advice gave Emer the confidence in her abilities to fight her daughter's anorexia. In line with Tracy, Melissa appeared to feel both confident and pressurised:

"I felt that nobody else could do it. And I think that was because what I was being told….they did make me realise the thing that I was saying about not giving up. And some of maybe the techniques that I could use... But there wasn't really much else that I was given. So yeah (sighs) so I don't know like I don't know that I'd ever felt empowered. I felt really quiet, I don't know, like it was failing a lot of the time to be honest." (Melissa)

Again, perceptions around levels of support, guidance and advice from clinicians appears to be a crucial factor influencing parents' feelings of pressure, empowerment and confidence in tackling their child's ED. This is supported by Christine's view:

"How can we treat something that we've got no understanding of? How can we possibly deal without that?" (Christine)

For Joanna, she felt empowered at times when she felt in control and that her efforts were effective, however, when her son did not respond to refeeding she felt demoralised:

"I felt empowered because you will sit there and we'll have a meal and you will try and eat as much as you possibly can… I did feel empowered. But I just felt sometimes like, "Aw, it's just like I'm trying to do things and then I'm working really hard and doing this and then it's not working." (Joanna)

Conversely, Anna reported feeling significantly empowered by the process of FBT. Learning more about FBT and anorexia appeared to be a significant factor in her sense of empowerment:

"If you told me today that that's what we were going to do in the next six months, I'd have said, "Not a chance." (laughs). When you're faced with it, something helps, something empowers you. I know I keep going on about it, but I do think FBT was a massive part…I think she's just kind of reaffirmed that nothing is impossible and actually, the family is a much powerful tool than you think." (Anna)

IMPACT ON FAMILY LIFE

An all-consuming task: *"It's all-encompassing"*

Melissa, Anna, Pauline, Simon, Christine and Joanna described adhering to FBT and supporting their child's recovery was an all-consuming task:

"I actually felt like all day you were dealing with eating. Because it wasn't just a case of, "Have this snack". It was a case of we sat there, sometimes about over two hours trying to just have a biscuit. It's you know. So it was all-consuming." (Melissa)

"the first few weeks, it was literally from morning to night. All you seemed to be doing was feeding her and encouraging her to eat because it would take so long to get through a meal and then it was a snack. And then you'd just be finished a snack and then it was another meal. That was just that was all you could think about." (Anna)

There was a strong sense that the refeeding phase was relentless and parents described their lives revolving around mealtimes, snack times and food shopping. Christine's account implies that fighting her daughter's ED was a constant, consuming battle which often involved moments of despair:

"And then getting up the next morning and thinking, fuck not another day. You know, it just, every day was like, "Oh, please don't give me another day" (Christine)

Due to the relentless nature of the refeeding phase, biographical disruption was experienced by most parents:

"I just took time off work. I just went em, I went off sick, and it just had to be through stress and things….And I'm glad I did it, because I think I needed to be with him. He was my main concern, you know to get him back to a better, decent health." (Pauline)

"I still worked all the way through this, although I worked less hours." (Emer)

Pauline took a number of months off work to focus on FBT, Joanna's husband took eight weeks off work and Emer reduced her hours in order to engage in FBT. Similarly, Jason Simon, Christine and

Anna reported that working from home or being self-employed gave them the flexibility and the time to focus on engaging in FBT:

> *"I'm fortunately self-employed, so I could juggle things about normally. I had to leave work at 7:00, but I would stay back and start work at 9:00, so I could feed her in the morning. Then at lunchtimes, I would go down and collect her or she would make her way to my office and we'd eat again at lunch together,"* (Jason)

> *"It must be hellish for single parents, but, um, fortunate for us, um, ChristineChristine is a stay-at-home mom. Um, if we were both working, I don't know how we would man - we'd have managed it. It might have been a case of one of us would have to give up our jobs to do it to be effective."* (Simon)

This suggests that parents feel FBT requires one parent to have a flexible working pattern or to be able to work part time in order to fully commit to the demands of FBT.

Impact on family relationships: *"he's been a wee bit neglected by it"*

FBT appeared to impact intra-family dynamics both positively and negatively. Jason, Joanna, Pauline, Tracy and Anna reported that it brought their families closer together;

> *"I think family eating made my husband and I realise do you know what? We've really got to rein this in and behave ourselves because this added tension in the house and impacts Connor as well…I think also I've changed as a person. I've given up shouting at my husband. It's not worth it."* (Joanna)

However, Anna, Melissa, Simon and Christine reported that the stress of refeeding could cause tension in marital relationships:

> *"one of the hardest things going through this, right, is I could see Christine doing something and I might not be happy with what she's done and then I don't say anything and then I could do something and Christine's not happy about it, but she doesn't say anything. And then, eventually, it all comes out and-and-and before you- b-before you know it you're having a fight between each other. Right? And it took us a wee while to-to stop that."* (Simon)

Most parents reported that despite their child recovering from their ED, trust within the parent-child relationship has diminished due to the secret nature of anorexia:

> *"I just know he's capable of those lies. Once you can do that you can do other things. I don't think he does bad things, but he's got that capability. So maybe it's not that I distrust him,*

but I know he's got the capability to not be trustworthy. It would be, what I would say, is what anorexia has left me with him." (Joanna)

For Joanna, the secrecy associated with anorexia has had a lasting impact on the trust within her relationship with her son. She reports ongoing hypervigilance despite her son now being at a healthy weight. The lasting impact of lost trust and the perceived need to be hypervigilant about warning signs was echoed by Christine, Emer, Tracy and Melissa:

"I never worried about things like EDs before, ever, ever, it's weird. But now I'm on the ball now, (laughs) there's nothing getting past me now (laughs)." (Tracy)

Financial cost: "*money was just flying out*"

Reference to the financial cost of refeeding was referred to across many parents' accounts. This does not appear to be referred to in the extant literature on FBT. Simon reported that although he was entitled to tax credits, he was "not in a headspace" where he could complete the detailed paperwork for this. His wife, Christine referred to the amount of money spent on refeeding their daughter:

"You know, our food bill was about £250 every week at least, because she would decide, "Oh, I'd want to eat that." You'd go to Morrisons. The next day, she's not gonna eat that. She wants these things and you're out again. So at Morrisons, you could be there four, five times a week and before we knew it, money was just flying out." (Christine)

Joanna, Christine and Anna all commented on a significant amount of food being purchased and wasted and the implications that this could have on families who were struggling financially:

"but it is costly. It drains your resources…And I think for that to hit a family that are already financially struggling…I think that would be a massive battle for parents to go through. It does take money." (Anna)

"I actually feel that I spent a horrendous amount on food. A lot of it went in the bin. A horrendous amount on food. If you don't get any money, how do you do it?" (Joanna)

Coping

Externalising the eating disorder from the young person: *"I'm fighting this demon*"

Separating the eating disorder from the child is a core feature of the FBT model. This strategy was adopted by all participants. This appeared to help parents cope with challenging behaviour, verbal abuse and the drastic changes they observed in their children:

"On the outside it's your daughter and on the inside it's anorexia. And it's an- i-i-if you like, it's an-an alien from another world that's-that's taken your daughter's body." (Simon)

Making this distinction allowed parents to draw on the resources required to fight anorexia which appeared to feel more comfortable and manageable than fighting with their child:

"But it's to separate the disease from the child…I'm not arguing with my daughter here whom I love and I want to cuddle and I want to protect, but I'm fighting this demon for lack of a better word. I think once you can do that, it makes you stronger in your approach to refeeding." (Anna)

For Anna, this allowed her to compartmentalise the ED behaviours exhibited by her daughter and separate them from her child who she loves and wants to support.

Similarly, Jason this strategy helped him to better understand that he was dealing with an illness within his daughter rather than responding to his daughter being unreasonable:

"When Heather used to rear up, I'd get quite, I'd get quite, go into this dark place because I thought I'd do anything for her, why is she rearing up when all I want to do is help? But once I realized that it wasn't actually Heather, it was the illness it was easy after that." (Jason)

Increasing Understanding of EDs

All participants reported that researching eating disorders was a helpful way of coping with this experience. Their methods of research varied across books recommended by clinicians and friends and online resources. Jason, Melissa and Anna referred to books written by Eva Musby being very helpful:

"it [book by Eva Musby] was really my go-to the whole time. And it's really a fantastic book, you can just dip into different parts…And it's honestly, it's brilliant. I think that helped me cope actually." (Melissa)

For Melissa, reading this book provided more depth to the advice she was given at FBT sessions. Within the book, she found stories from other parents very helpful in making her feel reassured that she was approaching her daughter's eating disorder correctly.

Interestingly, Simon reported when clinicians recommended books to him about eating disorders, he was in such high state of stress that his concentration was affected.

"When we went there we were told to read some books, so they give us a list of books to read. But my brain wasn't interested in reading, it was so fried by that time. So was Christine's." (Simon)

Both he and his wife, Christine reported that their first session was "a blur" due to their high stress levels at the time. Consequently, Simon did not feel willing or able to begin reading large volumes of information. He recommended that parents are given an information pack regarding warning signs, symptoms, what to expect and contact details for support services.

Anna reported that an online forum where other parents spoke about personal experiences helped her to cope:

> *"Feast forum again, I know I've mentioned it to you, but I found that really really helpful. Just knowing that there were parents thinking the same, there were parents doing the same."* (Anna)

This seemed to reduce feelings of isolation for Anna and to provide a sense of solidarity as well as providing reassurance.

SUPPORT

Experiences of FBT: *"it was effective"*

Anna, Tracy, Jason, Pauline and Joanna described the treatment they received from their FBT clinician very positively:

> *"Outstanding. I think she's amazing at her job… But I think she's got not just a passion, she certainly comes across as someone who genuinely cares. And she gets to know you."* (Anna)

While Anna perceived FBT to be a very effective intervention for her daughter's anorexia, she also valued that the FBT clinician got to know the whole family and found this to be an important part of FBT.

For Jason access to telephone support from the FBT clinician and being updated regularly helped him to feel confident and supported during his daughter's treatment;

> *"Oh they're brilliant, they're absolutely brilliant… And she was always there, she was always there to make sure that it was kept in the loop about things… I would phone the therapist quickly and she'd get back to me and she would say, "That's okay. You know do this."* (Jason)

Similarly, for Tracy, the offer of telephone support between sessions provided a feeling of security although she has not had to use it as of yet.

> *"The FBT therapist was very open in that it didn't matter when it was or what it was if there was anything bothering us at all just to give her a call, I think just knowing that there's somebody at the end of the phone…it's just knowing there's a safety net."* (Tracy)

Parents who encountered high levels of resistance and challenging behaviour from their child in the refeeding phase were less positive about FBT. Simon and Christine reported feeling that although they felt FBT was effective, they felt that this was down to them and they reported feeling that they were left to do the treatment alone with little guidance from clinicians:

> *"I just felt as though, what's the point of us constantly coming here dragging her here, much to her disgust you know. She didn't want to be here. Uh, like Simon said there—it was only for the weigh in that was the only thing we got from it."* (Christine)

Of note, Christine and Simon experienced increased levels of challenging behaviour including physical aggression and reported that their daughter regressed from phase two back into phase one at one point. Their accounts suggest that increased practical advice on managing and responding to challenging behaviour is required.

Similarly, while Melissa reported that FBT was very effective, she reported that it impacted negatively on her own mental health:

> *"I mean I do think that it definitely helped Lizzy recover really quickly. But I do think that that is down to the fact that I did everything that they told me to do to. You know to the detriment of, probably, my mental health, but I do think that has made Lizzy recover and she has now fully recovered."* (Melissa)

She felt if she had more reassurance from clinicians that she was responding appropriately to her daughter she would have felt more confident and less helpless. She reported, pleading, begging and shouting at her daughter to eat and reflects that looking back she is unsure if this was necessary.

Recommendations for Services: *"more one-to-one support for the parents"*

1. <u>Carers Groups</u>

Parents reported that a support group for parents and carers of children with EDs would reduce their sense of isolation and provide a space for them to discuss their feelings and how the ED has impacted on them;

> *"I think for the other people to go there and say, "You know, I'm not alone." You know, there's other people who are going through the same hell I'm going through."* (Christine)

Additionally, a carers group was perceived to be a potential opportunity to share advice on tried and tested strategies and techniques;

> *"They know what you're going through. They might have some suggestions about what you could do."* (Joanna)

2. Separate Parent Sessions

While parents reported the format of the family session was beneficial, others felt a separate parents session would be helpful to discuss the impact the illness was having on them:

> *"I never asked for separate sessions. But it may have helped more being able to get more of how you're feeling more like I say without Karen being there…sometimes it's easier to speak if your child isn't there."* (Emer)

Other parents whose children resisted their parents regaining control over their eating found family sessions less helpful. Melissa reflected that it was difficult to discuss ways of increasing their child's weight with the child in the room:

> *"she did hear a couple of things I didn't want her to hear such as I had to put things in her food to put the calories on like. But she heard these things being said… it would have been easier and less stress for me if she hadn't"* (Melissa)

Melissa felt that she would not have dealt with such challenging behaviour if her daughter did not hear about what weight gain strategies she was employing within the family sessions.

Christine reported a similar difficulty with the format of family sessions when she was advised on how to increase weight gain in front of her anorexic daughter:

> *"So then Polly is sitting there going, "oh aye right so you are, I don't think so." You know, and because she was there and knew exactly"* (Christine).

Simon felt that sharing these strategies in the family session in the presence of his daughter was;

> *"one of the biggest mistakes I think we made"* (Simon)

Consequently, some parents feel that when their child is resisting losing control of eating, a separate session for parents is likely to be more effective and easier for parents to manage.

Of note, although parents felt a separate session would be beneficial they were reluctant to request this from clinicians.

> *"I think I'd like just slightly more one-to-one with myself. I know that if I'd asked the therapist she would probably have said, yes. But I know everybody's busy and there's other people, it's not just us that's going through this and there are other families that need her time.* (Jason)

Both Joanna and Christine reported that questionnaires for parents to identify how they are coping would be helpful;

"Maybe there could be an opportunity for patients, maybe in a questionnaire or something to come from the person that's conducting the family therapy. Just to ask a confidential questionnaire, to find out how they were managing to do it." (Joanna)

Joanna suggested that questionnaires could include questions on how families are coping with the financial impact of FBT also. Christine felt that a questionnaire would give parents an opportunity to provide feedback on how FBT was for them:

"well I certainly can't remember, were we given a questionnaire, like even to fill out to help them to provide better information. Or we were never, "is this working for you? what other suggestions would you have for making the service better, we were never given anything like that." (Christine)

Christine suggests that by increasing opportunities for parents to feed back to clinicians on the FBT process, their support needs could be more effectively met.

3. Increase wider understandings of EDs

Parents reported that extended family members and schools' limited understandings of EDs exacerbated feelings of isolation and increased stigma as few people were aware of the severity of their child's illness.

Both Melissa and Pauline found that extended family members made hurtful comments which exacerbated their feelings of stress and upset during this difficult period;

"I think a few of the other male family couldn't understand why he just didn't eat. And that came over, and that hurt me a wee bit…It's not as simple as that." (Pauline)

This lack of understanding was difficult to deal with when parents were already managing challenging behaviour, the relentlessness of the refeeding phase and attempting to increase their own understandings of EDs.

Tracy, Emer and Melissa felt that education around EDs should be provided in schools:

"Like I said, I don't know whether they should maybe do more in school about that. Teaching them about it, I mean they teach them about all the other things, drugs and all those kind of things" (Tracy)

Melissa pointed out that emphasis on healthy eating in schools could have a detrimental effect on young people vulnerable to developing an ED:

"And then this massive thing at school about looking at labels of food, which I really have now got a different view on." (Melissa)

It is suggested that education on mental health in schools needs to include information on EDs particularly given that EDs tend to emerge in adolescence.

DISCUSSION

This IPA study revealed four major themes. Overall, findings highlight that while some characteristics of the FBT model are helpful for some parents, other aspects were not. Furthermore, increased supports could further empower parents and help to reduce feelings of isolation, pressure and perceptions of failure. Findings are discussed below in relation to the extant literature and implications for clinical practice and future research.

Key Findings

Agnostic stance

Findings highlighted that most parents' experiences were dominated by self-blame and guilt due to missing initial signs of their child's eating disorder. FBT's agnostic stance on the aetiology appeared to exacerbate these emotions as the cause of the eating disorder was not identified. A strong sense that parents were searching for answers regarding aetiology, was felt throughout some parents' accounts. This was interpreted as a coping mechanism for managing difficult emotions such as guilt, self-blame and anxiety. FBT's agnostic stance appeared to increase some parents' anxiety, stress and frustration as it was perceived as making it more challenging to prevent a relapse. This finding contrasts with Dimitropoulos *et al.'s* (2017) findings which cites the agnostic stance as a technique employed by clinicians to increase parental empowerment. Consequently, parents' feelings around aetiology should be considered towards the end of treatment when clinicians are developing relapse prevention plans with families.

Mixed views on empowerment

Findings relating to mixed views on empowerment were of particular interest. While some felt the responsibility FBT places on them as pressurising, others felt it increased confidence and skills required to re-nourish their child. In line with principals of FBT and Dimitropoulos *et al.'s* (2017) findings, externalisation of the eating disorder from the child was reported by all participants as helpful. This strategy appeared to empower parents by helping them to depersonalise hurtful comments from their child and mobilized them to take control of their child's eating. Additionally, parental empowerment increased when parents were reassured that their approaches to refeeding were appropriate and when their efforts were successful. Of note, a perceived need for directive, practical advice was heavily felt throughout some accounts, particularly for those who encountered challenging behaviour and resistance from their child in the refeeding phase. These parents reported higher levels of stress and less positive views of the service they received. This finding conflicts with FBT's proposal that the therapist should maintain a non-authoritarian stance (Rienecke, 2017). It highlights that some families require more directive advice from clinicians than others.

Impact on parents

Findings suggest that parents were unaware and unprepared for the all-consuming effort it requires to refeed their child to a healthy weight and the resulting biographical disruption to their lives. Parental accounts highlighted that the demands of FBT and their child's ED impacted on competing pressures such as rearing other children and required significant time off work and reduced working hours. Additionally, these demands appeared to add strain to marital relationships unless both parents were adopting a united front against the eating disorder. Lastly, while FBT is considered a cost-effective alternative to hospitalisation for services (Lock & Le Grange, 2013), the impact of refeeding on household incomes was repeatedly reported. Families reflected that refeeding was extremely costly and that often, significant amounts of food were wasted. Consequently, they suggested that dietetic input and financial support may be helpful for some families, particularly those that are in receipt of benefits or experiencing financial difficulties.

These findings echo McCormack and McCann's (2015) results, which highlight how a child's eating disorder can have a significant and negative effect on parents' social, financial and personal functioning. More importantly, findings highlight that parents feel unprepared for the demands of FBT and the enormity of the task ahead. Given that dropout rates are almost 27% for outpatient family-based interventions (DeJong, Broadbent and Schmidt, 2012), it is suggested that parents are better prepared for the demands of FBT at the outset of treatment. A study by Dean, Spice and Leathem (1992) indicates that preparation strategies employed before psychotherapy lead to initial decrease in patients' anxiety, accurate expectations of psychotherapy and improved therapy outcomes. While further research is required on the longterm impact of this, preparatory work with parents may help to identify and manage expectations, reduce anxiety and better prepare them for the impact FBT is likely to have on life at home, competing pressures and the psychosocial impact of FBT on parents and on the wider family.

Psychoeducation

Consistent with Dimitropoulos *et al. (*2017), results indicate that increasing knowledge of EDs increases confidence and empowerment. However, findings show that the format of psychoeducation should be considered and tailored to parents' needs and stress levels. Large volumes of information may not be appropriate for parents who are experiencing high levels of stress or those in crisis. Leaflets, pamphlets and signposting to reputable websites such as the *Beat Eating Disorders* charity may be more appropriate.

Implications for clinical practice

While most parents were very positive about FBT treatment, all participants felt further support for parents was needed. The following recommendations are proposed:

Carer support groups

As demonstrated by Pasold (2010), parent support groups for EDs provide a source of emotional support to parents and can increase understandings of ED symptoms and treatment (Pasold, 2010; Hodsoll *et al.* 2017). Furthermore, it is proposed that FBT support groups could offer an opportunity to share advice on tried and tested strategies for refeeding and managing eating disordered behaviours, helping to increase empowerment. Groups could be run by peer support workers who have completed FBT and supervised by FBT clinicians to reduce the impact on clinicians' capacity. Alternatively, therapist-led online support groups have been shown to increase parental coping and support parents to implement FBT (Binford *et al.* 2012).

Separate parents' sessions

Although Lock and LeGrange (2013) recommend a separate parent's session when the patient is not achieving expected weight gain, findings indicate that most parents would welcome the offer of a separate session. They reported that this would be helpful to discuss refeeding approaches, managing resistance, the impact of treatment on them and could provide an opportunity to give feedback on helpful and unhelpful aspects of FBT. However, findings show that parents are reluctant to request this as their focus is primarily on their child. Therefore, it is suggested that they are offered this session as part of routine treatment. Given that parents were very positive about the telephone support they received, a separate parent's telephone consultation may be sufficient for parents to feel more supported. Alternatively, a separate version or FBT, *parent-focused treatment* (LeGrange *et al.* 2016), has been shown to be effective in achieving remission. Parent-focused treatment involves the child being monitored and provided with brief supportive counselling from a nurse and therapy sessions are conducted separately with the parents and FBT therapist. This format may suit families who do not find the format of family sessions helpful.

Preparing parents for treatment

It is suggested that preparation for parents prior to commencing FBT would be beneficial. A focus of this work should be to identify parents' expectations of treatment, treatment outcomes and their levels of self-efficacy. A further focus should be on the provision of information on the nature of EDs, the demands of FBT and its potential impact on family life, work, finances. It is hoped that this may brace families for the task ahead. An assessment on parents' support needs and coping strategies and the provision of information on self-care prior to treatment may also be useful. This could be done in

session and subsequently parents could be signposted to online supports such as the Beat online chat groups, videos on the "Maudsley Parents" website, providing parents with brief information packs.

Implications for future research

This research highlights that parents' views on empowerment varied. This finding suggests that factors such as perceived levels of professional support from clinicians, perceived effectiveness of parents' strategies and the efforts they went to to refeed their children influence their sense of empowerment and sense of failure. Given that parental confidence in refeeding is considered a crucial factor in patients' recovery (Dimitropoulos *et al.* 2017; Murray *et al.* 2018), further research exploring parents' views on the factors that facilitate empowerment is recommended.

The financial cost of FBT for families may also warrant further research. This was repeatedly referred to in parents' accounts and it appears this topic has not received much attention in the literature to date. However, given these findings indicate that some families are not adhering to FBT protocol by buying multiple food items in line with their child's preferences and requests, this finding may not be as relevant for settings where adherence to FBT is greater.

Limitations

As the sample consisted of families who engaged and persisted with FBT, the findings are not representative of those who have disengaged with treatment. It would be helpful to have explored accounts of parents who disengaged from FBT to explore barriers to empowerment and engagement in treatment.

Additionally, while this study strived to recruit a homogenous sample, as participants were at different stages in their child's FBT, this may have impacted on their accounts. Parents who recently completed phase one found it more challenging to reflect on their own needs and coping strategies in comparison with parents who had completed treatment. It is suggested that if this study was replicated, a more homogenous sample should be recruited in terms of phase of treatment.

Lastly, the final interview was conducted with two participants and was challenging in terms of transcribing the data and in ensuring idiographic accounts from each account were identified. The researcher elicited idiographic accounts from each participant within this interview by ensuring to ask each question to both participants, by checking if either participant had anything further to add and how their experiences varied due to their different parental roles.

Conclusions

This research has provided an insider perspective of what it actually means to be a parent engaging in FBT. It has added to the evidence base by highlighting four patterns across participants' lived

experiences; 1) parenting challenges, 2) impact on family life, 3) coping and 4) support needs. Tentative recommendations for clinical practice were made to increase parental support while they engage in this challenging treatment. Recommendations for future research to further explore support needs and parental empowerment are also highlighted.

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Appendix 1:
AUTHOR GUIDELINES FOR SELECTED JOURNAL

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European EDs Review publishes authoritative and accessible articles, from all over the world, which review or report original research that has implications for the treatment and care of people with EDs and obesity, and articles which report innovations and experience in the clinical management of EDs. The journal focuses on implications for best practice in diagnosis and treatment. The journal also provides a forum for discussion of the causes and prevention of EDs, and related health policy.

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The journal

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Appendix 2:
MAJOR RESEARCH PROJECT PROPOSAL

University of Glasgow

Institute of Health & Wellbeing

DOCTORATE IN CLINICAL PSYCHOLOGY

SUBMISSION FRONT PAGE

Trainee Name: **Rachel Hanson**

Matriculation Number: 2292987H

Name of Assessment: MRP Proposal

Title of Project:

Engaging in family-based therapy for adolescent EDs: An interpretative phenomenological analysis of parental perspectives.

Academic Supervisor: Dr Alison Jackson

Field Supervisor: Dr Louise Beare
(If Applicable)

Clinical Supervisor:
(If Applicable)

Version Number: Approved Final Version

Word Count, including reference list (excluding appendices):

(maximum word count is 3000): 3548

Abstract

Background: Family Based Treatment (FBT) for anorexia nervosa (AN) and bulimia nervosa (BN) has been shown to be effective in reducing the number of hospitalisations and assist in the adolescent's recovery from restrictive EDs. However, this is contingent on parents being viewed as a resource who take an active role in the intervention. To date, few studies have explored the psycho-social impact that engagement in FBT has had on parental figure and on the parent child relationship.

Aims: The aims of this study are 1) to gain a rich understanding into the lived experience of family members of young people who are engaging in family-based therapy for restrictive EDs, 2) to explore the psychosocial impact that this has on them and 3) to draw conclusions from the extant research which may inform clinical practice in terms of how best to support families engaging in this intervention.

Methods: This will be a qualitative, interview study using interpretive phenomenological analysis (IPA). Ten adult participants will be approached by clinicians working in Scottish CAMHS services. Each participant will take part in a one-to-one, semi-structured interview. Interviews will be transcribed verbatim and transcripts will be analysed using IPA.

Applications: This study may inform clinical practice by shedding light on the experience of families engaging in FBT, the impact on interfamily dynamics and highlight the challenges they face, their support needs, any gaps in service.

Introduction

Family-based treatment (FBT) for anorexia nervosa (AN) and bulimia nervosa (BN) offer an alternative approach to hospital treatments for young people. FBT is an intensive, outpatient treatment which involves parents playing an active role in re-feeding their child by taking control of family meals to restore them to a healthy weight (LeGrange & Lock, 2011). The FBT approach gives the control over eating back to the young person (LeGrange & Lock, 2011). Unlike hospital treatments which are disruptive to the young person's life, normal adolescent development is encouraged, and in-depth discussions of the young person's development is a cornerstone of FBT. Treatment consists of 15-20 sessions, usually over the course of one year (LeGrange & Lock, 2011).

Family-based Treatment has been characterised by fewer in-patient hospital admissions, faster rates of remission and weight restoration and lower rates of relapse in comparison to controls (LeGrange & Lock, 2011). Furthermore, these outcomes were largely maintained at a five year follow up. It is now viewed as the best evidence-based treatment for anorexia nervosa where duration is three years or less (Le Grange & Lock, 2011). Consequently, both the Matrix (2015) and NICE (2017) recommend FBT for young people with AN and BN.

A recent meta-synthesis conducted by Fox, Dean and Whittlesea (2017) explored the impact that an ED has on family carers. It was found that EDs have a major negative impact on family members and that often caregiver needs are unmet (Fox *et al.*, 2017). While the research into caring for a loved one with an ED is still developing, there appears to be a lack of qualitative research exploring the experience of families engaging specifically, in FBT.

A quantitative study conducted by Allan, LeGrange, Sawyer *et al.* (2017) investigated whether high levels of parental expressed emotion (EE) was related to poorer outcomes in FBT for adolescent AN. This randomised control trial found that adolescents of mothers who demonstrated an increase in EE, or remained high in EE, were less likely to remit compared with adolescents for whom EE decreased or remained low. These results emphasise the importance of considering EE when implementing FBT for adolescents with anorexia nervosa.

Another quantitative investigation into FBT was conducted by Hughes, Burton, LeGrange and Sawyer (2017). This study investigated whether the rate of attendance of mothers, fathers and siblings in FBT sessions impacted treatment outcomes. Results showed that mothers were more likely to attend all sessions than fathers or siblings and that greater attendance by fathers predicted higher weight, reduced ED symptoms and remission rates at the end of treatment.

Both Hughes *et al.'s* (2017) study and Allan *et al.'s* (2017) research indicate that family dynamics, communication styles and participation in FBT are likely to impact outcomes of treatment. Despite

this, most qualitative research on FBT for adolescent EDs focuses on clinician's experiences of and perceptions of FBT. For example, in Canada, Dimitropoulos, Freeman, Lock and LeGrange (2017) explored clinicians' views of what principals of FBT are most effective. This focus group study employed thematic analysis. Results indicated that clinicians believe that parental empowerment was the most relevant principle of FBT, that adolescent, parental and family factors could hinder or enhance parental empowerment and that a range of clinical interventions could be used to increase parental empowerment (Dimitropoulos *et al.* 2017). They recommended that future research should focus on addressing barriers to parental empowerment.

A further qualitative study was recently conducted by Conti *et al.* (2017) which focused on families who have disengaged from FBT. Conti *et al.* (2017) conducted an in-depth case study with a female adolescent and her family who disengaged from FBT. It was found that initially, the patient found it comforting to pass the responsibility for eating to her family and that this restored a sense of control within the family (Conti *et al.* 2017). However, these results were not maintained (Conti *et al,* 2017). Both the patient and her family reported feeling blamed and felt disabled by the FBT approach. This study highlights the importance of identifying barriers to FBT treatment and progression within treatment.

To the best of the author's knowledge, no IPA study has explored the impact FBT has on the parent child relationship, wider interfamily dynamics, their support needs and the challenges and barriers that families face, has been conducted. This indicates a gap in the research. Furthermore, it is felt that the experience of families engaging in FBT for restrictive EDs is worthy of investigation given the negative impact of the caregiver role on family members and the very active role that parents play in their child's intervention and that this research could inform clinical practice.

Aims and Hypotheses

Research Question: What are family members experiences of engaging in FBT for adolescent EDs?

Aims:

1. To gain a rich and detailed understanding of family members lived experiences of engaging in family-based therapy to intervene in their child's ED.
2. To explore the psychosocial impact of being an immediate family member engaging in family therapy for a young person's ED.
3. To draw conclusions from the research which may highlight some tentative implications for support services for families engaged in this treatment.

Plan of Investigation

Participants - Inclusion and Exclusion Criteria

Inclusion: Participants must be 16 or over; be a parental figure or primary caregiver to a young person referred for FBT for with AN or BN, be engaging or previously engaged in FBT for AN or BN and be able to speak and read English fluently. This age limit has been set at 16 to include older siblings or kinship carers who may have taken on a parental role in FBT treatment.

Exclusion: Parents and carers who meet the above criteria and are identified by clinicians as unsuitable for participating in the research due to medium to high levels of suicide risk or child protection issues will be excluded from this study. It is felt that approaching families who are currently dealing with these issues as well as engaging in FBT for AN or BN may put additional and unnecessary pressure on these families. Siblings and extended family members who do not take a parental role in the life of the young person engaged in FBT will be excluded also.

Design

The proposed study considered a range of qualitative approaches including interpretative phenomenological analysis (IPA), grounded theory and thematic analysis. IPA is an experiential qualitative research approach which aims to explore participants' experiences of their social and personal world, how they make sense of these experiences and the meanings that they attach to these experiences (Smith 2004). It was felt that an IPA methodology would best fit with the research question and the aims of the present study for several reasons.

First, as families' experiences of engaging in FBT is an under-researched and poorly understood concept, an inductive approach is required to acquire depth of information on participants' perspectives (Smith 1996; Smith & Osborn 2008). Subsequently, as this study aims to generate a rich insight into family members' idiographic experiences of engaging in FBT rather than to develop theory, grounded theory was deemed to be an inappropriate approach.

Furthermore, thematic analysis was ruled out as this approach lacks an epistemological background and focuses on identifying patterns across the participant's narratives rather than interpreting the individual account of each participant. Its focus is descriptive and therefore has limited interactive power unless used within a theoretical framework. As no theoretical or conceptual framework for families' experiences of FBT is referred to in the extant literature, this

method of analysis is deemed to be inappropriate for the proposed study. Additionally, it was felt that this approach would not provide the richness and depth of insight or the rigour of analysis that the proposed study requires.

Finally, it was felt that IPA could add more to the research base by exploring the idiographic experience family members who have engaged in FBT, gaining a rich insight from participants themselves and linking cognition and language to explore how participants make sense of this experience.

Recruitment Procedures

In line with the IPA methodology, this study will employ a purposive sampling strategy. Participants who meet the inclusion criteria will be selected from the West of Scotland Family-Based Therapy (WOS FBT) database. This database was compiled in 2015 and is continually updated with details of FBT cases for EDs. Since 2015, 121 families across CAMHS services in NHS Lanarkshire, Greater Glasgow and Clyde, Ayrshire and Arran, the Highlands, Forth Valley, Dumfries and Galloway, have engaged in FBT for restrictive EDs. Their details and a range of quantitative data collected from these families is stored within the WOS FBT database. Recruitment is limited to these health boards given the high numbers of potential participants whose details are recorded in the WOS FBT database. Given the time and funding restraints associated with this project, it was decided that it is not feasible to expand recruitment to all Scottish health boards.

Clinicians working across these health boards will be asked to post information packs with opt in forms to families who area identified as meeting the inclusion criteria. These information packs will be made up and supplied by the researcher.

Each participant will take part in a one to one interview with the primary researcher. An information sheet and informed consent form will be given to each participant prior to interview. Once the consent form is signed the researcher will ask the participant for some descriptive information and the interview will commence. Descriptive data will include age, gender, postcode to identify Scottish Index of Multiple Deprivation (SIMD), relationship to the patient and time passed since the young person engaged in treatment. This information will be noted by the researcher on a demographic information sheet.

Semi-structured interviews will be used for data collection in line with Smith & Osborn's (2008) recommendation that this is the most appropriate method for data collection within an IPA study. Participant interviews will last up to 90 minutes. They will consist of questions regarding the

participant's experience of their involvement in FBT, their thoughts and feelings around this, what challenges they faced, the impact that this had on their wellbeing, relationships with others, work life, identity as a parent/carer, their support needs, their views on support services and the coping mechanisms that they engaged in.

When the interview has been completed participants will be debriefed to find out how the process was for them. Further details on debriefing process are referred to below in relation to ethical considerations.

Research Procedures

FBT clinicians within CAMHS teams in NHS Lanarkshire, Greater Glasgow and Clyde, Ayrshire and Arran, the Highlands, Forth Valley and Dumfries and Galloway will be briefed on this research study. On receipt of ethical approval from IRAS and each health boards' Research and Development departments, the researcher will request that clinicians identify any high-risk cases which should not be contacted regarding the research at this time. The researcher will supply clinicians with information packs which include an information leaflet, a stamped and addressed envelope and an opt in/out form. The researcher will ask the FBT clinicians to send these to their cases whose details are recorded in the FBT database. The opt in form will ask patients to return this form within a month of receiving it, stating whether they wish to be contacted by the researcher to discuss taking part in the research study.

Participants who opt in will be contacted by the researcher by telephone to arrange a suitable time and venue for an interview. Preferably, interviews will be conducted in person. However, where this is not possible telephone interviews may be conducted. It is felt important to include this option as attendance at interview may pose a barrier to participation for some individuals, particularly those who reside in rural regions.

One to one semi-structured interviews will be transcribed verbatim and analysed using IPA to interpret and identify common themes across participants experiences.

Data Analysis

In line with the IPA methodology, data analysis will adhere to the steps outlined by Smith, Flowers and Larkin (2009). These consist of reading and rereading the interview transcripts, taking initial notes, developing emergent themes, moving to the next case and then looking for patterns across cases (Smith, Flowers and Larkin, 2009).

Justification of sample size

As this study will adopt an IPA approach, breadth of data will be sacrificed for depth. There are no strict guidelines on sample sizes for IPA studies and studies employing this methodology have been published with sample sizes ranging from one to fifteen (Pietkiewicz & Smith, 2012).

Turpin *et al.* (1997) argue that 6-8 participants is acceptable for an IPA study conducted by clinical psychology doctoral level students. While this sample size would facilitate examination of commonalities and differences between participants' experiences (Turpin *et al,* 1997), it was felt that a larger sample would increase the likelihood of publishing this research. Given that the two IPA studies included in Fox *et al's* (2017) meta-synthesis conducted by Cottee-Lane et al (2004) and Huke and Slade (2006) used sample sizes of 11 and 8 respectively, a sample size of 10 is proposed for the present study.

Settings and Equipment

Interviews will take place at NHS services. Locations will be agreed with participants in advance of interviews and the primary researcher will aim to conduct interviews at services which are convenient to participants. Interviews will be audio recorded using a password protects digital Dictaphone.

Health and Safety Issues

Participants will be interviewed in NHS premises in the region where the participant resides. All sites at which interviews will be conducted will be assessed in terms of health and safety. A minimum requirement will be that the building is staffed with at least one staff member when interviews are taking place to ensure both the safety of the participants and the researcher.

Participants will be interviewed by a trainee clinical psychologist who is experienced in counselling individuals who are discussing personal and emotive topics. Participants will be provided with an information sheet outlining the aims of this research and what participation involves in advance of their interview. Additionally, participants will be fully debriefed following their interview.

Ethical Issues

The wellbeing of each participant is of highest priority throughout the research process. Ethical issues will be continuously considered, and the necessary precautions will be followed to decrease the chances of any ethical matters arising. The following precautions will be taken.

Participation in the study will be voluntary and participants will be made aware that they can withdraw at any time during the study, pause the interview at any time and that they are not required to answer any questions that they do not wish to answer.

Participants will be informed that all interviews will be audio recorded and transcribed verbatim. Each participant will be assigned a pseudonym to protect their anonymity and all identifying information will be anonymised. Only the primary researcher will have access to the audio recordings of the participants' interviews. The anonymised transcripts will be shared with the supervisory team. Hard copies of transcripts will be kept in a locked filing cabinet which only the primary researcher will have access to. Soft copies of the audio recordings and transcripts will be stored on the Glasgow University server which only the researcher will have access to. All files will be password protected.

An interview schedule will be created and submitted for ethical approval prior to data collection. As the proposed study will investigate an emotive area; a loved one's mental illness, consideration of the way in which questions are worded or phrased is important in order to minimise the possibility of causing upset to the participants.

Participants will be debriefed following the interview to see how they found the process. A debriefing document outlining the contact details of NHS 24, the Samaritans and the Breathing Space Helplines will be given to each participant following their interview in case they feel upset by any topics covered in the interview and would like to talk to someone about this.

Financial Issues

An application for costs covering postage has been made to the DClin Psy programme at University of Glasgow. Furthermore, as data collection spans across five different health boards and participants will ideally be interviewed in person, the primary researcher will be driving considerable distances for data collection. The researcher is in discussion with her health board regarding funding travel expenses for this project. If this is not possible an application for travel expenses will be made to the

Practical Applications

This project aims to provide insight into families' experiences of engaging in FBT. By highlighting the impact that it has on family members and identifying the challenges they face, and the support needs they identify, it can inform future practice of FBT for AN.

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Appendix 3:
Ethical Approval Letter from Research Ethics Service

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 5
West of Scotland Research Ethics Service
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ

Ms Rachel Hanson
Institute of Health and Wellbeing
Administration Building, Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

Date 29 January 2019

Direct line 0141 232 1809
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Hanson

Study title: **Engaging in family-based therapy for adolescent eating disorders: An interpretative phenomenological analysis of parental perspectives.**
REC reference: **18/WS/0215**
Protocol number: **N/A**
IRAS project ID: **252339**

Thank you for your revised documents submitted on 28 January 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 23 January 2019.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Other [Opt In Opt Out Form]	4	28 January 2019
Other [Participant Demographics Sheet]	5	28 January 2019
Participant information sheet (PIS) [PIS V1 22.06.18]	4	28 January 2019

Approved documents

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

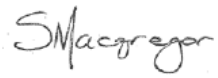
Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview Schedule V2 17.08.18]	2	17 August 2018
IRAS Application Form [IRAS_Form_29102018]		29 October 2018
Letters of invitation to participant [Letter of Invitation]	1	13 January 2019
Other [Debriefing Doc V1 22.06.18]	1	22 June 2018
Other [Use of Personal Information Leaflet]	V4	18 May 2018

Other [NHSL Peer Review Form]		20 June 2018
Other [Opt In Opt Out Form]	4	28 January 2019
Other [Participant Demographics Sheet]	5	28 January 2019
Participant consent form [Consent Form V1 22.06.18]	1	22 June 2018
Participant information sheet (PIS) [PIS V1 22.06.18]	4	28 January 2019
Research protocol or project proposal [Research Proposal]	4	25 May 2018
Response to Request for Further Information [email]		13 January 2019
Summary CV for Chief Investigator (CI) [Rachel Hanson CV]		
Summary CV for supervisor (student research) [AJackson CV]		

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

18/WS/0215	**Please quote this number on all correspondence**

Yours sincerely



Sharon Macgregor
REC Manager

Copy to: Mr Raymond Hamill, NHS Lanarkshire
Ms Cynthia Dolier, NHS Lanarkshire

Lead Nation - Scotland: nhsg.NRSPCC@nhs.net

Appendix 4:
PARTICIPANT INFORMATION SHEET

University of Glasgow | College of Medical, Veterinary & Life Sciences

NHS Lanarkshire

PARTICIPANT INFORMATION SHEET

Title of Project: Engaging in family-based therapy for adolescent EDs: An interpretative phenomenological analysis of parental perspectives.

You are being invited to take part in a research study. A member of your NHS care team has identified that you meet the inclusion criteria for this study. Please take time to read the following information.

Purpose of the Research:

The purpose of this study is to explore the experience of parents and caregivers engaging in family-based treatment for a young persons' ED. The findings of the project will be useful because currently, little is known about how the treatment impacts on parents' and carers' lives, the challenges they face and their support needs during treatment. It is hoped that this research can inform healthcare professionals about parents' and carers' experiences of family-based therapy and offer insight into how families support needs can be met.

You have been invited to take part in this study because you have been identified as a parent or carer who has previously engaged in or is currently engaging in family-based therapy for a young person with an ED.

What Participation Involves:

Participation in this study is voluntary. If you do not wish to take part this will not impact in any way on the treatment you or family members are receiving from the NHS.

If you agree to participate in this study, you will be asked to take part in an interview with the researcher. Interviews will cover the following topics; your overall experience of engaging in family-based treatment, challenges experienced during treatment, your support needs during and after treatment, the impact of treatment on yourself and other family members and any recommendations you may have for service improvement.

Interviews will be arranged at a health centre or hospital that is convenient for you. Your interview will be audio recorded and transcribed by the researcher. Your interview transcript and other participants transcripts will be read and analysed by the researcher by coding transcripts for common themes. You will be free to withdraw from the study at any stage without reason and you will be free to pause the interview at any point. You will be free to decline to answer any questions that you do not wish to answer. The whole procedure should take no longer than 90 minutes.

Please return the opt in/out slip to the researcher within 30 days of receiving this information pack and indicate whether you wish to participate in this study or not. If we do not hear from you within 30 days of receiving this information pack your NHS clinician will contact you by phone to identify whether or not you wish to take part in the research study.

Participant Confidentiality:

All data will be completely anonymous and confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the researcher may be obliged to contact relevant statutory agencies.

Data Protection:

Any data in paper form will be stored in locked cabinets which only the researcher has access to. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other

information which could identify you. Data will be stored for 10 years in University of Glasgow archiving facilities in accordance with Data Protection policies and regulations. If you decide to withdraw from the research, your data will be destroyed and will not be included in the study.

All study data will be held in accordance with The General Data Protection Regulation (2018). Please see the enclosed Use of Personal Information sheet for further information.

Advantages of Participation:

Although you will receive no direct benefit from taking part in this study, the information you provide will give us a better understanding of the experiences of parents and carers engaging in family-based therapy for EDs. It is hoped that this information will improve the supports available for other families receiving family-based therapy for an ED.

Results of Research Study:

The results may be published in a journal or presented at a conference. Results may include direct quotes from interviews. Again, all identifying information published will be anonymised. If you would like to know about the results of this study please let the researcher know at the end of your interview and a summary document will be sent to you once the research has been completed. This may take up to twelve months from the date of your interview.

This research study is sponsored by NHS Lanarkshire and is being conducted as part of the Doctorate in Clinical Psychology course at University of Glasgow. Should you require more information about any aspect of the research, please contact: r.hanson.1@research.gla.ac.uk

Thank you for taking the time to read this information sheet

Appendix 5:
Consent Form

University of Glasgow | College of Medical, Veterinary & Life Sciences

NHS Lanarkshire

Project Number: _____ Participant Identification No: _____

Title of Project: Engaging in family-based therapy for adolescent EDs: An interpretative phenomenological analysis of parental perspectives.

Name of Researcher(s): Rachel Hanson

CONSENT FORM

Please initial box

I confirm that I have read and understood the Participant Information Sheet version 1 dated 22/06/18. ☐

I have had the opportunity to think about the information and ask questions and I understand the answers I have been given. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers. ☐

I agree that my name, contact details and data described in the demographic sheet will be kept for the purposes of this research project. ☐

I agree to take part in the study. ☐

I agree to my interview being audio-recorded. ☐

I understand that the recorded interview will be transcribed word by word and the transcription stored for up to 10 years in University of Glasgow archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in an interview may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

_____	_____	_____
Name of participant	*Date*	*Signature*
_____	_____	_____
Researcher taking consent	*Date*	*Signature*

(1 copy for participant; 1 copy for researcher)

Appendix 6:
Opt In/Out Form

Ref No: _____

Opt In/ Out Form

Please complete this form and return using the enclosed, stamped, addressed envelope. If we do not receive this form within 30 days, a member of your direct clinical care team will contact you by phone to ask whether you would like to take part in this research.

Participation involves taking part in an interview and discussing your experience of engaging in family-based therapy for your child's ED. Interviews are likely to last approximately 60 minutes. Please tick the appropriate box below:

I would like to take part in this research study ☐

I do not wish to take part in this study ☐

Please provide your name and contact number below if you do wish to take part. If you do not wish to take part in the study this is not required.

Name: _____

Phone No: _____

If you have any questions or wish to discuss this research project further, please contact Rachel Hanson on r.hanson.1@research.gla.ac.uk

Appendix 7:
INTERVIEW SCHEDULE

Experience of Family Based Therapy for Anorexia Nervosa (FBT-AN)

1. How did you feel about engaging in family based treatment for your loved one's ED?
2. FBT involves parents initially taking control of their child's eating and is thought to empower parental figures. What aspects of this treatment did you find empowering? Were any aspects of it disempowering?
3. What impact (if any) did this treatment have on your relationships with other family members?
4. What was the most challenging part of treatment for you?
5. In what ways (if at all), did this experience impact your physical and mental wellbeing?
6. Talk me through the main challenges that you faced while your loved one was receiving treatment.
7. What were your support needs during this time?
8. Did you receive support during this time?

Informing Future Clinical Practice

9. How did you feel about the support your loved one received from services?
10. How do you feel about your loved one's ED now?
11. What do you think would be helpful for other families who are engaging in FBT EDs?
12. What positives have come out of your experience of FBT for your loved one's ED?
13. Is there anything that we've not covered today that you think is important or relevant to your experience of FBT?

Appendix 8:
ANNOTATED INTERVIEW TRANSCRIPT

Anna: Yeah, yeah, definitely. I do trust her. I do kind of now, you know she's got complete control of her snacks and things. She did cook before, but we were told not to. We were told she had to be kept out of the kitchen. And the magic plate theory, what we're having for dinner, you know you'll see it when you get it and all I'm asking you to do is finish it. Nothing else, no worries, no responsibility, just finish what's on your plate. And that worked, it sounds crazy. I was very skeptical. I thought how can something 'cos we've talked to you, something we've been trying to do for months, suddenly work, but it does. I think it's that empowerment. I think FBT certainly gives, well certainly gave my husband and I the confidence that we're not fighting her, we're fighting a disease and she can't do it herself. We need to do it for her. And I think that's maybe one of the strengths of FBT. Where if you go into hospital, it's the doctors' and nurses' responsibility. And therefore, I just think it's different.

Support
Doubt in FBT
Coping
Identity
Commitment to FBT
Stopping up

Interviewer: It sounds like that responsibility for refeeding her, that you really managed to step up to that.

Anna: Well yeah, we did because one, I knew she didn't want to go into hospital and I didn't really want her to go into hospital. Because I don't know if I could have coped with not being able to see her, and not being able to be there and comfort her. Although she didn't want any of that at first, because through anorexia, she was totally non-tactile. You couldn't go near her. You couldn't. And that was a massive change because she was a very cuddly wee girl. I think the responsibility has probably been one of the biggest challenges we've faced in our twenty-four years of marriage because it's a horrible fight. And it is twenty-four seven. And Maria sadly was self-harming as well, so we had to keep a twenty four hour watch on her. And because she didn't want people to know, we had no outside help at all. So FBT was definitely our lifeline (becomes tearful).

Commit to FBT
Identity
Rel. changed
Trust impact
Fear of child going to hospital
Isolation

Interviewer: Oh gosh, that sounds like a huge amount to deal with.

Anna: Well yes and no. I mean I suppose looking back and I think now exhaustion's setting in further down the line because you do let go of that bit of control. I think my husband and I were very lucky because we tend to play to each other's strengths. And there was things, he would speak to her in a way that I really struggled with. And I'd be like you can't do that because she's not capable of taking that. And she would say, Mum, just let dad be dad. Whereas I was possibly overprotective as her mom. But I think we kind of had to say, you need to do it your way and I need to do it my way an we just need to kind of meet in the middle and be strong for Maria.

Support
Family
Identity - protect

Interviewer: Okay. So it sounds like maybe your styles complemented each other in some ways?

Anna: Hopefully, well hopefully. We were very lucky in that my husband is self-employed. And although he was actually quiet on the lead up to Christmas, and financially, that was a massive worry to us. I kind of think and this is where my religion comes into it because I prayed for her all the time. But I think that was God's way of helping. Because he was there and normally, he works very long hours and I'm on my own. And I think that kind of helped, and me being a child minder as well, I'm at home anyway. And then there's babies in the house and then many times that was how she'd get up out of bed to spend time with the babies so it could be hidden,

Stress competing pressures
Self Employed
time easier

File name P5 Interview MRP.MP3

3

Appendix 9:
DEBRIEFING DOCUMENT

University of Glasgow | College of Medical, Veterinary & Life Sciences

NHS Lanarkshire

DEBRIEFING SHEET

Title of Project: Engaging in family-based therapy for adolescent EDs: An interpretative phenomenological analysis of parental perspectives.

Thank you for taking the time to take part in this research project. Your time and input are greatly appreciated.

The aims of this study were:

- to gain a rich understanding into the lived experience of parents and carers of young people who are engaging in family-based therapy for EDs,
- to explore the psychosocial impact that this has on parents and carers,
- to draw conclusions from participants data which may inform clinical practice on how best to support families engaging in this treatment.

It is hoped that the findings from the project can be used to inform healthcare professionals on the support needs of parents and carers of young people with EDs, the challenges parents and carers face and how services can more effectively meet their needs.

If you have been affected by the content of the interview, please do not hesitate to contact the following helplines:

NHS 24 Helpline
- Ph: 111
- Website: http://www.nhs24.com/

Breathing Space Helpline
- Ph: 0800 83 85 87
- Website: http://breathingspace.scot/

Samaritans
- Ph: 08457 90 90 90
- Website: http://www.samaritans.org/

All results will be handled only by the research team and appropriate governance staff. Results will be held on a password protected computer and in a locked filing cabinet. The findings may be published in an academic journal or discussed at a conference but, due to the anonymous nature of the interview no individuals will be personally identifiable.

Any further questions about this study can be directed to the primary researcher, Rachel Hanson at r.hanson.1@research.gla.ac.uk. Also, if you would like to know about the results of this study please let the researcher know via email and she will be happy to provide you with a summary of the key findings. Results will be communicated when the research has been completed, this may take to twelve months from the date of your interview.

Thank you again for your participation.

APPENDIX 10

Supplementary Coping Subthemes

Respite

Parents reported that respite from their caring role helped them to better cope with the enormous task of supporting their child's recovery. Emer viewed going to work as a break from the relentlessness of refeeding at home:

> *"I felt my work was my release, that was like my therapy. Going away and cleaning someone's house and knowing that Karen was with my mum, and I knew my mum would look after her"* (Emer)

Similarly, Joanna reported that her son staying at his brothers meant she had some respite from her caring and refeeding role:

> *"when Connor was hating us, then it was a good time to go to his older brother's because he saw him not as parents, although he knew to do the same things… It was respite for me. Just getting him out of the house without having to worry. That they had him, and he was safe, and they were feeding him, because they knew what to feed him. Yes. Sometimes just not having that worry."* (Joanna)

For Emer and Joanna, it seems that knowing their child is being looked after by someone who is aware of FBT is crucial to their experience of getting respite from their caring role. It gave them reassurance that in those moments they do not need to worry about their child.

Christine who is a stay at home mother reported getting no respite from her caring role and that this was very challenging:

> *"I'm living with it morning, noon and night, I'm not getting away from it for even five minutes. To go to the toilet is the only time I've been getting away from it. You're so frazzled that you allow it. You do back down on certain things because you're so wasted that you can't even think."* (Christine)

This lack of respite impacted her energy and she perceived that her capacity to battle with the eating disorder was decreased as a result.

Suppressing Own Needs

It was observed that parents appeared to suppress their own needs during the more challenging phases of treatment, the refeeding phase:

> *"Yes, stress levels at some points were through the roof, I mean completely through the roof…It's very stressful, yes, but you've got to try and push that aside as best you can, because it's not about me. It's about Heather or the person that's suffering from that particular illness."* (Jason)

Similarly, Simon reported disconnecting from his emotions in order to cope with the demands of FBT:

> *"Emotionally, I was, um, disconnected for that period of time"* (Simon)

These accounts suggest that during the most stressful stages when parents are feeling anxious, under pressure and are dealing with challenging behaviour the only way for them to carry on with this intensive treatment was to suppress their own needs and maintain a single focus on supporting their children to restore weight.

> *"I knew that I was finding it really, really hard, yeah. And I was very emotional. So I suppose I was aware of it, but I was just more focused on getting her better because her illness definitely was a priority."* (Melissa)

Melissa's account captures the sense that parents are so embroiled in their battle against the eating disorder that there is simply no time or headspace to reflect on their own needs until their child is healthy again.