

**How do patients with anorexia and their carers experience
Community Treatment Orders?**

Kim Mihaljevic

**DClinPsy Thesis (Volume 1), 2020
University College, London**

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



Name: Kim Mihaljevic

Date: 10th July 2020

Overview

Part one of this volume is a systematic review examining the evidence base for interventions for carers within the eating disorder population. A total of 21 studies were identified. The majority of case-control studies found significant improvements in measures of carer wellbeing, self-efficacy and caregiving burden. This was change was not found in randomised control trials. Overall the studies provide promising findings for the emerging field of carer interventions but suggest a need for greater follow-up to ensure long-term efficacy.

Part two is a qualitative study that explored how patients with anorexia and their carers experience Community Treatment Orders. This project was conducted jointly with another trainee clinical psychologist, Vallabhi Khurana. Semi-structured interviews were conducted with six patients and four carers and analysed using Interpretive Phenomenological Analysis. Patients and carers both felt that experiences of the CTO were dependent on methods of implementation and enhanced by positive relationships with professionals. Patients discussed the difficulties of engaging with the CTO due to their anorexia, and carers talked about the impact of the CTO on their lives, in particular their relationship with patients.

Part three is a reflective discussion of the process of developing and carrying out the qualitative study. It focuses on three areas: the background of the researcher, reflections on conducting qualitative research in eating disorders and the process of data analysis.

Impact statement

Anorexia Nervosa is a serious illness with the highest mortality rate amongst mental illnesses disorders. Statistics suggest that in 20% of individuals, the illness develops a chronic course. This can lead to ongoing fluctuations in weight that require frequent hospitalisation. Eating disorders have their peak onset during adolescence, when children are living at home with their parents, and have significant impacts on the family. As adults, these individuals may require high levels of support, which is often provide by family carers who have very little formal training. As patients with eating disorders are often highly ambivalent to treatment and recovery, supporting patients with their recovery can have a significant impact on carer wellbeing. Research suggests that carer burden within this population is extremely high, and that carers are often offered very little support. This thesis aimed to explore two aspects of eating disorders treatment: what interventions are available for carers, and how patients and carers experience one form of community management of the illness, Community Treatment Orders.

Overall, this thesis aimed to investigate less explored treatment routes within the eating disorders population. The systematic review found that there has been a significant increase in interest in the wellbeing of carers over the last ten years. This review aimed to update a previous meta-analysis and included 13 additional studies. The review also expanded on previously reviewed outcomes, to include an examination of associated patient outcomes, and exploration of treatment adherence across interventions. Results from this review could be used to guide the future direction of research. Of particular importance would be the need for more consistent follow-up within studies, a greater consideration of the effect of patient and carer demographics on carer outcomes, and the consideration of patient outcomes in response to interventions.

The empirical paper is the first to investigate how Community Treatment Orders are experienced in an eating disorder population. The qualitative nature of

the study allowed for an in-depth analysis of the experiences of patients and carers. Findings reflected commonalities with previous research in psychosis populations, but with additional consideration of the role of anorexia in adherence and engagement. They suggest clinical implications around the need for clear, transparent communication from professionals, and collaboration with patients and carers around treatment goals. They suggest additional considerations of how CTOs can be used more effectively within this population. This includes the implementation of additional support in the community and setting goals for not only weight but to further develop a patient's identity. These findings can also be used as guidance for further research to investigate CTO implementation and effectiveness.

Table of Contents

Acknowledgements	8
Part 1: Literature Review	9
Abstract	10
Introduction.....	11
Caring for individuals with mental health difficulties	11
Caregiving in Eating Disorders	11
Interventions for carers.....	13
Research to date	14
Method	16
Search strategy and criteria.....	16
Selection.....	16
Outcomes	17
Data-synthesis.....	21
Results	21
Quality Appraisal	21
Sample characteristics	24
Carer interventions and treatment adherence.....	28
Impact on carers.....	30
Impact on patients	38
Discussion	40
Limitations and future research	42
Conclusion.....	43
References	44
Part 2: Empirical Article.....	54
Abstract	55
Introduction.....	56
Anorexia Nervosa	56
What are Community Treatment Orders?	57
Effectiveness of CTOs.....	58
Patient experiences	59
Carer involvement	60
CTO use in Eating Disorder Services.....	61
Research Aims	62
Method	62
Recruitment	62
Ethics.....	63
Participants.....	63
Data Analysis.....	66
Reliability and Validity.....	67
Researcher's perspective	68
Results	68
Contextual data	68
Organisation of themes	69
CTO as a framework	70
Patient Themes	74
Carer Themes.....	78
Summary of main findings	81
Discussion	82
Experiences of CTOs	82
The impact of anorexia	84
Limitations of the study.....	85

Clinical implications	87
Research implications	88
Conclusion.....	88
References	90
Part 3: Critical Appraisal	98
Background	99
Conducting research in eating disorders.....	100
Qualitative analysis	103
References	106
Appendix A: Adapted Qualsyst Tool	107
Appendix B: Flyer for patients	108
Appendix C: Patient information sheet	109
Appendix D: Carer information sheet.....	113
Appendix E: Joint trainee contributions	118
Appendix F: Letters of Approval (REC and HRA)	119
Appendix G: Consent form for patients	124
Appendix H: Consent form for carers	125
Appendix I: Interview Schedule for Patients	126
Appendix J: Interview schedule for carers	129
Appendix K: Example of initial coding stage	132
Appendix L: Example of coding emerging themes.....	133
Appendix M: Example of table grouping themes	134
Appendix N: Master and subthemes developed for carers.....	135

List of Tables and Figures

Table 1. Quality assessment of studies.....	23
Table 2. Sample characteristics across studies	25
Table 3. Significant findings in carer outcomes.....	31
Table 4. Significant findings in patient outcomes	38
Table 5. Patient Themes	69
Table 6. Carer Themes	70
Figure 1. Carer involvement within the maintenance of an eating disorder	13
Figure 2. Flow diagram of study search and selection.....	17

Acknowledgements

Firstly, I would like to thank both my supervisors, Dr John King and Dr Lucy Serpell for their invaluable support throughout this process. John has stuck with me throughout the long process and has been a constant calming presence, whilst Lucy has always been there to energise and provide sound advice from her experience working within the field.

I am enormously grateful for my research counterpart and friend, Vall, without whom I could still be lost amongst the sea of thesis projects. She has been a great research partner and the whole process feels like it was just that slight bit easier having her by my side.

A massive thank you to the patients and carers who shared with us their experiences and reflections, and without whom this research wouldn't have been possible. I would also like to thank our service user representative, who fed back on our interview questions and provided invaluable insight into her experiences so we could further tailor our questions. I am also indebted to all the professionals who took the time to speak to us about our research and put in so much effort to ensure that we were able to recruit participants.

Last but not least, I'd like to thank my friends and my family for their unyielding support over the last two years (and more). I am particularly grateful to Chris, for pulling me out of the hole of thesis

Part 1: Literature Review

Interventions for Carers of Individuals with Eating Disorders: A Systematic Review

Abstract

Aims: There has been a recent emergence in the literature surrounding interventions targeted at reducing caregiver burden in carers of individuals with eating disorders. This review aimed to update a previous meta-analysis to develop a greater understanding of the efficacy of interventions on both carer and patient outcomes.

Method: Studies were identified through a systematic search of online databases: PsycINFO, Medline and Web of Science. Only quantitative studies were included, and a quality analysis was completed using an adapted version of the Quallsyst tool (Kmet, Lee & Cook, 2004).

Results: A total of 21 studies were included in the review. There was a higher rate of adherence to workshop over self-help interventions across studies. Case-controlled studies found consistent improvements in carers wellbeing, feelings of self-efficacy, caregiving experiences and expressed emotions. However, no consistent changes were identified in randomised control trials or for patient outcomes across studies.

Conclusions: This review builds on previous findings about the effectiveness of carer interventions in this population. As the research remains in its infancy, many studies were designed as proof-of concept and therefore had small sample sizes and inconsistent reporting of follow-up data. Further research is needed to assess longer-term outcomes and compare the efficacy of workshop and web-based approaches.

Introduction

Caring for individuals with mental health difficulties

A carer is described as anyone who looks after a family member, partner or friend who needs additional help because of their illness, disability or mental health problem, and cannot manage without their support (Commissioning for Carers, 2014). Across mental health services over the last 30 years, there has been a shift towards community care, and there are currently 1.5 million carers of individuals with mental health difficulties. These carers play a vital role by providing individuals with long-term practical and emotional support (Lauber, Eichenberger & Luginbuhl, 2003; Magliano et al., 2007).

Caring for someone with mental health difficulties is a dynamic process that must adapt to an individual's changing condition. Caring responsibilities have been found to have an adverse impact on the physical and mental health, education and employment potential of those who care (Oyebode, 2005). Research suggests that carers show an increase in emotional distress and depressive symptoms, and that there is a decrease in engagement in health promotion actions amongst this group (Amirkhanyan & Wolf, 2003; Danhauer et al., 2004; De Fazio et al., 2015; Ogilvie et al., 2005; Shah, Wadoo & Lato, 2010). Caregiver burden, the strain caused by caring for an individual with a chronic illness, is a key outcome identified across the caregiving literature (Zabala, Macdonald & Treasure, 2009). Caregiver burden is generally associated with poorer mental health, lower quality of life, and experiencing negative aspects of care more intensely (de la Rie et al., 2005; Martin et al., 2013). These difficulties often have a direct effect on the nature and quality of caregiving abilities (Askey et al., 2009).

Caregiving in Eating Disorders

Eating disorders (EDs) are serious mental disorders characterised by abnormal eating patterns and severe subjective concern about body weight or shape (Klump, 2013). All eating disorders have an impact on an individual's mental

and physical health, with anorexia being the leading cause of mental health related deaths (Chesney, Goodwin & Fazel, 2014). They have their peak onset in adolescence, at a time when most individuals are still living at home with parents (Gendall & Bulik, 2005).

Caring for a child with an ED can have a significant emotional impact on the family (Kyriacou, Treasure & Schmidt, 2008b). Research suggests that there is no 'typical family' in cases of ED, however family members can become engaged in unhelpful patterns of behaviour that maintain the illness (Treasure, et al., 2007). For example, some families may turn a blind eye to an individual's eating during mealtimes or give in to an individual's rules associated with eating, such as accepting the use of scales to weigh out portions. Highly stressed and anxious parents are also at risk of developing higher levels of expressed emotion. For example, this could involve parents becoming emotionally overinvolved and limiting the individual's independence or becoming highly critical of the individual.

Though these patterns are described in families with young children, research suggests that these patterns also occur in families with adults with ED (Anastasiadou et al., 2014; Treasure et al., 2007). Additionally, these difficult patterns of interaction have been found to have a further negative impact on ED symptoms and hinder an individual's recovery. The interpersonal maintenance model of anorexia nervosa exemplifies the pattern that families can become entrenched in when caring for an individual with anorexia (Figure 1; Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

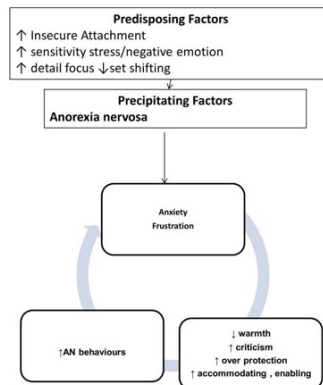


Figure 1. Carer involvement within the maintenance of an eating disorder

Interventions for carers

Current guidelines advocate for the involvement of family members in treatment (National Institute for Health and Care Excellence, 2017). They are considered as part of the solution and possibly the best resource for aiding in their relative's recovery (Downs & Blow, 2013; Eisler, 2005). However, Winn et al. (2004) found that carers felt that they often do not have the skills or resources to support an individual with ED. They identified several helpful important factors, including the need for information about ED earlier, practical advice, and guidance on how to manage ED-related behaviours. Additional research into this area has found confusion amongst carers about their role in an individual's treatment, which can contribute to communication difficulties within families and with professionals, and conflict with the patient (Graap et al., 2008; Haigh & Treasure, 2003).

A range of interventions have been developed to increase carers' knowledge and capabilities, in turn helping to make the caregiving role less burdensome and stressful. Family-based therapy (FBT) in the community is the first line of treatment recommended by NICE guidelines for Anorexia Nervosa and Bulimia Nervosa in young people (NICE, 2017). The focus of FBT is to equip parents with knowledge and behaviour change skills, such that they feel able to actively monitor and assist their child in returning to a healthy weight. However, it has only been found to be

effective for children and young people, and has not been found to be effective in adult cases (Fisher, Hetrick & Rushford, 2010).

Specific carer interventions have been studied in predominantly adult ED populations and range from self-help workbook and web-based interventions to psychoeducation groups and workshops. Self-help materials are extremely common as they are easy to develop and disperse to large groups of people. This has been seen as a benefit especially in remote areas. Due to the lack of contact with professionals, several studies have investigated the additional impact of therapeutic guidance in these interventions, mainly in the form of telephone coaching (Hoyle et al., 2013). Groups and workshops have been identified as having the alternate benefit of allowing caregivers to meet other people in a similar situation and share their stories (Dimitropoulos et al., 2019).

Interventions also varied by their content and the way they targeted caregiver distress. Several studies have designed their interventions around the interpersonal maintenance model of anorexia (Schmidt & Treasure, 2006) such that they target unhelpful patterns of interaction between caregivers and individuals with ED. Other studies used therapeutic techniques from motivational interviewing and cognitive behavioural therapy to produce behaviour change, or specific management skills based on exposure models. Some more recent studies have investigated the use of a more transdiagnostic approach to target impairments in emotional regulation that may be present in ED, using emotion-focussed family therapy. However, despite the shift towards community support, interventions for carers in the ED community remain early in development.

Research to date

A recent meta-analysis by Hibbs et al. (2015b) found 13 studies matched their criteria for a review of interventions for caregivers within this field. They concluded that interventions were associated with a decrease in carer distress, caregiver burden and expressed emotion over time, though found no difference in

carer contentedness. They noted limitations including high heterogeneity of samples and the inclusion of only five Randomised Control Trials that may have impacted on the robustness of their analysis.

Rationale and aims

The current review will update the literature on available evidence on caregiver interventions. Due to the variation of data presentation across studies and lack of RCTs, it was decided that a systematic narrative synthesis of the literature would provide a more inclusive indication of the current state of the literature.

This review aimed to:

- 1) Explore the pattern of intervention adherence across studies
- 2) Explore changes in carer outcomes post-intervention and at follow-up
- 3) Explore changes in patient outcomes

Method

Search strategy and criteria

Electronic databases were used to identify relevant articles. The databases used were: PsycINFO (between January 1, 1806 and October 9, 2019), Medline (between January 1946 and October 9, 2019), and Web of Science (between January 1, 1900 and October 9, 2019). Additional searching through reference lists and relevant journals was also performed.

A search strategy was developed based on strategies used by Hibbs et al (2015b). The search terms used were: "eating disorder" or anorexia or bulimia or "disordered eating" AND carer or "primary carer" or parent or caregiver AND skill* or "self-efficacy" or communication or burden or "quality of life" or understanding or coping or wellbeing or anxiety or depression or "mental health" AND intervention or treatment or workshop* or "parent* group" or "carer group".

The inclusion criteria for the study was: a) focus on caregivers of individuals with an ED, b) employed the use of an intervention, c) published in English in peer-reviewed journals, d) minimum of 15 participants per group, and e) outcomes were assessed quantitatively. An intervention was defined as any program designed to increase caregiver's knowledge and skills when caring for an individual with an eating disorder.

Selection

Study selection was conducted by one researcher. Articles sourced from the initial search were then screened by the content of their abstracts and then relevant manuscripts retrieved. Full text articles were then assessed further for suitability (see Figure 2 for CONSORT diagram of study selection). A manual search of the literature revealed two further studies. Two studies included the same measures for the same sample, Hodsoll et al. (2017) and Salerno et al. (2016). Hodsoll et al. (2017) was chosen as they reported the two interventions groups separately, while Salerno et al. (2016) amalgamated intervention groups into one.

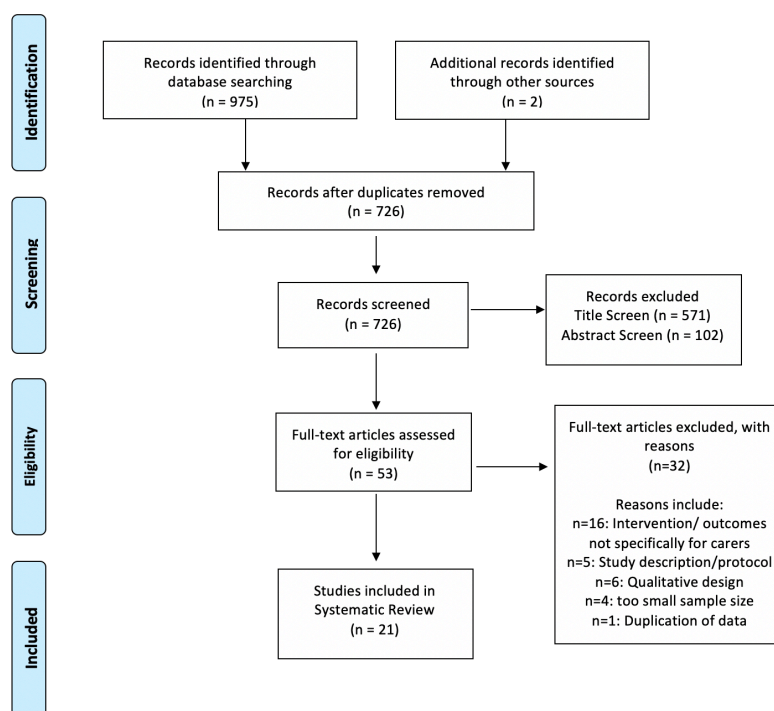


Figure 2. Flow diagram of study search and selection

Outcomes

The initial search yielded outcomes for the following carer variables: a) psychological distress, b) caregiving experience, c) accommodation and enabling behaviours, d) expressed emotion, and e) carer self-efficacy. All outcome measures were obtained pre- and post-intervention. Sixteen studies had measured outcomes at follow-up. Descriptions of the different instruments used to measure these are given below.

Seven studies also took into account patient variables in their analysis. The most commonly reported variables across studies were a) psychological distress, b) body mass index, and c) eating disorder features.

Psychological distress

The following questionnaires were used across both carer and patient groups:

General Health Questionnaire (GHQ-12). This assesses for the presence of psychiatric disorders and it consists of 12 items with a four-point Likert scale (Goldberg & Williams, 1988). Higher scores indicate higher distress.

Hospital Anxiety and Depression Scale (HADS). This measures levels of anxiety and depression (Zigmond & Snaith, 1983). It consists of 14 items on a four-point Likert scale, that are separated into two subscales, anxiety and depression. Higher scores indicate higher levels of anxiety and depression.

Depression, Anxiety and Stress Scale (DASS-21). This consists of 21 items scored in a four-point Likert scale (Lovibond & Lovibond, 1995). The DASS measures depression, anxiety and stress on three separate subscales consisting of seven items each. Higher scores indicate higher levels of each domain.

Caregiving experience

Experience of Caregiving Inventory (ECI). This measures the experience of caring for an individual with a severe mental illness (Szmukler et al., 1996). It consists of 66 items assessed with a five-point Likert scale. Questions are grouped into two dimensions: a negative dimension of caring and a positive dimension of caring. The negative dimension consists of eight subscales: difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need to backup, dependency and loss. The positive dimension consists of two subscales: positive personal experiences and good relationship with the patient. Higher scores indicate a more positive or negative appraisal of caregiving.

Eating Disorder Symptom Impact Scale (EDSIS). This measures the specific impact of the ED symptoms on the caregiver and family life (Sepulveda et al., 2008). This more specifically refers to the symptoms of nutrition, dysregulated behaviours, guilt, and social isolation. It consists of 24 items using a five-point Likert scale. Higher scores indicate a more negative impact on the family.

Accommodation and Enabling Behaviours

Accommodation and Enabling Scale for Eating Disorders (AESED). This is a 33-item questionnaire with a five-point Likert-scale (Sepulveda, et al., 2009). It measures the extent to which the caregiver tolerates or allows ED behaviours at home. This more specifically includes avoidance and modifying routines, reassurance seeking and “turning a blind eye.” Higher scores indicate higher levels of accommodation to the ED symptoms by the family.

Expressed Emotion

Five-Minute Speech Sample (FMSS). This involves a five-minute interview with a key relative (Magaña et al., 1986). EE ratings are calculated for criticism (high EE is one or more critical comments), and/or the presence of hostility, and/or a rating of three or more on the emotional over-involvement (EOI) scale. The interviews are scored quantitatively on the different EE indices, or in a dichotomous fashion, either high in EE, criticism or EOI, or low in EE, criticism or EOI.

Level of Expressed Emotion Scale (LEE). This has two versions, of which the caregivers' version is used across studies in this review (Cole & Kazarian, 1988). It consists of 60 items with two responses, false or true. It measures intrusiveness, emotional response, attitude towards the illness and tolerance or expectations. A higher total EE score indicates higher levels of EE. The authors have given a cut-off point for the global score to define high-EE caregivers (Cole & Kazarian, 1993).

Family Questionnaire (FQ). This consists of 20 items with a four-point Likert-scale (Wiedemann et al., 2002). Items are then grouped into two subscales: Criticism and EOI. Higher scores indicate higher levels of EE.

Self-efficacy

Parent Versus Anorexia Scale (PVA). This is a 7-item measure (Rhodes, Baillie, Brown, & Madden, 2005). Each item is rated on a 5-point Likert scale. Higher scores indicate greater parental self-efficacy.

Revised Scale for Caregiving Self-Efficacy (RS-CSE). This contains 15 items and assesses caregivers' beliefs about their ability to carry out several caregiving activities (Steffen et al., 2002). Each item is rated on a scale from 0 to 100. The Spanish validation of the Revised Scale for Caregiving Self-Efficacy used in Sepulveda et al. (2018) showed appropriate psychometric properties with Cronbach's α between 0.79 and 0.86 (Márquez-González et al., 2009).

Body Mass Index (BMI)

BMI was calculated across studies from a comparison of patients' height and weight.

Eating Disorder Questionnaire

The Eating Disorder Examination Questionnaire (EDE-Q) is a well-established measure designed to assess eating disorder psychopathology (Fairburn & Beglin, 2008). It is derived from the Eating Disorder Examination (EDE) interview (Fairburn & Beglin, 2008). It is comprised of 28 items assessing eating disorder behaviours, attitudes and feelings.

Quality Assessment

All papers that met the inclusion criteria were subject to a formal assessment using the Quallsyst tool for quantitative research papers (Kmet, Lee & Cook, 2004). It was selected for its ability to assess and compare clinical outcomes across the range of study designs presented in this review. This tool appraises fourteen categories of methodological and reporting factors, including sufficient description of research aims, methods and selection, data analysis and results presentation.

The tool was adapted for use, and as such included fifteen categories. No studies were able to blind participants to trial group, and so this category was removed. The researcher decided that it was also important to include information about intervention completion, and degree of follow-up of participants, and so these categories were added (see Appendix A for adapted checklist).

Qualsyst operates on a scoring system ranging from 0-2, with a higher score indicating greater quality of design and reporting. Regarding completion rates, this scoring system was adapted such that studies with greater than 80% of participants completing the intervention scored 2, studies with 60 and 80% of participants completing the intervention scored 1, and studies with less than 60% of participants completing the intervention, or no information about completion rates, scored a 0.

As the tool is intended to cover a broad range of study designs, some criteria were not deemed applicable across all studies, for example use of a control group. Studies where certain criteria were deemed inapplicable were separated by type. Consequently, three categories of studies emerged from the data: Randomised Control Trials (RCTs), Intervention Comparison (IC) Studies and Pre-Post Design (PPD) Studies. PPD studies involved one group of participants where measures were taken before and after intervention, and so could not be rated on control design or randomisation. IC studies involved two interventions being compared but did not include a control group, and RCTs involved at least two groups where one acted as a control for comparison.

Data-synthesis

The focus of this review was on change pre- and post- intervention. A meta-analysis was considered, however due to the heterogeneity of the outcome data across studies, this was not deemed possible. Consequently, the data is presented in a narrative format.

Results

Quality Appraisal

Overall the studies included in the current review ranged in quality between 50% and 93%, representing a broad spectrum of study quality. Scores for each criterion and summary scores can be seen in Table 1 below. To ensure that the quality of studies remains relevant, this analysis will be referred to across the results and discussion sections.

This analysis identified five studies as scoring below 60%, of which two were RCTs (Hoyle et al. 2013; Robinson et al, 2016; Spettigue et al, 2015; Strahan et al, 2017; Uehara et al, 2001). Of the two RCTs, Hoyle et al. (2013) used a web-based intervention and Spettigue et al. (2015) used a workshop intervention. These studies rated low as they did not meet criteria regarding study participants, used an inadequate sample size, did not control for confounding variables and did not have adequate follow-up of participants. Additionally, though Hoyle et al. (2013) reported a control group in their CONSORT diagram, there was no reference to the control group throughout the results and discussion section. The remaining three papers (Robinson et al, 2016; Strahan et al, 2017; Uehara et al, 2001) were all PPD studies and implemented workshop interventions. These did not meet quality criteria due to inadequate reporting of study participants and sample size, high attrition rates throughout the intervention and a lack of follow-up. There was also no mention of controlling for confounding variables, including missing data.

In contrast, the highest score for RCTs was 93% (Hibbs et al., 2015a), and two additional RCTs scored 90% (Magill et al., 2016; Hodsoll et al., 2017). All studies used a self-help format and were conducted by King's College, London. Hibbs et al. (2015a) and Magill et al. (2016) reported on the same study but at different time points, at 6 and 12 months, and 24 months respectively. Hibbs et al. (2015a) was methodologically strong in its description of the randomisation and blinding procedures, and thorough reporting of the results. The only criteria rated partial were intervention completion, as 68% completed minimum threshold, and follow-up, as there was follow-up but over 30% attrition. In addition to this, Magill et al. (2016) received a partial criterion for their reporting of sample characteristics. Hodsoll et al. (2017), had sound methodology however a very low intervention completion rate, where an average of 36% of the intervention group read more than 50% of the books, and 22.5% watched more than 50% of DVDs.

Across the IC and PPD studies, Sepulveda et al. (2008) and Sepulveda et al. (2010) rated over 90% at 96% and 92% respectively, both workshops run by King's College, London. Both studies only partially fulfilled the sample size criterion (35 and 47 carers respectively) but benefitted from high intervention completion and follow-up rates, and sound reporting of methodology and results.

Table 1. Quality assessment of studies

	Aim described?	Study design?	Subject Selection?	Subject characteristics?	Random Allocation?	Blinding?	Outcomes robust?	Sample Size appropriate?	Data analysis described?	Estimate of variance?	Intervention completed?	Confounders?	Follow-up?	Results reported?	Conclusions supported?	Score
Pre-Post Design Studies																
Uehara et al. (2001)	Green	Green	Green	Yellow	-	-	Yellow	Red	Red	Green	Yellow	Red	Red	Green	Green	58%
Sepulveda et al. (2008)	Green	Green	Green	Green	-	-	Green	Yellow	Green	Green	Green	Green	Green	Green	Green	96%
Sepulveda et al. (2010)	Green	Green	Green	Green	-	-	Green	Yellow	Green	Green	Green	Yellow	Green	Green	Green	92%
Gisladdottir & Svavarsdottir (2011)	Green	Green	Green	Yellow	-	-	Yellow	Red	Red	Green	Green	Red	Red	Green	Green	61%
Grover et al. (2011a)	Green	Green	Green	Green	-	-	Yellow	Yellow	Green	Green	Green	Green	Yellow	Green	Green	88%
Gisladdottir et al. (2016)	Green	Green	Green	Yellow	-	-	Yellow	Yellow	Green	Green	Green	Green	Green	Green	Green	88%
Robinson et al. (2016)	Green	Yellow	Green	Red	-	-	Yellow	Red	Yellow	Green	Red	Red	Red	Green	Green	50%
Jenkins et al. (2017)	Green	Yellow	Green	Green	-	-	Yellow	Green	Green	Green	Green	Yellow	Red	Green	Green	81%
Strahan et al. (2017)	Green	Green	Red	Red	-	-	Yellow	Green	Red	Green	Red	Red	Red	Green	Green	50%
Ganci et al. (2018)	Green	Green	Green	Yellow	-	-	Green	Yellow	Red	Green	Green	Red	Yellow	Green	Green	73%
Intervention Comparison Studies																
Goddard et al. (2011)	Green	Green	Red	Green	Green	Red	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	83%
Dimitropoulos et al. (2018)	Green	Green	Green	Yellow	Green	Red	Green	Yellow	Yellow	Yellow	Green	Green	Green	Red	Yellow	67%
Quiles Marcos et al. (2018)	Green	Green	Green	Green	Green	Green	Yellow	Yellow	Green	Green	Red	Yellow	Yellow	Green	Green	80%
Sepulveda et al. (2018)	Green	Green	Green	Green	Yellow	Red	Green	Red	Green	Green	Green	Yellow	Yellow	Green	Green	77%
Randomised Control Trials																
Grover et al. (2011b)	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Red	Green	Yellow	Yellow	Green	83%
Hoyle et al. (2013)	Green	Yellow	Yellow	Red	Yellow	Green	Green	Red	Red	Green	Green	Red	Yellow	Red	Yellow	50%
Hibbs et al. (2015a)	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Yellow	Green	Green	93%
Spettigue et al. (2015)	Green	Yellow	Green	Red	Yellow	Red	Yellow	Red	Green	Green	Red	Red	Green	Green	Green	57%
Magill et al. (2016)	Green	Green	Green	Yellow	Green	Green	Green	Green	Green	Green	Green	Yellow	Yellow	Green	Green	90%
Hodsoll et al. (2017)	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Red	Green	Yellow	Green	Green	90%
Quadflieg et al. (2017)	Green	Green	Green	Green	Green	Red	Yellow	Green	Green	Green	Green	Green	Yellow	Green	Green	87%
Key	Green	Yellow	Red				Light Green	Yellow	Red							
	Criteria fully met	Criteria partially met	Criteria not met				Score >80%	Score between 60-80%	Score <60%							

Sample characteristics

Sample characteristics can be found in Table 2 below. Regarding the carer sample, the mean age of carers ranged from 45.4 to 53.3, and the majority, between 53% to 100%, were female. The majority of carers (>69%) lived with the patient, and an equal proportion of carers spent high (>21 hours) and low (<21 hours) amounts of time with patients throughout the week.

Patients ranged in diagnosis across studies. Only five studies recruited only patients with anorexia and one study recruited patients waiting for an assessment and diagnosis of an ED. The remaining studies recruited carers of patients with a range of diagnoses, including anorexia, bulimia and eating disorder not otherwise specified (EDNOS). The mean age of patients ranged between 15.2 and 28 years, where only two studies specified recruitment of children and young people (up until the age of 24). The majority of patients were female, between 80-100%. Illness duration was on average between 1 to 6 year, however it was unclear whether this was from diagnosis or from parental report of symptom onset.

Table 2. Sample characteristics across studies

Authors	Carer Details					Patient Details			
	Gender of Carer	Relationship to patient	Age (Years, Range)	Living with patient	Time with Patient (hours)	ED type	Age (years)	Gender	Illness Duration (years)
Uehara et al. (2001)	Female 93% Male 7%	Parents 93% Other 7%	NR	NR	NR	AN 69% BN 27% EDNOS 4%	20.1 (8.1)	Female 96% Male 4%	4.5 (4.7)
Sepulveda et al. (2008)	Female 82.1% Male: 17.9%	Parents 92.9% Spouse 3.6% Other 3.6%	52.7 (7.2), Range: 28-68	75%	<21 hrs: 41% >21hrs: 59%	AN 78% BN 22%	22.7 (7.7), Range: 15-33	Female: 100%. Male: 0%	6.1 (6.1)
Sepulveda et al. (2010)	Female 91.5% Male 4%	Parents 95.6% Sibling 4.4%	53.33 (7.7), Range: 28-78	76%	<21 hrs: 37.8% >21hrs: 62.2%	AN 77.8% BN 22.2%	21.5 (5.3), Range: 9-43	Female: 93.5%. Male: 6.5%	3.07 (3.1), Range: 1-12
Gisladottir & Svavarsdottir (2011)	NR	Unclear	NR	NR	NR	BN 57% AN 19% EDNOS 10% Unknown 14%	21, Range: 15-31	Female: 100%. Male: 0%	NR
Goddard et al. (2011)	Female 89% Male 11%	NR	ECHO: 50.5 (6.9) ECHOc: 48.7 (9.1)	79%	<21 hrs: 40% >21hrs: 60%	AN 85% BN 9% EDNOS 6% Recovered 3.7%	ECHO: 20.8 (6.9) ECHOc: 20.9 (6.8)	Female: 95.4%. Male: 4.6%	ECHO: 3 (7) ECHOc: 4 (7)
Grover et al. (2011a)	Female 63% Male 33.3% Unknown: 3.7%	Parents 74.1% Spouse 22.2% Sibling 3.7%	50 (12.4), Range: 19-65	NR	NR	AN 88.9% EDNOS 7.4%	28 (9.45), Range: 14-55	NR	7 (8.37)
Grover et al. (2011b)	Female 79.4% Male 15.8% Unknown: 4.8%	Parents 87.3% Spouse 7.9% Other 4.8%	OAO: 47.3 (8.7), Range: 22-61 TAU: 49.1 (6.2), Range: 33-57	78%	NR	AN 77.8% EDNOS 20.6% Unknown 1.6%	OAO: 21.1 (7), Range: 12-44 TAU: 19.7 (5.2), Range: 13-33	NR	OAO: 4.7 (4.9), Range: 0.5-18 TAU: 3.8 (4), Range: 0.3-17
Hoyle et al. (2013)	Female 89% Male 11%	NR	NR	83%	NR	AN	NR	NR	NR

Abbreviations: AN, Anorexia Nervosa; BN, Bulimia Nervosa; EDNOS, Eating Disorder Not Otherwise Specified; NR, Not Reported; ECHO, Experienced carers helping others; OAO, Overcoming Anorexia Online

Table 2. Sample characteristics across studies cont.

Authors	Carer Details					Patient Details			
	Gender of Carer	Relationship to patient	Age (Years, Range)	Living with patient	Time with Patient (hours)	ED type	Age (years)	Gender	Illness Duration (years)
Hibbs et al. (2015a)	Female 60% Male: 40%	Parents 84% Spouse 10.4% Other 5.6%	ECHO: 52.22, Range: 22.22-78.54 TAU: 53.18, Range: 19.7-78.88	NR	<21 hrs: 52% >21hrs: 48%	AN	ECHO: 23.2, Range: 12.5-62.7 TAU: 24.3, Range: 13.7-57.3	Female: 83.5% Male: 16.5%	ECHO: 6, Range: 1-38 TAU: 6.5, Range: 0.75-40
Spettigue et al. (2015)	Female 92.2% Male 7.8%	Parents 98% Other 2%	NR	NR	NR	Awaiting assessment	NR	NR	NR
Gisladottir et al. (2016)	Female 81% Male 13% Unknown 6%	Parents 94% Other: 6%	45.4, Range: 30-62	NR	NR	AN 78.1% BN 12.5% EDNOS 9.4%	16.2, Range: 12-24	NR	Range: 2-6
Magill et al. (2016)	NR	Parents 84% Partner 10% Other 5.6%	NR	69%	<21 hrs: 52% >21hrs: 48%	AN	27 (9)	NR	NR
Robinson et al. (2016)	Female 73% Male 27%	Mothers 73% Fathers 27%	NR	NR	NR	NR	NR	NR	NR
Hodsoll et al. (2017)	NR	Parents 98% Other 2%	ECHOg: 49.1 (5.7) ECHO: 47.7 (8.9) TAU: 47.8 (7.7)	NR	ECHOg: 45 (10.5-104) ECHO: 62 (22.5-105) TAU: 51 (19.5-132) *median, IQR	AN	ECHOg: 16.7 (2.4) ECHO: 17.2 (2.0) TAU: 16.9 (2.1)	Female: 91.9% Male: 8.1%	ECHOg: 1.0 (0.25-7) ECHO: 1.1 (0.17-9.2) TAU: 1.25 (0.17-9)
Jenkins et al. (2017)	Female 67% Male 33%	Parents 89% Spouse 4% Other 7%	49.9 (8.7), Range: 21 - 71	83%	9.2 hours	AN, BN, EDNOS	19.6 (6.3), Range: 10-46	Female: 91.9% Male: 8.1%	2.6 (4.8), Range: <1-32

Abbreviations: AN, Anorexia Nervosa; BN, Bulimia Nervosa; EDNOS, Eating Disorder Not Otherwise Specified; NR, Not Reported; ECHO, Experienced carers helping others; OAO, Overcoming Anorexia Online

Table 2. Sample characteristics across studies cont.

Authors	Carer Details					Patient Details			
	Gender of Carer	Relationship to patient	Age (Years, Range)	Living with patient	Time with Patient (hours)	ED type	Age (years)	Gender	Illness Duration (years)
Quadflieg et al. (2017)	NR	Parents 88.8% Spouses 10.5% Other 0.7%	Intervention: 48.7 (7.7) Control: 48 (8.4)	82%	NR	AN 67.2% BN 23.1% EDNOS 9.7%	Intervention: 19.7 (5.9) Control: 22.1 (6.8)	Female 96.3% Male 3.7%	Intervention: 4 (4.9) Control: 5.9 (5.1)
Strahan et al. (2017)	Female 67.2% Male 33.8%	Parents 94% Other 6%	NR	NR	NR	NR	NR	NR	3.16 (3.62)
Dimitropoulos et al. (2018)	Female 70% Male 30%	Parents 94% Partner 4% Friend 2%	51.05 (9.67) Range: 23.89-66.53	NR	NR	AN, BN, EDNOS with comorbid diagnoses	NR	NR	NR
Ganci et al. (2018)	Female 53% Male 47%	Mothers 53% Fathers 47%	NR	NR	NR	AN	Workshop: 15.2 (1.7) Control: 15.2 (1.5)	Female 80% Male 20%	NR
Quiles Marcos et al. (2018)	Female 59.4% Male 40.6%	Parents 92.2% Spouse 3.1% Sibling 4.7%	48.46 (8)	90.30%	NR	AN 75.7% BN 13.5% EDNOS 10.8%	20 (6.78)	Female 91.9% Male 8.1%	4.77 (5.12)
Sepulveda et al. (2018)	Female 98% Male 2%	NR	Skills: 53.73 (6.51) Psychoeducation: 55.26 (7.89)	81%	NR	AN, BN, EDNOS	Skills: 23.37 (6.06) Psychoed: 24.46 (24.46)	Female: 90.5% Male: 9.5%	Skills: 3.96 (3.46) Psychoeducation: 5.5 (6.64)

Abbreviations: AN, Anorexia Nervosa; BN, Bulimia Nervosa; EDNOS, Eating Disorder Not Otherwise Specified; NR, Not Reported; ECHO, Experienced carers helping others; OAO, Overcoming Anorexia Online

Carer interventions and treatment adherence

Several common interventions were investigated across the identified studies, see Table 3 for an overview. These were: the Collaborative Care Skills Workshop (CCSW), which provided general information about ED and cognitive, behavioural and emotional strategies to manage stress; Overcoming Anorexia Online (OAO), implemented in various formats that used a systemic CBT approach to formulate carer difficulties; and Experienced Caregivers Helping Others (ECHO), that used a self-help format to help build skills around resilience, communication and emotion regulation. The latter two accounted for all self-help interventions and all were developed and investigated by the King's College, London group. The majority of the workshop studies used a psychoeducation format with some skill development, and two studies specifically investigated the applicability of Emotion-Focussed Family Therapy.

Twelve studies used a workshop or group intervention, two used a self-help web-based format, six used a self-help book and DVD format, and one study compared a web-based and workshop interventions. All PPD studies used a workshop design, except for Grover et al. (2011a) who completed an initial pilot study of the OAO over the internet. The RCTs predominantly investigated self-help approaches, using OAO and ECHO. Only Spettigue et al. (2015) used a psychoeducation workshop. Two IC studies compared the CCSW to a psychoeducation group, and one compared ECHO with ECHOc, the guided version. Dimitropoulos et al. (2018) was the only study to compare web- and workshop-based versions of the OAO intervention.

Table 3. intervention Details

	Intervention Details							
	Country of Study	Intervention	Mode of Delivery	Intervention completion rate	Carer Sample Size	Carer Measures	Patient Sample Size	Patient Measures
Uehara et al. (2001)	Japan	Psycheducation	Workshop	70%	30	FMSS		
Sepulveda et al. (2008)	UK	Collaborative Care Skills Workshop	Workshop	94.30%	35	ECI, EDSIS, GHQ-12		
Sepulveda et al. (2010)	UK	Collaborative Care Skills Workshop	Workshop	93%	47	ECI, FMSS, GHQ-12		
Gisladottir & Svavarsdottir (2011)	Iceland	Education & Support group	Workshop	87.50%	24	FQ, LEE		
Goddard et al. (2011)	UK	ECHO	Self-Help (Books & DVD) + guidance	ECHO - 81% ECHOc - 92%	ECHO: 80 ECHOc: 73	AESED, ECI, EDSIS, FQ, GHQ-12, HADS, RS-CSE		
Grover et al. (2011a)	UK	Overcoming Anorexia Online	Self-Help (Books) + guidance	81%	27	ECI, EDSIS, HADS, LEE		
Grover et al. (2011b)	UK	Overcoming Anorexia Online	Self-Help (Online) + guidance	52%	64	AESED, ECI, EDSIS, HADS, LEE		
Hoyle et al. (2013)	Australia/ UK	Overcoming Anorexia Online	Self-Help (Online) + guidance	81%	37	DASS-21, ECI, EDSIS, GHQ-28, LEE		
Hibbs et al. (2015a)	UK	ECHO	Self-Help (Books & DVD) + guidance	68%	ECHO: 134 TAU: 134	AESED, DASS-21, EDSIS, FQ	ECHO: 86 TAU: 92	BMI, DASS-21, EDE-Q
Spettigue et al. (2015)	Canada	Psycheducation	Workshop + guidance	96%	Intervention: 27 TAU: 24	EDSIS, PVA	Intervention: 20 TAU: 16	EDEQ-A
Gisladottir et al. (2016)	Iceland	Therapeutic Conversation Intervention	Workshop	86%	50	AESED, ECI, RS-CSE		
Magill et al. (2016)	UK	ECHO	Self-Help (Books & DVD) + guidance	68%	ECHO: 134 TAU: 134	AESED, DASS-21, EDSIS, FQ	ECHO: 86 TAU: 92	BMI, DASS-21, EDE-Q
Robinson et al. (2016)	Canada	Emotion-Focused Family Therapy	Workshop	NR	33	PVA		
Hodsoll et al. (2017)	UK	ECHO	Self-Help (Books & DVD) + guidance	>50% (Books) - 36% >50% (DVDs) - 23%	ECHO: 72 ECHOc: 78 TAU: 76	AESED, CASK, DASS-21, FQ	ECHO: 50 ECHOc: 49 TAU: 50	BMI, DASS-21
Jenkins et al. (2017)	UK	Collaborative Care Skills Workshop	Workshop	100%	77	CASK, PVA		
Quadflieg et al. (2017)	Germany	ECHO	Self-Help (Books & DVD) + guidance	90% average	ECHO: 147 TAU: 138	AESED, EDSIS, GHQ-12		
Strahan et al. (2017)	Canada	Emotion-Focused Family Therapy	Workshop	NR	117	PVA		
Dimitropoulos et al. (2018)	Canada	Overcoming Anorexia Online	Self-Help (Online) vs Workshops	80%	Web: 23 Workshop: 27	AESED, EDSIS, FQ		
Ganci et al. (2018)	Australia	Interactive Group	Workshop	100%	45	PVA	45	BMI, EDE
Quiles Marcos et al. (2018)	Spain	Collaborative Care Skills Workshop vs Psychoeducation	Workshop	NR	CCSW: 40 Psychoed: 24	AESED, EDSIS, FQ, GHQ-12, HADS, LEE	CCSTW: 23 Psychoed: 14	GHQ-12, HADS
Sepulveda et al. (2018)	Spain	Collaborative Care Skills Workshop vs Psychoeducation	Workshop	84%	CCSW: 27 Psychoed: 26	AESED, ECI, EDSIS, FQ, GHQ-12, HADS, RS-CSE	CCSW: 10 Psychoed: 12	GHQ-12, HADS

ECHO, Experienced carers helping others; OAO, Overcoming Anorexia Online; Measures: DASS-21, Depression, Anxiety and Stress Scale

AESED, Accommodation and Enabling Scale for Eating Disorders; BMI, Body Mass Index; CASK, Caregiving Skills Scale

ECI, Experience of Caregiving Inventory; EDE-Q (A), Eating Disorder Examination Questionnaire (Adolescents); EDSIS, Eating Disorder Symptom Impact Scale

FMSS, Five Minute Speech Sample; FQ, Family Questionnaire; GHQ-12/28, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale

LEE, Level of Expressed Emotion; PVA, Parent Versus Anorexia Scale; RS-CSE, Revised Scale for Caregiving Self-Efficacy

Among the studies implementing workshop interventions there was a variation in the rates of intervention completion that ranged between 70 to 100%. However, three PPD studies did not report any data. Of the six studies using ECHO, three reported completion

rates over 80%, two reported on the same trial where the completion rate was 68%, and one study found very low adherence, where 36% of participants had read over 50% of the materials (Hodsoll et al., 2017). Of the two web-based interventions, one had a very low completion rate at 52%, while the other had a good completion rate of 81%.

Impact on carers

Table 4 shows which studies reported significant change, as well as lack of significant change across different measures for carers. Studies differed widely in how they reported results, and so it was often not possible to distinguish post-intervention from follow-up scores. Consequently, all timepoints will be reported in the same section.

Table 4. Significant findings in carer outcomes

	Intervention Type	Distress	AESED	EE	EDSIS	Positive ECI	Negative ECI	Self-efficacy
Pre-Post Design Studies								
Uehara et al. (2001)	Workshop			+				
Sepulveda et al. (2008)	Workshop	◇			□	■	□	
Sepulveda et al. (2010)	Workshop	◇		+		■	□	
Gisladottir & Svavarsdottir (2011)	Workshop			○	◇			
Grover et al. (2011a)	SH (Book)	○		○	■	□	■	
Gisladottir et al. (2016)	Workshop		■					△
Robinson et al. (2016)	Workshop							○
Jenkins et al. (2017)	Workshop							○
Strahan et al. (2017)	Workshop							○
Ganci et al. (2018)	Workshop							○
Intervention Comparison Studies								
Goddard et al. (2011)	SH (book)	○	◇	■	◇	■	■	△
Dimitropoulos et al. (2018)	SH (online vs workshop)		□	◇	□			
Quiles Marcos et al. (2018)	Workshop	◇	○	□	○	◇	■	
Sepulveda et al. (2018)	Workshop	◇	○	□	◇	■	■	△
Randomised Control Trials								
Grover et al. (2011b)	SH (Web)	○	■	○	■	■	■	
Hoyle et al. (2013)	SH (Web)	△	◇	○	□	■	□	
Hibbs et al. (2015a)	SH (Book)	△	■	◇	□			
Spettigue et al. (2015)	Workshop				■			○
Magill et al. (2016)	SH (Book)	△	■	◇	■			
Hodsoll et al. (2017)	SH (Book)	△	■	◇				
Quadflieg et al. (2017)	SH (Book)	◇	□		■			

^aIC significance findings are for pre-post interventions rather than between groups

Key

Abbreviation: SH= self help

Significance: ■ p>.05 □ p<.05 ○ p<.01 △ p<.001

Measure directly related to heading: □

Wellbeing: GHQ= ○ DASS-21= △ HADS= ○

EE: FQ= ○ LEE= ○ FMSS= +

Self-efficacy: PVA= ○ RS-CSE= △

Carer Wellbeing

Six RCTs reported on carer well-being, of which four used the DASS-21 (Hibbs et al., 2015a; Hodsoll et al., 2017; Hoyle et al., 2013; Magill et al., 2016), two used the GHQ-12 (Hoyle et al., 2013; Quadflieg et al., 2017), and one used the HADS (Grover et al., 2011b). Magill et al. (2016) reported on the same data set as Hibbs et al. (2015a), but at a 24-month timepoint. Only Grover et al (2011b) found a significant difference between groups post-intervention. For the intervention group they found that scores on the HADS decreased significantly when compared to controls and at follow-up there were no additional changes. This indicated that the initial significant decrease had been maintained over time. Quadflieg et al. (2017) did not find a difference between groups on the GHQ-12. However, they reported an effect of time on the overall sample, such that scores were found to reduce over time for both intervention and control groups.

Three IC studies reported on carer well-being, all using both the HADS and GHQ-12 (Goddard et al., 2011; Quilles Marcos et al., 2018; Sepulveda et al. 2018). Across these studies there was no significant difference between intervention groups at any timepoint. Goddard et al. (2011) investigated guided and non-guided versions of ECHO and found a significant effect of time across all three timepoints for both groups when the data was combined. Scores decreased on the HADS and GHQ-12. No further post-hoc analyses were discussed and so it is unclear between which timepoints these differences were located. Sepulveda et al. (2018) compared a skills-based workshop with a psychoeducational workshop. They found an effect of time across the three timepoints on the GHQ-12, but no differentiation between groups. No significant change in the HADS was found. Quilles Marcos et al. (2018) compared CCSW with a psychoeducation group. For the CCSW group, they found a significant effect of time at post-intervention but not at follow-up for both the GHQ-12 and for the HADS Depression scale. They also found significant changes between baseline, post-intervention and follow-up for both the GHQ-12 and HADS for the Psychoeducation Group.

Three PPD studies reported on carer well-being and all reported significant results (Grover et al., 2011a; Sepulveda et al., 2008; Sepulveda et al., 2010). Grover et al. (2011a) found a significant decrease in HADS scores and post-hoc analysis found significant differences between baseline and both post-intervention and follow-up, indicating that changes were maintained over time. Sepulveda et al. (2008) found a significant decrease in GHQ-12 scores and post-hoc tests similarly showed changes maintained into follow-up. Sepulveda et al. (2010) also reported a decrease in GHQ-12 scores with a similar pattern of the decrease being maintained at follow-up.

Accommodation and Enabling

Five RCTs used the AESED in their studies (Grover et al., 2011b; Hibbs et al., 2015a; Hodsoll et al., 2017; Magill et al., 2016; Quadflieg et al., 2017). Only Quadflieg et al. (2017) found a significant difference between groups, where the intervention group's scores decreased significantly more than the control group. However, there was also an overall significant effect of time, where scores for both groups decreased from baseline to post-intervention.

All four IC studies found significant changes on the AESED (Dimitropoulos et al., 2018; Goddard et al., 2011; Quiles Marcos et al., 2018; Sepulveda et al., 2018). Goddard et al. (2011) found a significant decrease in scores on the AESED for the self-guided intervention but there was no additional benefit of telephone coaching. Dimitropoulos et al. (2018) found no significant difference between web- and workshop-based interventions but reported in the discussion that there was an overall significant decrease in scores. Quiles Marcos et al. (2018) also reported a reduction in the AESED total score, between baseline and follow-up in the CCSW group, and between all three time points for the psychoeducation group. Sepulveda et al. (2018) found an overall significant decrease in scores across groups over time, but no differences between the individual groups.

Of the PPD Studies, only one paper reported on AESED scores (Gisladottir et al., 2016). They found an overall decrease in the total AESED score with post-hoc contrasts revealing the significant change occurring between baseline and follow-up scores.

Expressed Emotion

Five RCTs reported on Expressed Emotion (EE); three using the Family Questionnaire (FQ; Hibbs et al., 2015a; Hodsoll et al., 2017; Magill et al., 2016), and two using the Levels of Expressed Emotion (LEE; Grover et al., 2011b; Hoyle et al., 2013). Only two studies found significant changes in EE scores. Hoyle et al. (2013) found no change in overall LEE scores but found an effect of time on the intrusiveness scale. They also found a difference between guided and non-guided groups on the irritability scale, where the guided group maintained changes over time at follow-up. Hibbs et al. (2015a) found no significant difference between groups post-intervention, however they found a significantly lower score for the intervention group at 6 months post-discharge. They found no further significant difference between groups at 12 months, and Magill et al. (2016) did not find any significant differences for the same participant group at 24 months.

All four IC Studies reported on EE, with three using the FQ (Dimitropoulos et al., 2018; Goddard et al., 2011; Sepulveda et al., 2018), and one using the LEE (Quiles Marcos et al., 2018). Only Sepulveda et al. (2018) found no significant differences between groups. Dimitropoulos et al. (2018) found no significant differences between web- and workshop-based interventions but reported a significant decrease in scores on the FQ. Goddard et al. (2011) found a significant decrease in FQ scores at post-intervention which decreased further at follow-up. Quiles Marcos et al. (2018) found a significant decrease in LEE scores for both CCSW and the Psychoeducation group with post-hoc testing revealing a change for both groups between baseline and post-intervention. They also found a significant decrease in all subscales of the FQ for both groups, where each measure was significantly lower at both post-intervention and discharge.

Four studies in the PPD category assessed EE, where two used the FMSS (Sepulveda et al., 2010; Uehara et al., 2001), one used the LEE (Grover et al., 2011) and one used both the FQ and LEE (Gisladottir & Svavarsdottir, 2011). Grover et al. (2011) found a significant decrease in LEE scores between baseline and post-intervention, though there was then a small increase in scores at follow-up. Sepulveda et al. (2010) found that

the proportion of carers rated as having high EE decreased over time, where it fell from 55% to 24% from baseline to post-intervention. Similarly, Uehara et al. (2001) found an overall decrease in the rates of high-EE in carers, from 28.6% to 3.6%. Gisladdottir & Svavarsdottir (2011) found a significant decrease over time in the *Understanding* subscale of the LEE but found no further significant change for any other subscales or on the FQ.

Caregiving Experience

EDSIS. Six RCTs reported on caregiving burden using the EDSIS (Grover et al., 2011b; Hibbs et al., 2015a; Hoyle et al., 2013; Magill et al., 2016; Quadflieg et al., 2017; Spettigue et al., 2015). Only two studies found significant differences between groups. Hibbs et al. (2015a) found a decrease in EDSIS scores in the intervention group at discharge, however this was not maintained at 6- or 12-month follow-up, or by Magill et al. (2016) who reported on the same sample at 24 months. Hoyle et al. (2013) found a decrease in scores on the *starvation* and *guilt* subscales for both guided and non-guided groups.

All four IC studies used the EDSIS, with only one study finding no significant results (Sepulveda et al., 2018). Dimitropoulos et al. (2018) reported in the discussion that there was a significant decrease in scores on the EDSIS. Goddard et al. (2011) found a decrease in scores across both groups, and no additional benefit of guidance. Quiles Marcos et al. (2018) found a significant decrease in EDSIS scores in both CCSW and Psychoeducation groups at both post-intervention and follow-up.

Two studies in the PPD category reported on caregiving experience using the EDSIS (Grover et al., 2011a; Sepulveda et al., 2008). Sepulveda et al. (2008) found a significant decrease in scores over time with the main difference identified as between baseline and follow-up. Grover et al. (2011a) found a significant decrease in scores over time with significant comparisons between every point; baseline and post-intervention, baseline and follow-up, and post-intervention and follow-up.

Experience of Caregiving Inventory. Two RCTs used the ECI in their studies, reporting on both positive and negative dimensions (Grover et al., 2011b; Hoyle et al., 2013). Grover et al. (2011b) did not find any significant differences between groups. Hoyle et al.

(2013) found an overall significant decrease in scores over time for both guided and non-guided intervention groups on the negative ECI subscale, though no change on the ECI positive subscale.

Two IC studies used the ECI to measure experiences of caregiving (Goddard et al., 2011; Sepulveda et al., 2018). Goddard et al. (2011) found a significant improvement in the negative ECI scores between baseline and post-intervention on the ECHO non-guided group, with no added effect of guidance. Sepulveda et al. (2018) similarly found no difference between groups but found a significant improvement in overall scores over time for both negative and positive ECI dimensions.

Four studies in the PPD category reported on experiences of caregiving (Gisladottir et al., 2016; Grover et al., 2011a; Sepulveda et al., 2008; Sepulveda et al., 2010). Gisladottir et al. (2016) reported all ten subscales of the ECI separately, and found that eight out of the ten subscales showed a significant decrease, all apart from *problems with services* and *good aspects of relationship*. Grover et al. (2011) found a significant decrease in both negative and positive dimensions of the ECI, with post-hoc analyses finding significant changes for the negative dimension between baseline and post-intervention, and between baseline and follow-up. For the positive dimension, significant changes were found between baseline and post-intervention, and between post-intervention and follow-up. Sepulveda et al. (2008) found no significant change over time for the positive dimension of the ECI but found a significant change over time for the negative dimension of the ECI. Post-hoc tests revealed these differences were predominantly between baseline and post-intervention, and between baseline and follow-up. Sepulveda et al. (2010) found similar results, in that there was no significant change for the positive dimension of the ECI but found a significant change over time for the negative dimension of the ECI, with post-hoc tests revealed significance between baseline and post-intervention.

Parental Self-Efficacy

Spettigue et al. (2015) was the only RCT to report on parental views of self-efficacy using the PVA. Results found a significant interaction effect between group and time and

also significant main effects of both group and time. This shows that scores for both intervention and group scores increased, however the intervention group's score increased to a greater extent than the control.

Two IC studies used the RS-CSE to measure self-efficacy (Goddard et al., 2011; Sepulveda et al., 2018). Sepulveda et al. (2018) found no significant change. Goddard et al. (2011) found a significant increase in scores for the ECHO non-guided group, with no added benefit from the guided group.

Five PPD intervention studies investigated parental feelings of self-efficacy. One study used the RS-CSE (Gisladdottir et al., 2016), and the remaining four used the PvA (Ganci et al., 2018; Jenkins et al., 2017; Robinson et al., 2016; Strahan et al., 2017). Jenkins et al. (2017) was the only study that did not show any significant changes in scores over time. Gisladdottir et al. (2016) reported the RS-CSE using individual subscales and found a significant increase in the *disruptive behaviour* subscale. Post-hoc analyses revealed these changes were significant between baseline and both post-intervention and follow-up. Robinson et al. (2016) found a significant improvement in PvA scores between baseline and post-intervention, and Strahan et al. (2017) similarly found a significant increase in scores using t-tests between baseline and post-intervention. Ganci et al. (2018) used a carer workshop to enhance FBT and compared the intervention to a control group. They found no change in PvA scores for fathers but found a significant increase in maternal PvA scores at each follow-up timepoint (week 4, week 12 and end of treatment).

Summary of carer data

Across the 21 identified studies, carer outcomes varied greatly. Very few RCTs reported significant differences between intervention and control groups, and two studies did not report any significant changes. The majority of PPD studies reported significant changes in scores across all outcomes. However, PPD studies published after 2012 only reported on measures of self-efficacy. Three out of four IC studies found significant changes pre-post intervention across study designs and outcomes. However, no studies reported any significant differences between intervention groups.

Impact on patients

Table 5 shows the seven studies that reported on patient measures, and whether or not they found significant changes. Across the studies, there were additional patient measures used, however due to the large variation in measures, only the most common were reported.

Table 5. Significant findings in patient outcomes

	Intervention type	BMI	Distress	EDE-Q
Pre-Post Design Studies				
Ganci et al. (2018)	Workshop			
Intervention Comparison Studies				
Quiles Marcos et al. (2018)	Workshop			
Sepulveda et al. (2018)	Workshop			
Randomised Control Trials				
Hibbs et al. (2015a)	SH (book)			
Spettigue et al. (2015)	Workshop			
Magill et al. (2016)	SH (book)			
Hodsoll et al. (2017)	SH (book)			

Key
 Abbreviation: SH= self help
 Significance: p<.05 p<.05 p<.01 p<.001
 Measure directly related to heading:
 GHQ= HADS= DASS-21=

Patient wellbeing

Three RCTs investigated patient distress, all using the DASS-21. No studies found significant changes between intervention and control groups (Hibbs et al., 2015a; Hodsoll et al., 2017; Magill et al., 2016).

Two IC studies investigated patient distress using both the GHQ-12 and HADS (Quiles Marcos et al., 2018; Sepulveda et al., 2018). Sepulveda et al. (2018) found only a marginal effect of time on GHQ-12 scores across both groups. Quiles Marcos et al. (2018) found a significant reduction in HADS and GHQ-12 scores for the CCSW group, but no change in distress for the psychoeducation group.

Body Mass Index

Four RCTs reported on patient BMI (Hibbs et al., 2015a; Hodsoll et al., 2017; Magill et al., 2016; Spettigue et al., 2015). Three studies found no significant difference between intervention and control groups (Hibbs et al., 2015a; Magill et al., 2016; Spettigue et al., 2015). Hodsoll et al. (2017) also found no difference between intervention and control groups. However, upon breakdown of treatment effects, the non-guided group showed a significant moderate increase in BMI at 6 months. However, when this was compared to the guided group, the non-guided group was only marginally significant at $p = 0.054$.

Ganci et al. (2018) was the only PPD study that looked at BMI. They found a significant increase in BMI at four weeks post-workshop in the intervention group compared to the control group. However, this difference between groups was not maintained by end of treatment, where both groups had increased significantly.

Eating Disorder Symptomology

Three RCTs reported on patient EDE-Q scores (Hibbs et al., 2015a; Magill et al., 2016; Spettigue et al., 2015). Spettigue et al. (2015) did not find any significant differences between groups. Hibbs et al. (2015a) found no difference between intervention and control groups at discharge, however found a significant decrease in EDE scores in the intervention group at 6 months. This score remained decreased at 24 months but was not significantly different to controls, as found in a follow-up study (Magill et al., 2016).

As the only PPD study, Ganci et al. (2018) found a significant decrease in scores over time. However, this was not a significant difference.

Summary of patient data

Across the seven studies that were identified to include patient outcomes, there was no consistent pattern of significant change. Three studies found no significant changes, two studies found significant changes in EDE-Q scores, but this was not maintained over time, and one study each found significant changes in measures of patient distress and BMI.

Discussion

The overall aim of this review was to update the meta-analysis conducted by Hibbs et al. (2015b) on caregiver interventions in ED services, with the additional consideration of patient outcomes and intervention adherence. Overall 21 studies were included in the review, 11 of which had been published since the meta-analysis reflecting a growing evidence base. Seven RCTs were included, where an intervention group was compared to TAU, and in some cases an additional guidance group was included.

The first aim of this review was to investigate adherence to treatment across self-help and workshop designs. Completion rates for interventions varied vastly across the studies. Across workshop studies, participants attended at least 70% of workshops. In contrast three RCTs reported adherence to self-help treatments was below 60%, though other studies with similar designs found higher adherence rates. The variation of treatment adherence across study designs is striking. It suggests that workshops may have been more engaging for carers possibly due to the social aspect of them. It may also have been that carers found it easier to attend a group for a set period of time, rather than self-studying at home. Across self-help studies there was variation in where samples were recruited from, including inpatient units, day-units and community services. If patients were not staying with their carers at the time of intervention, this may have allowed the carer more time or motivation to commit to completing the intervention at home. However, recruitment methodology and living with patients, though reported, was not commonly investigated in regard to treatment outcomes.

Dimitropoulos et al. (2018) was also the only study to compare web-based and workshop interventions. They noted that 14 people dropped out of the study pre-randomisation as they did not want to risk being randomised to the web-based intervention. This was discussed further in the qualitative feedback, where carers reported a desire to connect with other carers for emotional support. This is in line with the general literature, which highlights the isolation and shame many carers experience in eating disorder populations (Treasure et al., 2001). However, despite this feedback, researchers reported

similar rates of intervention completion across both web-based and workshop groups, about 20%. This indicates that despite the lack of social contact, when participants began the intervention there may have been other advantages that motivated carers to engage. For example, this could have been taking the intervention at their own pace or being able to access it from remote areas without having to travel.

The second aim looked at change in carer outcomes post-intervention and at follow-up. PPD and IC studies generally found significant changes over time, however RCT results were more scattered and difficult to interpret. The majority did not find differences between control and intervention groups. In contrast to these findings, the previous meta-analysis (Hibbs et al., 2015b) suggested that carer outcomes around distress, burden and expressed emotion improved over time. This may be partly because when completing their analysis, Hibbs et al. (2015b) only compared pre- and post- scores, rather than control to intervention scores in RCT groups. This was to allow for a comparison across studies, however it suggests there could have been an impact of regression to the mean or symptom-level changes that were not due to the specific intervention. Additionally, Hibbs et al. (2015b) did not report a quality analysis of their included studies. Two out of the 13 studies analysed were rated as low-quality by this review, and four studies were excluded from this study due to sample sizes smaller than 15 participants. Though the meta-analysis would have accounted for sample size, the number of studies that were of low quality indicate that the results may be significantly under-powered, making it difficult to draw solid conclusions.

An interpretation of the variation in outcomes between study designs differences could be that workshop designs are more effective than self-help designs. However previous research in CBT for depression (Cowpertwait & Clarke, 2013), and findings from Dimitropoulos et al. (2018) suggest that study design had little impact on treatment effectiveness. Across several of the RCT studies, it was noted that there were significant differences between control and intervention groups in terms of demographics, for example age of patient and levels of carer distress. Previous research suggests that higher carer burden can impact on a carers' motivation to access and engage with interventions

(Sepulveda et al., 2012). Longer illness duration in particular has also been found to be associated with increased scores on the AESED and EDSIS (Anastasiadou et al., 2014). Consequently, a lack of homogeneity between comparison groups may have impacted the extent to which researchers were able to determine the effectiveness of interventions. Consequently, using pre-post designs may have been a more effective method of controlling for individual variance in the groups and illustrating a more coherent pattern of change.

Outcomes for carers at follow-up were also included in this research aim but were difficult to separate in the literature due to variation in reporting. Many studies reported overall change over time (e.g. between all three time points including follow-up), rather than individual change between time points. Significant changes over time were minimal, especially in the RCTs reporting more long-term follow-up. Some studies suggested a booster session at later time points would be beneficial to maintain effects of treatment. However, due to the lack of data it is difficult to draw any firm conclusions regarding long-term outcomes.

The third aim looked at patient outcomes, which were limited to seven studies. Results across studies were inconsistent, with some studies finding significant changes in individual measures, and others showing no significant changes. Four of these studies were RCTs where minimal change was also found in carers. It may be that the variation in treatment outcomes was due to the interpersonal model of anorexia, such that changes to carer distress or self-efficacy were associated with changes in patients. However due to the lack of consistent outcomes, it is very difficult to draw any firm conclusions.

Limitations and future research

Similar to Hibbs et al. (2015b), we found that there was a wide heterogeneity in patient characteristics, in particular stage/duration of illness. Studies varied from investigating carers of young people who were in the process of being assessed for an eating disorder, to those who could be classed as 'severe and enduring'. Some RCTs reported significant differences in demographics between control and intervention groups. Additionally, there was a wide variation in sample recruitment across literature, between

community and inpatient services that also led to variations in the time carers spent with patients. However, as very few of these factors were further investigated in the studies, it is unclear how these factors may have played a role in treatment outcomes. This is something that could be considered in future reviews to ensure that participant views are considered alongside quantitative data.

Unfortunately, a meta-analysis could not be conducted on the identified studies. This would have been extremely helpful to extend the research by Hibbs et al. (2015b) but was not possible due to the variation in data presentation. As many of the studies were designed as proof of concept, qualitative components were also used to consider carer feedback regarding intervention. It could also have been helpful in this review to analyse this feedback. This could have been done using thematic analysis to identify what parts of treatment participants found helpful, especially when comparing self-help and workshop groups. These aspects would be particularly important to build on in future studies to establish a better indication of the factors that contributed to effective interventions.

Conclusion

There is an emerging body of research trialling a range of interventions for caregivers of patients with ED. This is important as studies have found that caring for a patient with ED has a significant impact on multiple aspects of family functioning. In line with Hibbs et al. (2015b), this review found some good outcomes amongst studies that involved comparison of intervention groups and pre-post designs. However, in contrast there was limited evidence from RCTs. Several of these studies have been pilots, consequently recruiting smaller sample sizes, and only a few included patient outcomes. All but a few studies did not have a follow-up period over three months and only one study thus far has compared self-help and workshop study designs. Consequently, though there is some evidence for the efficacy of carer interventions, further studies including control comparisons and long-term follow-up are required.

References

- Amirkhanyan, A.A., & Wolf, D.A. (2003). Caregiver stress and non-caregiver stress: Exploring the pathways of psychiatric morbidity. *The Gerontologist*, 43, 817-827.
<https://doi.org/10.1093/geront/43.6.817>
- Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating behaviors*, 15(3), 464–477.
<https://doi.org/10.1016/j.eatbeh.2014.06.001>
- Askey, R., Holmshaw, J., Gamble, C. & Gray, R. (2009). What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. *Journal of Family Therapy*. 31. 310 - 331. 10.1111/j.1467-6427.2009.00470.x.
- Chesney, E., Goodwin, G.M. & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry*, 13, 153-160.
doi:[10.1002/wps.20128](https://doi.org/10.1002/wps.20128)
- Cole, J.D., & Kazarian, S.S. (1988). The Level of Expressed Emotion Scale: A new measure of expressed emotion. *Journal of Clinical Psychology*, 44(3), 392–397. [https://doi.org/10.1002/1097-4679\(198805\)44:3<392::AID-JCLP2270440313>3.0.CO;2-3](https://doi.org/10.1002/1097-4679(198805)44:3<392::AID-JCLP2270440313>3.0.CO;2-3)
- Cole, J.D., & Kazarian, S.S. (1993). Predictive validity of the Level of Expressed Emotion (LEE) Scale: Readmission follow-up data for 1, 2, and 5-year periods. *Journal of Clinical Psychology*, 49(2), 216-218. [https://doi.org/10.1002/1097-4679\(199303\)49:2<216::AID-JCLP2270490214>3.0.CO;2-G](https://doi.org/10.1002/1097-4679(199303)49:2<216::AID-JCLP2270490214>3.0.CO;2-G)
- Commissioning for Carers, 2014. Principles and resources to support effective commissioning for adult and young carers. Retrieved from <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/12/comm-carers-princ-091214.pdf>

- Cowpertwait, L. & Clarke, D. (2013). Effectiveness of web-based psychological Interventions for depression: A meta-analysis. *International Journal of Mental Health and Addiction*, 11. doi:10.1007/s11469-012-9416-z.
- Danhauer, S.C., McCann, J.J., Gilley, D.W., Beckett, L.A., Bienias, J.L. & Evans, D.A, (2004). Do behavioural disturbances in persons with Alzheimer's disease predict caregiver depression over time? *Psychology and Aging*, 19, 198-202.
- De Fazio, P., Ciambrone, P., Cerminara, G., Barbuto, E., Bruni, A., Gentile, P., Talarico, A., Lacava, R., Gareri, P. & Segura-García, C. (2015). Depressive symptoms in caregivers of patients with dementia: demographic variables and burden. *Clinical interventions in aging*, 10, 1085–1090. doi:10.2147/CIA.S74439
- Dimitropoulos, G, Landers, A, Freeman, V, Novick, J, Schmidt, U. & Olmsted, M. (2019). A feasibility study comparing a web-based intervention to a workshop intervention for caregivers of adults with eating disorders. *European Eating Disorders Review*, 27, 641– 654. Doi: <https://doi-org.libproxy.ucl.ac.uk/10.1002/erv.2678>.
- Downs, K.J., & Blow, A.J. (2013). A substantive and methodological review of family-based treatment for eating disorders: the last 25 years of research. *Journal of Family Therapy*, 35(51), 3-28. <https://doi-org.libproxy.ucl.ac.uk/10.1111/j.1467-6427.2011.00566.x>
- Eisler, I. (2005), The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*, 27, 104-131. doi:10.1111/j.1467-6427.2005.00303.x
- Fairburn, C.G., Beglin, S.J. (2008). Eating Disorder Examination Questionnaire (EDE-Q 6.0). *Cognitive Behavior Therapy and Eating Disorders*. Edited by Fairburn CG. New York, Guilford.
- Fisher, C.A., Hetrick, S.E. & Rushford, N. (2010). Family therapy for anorexia nervosa. *Cochrane Database of Systematic Reviews*, DOI: 10.1002/14651858.CD004780.pub2.

- Ganci, M., Pradel, M., & Hughes, E.K. (2018). Feasibility of a parent education and skills workshop for improving response to family-based treatment of adolescent anorexia nervosa. *International Journal of Eating Disorders*, *51*, 358-362. Doi: <https://doi-org.libproxy.ucl.ac.uk/10.1002/eat.22834>
- Gendall, K., & Bulik, C. (2005). The Long-Term Biological Consequences of Anorexia Nervosa. *Current Nutrition & Food Sciences*, *1*, 87-96. DOI: 10.2174/1573401052953267
- Gisladottir, M. and Svavarsdottir, E.K. (2011), Educational and support intervention to help families assist in the recovery of relatives with eating disorders. *Journal of Psychiatric and Mental Health Nursing*, *18*, 122-130. doi:10.1111/j.1365-2850.2010.01637.x
- Gisladottir, M., Treasure, J. and Svavarsdottir, E.K. (2017), Effectiveness of therapeutic conversation intervention among caregivers of people with eating disorders: quasi-experimental design. *Journal of Clinical Nursing*, *26*, 735-750. doi:10.1111/jocn.13412
- Goddard, E., Macdonald, P., Sepulveda, A., Naumann, U., Landau, S., Schmidt, U., & Treasure, J. (2011). Cognitive interpersonal maintenance model of eating disorders: Intervention for carers. *British Journal of Psychiatry*, *199*(3), 225-231. doi:10.1192/bjp.bp.110.088401
- Goldberg, D., & Williams, P. (1988). A user's guide to the General Health Questionnaire. Windsor, UK: NFER-Nelson
- Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J., & de Zwaan, M. (2008). The needs of carers of patients with anorexia and bulimia nervosa. *European eating disorders review: the journal of the Eating Disorders Association*, *16*(1), 21–29. <https://doi.org/10.1002/erv.804>
- Grover, M., Naumann, U., Mohammad-Dar, L., Glennon, D., Ringwood, S., Eisler, I. & Schmidt, U. (2011b). A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychological Medicine*, *41*(12), 2581-2591. doi:10.1017/S0033291711000766

- Grover, M., Williams, C., Eisler, I., Fairbairn, P., McCloskey, C., Smith, G., Treasure, J. & Schmidt, U. (2011a), An off-line pilot evaluation of a web-based systemic cognitive-behavioral intervention for carers of people with anorexia nervosa. *International Journal of Eating Disorders*, 44, 708-715. doi:10.1002/eat.20871
- Haigh, R., & Treasure, J. (2003). Investigating the needs of carers in the area of eating disorders: Development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review*, 11(2), 125-141, <https://doi.org/10.1002/erv.487>
- Hibbs, R., Magill, N., Goddard, E., Rhind, C., Raenker, S., Macdonald, P., Todd, G., Arcelus, J., Morgan, J., Beecham, J., Schmidt, U., Landau, S., & Treasure, J. (2015a). Clinical effectiveness of a skills training intervention for caregivers in improving patient and caregiver health following in-patient treatment for severe anorexia nervosa: pragmatic randomised controlled trial. *BJPsych Open*, 1(1), 56–66. <https://doi.org/10.1192/bjpo.bp.115.000273>
- Hibbs, R., Rhind, C., Leppanen, J. & Treasure, J. (2014). Interventions for caregivers of someone with an eating disorder: A meta-analysis: Interventions for Caregivers of Someone with an ED. *The International journal of eating disorders*. 48. Doi: 10.1002/eat.22298.
- Hodsoll, J., Rhind, C., Micali, N., Hibbs, R., Goddard, E., Nazar, B. P., Schmidt, U., Gowers, S., Macdonald, P., Todd, G., Landau, S., & Treasure, J. (2017). A Pilot, Multicentre Pragmatic Randomised Trial to Explore the Impact of Carer Skills Training on Carer and Patient Behaviours: Testing the Cognitive Interpersonal Model in Adolescent Anorexia Nervosa. *European Eating Disorders Review*, 25, 551– 561. doi: 10.1002/erv.2540.
- Hoyle, D., Slater, J., Williams, C., Schmidt, U., & Wade, T.D. (2013). Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: a randomized controlled trial. *The International Journal of Eating Disorders*, 46(6), 634–638. <https://doi.org/10.1002/eat.22144>

- Jenkins, P.E., Bues, S., Cottrell, J., Hawkins, J., Pinder, L., Price, S. & Stewart, A. (2018). A collaborative care skills workshop for carers: Can it be delivered in 1 day? *Clinical Psychology & Psychotherapy*, 25(1), 130-137. <https://doi-org.libproxy.ucl.ac.uk/10.1002/cpp.2119>
- Klump, K.L., (2013). Puberty as a critical risk period for eating disorders: a review of human and animal studies. *Hormones and Behaviour*. 64(2), 399–410.
- Kmet, L.M., Lee, R.C. & Cook, L.S. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. *Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR). AHFMR - HTA Initiative #13.*
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding how parents cope with living with someone with anorexia nervosa: modelling the factors that are associated with carer distress. *The International journal of eating disorders*, 41(3), 233–242. <https://doi.org/10.1002/eat.20488>
- Lafrance Robinson, A., Dolhanty, J., Stillar, A., Henderson, K., & Mayman, S. (2016) Emotion-Focused Family Therapy for Eating Disorders Across the Lifespan: A Pilot Study of a 2-Day Transdiagnostic Intervention for Parents. *Clinical Psychology and Psychotherapy*, 23, 14– 23. doi: 10.1002/cpp.1933.
- Lauber C., Eichenberger A. & Luginbuhl P. (2003). Determinants of burden in caregivers of patients with exacerbating schizophrenia. *European Psychiatry*, 18(6), 285-289.
- Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation.
- Magaña, A.B., Goldstein, J.M., Karno, M., Miklowitz, D.J., Jenkins, J. & Falloon, I.R. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry research*, 17(3), 203–212. [https://doi.org/10.1016/0165-1781\(86\)90049-1](https://doi.org/10.1016/0165-1781(86)90049-1)
- Magill, N., Rhind, C., Hibbs, R., Goddard, E., Macdonald, P., Arcelus, J., Morgan, J., Beecham, J., Schmidt, U., Landau, S., & Treasure, J. (2016) Two-year Follow-up of a Pragmatic Randomised Controlled Trial Examining the Effect of Adding a Carer's

- Skill Training Intervention in Inpatients with Anorexia Nervosa. *European Eating Disorder Review*, 24, 122–130. doi: 10.1002/erv.2422.
- Magliano L., McDaid D., Kirkwood S. & Berzins K. (2007). Carers and families of people with mental health problems. In: *Mental health policy and practice across Europe* (eds). M. Knapp, D. McDaid, E. Mossialos, G. Thornicroft), pp. 374-396, McGraw-Hill: Berkshire.
- Márquez-González, M., Losada, A. & Lopez, J. (2009). Reliability and Validity of the Spanish Version of the Revised Scale for Caregiving Self-Efficacy. *Clinical Gerontologist*, 32. Doi:10.1080/07317110903110419.
- Martín, J., Padierna, A., Aguirre, U., González, N., Muñoz, P., & Quintana, J.M. (2013). Predictors of quality of life and caregiver burden among maternal and paternal caregivers of patients with eating disorders. *Psychiatry research*, 210(3), 1107–1115. <https://doi.org/10.1016/j.psychres.2013.07.039>
- National Institute for Health and Care Excellence (2017). Eating disorders: recognition and treatment. Retrieved from: <https://www.nice.org.uk/guidance/ng69>
- Ogilvie AD, Morant N, Goodwin GM. The burden on informal caregivers of people with bipolar disorder. *Bipolar Disorders* 2005; 7 (Suppl. 1): 25–32. ^a Blackwell Munksgaard, 2005
- Oyebode, J.R. (2005). Carers as partners in mental health services for older people. *Advances in Psychiatric Treatment*. 11, 297-304
- Quadflieg, N., Schädler, D., Naab, S., & Fichter, M.M. (2017) RCT of a Video-based Intervention Program for Caregivers of Patients with an Eating Disorder. *European Eating Disorders Review*, 25, 283– 292. doi: 10.1002/erv.2521.
- Quiles Marcos, Y., Quiles Sebastián, M.J., Escolano Herrera, M., Sanmartín, R. & Treasure, J. (2018). Testing carer skill training programs in Spanish carers of patients with eating disorders. *Psicothema*, 30(3), 295-303. doi:10.7334/psicothema2017.368

- Rhodes, P., Baillie, A., Brown, J. & Madden, S. (2005), Parental efficacy in the family-based treatment of anorexia: preliminary development of the Parents Versus Anorexia Scale (PVA). *European Eating Disorders Review*, 13, 399-405. doi:10.1002/erv.661
- de la Rie, S.M., van Furth, E.F., De Knoning, A., Noordenbos, G. & Donker, M.C. (2005). The quality of life of family caregivers of eating disorder patients. *Eating Disorders*, 13(4), 345-351
- Salerno, L., Rhind, C., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K., Lo Coco, G. & Treasure, J. (2016). A longitudinal examination of dyadic distress patterns following a skills intervention for carers of adolescents with anorexia nervosa. *European Child and Adolescent Psychiatry*, 25, 1337–1347 (2016). <https://doi.org/10.1007/s00787-016-0859-9>
- Schmidt, U. & Treasure, J. (2006), Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, 45, 343-366. doi:10.1348/014466505X53902
- Sepulveda, A. R., Whitney, J., Hankins, M., & Treasure, J. (2008). Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health and quality of life outcomes*, 6, 28. <https://doi.org/10.1186/1477-7525-6-28>
- Sepulveda, A.R., Graell, M., Berbel, E., Anastasiadou, D., Botella, J., Carboles, J. A., & Morande, G. (2012). Factors associated with emotional well-being in primary and secondary caregivers of patients with eating disorders. *European Eating Disorders Review*, 20(1), e78–84. doi: 10.1002/erv.1118.
- Sepulveda, A.R., Lopez, C., Todd, G., Whitaker, W. & Treasure, J. (2008). An examination of the impact of “the Maudsley eating disorder collaborative care skills workshops” on the well-being of carers. *Social Psychiatry and Psychiatric Epidemiology*, 43, 584–591. <https://doi.org/10.1007/s00127-008-0336-y>
- Sepulveda, A.R., Todd, G., Whitaker, W., Grover, M., Stahl, D. & Treasure, J. (2010), Expressed emotion in relatives of patients with Eating Disorders following skills

training program. *International Journal of Eating Disorders*, 43, 603-610.

doi:10.1002/eat.20749

- Sepulveda, A., Kyriacou, O. & Treasure, J. (2009). Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders. *BMC health services research*. 9, 171. 10.1186/1472-6963-9-171.
- Sepúlveda, AR, Anastasiadou, D, Parks, M, & Gutiérrez, E. (2019). A controlled study of the Collaborative Care Skills Workshops versus Psycho-educational Workshops among Spanish caregivers of relatives with an eating disorder. *European Eating Disorders Review*, 27, 247– 262. <https://doi-org.libproxy.ucl.ac.uk/10.1002/erv.2658>
- Shah, A.J., Wadoo, O., & Latoo, J. (2010). Review Article: Psychological Distress in Carers of People with Mental Disorders. *British Journal of Medical Practitioners*, 3(3), 327.
- Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. *The journals of gerontology. psychological sciences and social sciences*, 57(1), P74–P86. <https://doi.org/10.1093/geronb/57.1.p74>
- Strahan, E.J., Stillar, A., Files, N., Nash, P., Scarborough, J., Connors, L., Gusella, J., Henderson, K., Mayman, S., Marchand, P., Orr, E.S., Dolhanty, J. & Lafrance, A. (2017). Increasing parental self-efficacy with emotion-focused family therapy for eating disorders: a process model, *Person-Centered & Experiential Psychotherapies*, 16(3), 256-269, DOI: 10.1080/14779757.2017.1330703
- Szmukler, G.I., Burgess, P., Herrman, H., Benson, A., Colusa, S. & Bloch, S. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology*, 31, 137–148. <https://doi.org/10.1007/BF00785760>
- Treasure J, Sepulveda AR, MacDonald P, Whitaker W, Lopez C, Zabala M., Kyriacou, O. & Todd., G. (2007). The Assessment of the Family of People with Eating Disorders. *European Eating Disorders Review*, 15, 1-9. 10.1002/erv.758.

- Treasure, J., Murphy, T., Szmukler, T., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 36(7), 343-347.
- Treasure, J. & Schmidt, U. (2013). The Cognitive-Interpersonal Maintenance Model of Anorexia Nervosa Revisited: A summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, 1. Doi: 10.1186/2050-2974-1-13.
- Uehara, T., Kawashima, Y., Goto, M., Tasaki, S. I., & Someya, T. (2001). Psychoeducation for the families of patients with eating disorders and changes in expressed emotion: A preliminary study. *Comprehensive Psychiatry*, 42, 132–138. <http://dx.doi.org/10.1053/comp.2001.21215>.
- Spettigue, W., Maras, D., Obeid, N., Henderson, K.A., Buchholz, A., Gomez, R. & Norris, M.L. (2015) A Psycho-Education Intervention for Parents of Adolescents With Eating Disorders: A Randomized Controlled Trial, *Eating Disorders*, 23(1), 60-75, DOI: 10.1080/10640266.2014.940790
- Wiedemann, G. & Rayki, O. & Feinstein, E. & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry research*, 109, 265-79. 10.1016/S0165-1781(02)00023-9.
- Winn, S., Perkins, S., Murray, J., Murphy, R. & Schmidt, U. (2004), A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: Carers' needs and experiences of services and other support. *International Journal of Eating Disorders*, 36, 269-279. doi:10.1002/eat.20068
- Zabala, M.J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden expressed emotion and psychological distress in families of people with eating disorders: a systematic review. *European Eating Disorders Review*, 17(5), 338–349. <https://doi.org/10.1002/erv.925>

Zigmond, A.S. and Snaith, R.P. (1983), The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67: 361-370. doi:10.1111/j.1600-0447.1983.tb09716.x

Part 2: Empirical Article

How do patients with anorexia and their and carers experience Community Treatment Orders?

Abstract

Aims: Community Treatment Orders (CTOs) are used in eating disorder populations to enforce engagement in treatment in the community. Research into CTOs has been limited to psychosis populations, and as such there is no research to guide its use in eating disorders. This paper aimed to investigate how patients and carers experience CTOs and consider how anorexia can impact on a patient's ability to adhere to and engage with the CTO.

Method: Semi-structured interviews were conducted with six patients and four carers. Transcripts were analysed using Interpretive Phenomenological Analysis. Patient and carer groups were analysed separately to allow for a comparison of their experiences.

Results: The analysis yielded three over-arching themes for each group. Patients and carers both reported the theme of experiencing the CTO as a framework whose implementation depended on professionals. Patients discussed their ambivalence to treatment and the challenge of managing the competing demands of their anorexia and the CTO. Carers spoke about how they felt the CTO was necessary but not sufficient for recovery, and the impact of the CTO on their relationship with the patient.

Conclusions: Patients and carers felt that the CTO was a necessity for patient wellbeing and highlighted the relationship with professionals as important to motivate engagement with the CTO. However, the CTO was perceived as a challenge by all patients due to the competing demands of the anorexia. Future research should focus on further understanding how CTOs are used by professionals, and the role they play in a patient's recovery.

Introduction

Anorexia Nervosa

Anorexia Nervosa is a serious illness with the highest mortality rate amongst mental illnesses (Harris & Barraclough, 1998; Keel & Brown, 2010). Research suggests that over 50% of individuals with anorexia recover, but for 20% of individuals, their anorexia develops a more chronic course (Papadopoulos et al., 2009). This is characterised by periods of stable or increased weight, followed by frequent periods of malnutrition. This can lead to life-threatening and destructive complications and hospitalisation for long periods of time.

Anorexia can have a considerable physical impact on the body. This may include the development of osteoporosis, kidney damage and heart failure (Lowe et al. 2001). Medical instability, for example fainting or dehydration, can often lead to admission onto a general medical ward to stabilise the individual before transfer to a specialist inpatient unit (Richard, 2005). Specialist admissions aim to help the patient reach a safer body weight before moving back into the community (Lund et al., 2009; Steinhausen et al., 2008). Goals are often focused on a weight that the patient is required to maintain before being discharged to the community.

Though much of the literature focuses on the consequences of anorexia, research suggests that patients often hold quite positive beliefs about their condition. Anorexia has been perceived by many to be a guardian, and patients report feeling looked after, safe and protected by the condition (Serpell et al., 1999). Anorexic symptoms have been found to be highly valued and give patients a sense of control over their lives (Garner & Bemis, 1982; Vitousek et al., 1998). Many patients also experience the presence of an anorexic voice, which is additional to eating-related cognitions. This has been described as a critical internal voice that provides a running commentary on the actions of an individual and consequences that relate to eating, weight and shape (Pugh & Waller, 2017). The goals of anorexia, control and thinness, are often in line with those of the individual, contributing to the ego-syntonic role that anorexia plays in an individual's life (Garner & Bemis, 1982; Vitousek et al., 1998). These factors mean that even when a patient is able to recognise the costs of anorexia,

there are strong feelings of ambivalence towards treatment and recovery (Darcy et al., 2010; Federici & Kaplan, 2008). This has a consequent impact on treatment engagement and leads to high dropout rates within this population (Cooper, 2005; Eivors et al., 2003).

What are Community Treatment Orders?

Community Treatment Orders (CTOs) are an international concept that were first established in England and Wales in 2008 as an extension of the Mental Health Act (Mental Health Act, 2007). They were initially implemented in general adult mental health settings, predominantly with individuals with psychosis or mood disorders. It was felt that recurring hospital admissions were most often associated with a lack of adherence to medication and engagement with appointments in the community (Churchill et al., 2007; Human Rights Act, 1988). Consequently, they aim to reduce the frequency of mental health admissions by compelling engagement in treatment in a less restrictive setting.

CTOs provide a legal framework permitting the compulsory treatment of individuals in the community (HM Courts & Tribunal Service, 2014). They require the joint decision making of a Responsible Clinician (RC) usually a psychiatrist, and an Approved Mental Health Professional (AMHP), usually a social worker. They are initially designed to last 6 months but can be renewed at regular intervals. They may be ended by the RC when clinically indicated, or at a Mental Health Review Tribunal. The order includes two mandatory conditions, that patients must make themselves available to complete a mandatory review concerning treatment without consent and make themselves available for assessment concerning the renewal of the CTO. Additionally, the RC and AMHP may also specify discretionary conditions that are required to ensure the patient receives medical treatment, and to prevent risk of harm to the patient or others in the community. These are based on professionals' knowledge of the patient and can be changed over time. Though administration of treatment is not forceful, patients on a CTO may be recalled to hospital for up to 72 hours if they breach a mandatory condition, or if they require further treatment in hospital and would be a risk of harm to themselves or others if not recalled. Following the

72-hour recall period of assessment, patients may return to the community under a CTO, remain in hospital or be discharged from involuntary care.

Much of the literature suggests that enforced community treatment is preferable to hospital. Nevertheless, the nature of CTOs suggests that patients would not accept this treatment if they were able to choose freely. Much of the historic literature has debated the need for coercive treatment within the community. However, more recent studies have focused on clinical outcomes as indicators of effectiveness (Francombe Pridham et al., 2014).

Effectiveness of CTOs

To date, there have been three randomised control trials (RCTs) of CTOs, and a small number of non-randomised trials. Two RCTs were conducted in the United States and a subsequent one was conducted in the UK (Burns et al., 2013; Steadman et al., 2001; Swartz et al., 1999). All three involved patients with diagnoses of psychosis and mood disorder. A meta-analysis of these studies concluded that CTOs were not associated with a reduction in readmission rates or reduced bed days, and no differences were found in psychiatric symptoms in the subsequent 12 months (Kisely & Hall, 2014). Subsequent reviews have built on these findings. Barnett et al. (2018) found higher levels of engagement with community services and treatment, and increased service provision in those on a CTO. More specifically, studies found that CTOs could lead to an increase in contact with service providers and improved medication adherence (O'Brien, Farrell & Faulkner, 2009; Swartz et al., 2010).

Overall the quantitative literature around CTO effectiveness lacks any robust evidence for the positive impact of CTOs on patient outcomes. However, the literature has been extremely limited by small sample sizes and a lack of consistency in CTO application and measurement and use of comparison groups. An additional difficulty inherent to CTOs is selection bias. As the CTO is used to treat those ambivalent towards treatment, there may be a significant proportion of individuals who either disengage from the CTO or lack the capacity to consent to participation. This suggests that quantitative studies may struggle to

reflect the wider experiences of individuals. Therefore, researchers have turned to qualitative methodology to further explore and understand the perspectives of professionals, patients and family members.

Patient experiences

Several studies have interviewed patients to explore the implementation and impact of CTOs. A systematic review of qualitative studies by Corring et al. (2017) identified 10 key themes from patient's experiences. One related to how the CTO drove engagement with professionals and treatment when patients would otherwise disengage. This was discussed alongside feelings of coercion and being controlled. Negative feelings were heightened when patients felt there was a lack of respect or dignity from professionals. However, these feelings were also mitigated by good relationships with professionals and increased service provision. These experiences were also highlighted by Francombe Pridham et al. (2014), who found that feelings of coercion were impacted by contextual factors. This included having no information about the CTO or its alternatives, feeling heard by professionals, and the way in which the CTO conditions were implemented. Ambivalence towards the CTO was common, and many patients spoke about feeling frustrated at the enforced treatment, as well as finding benefits from it.

Stuen et al. (2015) investigated an Assertive Community Treatment Team in Norway, of which over 30% of patients were subject to a CTO. Implementing findings from previous research, this team shifted its focus from medication adherence to addressing unmet needs, future crises and finding solutions to daily problems within this population. Some participants reported finding the CTO unhelpful till the very end, however others reported gradually recognising the CTO as an acceptable solution. In these cases, supportive relationships with the team and professionals' attitudes made a significant difference in perceptions. The importance of relationships is further highlighted by McMillan et al. (2019). They found that patients who benefitted more from the CTO were found to have an increased trust in the potential for the CTO, system or particular workers to help them in the recovery process.

These studies suggest that CTOs can be experienced in a number of ways. Though CTOs are a coercive measure, findings suggest that many factors can play a role in mitigating or enhancing these experiences. These studies also noted that there were significant difficulties in recruitment, whereby participants who did not see the benefit in engaging with treatment would have also been less likely to take part in the studies and express their opinions. Consequently, these studies may be biased to reflect a more positive view of the CTO.

Carer involvement

The revised Mental Health Act Code of Practice (2007) recommends the involvement of carers in the care process. Clinicians have been instructed to pay greater attention to carer's requests and concerns and use this information as prompts for reviews of patient health. A focus group run by Glacco et al. (2017) found that carers felt that their involvement in inpatient care should involve inclusion in care planning and discharge, and provision of their own emotional support. They strongly felt that they had personal knowledge of the patient and could be helpful to professionals in this capacity.

Despite these recommendations, families' experiences of services are often perceived as one of exclusion from the care planning process and a lack of appreciation from health professionals (Blomqvist & Ziergert, 2011; Eassom et al. 2014). A review by Doody et al. (2017) highlighted how families could feel marginalised and disempowered by professionals. Families often reported that professionals did not invite them to care planning meetings or, when they were invited, they experienced negative attitudes and a lack of information. However, more positive carer experiences have also been reported. This has been experienced when patients invite participation from carers early in the process, and carers have ongoing access to known professionals (Rusner et al., 2012).

Fewer studies have examined the specific experiences of relatives and carers in relation to CTOs. Studies in the psychosis literature found that carers consider the CTO as a helpful legal mechanism that they can use with patients. The threat of recall was suggested as giving 'teeth' to the CTO, as it was felt to be associated with increased medication

adherence and engagement with professionals (Canvin et al., 2014). It also relieved some of the carers' own anxieties about the patient's well-being as they knew that the patient was being monitored by professionals who could intervene if any concerns arose (Stensrud et al., 2015). Some carers also talked about the increased support allowed by the CTO (Stroud et al., 2015; Swartz & Swanson, 2004). However, others reflected on how limited resources in the NHS impacted on CTO implementation and further support in the community, and consequently impacted on patient outcomes. (Light et al., 2014). Carers also reported experiencing a varying degree of consultation. Some reported becoming more involved under the CTO, particularly in relation to monitoring of medication adherence. However, other carers reported experiencing insufficient consultation and did not feel listened to by professionals when trying to express their opinions (Canvin et al. 2014; Rugkasa & Canvin, 2017; Stroud et al., 2015).

CTO use in Eating Disorder Services

CTOs are not commonly used in eating disorder services and though no specific figures are available, professionals anecdotally suggest that their use has increased over the past few years. Within these services, they are most often used as a tool to help individuals engage with treatment in the community. In practice, this means that there are often minimum weight conditions set that patients must maintain. If they drop below this weight, they will be recalled to hospital. There may also be conditions around appointment attendance, medication, exercise and weekly weight loss. These conditions are often put in place to restrict behaviours that may trigger a cycle of weight loss and lead to recall.

There is no research into the efficacy of CTOs or how individuals experience their implementation within eating disorder services. Only one survey has been completed by members of the Eating Disorders Section Executive Committee Meeting (EDSECT). This looked at eating disorder professionals' use of the Mental Health Act and CTOs (EDSECT, 2012). CTOs were commonly reported as a way of managing patients with a history of rapid weight loss, and professionals felt that the threat of recall acted as a deterrent to weight loss. There were mixed perceptions of their helpfulness. Positive views included how it helped

enable care plans to be consistent and transparent, helped clients maintain weight and allowed for proper community follow-up. Professionals also raised concerns about the negative impact of CTOs on the therapeutic relationship. However, it must be noted that this survey was not intended as research but rather to inform clinical practice.

Research Aims

The main aim of the study was to investigate patients' and carers' experiences of CTOs within an eating disorder setting. Throughout the interview process, the complex nature of anorexia and ambivalence to treatment arose across all interviews. Consequently, an additional research question was added to further explore how anorexia influenced patient's engagement in and adherence to CTOs.

The study hoped to address the following research questions:

1. How are CTOs experienced by patient and carer groups? What are the similarities and differences in these experiences?
2. How do CTOs interact with an individual's experience of anorexia and impact on engagement in treatment?

Method

Recruitment

This study aimed to recruit patients from eating disorder services across four NHS Trusts in London. However, patients were recruited from three of these trusts, and carers were recruited from only two of these trusts. The researchers presented the study to professionals within these services and sent out flyers (see Appendix B) and information sheets (see Appendices C and D for patient and carer versions) to be distributed to eligible patients and carers. Professionals identified patients who met the criteria for the study and contacted them to gain initial consent. Researchers would then contact the patients to further discuss the study, and also ask for permission to contact their carers.

This research was conducted jointly by the researcher and a fellow trainee (see Appendix E for a breakdown of trainee contributions). It was planned that six interviews would be conducted for each participant group. In line with IPA methodology, this was felt to

be an appropriate sample size as it would allow for a sufficiently broad range of experiences whilst also being achievable within the time constraints (Clarke, 2010). Recruitment was planned to take place between October 2019 and May 2020. However due to COVID-19 restrictions, the final recruitment drive for carers was cancelled.

Ethics

Ethical approval for the study was gained from the London - Riverside Research Ethics Committee, REC reference: 19/LO/0806 (see Appendix F for REC and HRA letters).

Participants

Participant criteria

Professionals working with eating disorders across four trusts assisted in the identification of potential participants. Patients were required to either currently be under a CTO or have previously been under a CTO as per the Mental Health Act. Carers were considered family members who had been involved in the patient's care, and consent for their involvement was obtained from the patient.

Participant details

Researchers approached 11 patients who had consented to be contacted. Six agreed to participate, three declined as they did not feel able to talk about the CTO at that time, and two did not respond to attempted contact. Of the nine who responded to initial contact, four did not consent for their carer to be involved. One carer was contacted but was due to go on an extended holiday and was therefore unable to participate.

Procedure

Following initial consent gained from professionals, a researcher would contact the patient by phone to discuss the study further. This involved giving further information about the study and allowing them to ask any questions. A mutually convenient time to conduct the interview was then agreed upon. If the patient did not have a copy of the information sheet, this would also be forwarded to them before the interview alongside the consent form (See Appendices G and H for patient and carer forms). If the patient agreed for their carer to be involved, the carer's details were taken, and patients were asked to discuss the study with

family members before contact was made by the researcher. This process was then repeated with carers.

All interviews were carried out either at the patient's local eating disorder service or over the phone. They lasted between 1-1.5 hours and were audiotaped. Written consent was obtained at the beginning of a face-to-face meeting, and verbal consent (using the same form) was gained over the phone if the participant did not have a printer. All participants were reimbursed £10 an hour, in addition to a £5 travel allowance for those who travelled to the clinic.

Semi-structured Interviews

The aim of the semi-structured interviews was to obtain a rich and detailed account of how patients and carers experienced CTOs. This methodology was chosen due to its structured format that had enough flexibility to allow for exploration of any issues that may arise unexpectedly (Smith, 1995).

Interviews for patients were conducted by researchers KM and VK. Each researcher conducted three patient interviews, and KM conducted all carer interviews. Interviews always began with an outline of the interview, to allow participants to develop an idea of what questions would be asked. More general questions about the participant's life were asked to aid engagement and establish a rapport. Some closed questions were also asked in the hopes that they would be easier to answer before moving into more open-ended, difficult and/or emotional questions (Wynngaarden, 1981).

Interview Schedules

Parallel forms of the same semi-structured interview schedule were used for both patients and carers (see Appendices I and J respectively). However, one further question was added to the carer interviews to further elicit the impact of the CTO on themselves. The aim of these questions was to elicit a deeper understanding of participant's understanding and experiences of the CTO. These were developed in line with guidelines from Smith et al., (2009). The areas for exploration were determined by a combination of a review of the CTO literature, the research questions and initial conversations with our supervisor.

Once a draft of the interview schedules had been produced, it was given to our supervisor who has significant experience working with eating disorders, and a service user with experience of CTOs for comment. It was then revised in light of the recommendations, which identified several additional questions pertaining to the patient's experience of CTOs, and a shift in terminology describing management of eating disorders instead of recovery.

The interview schedule included the following areas:

1. General information

This section was used to orient participants to the interview and help put them at ease. In line with Smith (1995), this early part was used to focus on more general questions to gather information about the participant, their current life context and their CTO.

2. Views of CTOs

This area aimed to explore participant's knowledge and feelings about CTOs. Questions were initially asked about their understanding of CTOs more generally and how they were introduced to the concept. This was followed up with questions about their feelings towards the CTO, including any agreements or disagreements, any aspects that were helpful or unhelpful and whether they felt that the conditions were fair.

3. Impact of CTOs

This section was concerned with how participants perceived the CTO had impacted their lives. This involved questions about how it impacted their personal life, their anorexia, and their experience of recall if it had happened. With carers, these questions asked about how they felt the CTO had impacted the patient, as well as themselves and their relationship with the patient.

4. Freedom

These questions were used to explore the ways in which the patient might have felt coerced or forced by the CTO, and what helped or stopped them from feeling able to express their opinions.

5. Summary questions

The final part of the interview aimed to help participants reflect on their experience of CTOs by giving them space to summarise their views of the general advantages and disadvantages. They were also asked to consider any recommendations they would make about its use and add anything further that they felt was important.

Data Analysis

Interpretative Phenomenological Analysis (IPA) was used as a framework to develop the interview schedule and analyse the data. Guidelines from Smith et al. (2009) were followed for the data analysis. Each interview was first transcribed by the researcher who had completed it. This meant that the transcribed three patient interviews and four carer interviews. All interviews were transcribed verbatim using the automated transcription software, Trint, which was then carefully checked by researchers prior to analysis. Due to time constraints, the majority of transcription occurred after the bulk of interviews had been completed.

Following transcription, each transcript was read and re-read to develop the researcher's familiarity with the data. During reading, margins were used to note significant aspects of the transcript. In line with IPA methodology, these were colour-coded to show descriptive comments, linguistic comments and conceptual comments on the data. They reflected key words, preliminary reflections and initial interpretations that were felt to convey the essential quality of the participant's account. An example of this stage of the analysis is presented in the appendix (see Appendix K). These comments, alongside the initial transcript, were then used to identify emerging themes across the data. These were recorded on a word document (see Appendix L for an example).

The next stage involved summarising emerging themes onto a word document to begin to identify connections between themes. A table of emerging themes with all relevant excerpts from the original transcript was created for each individual participant (see Appendix M). This enabled the researcher to continually and easily check that interpretations were based on the actual content of what participants had said. This process was completed for each transcript before coding for the next transcript was started. The researcher aimed to

be open to new themes emerging from each transcript but was also guided by the analysis of the previous transcripts.

When this procedure had been completed, four patient interviews were co-coded with fellow researcher VK to ensure rigidity to the framework and reduce researcher bias. In this case, the researcher re-coded transcripts with thematic analysis in mind, while VK recoded using an IPA framework. Codes were then compared, and a high level of agreement was found across researchers. Themes were also discussed with the supervisor to further allow for the identification of connections and inter-relationships. Emerging themes were then organised into lists of master and sub-themes, separately for each transcript (See Appendix N for carer example)

Once all individual analyses were complete, themes were integrated into a master list of themes for patient and carer groups separately. This process was then discussed with the supervisor to allow for consideration of how themes had been integrated and provision of a different perspective on the data. A final summary table was produced for each of the two groups, presenting a clear overview of themes in a coherent manner.

Reliability and Validity

IPA requires the balancing a systematic and rigorous approach to research alongside allowing for the researcher's own curiosity and creativity in the process of interpretation (Smith et al., 1999). To ensure methodological rigidity, Elliott, et al. (1999) developed a set of guidelines to assess queries of reliability and validity in qualitative research. The following guidelines were incorporated into the current study:

Owning one's perspective: As discussed in the section below, the author considered and addressed their theoretical orientations and personal anticipations that were relevant to the research.

Situating the sample: Basic information about participants was provided to aid the reader in judging the range of persons and situations to which the findings might be relevant.

Grounding in examples: Examples of the data have been provided throughout the paper to illustrate both the analytic procedure and understanding developed in light of the data.

Providing credibility checks: The researcher asked two colleagues, a fellow researcher and a professional in the field of eating disorders, to look over the analysis and supporting data. This was to allow for the minimisation of researcher bias.

Researcher's perspective

Qualitative research recognises the importance of acknowledging the researcher's perspective to enhance the validity of the analysis (Caelli & Mill, 2003). I am a white female in my late 20s, born in Australia and have been living in the UK for the past six years. I have a strong interest in working with children and adolescents, and as such take a systemic view that locates problems outside of the individual. I have had no experience working with eating disorders but have experienced working with young people with eating difficulties. My experience of CTOs has been in a Community Mental Health Team, where there was a strong focus on risk management. As such, I have some pre-conceptions about why CTOs are important for risk management. However, throughout my clinical training I have also developed a curiosity about how patients and carers experience professionals, particularly in settings where their voice may not be as loudly heard. While conducting this research, I attempted to reflect on and "bracket" my own beliefs and assumptions. This was facilitated by ongoing discussions with my colleague and supervisors (Fischer, 2009).

Results

The results section is organised into five subsections: contextual details to situate the findings, organisation of themes, discussion of the overlapping themes, individual patient themes and individual carer themes.

Contextual data

Six patients and four carers participated in this study. Three of the carers were directly related to three of the participating patients. For reasons of confidentiality and

anonymity across patient and carer groups, identifying details will not be directly associated with participants.

Patient demographics

All patients interviewed were women, three were under 30, and three were over 40. Ethnicities included four who were White British, one who was Black British and one who was Asian. Three lived in supported accommodation, one lived with a parent, whilst the remaining two lived independently. One patient had been on a CTO for less than six months, one was no longer on a CTO at the time of participation, three had been on CTOs for about two years and one had been on a CTO for more than five years. Two patients had never been recalled and the remaining four had been recalled at least once.

Carer demographics

Two carers were mothers, one was a father and one was a brother. Ethnicities included three who were White British, and one who was Asian. Three carers were over the age 55, and one was under the age of 40.

Organisation of themes

The themes for each group, patients and carers, were generated individually. These are presented separately in Tables 6 and 7 below. Each analysis revealed three overarching themes with a number of subthemes. The theme of 'CTO as a framework' was common to both groups. To reduce repetition, carer and patient findings will be presented together.

Table 6. Patient Themes

Master Themes	Subordinate Themes	P01	P02	P03	P04	P05	P06
CTO as a framework	Framework for risk management	X	X	X	X	X	X
	Power of professionals to drive implementation	X	X	X	X	X	X
	Relationship with professionals	X	X	X	X	X	X
	Flaws in the framework	X	X	X	X		
Ambivalence	Power of anorexia	X	X	X	X	X	
	Ambivalence around CTO	X	X	X	X	X	X
	Patient engagement in process guiding change	X	X	X	X	X	X
	Additional support on top of CTO	X	X				X
External perceptions of CTO	Family involvement	X	X	X	X	X	X
	Stigma		X		X		

Table 7. Carer Themes

Master Themes	Subordinate Themes	C01	C02	C03	C04
CTO as a framework	Framework for risk management	X	X	X	X
	Power of professionals to drive implementation	X	X	X	X
	Relationship with professionals	X	X	X	X
	Flaws in the framework	X	X	X	
CTO as necessary but not sufficient	Patient engagement needed for change	X	X	X	X
	CTO driving engagement	X	X		X
Carer relationship	Wider impact of anorexia on the carer	X	X	X	X
	Impact of CTO on relationship	X	X		X

CTO as a framework

CTO as a framework for risk management

Patients and carers talked about how the CTO was initially introduced by professionals to manage risk in the community. This was due to patients' histories of rapid deterioration and hospitalisation. They spoke about its necessity due to the risk inherent in being at a significantly low weight, and carers spoke about being unable to help the patient when they were at home:

P03: You're a risk to yourself, your health. Especially when you're very malnourished and very low in weight...your weight and your BMI is very low. The only option is to be on a CTO.

C03: Another pair of eyes was looking at her because quite clearly, my wife and I, our eyes aren't really good enough because we have gotten into some very awkward situations in the past.

Recall was often seen as a way of getting patients into hospital sooner, to prevent further deterioration and make recovery of weight quicker:

P02: But then on the other hand it got me into hospital sooner, things didn't deteriorate as much as they could have done.

Overall many patients and carers likened the CTO to be a safety net that would monitor patients more closely and 'catch' them before they deteriorated too quickly:

C03: All I can say to you is my understanding is, in inverted commas, 'safety net'. That's what it means to me.

Power of professionals to drive implementation

All participants experienced professionals as being in a position of power, dictating both the implementation of the CTO and the nature of their relationships. Some patients described feeling that the CTO was implemented too strictly with no flexibility, for example not being able to move appointments if they needed. This led to them feeling trapped as they believed that if they did not comply with the conditions, professionals would immediately use the more forceful means of recall:

P03: They're very, very strict when it comes to CTOs. Even when I was at death's door I still had to come, and it was wintertime.

However, patients also reported that implementation became more flexible over time. They felt that as professionals recognised that patients were adhering to conditions more willingly, they did not feel the need to enforce conditions on them as rigidly:

P03: Until towards the end when they knew I was maintaining my weight they were quite lenient.

Some patients and carers talked about feeling that though the initial conditions were appropriate, their enforcement by certain professionals was overly restrictive:

C01: So as far as the [supported accommodation] are concerned, it is like a sledgehammer to crack a nut type of thing, having a CTO. Because if ever they wanted to justify any of their sanctions that they were imposing, it was "we have to stick to your CTO".

There was also discussion about how conditions were often not followed by professionals, but expected to be followed by the patients themselves, with a couple of participants noting the injustice of that power dynamic:

P05: But yeah, I even said to my liaison nurse, "if that would have been me not seeing her, or if I didn't stick to one of my conditions then I would get into trouble for that. She's not sticking to the conditions that are stated on my community treatment order."

C03: She had to see her regularly for meetings. And you know as well as I do that these professionals are up to their eyeballs in work. But what was a 'must attend' the meeting happened perhaps once every six weeks. I'm afraid [patient] lost contact with any form of community treatment order and she's done it more than once. And I wouldn't blame [patient] for that.

Relationships with professionals

Relationships with professionals were described as important by patients and carers. Both talked about the importance of collaboration and being heard in discussions:

P06: We came up with all the rules together you see. And so, we came up with the rules of like staying above an okay BMI and abiding by the rules of the house.

C01: And I was given the opportunity to speak at all those meetings, including her CTO meetings, I was always asked if I wanted to say anything. So I felt very included.

Their relationships with, and expectations of, professionals often impacted on their involvement and engagement in the CTO process. This was particularly important if a patient was on the brink of recall and professionals worked with her to avoid admission:

P02: I had a session with [therapist] and she had said, "how are we going to avoid admission because the way that you're going now, you're going to lose your job, you're going to lose your house". Because they had said that I wouldn't be able to go back to my house.

However, many participants felt that their opinions were not heard. This was particularly common when talking about conditions they were meant to adhere to but disagreed with. This left many feeling like there was a considerable 'us and them' dynamic, and that they were powerless to influence any decisions:

P05: But then I thought "what's the point? I'm never going to win the argument or whatever". So I didn't kind of really pursue it any more than I had to.

C02: And I said quite clearly, "you guys are making a huge mistake in releasing her, I know her, and I know this isn't gonna work. She's going to start losing

weight, she's going to play up." I put my foot down but obviously that's what they chose to do, and she was released [from hospital], and I was proven right.

Flaws in the framework

The majority of participants talked about flaws in the CTO that were most often due to a lack of funding and resources. This had a particularly strong impact on individuals that did not have additional support in the community, either carers for whom the patient was living at home, or patients who were not living in supported accommodation. Patients who were not in supported accommodation reflected on the lack of support they received in the community, particularly as the activities had previously engaged with previously were no longer run:

P04: But also, it seems like CTOs in general, they are carried out in the community but actually there is no care in the community.

Patients and carers who had experienced recall talked about how the team had often struggled to find beds because they were not viewed as critically ill. This meant that their weight had often dropped even lower by the time they reached hospital, which made restoration more difficult:

P02: And I didn't know what to do because they were trying to find a bed, but it was quite hard again because my weight wasn't dangerously low, and, physically I was struggling, but I wasn't in a critical state. So, it took a few weeks to find me a bed.

And one carer even challenged the reasoning behind the CTO. Due to a substantial lack of resources in their community, they described feeling that the CTO was more of a box ticking exercise that helped professionals feel that everything necessary had been done, but did not relate to genuine support in the community:

C03: Sorry, there has been very little other than...it's almost as if they should be called a CAO, a community administration order. It's a tick box task, isn't it? This person of this condition, they go home, they attend here, they do this, tick the boxes and everything's got to be okay, hasn't it?

Patient Themes

Ambivalence

Power of anorexia. Patients talked about their experience of anorexia as dominating their thoughts, goals and ability to manage the conditions of the CTO. They described how this anorexic voice caused an internal conflict, as the CTO was perceived to be in opposition to it. This was sometimes further seen as going against the patient's own sense of self. Some patients talked about how adhering to the CTO elicited accusations from the voice about being weak, and led to guilty feelings:

P05: Well it's like, when I'm having the drinks, or when I step on the scales and think that I've put on weight. It really makes me think like "gosh why are you doing this? Why are you not arguing against it or something?" So, I think I'm being weak and stupid and [it] leads into a bit of a spiral really.

When asked about the CTO's impact on their sense of self, many patients talked about how sticking to the conditions by eating more made them feel extremely uncomfortable in their own bodies:

P04: Well definitely because I would like to be a lot smaller and it just gives me so much stress because I would be eating more, and I wouldn't be very comfortable with myself...So it's made me feel way worse about myself.

And even when trying to adhere to the CTO, some patients reflected on how difficult it was to manage the anorexic voice by themselves. One patient talked about how professionals had to step in to help her manage food in the community for a short period of time:

P02: So, she [dietitian] was like, "okay I think you're not going to like this, but I think we need to give the staff control of all your meals. Because I was just chipping away at everything."

Ambivalence around CTO. All patients talked about the challenges they faced regarding the CTO and the negative impact it had on their life. Very few patients

acknowledged anything helpful, as it was seen by many as going against their sense of self. However, they commonly agreed that it was necessary for them to stay alive:

P03: It helped me...it's a struggle but it helped me, and it got me to where I am now. Without the CTO I wouldn't be sitting here; I'd probably be dead.

One patient talked about how the threat of going back to hospital had helped motivate her to adhere to the conditions:

P06: I don't think about it a whole lot to be honest with you. But when I do think about it, I think it is a good thing. And I think it's probably what's kept me going at the moment, because I know that there is a chance that if I don't follow the rules or something that I could be taken back.

However other patients felt that the weight condition of the CTO put unnecessary stress on them due to its conflict with their own goals. Consequently, they felt they spent so much time and effort into maintaining their weight, that they were unable to engage in and develop other aspects of their life:

P03: Because I had to maintain my weight that was quite of a struggle. When you have an eating disorder and you have a boyfriend or a best friend, you have to push them away just so I can go and have what I need to have to maintain my weight, like my drinks.

Many patients also talked about how recall and hospitalisation felt inevitable. One patient related the feeling to being on death row. She felt that whilst on the CTO, she was just waiting to be recalled back to hospital as there was not any other option of it ending:

P05: I have sometimes used expression to the professionals and have said that I feel like I'm on death row...they [prisoners] never know when it's going to happen, and that's what it feels like. Because obviously, you know, it is in your conditions that you can be recalled back to hospital and you never know what's going to happen.

Patient engagement in process guiding change. Patients talked about the effort and responsibility that was required from them to maintain their weight and stay out of

hospital. Some patients talked about engaging with the CTO to move forward with their lives. They described using it as a tool to give themselves permission to go against the ED:

P02: But in my logical brain, I understood it. But then my anorexic brain I was like, oh, this is horrible, like I'm going to end up back in hospital. I'm not allowed to lose weight. And so, it was kind of keeping that part of my head quiet and trying to remember I had a lot to lose because I'd managed to get myself a job.

They also described how, with the CTO in place, they had felt more able to explore and develop other aspects of their identity:

P02: In the letter I said I've never been able to get on with my life because the temptation to lose weight has always been so strong above everything else that I give into it. So there was no room for getting a job, there was no option to develop relationships with people, like the temptation to lose was always so strong that I would just do that. So when that gets taken away, I can actually work on building up my life and like, kind of not just focussing on how much weight can I lose this week.

Others talked about their motivation to avoid recall and hospitalisation that led them to adhere to conditions:

P03: When I was on a CTO, I had to...that was a really big struggle to try and make sure I didn't lose any weight because otherwise I was going in.

One patient even talked about using the threat of recall to motivate herself to maintain her weight even though her CTO had ended:

P03: Um, say if I'm slipping and I'm not getting any encouragement from my family or friends. I just pretend I'm on it, just to focus, "look, you've got to remember, you don't want to go back in. You don't want to do that."

However, another patient talked about not adhering to the conditions until the recall process had been initiated, at which point she did everything she could to not be recalled:

P04: Well because they tell you when they recall you, they've told me I need to go to hospital at a certain time and a certain place. So you always know that you

need to go somewhere and that there's a time limit... so I'm thinking that "oh you need to go to hospital in 10 days time, I've got 10 days to get out of it..." So I just try and think if there's a way out.

Additional support on top of the CTO. A few patients talked about the importance of additional support on top of the CTO, particularly those living in supported accommodation. One patient reflected on the importance and necessity of this support to help her to begin to build up her life:

P06: They basically try and build you a life that you would have outside of the eating disorder. And you know, I think that's just been so helpful. It's just the continued support you get every single day, 24/7 there is always support.

External perceptions of the CTO

Family involvement. Family involvement was mentioned by all patients however the extent to which they were involved varied. Patients felt that the CTO was mainly helpful for carers as a way of taking the pressure of monitoring off them:

P02: But with my mom and dad it took the pressure on them- it took that away. So, they were like, "well, at least she's not going to die because she's being cared for."

Though many families were heavily involved in the process, for patients that did not agree with the CTO, they often felt that their families sided more with professionals than themselves:

P03: They [family] felt that it was better for me to be on it...it's their [professional's] choice, not my choice (to end the CTO). So, they [family] were on their [professional's] side, basically.

Stigma. Some patients talked about a lack of understanding about both eating disorders and CTOs from the people around them. They often felt unable to talk about their CTO, which added increased pressure to their ability to manage day-to-day:

P02: I especially feel weird like when I'm talking about the CTO and I say that I wanted it in the first place. And I think there's a judgment that comes from that,

because people that don't understand might just think like, "oh she just wants to be in hospital", or "like she just wants the attention" or...that's always a worry.

Carer Themes

CTO as necessary but not sufficient

CTO driving engagement. Carers believed that CTOs were necessary to drive patients' engagement with community services following hospitalisation. One carer spoke about how she felt that the CTO had initially prevented the patient from leaving her supported accommodation:

C01: To be honest I think initially it stopped her just walking out. I think she knew that if she dropped out of the boundaries set in the CTO, the [supported accommodation] would transfer her somewhere else.

Patient engagement needed for change. All carers agreed that, though the CTO was necessary, patient engagement was also essential for change. One carer talked about how, though a patient initially lost weight on the CTO, there was a turning point at which she appeared more motivated to end the CTO. This led to her more adhering to the conditions more consistently:

C02: So, her mission- it was to get off it. At first it wasn't. At first, she was losing weight and then it became her mission to get off it. And, you know, she did well to come off it. I think that's probably what drove her to come off it, because of the fear of going into hospital again.

Another carer reflected on the shift in the patient, not in their anorexia specifically but in their general outlook on life, and how that impacted on the recovery process:

C01: So that's been the biggest difference with [patient] is that she has changed quite significantly in her outlook...and it has significantly altered her mental well-being. Which, although the [supported accommodation] wants to think that they're the ones who are moving her into rehabilitation, actually that [her changed outlook] is what's moving [patient] into rehabilitation.

In contrast, another carer reflected on a patient's inability to engage with the CTO, due to the dominance of the anorexic voice, which appeared to be driving her decision making:

C03: We would say- my wife and I would say it's the anorexia making the decision.

Carer relationship

Wider impact of anorexia on the carer. Carers talked about the devastating impact the anorexia had, not only on the patient but on themselves. It was often difficult to differentiate between the impact of the CTO and the more general impact of the anorexia on their relationship. One carer spoke about not being able to relax due to the fear of the next incident of rapid weight loss:

C01: But even when we're supposedly having fun, I think, you know, I'm not quite sure whether this is enjoyable or not, because I'm always worried about what the next thing is going to be.

Several carers also talked about their own frustrations with the illness. Though they understood the anorexia on a rational level, they found it difficult to not question patients' priorities:

C04: You know, it's quite a frustrating illness. Apart from being completely devastating and it's quite frustrating because I'm looking at her thinking, "Why? Why will you not eat? Why would you rather not eat and be in hospital than be with your family?"

Impact of CTO on relationship. CTOs were most commonly viewed by carers as tools that allowed them to distance themselves from the food-related aspects of their relationship with the patient. Multiple carers talked about the peace of mind they had knowing that the patient was being looked after:

C02: I think that was the other thing as well that gave me a bit of peace and that the fact she was being regularly checked.

It also decreased the number of arguments during interactions, as carers felt that their words and requests were backed up by the greater authority:

C04: I think there's more of a...less arguments. You know, I've got a bit of a backup to a certain extent if I'm talking to her about different things. I can say "yes but [patient] you've got to do this because da da-da da-da".

However, carers still found themselves trying to navigate difficult situations with patients. This happened most often when there were differing opinions about the patient's treatment plan, for example when the carer was in agreement with the CTO, but the patient was not:

C01: I'm also very careful with how I communicate with [patient], because still she can get very upset, defensive if I say the wrong thing. So, I'm always very wary of what I say. That means I don't think I can always be a hundred percent honest with her.

Carers reported juggling multiple roles in the process that sometimes led to difficulties in interactions with the patient and professional team. They found themselves trying to manage the conflicting roles of themselves as the expert carer and as an advocate for the patient. Parents also talked about the conflict between wanting both what was best for their child, which was often supported accommodation, but also wanting their child at home with them. These conflicts in roles were not often addressed by professionals. However, some parents felt that the CTO helped alleviate some of these conflicts, in particular when patients were in supported accommodation as this was a clear boundary set in the CTO:

C04: So [patient] knows that she can't come home. And that I am a strong enough person, however hard it is. I might cry behind closed doors, but I'm not going to give in and say she can come home. So, if she doesn't adhere to the guidelines at the [supported accommodation], she knows that she's going to go back into hospital.

Summary of Main Findings

Patient and carers had similar views about the importance of the CTO for risk management, and how it was implemented by professionals. Conditions were most often seen as guidelines and enforced through the threat of recall. This acted as a safety net, as patients were monitored closely, and admission was facilitated to allow for earlier interruption of rapid weight loss. All participants described the importance of a collaborative approach from professionals that led to them feeling involved in and engaged with the CTO.

The majority of patients felt that the CTO was a tool that contributed to keeping them well and engaged in community services. However, CTOs were generally disliked across the group, and seen as challenging to engage with. This was partly due to the way in which the CTO challenged a patient's anorexia. Patients who engaged with the CTO found it helpful as a tool to give themselves permission to go against this anorexic voice. Other patients were more motivated to engage with the CTO to stay out of hospital. However, one patient reported feeling that the CTO was completely unnecessary. She reported feeling that she was not ill enough to justify its use, and that the challenge of maintaining her weight had an overwhelming impact on her ability to manage day-to-day activities.

Carers felt that the CTO was important for the engagement of the patient in, at the very least, maintenance of their weight due to the threat of recall. However, they also felt that it was also necessary for the patient to be engaged with the conditions of the CTO. A shift in mindset was seen as the key driver of change, which was then physically seen in through weight gain or eating food. Additional monitoring from the CTO gave most carers a peace of mind, which allowed them to step back from food-related discussions and led to fewer arguments in the family. However, one carer notably reflected on how the CTO was a good idea in principle but had not been effectively implemented. This was due to a lack of adherence to the CTO by professionals and led to a description of the CTO as a "safety net riddled with holes".

Discussion

Experiences of CTOs

The main aim of this study was to investigate patients' and carers' experiences of Community Treatment Orders in an eating disorder population. Previous research into CTOs has only included individuals with psychosis and mood disorders, where the focus is on medication adherence. In contrast, CTOs within the eating disorder populations focus more on weight management. Despite this initial difference, this study found that patients and carers reported some experiences that were common to both populations.

Patients and carers identified a wide range of positive and negative factors that influenced their perceptions and experiences of the CTO. The majority of participants viewed the CTO as a tool for risk management and necessary for an individual's transition to, and management in, the community. Recall was also seen as important to stop the cycle of weight loss before it became too dominant (Dignon et al., 2006). In line with previous research, good relationships with professionals were found to be a key factor that helped patients accept and engage with aspects of the CTO (Corring et al., 2017). Negative relationships with professionals were more often reflected by patient's negative views of the CTO. Carers who felt more listened to and involved also felt that more engaged with the CTO, whilst those who felt ignored by professionals had a more negative view of it (Rugkasa, 2017; Stensrud et al., 2015).

Recent developments in guidelines and the literature advocate strongly for the integration of patients and carers in decision making processes (Glacco et al., 2017; Langer, Mooney & Wills, 2015; Mental Health Act Code of Practice, 2017). Pridham et al. (2016) discussed how clear communication from professionals, listening to the patient voice in the planning process and patients feeling treated with respect are important factors that contribute to positive relationships with professionals. Studies have also found that the fairer the decision process is perceived to be, the less coerced individuals may feel (Lidz, 1998; McKenna et al., 2000). Additionally, a recent review of coercion in psychiatric settings also highlighted that a lack of input into treatment decisions increased patients' perceptions of

coercion and generated negative impressions of treatment (Newton-Howes & Mullen, 2011). Consequently, there is a large amount of evidence highlighting the importance of patient and carer involvement, and suggestions for how this can be better integrated in care.

A key theme found across both participant groups was how a lack of NHS resources impacted on CTO implementation. This was discussed in terms of the support some participants were able to access in the community, and delays in recall due to bed shortages. This is in line with research by Canvin et al. (2014), where carers talked about the importance of additional support, as it was felt that a focus on adherence to conditions not sufficient for patient welfare. Previous research has also suggested that when participants have high levels of support it can be difficult to differentiate the positives of this from the benefits of compulsory treatment (Stroud et al., 2015). This suggests that, with the right community support, CTOs may not always be necessary.

All patients agreed that being on a CTO was preferable to being in hospital, despite negative views about the CTO. Hospital was described as an awful environment, where patients had experienced restraint, nasogastric feeding and enforced weight gain. Patients' motivation to stay out of hospital was often stronger than their ambivalence towards the CTO, which is in line with previous research in the psychosis literature (Swartz et al., 2004). Consequently, recall was seen as a threat, aligning with previous research that described it as giving 'teeth' to the CTO (Stroud et al., 2015). However, patients also reported finding the recall process confusing and unpredictable. This is in line with findings from Canvin et al. (2014) where researchers discussed how patient confusion was also reflected by professionals' own uncertainty about the enforceability of discretionary conditions. This highlights the need for guidelines on CTO use that are communicated and followed by professionals.

Carers' experiences of the CTO were often complex and difficult to differentiate from their general relationship with the patient and the anorexia. They reflected previous psychosis literature that found a variation in the levels of involvement in the process. This

had been previously attributed to a number of factors, including patient choice, carer level of concern and professional decision making (Rugkasa & Canvin, 2017).

When involved in these processes, carers were often expected to hold a range of different roles. These included the role of the expert, the advocate and the loved one. Parents in particular discussed these conflicting roles at length and reflected on how they were unsure about which of these roles to take on. For example, one carer reflected on how she was asked by the patient to advocate for her, but also wished to express her own contrasting opinion. Management of these conflicting roles can have significant impacts on carer-patient relationships, as well as on relationships with professionals. In these examples, the CTO appeared to assist in managing some of these role choices. It was often used as a tool to back carer suggestions to patients and also allowed them to step back from food-related conversations. However, these conflicts have been previously discussed in the literature and there is a strong consensus that professionals should spend time with carers to discuss their expectations and allow for meaningful engagement in the care process (Rugkasa & Canvin, 2017).

The impact of anorexia

The second question of this study aimed to consider how experiences of the CTO were influenced by the patients' anorexia. The majority of patients described struggling with the CTO due to competing demands from their anorexia. This was described by one patient as a 'tug of war' between the anorexic voice, which wanted them to lose weight, and the 'logical part of their brain', which acknowledged the importance of the CTO. This struggle often led to increased stress and negative thoughts, particularly when patients aligned themselves with the CTO and adhered to the weight condition.

Research into the anorexic voice offers a way of understanding these patient's experiences. Many patients described a highly critical voice that focused on the importance of engaging in anorexic behaviours (Tierney & Fox, 2010; Williams & Reid, 2012). It has been found that the strength of this voice is associated with eating attitudes, such that a stronger voice will lead to more negative eating attitude (Pugh & Waller, 2016). Patients who

appeared to be more aligned with this voice were also those who found it more difficult to maintain their weight. They often found the CTO more difficult because it was 'going against the anorexia', and for one patient in particular this felt overwhelming. These patients often talked about their belief that recovery was unachievable for them. This left them feeling like they were barely able to maintain their weight and were not able to engage in what they wanted to do because of the CTO (Gregertsen et al., 2017; Mulkerrin et al., 2016).

In contrast, some patients spoke about using the CTO as a tool against the anorexia to give themselves permission to focus on other parts of their lives. This was still described as challenging, due to their strong affiliation with the anorexia. However, these patients spoke about the consequences of weight loss and subsequent recall as having to a significant impact on their life and budding identity. For example, this included the potential loss of work or their supported accommodation if they were recalled. These factors, the acknowledgment of the consequences of anorexia, and an ability to engage in consideration of a wider self-concept, have been previously associated with increased engagement in the process of recovery (Cockell et al., 2003; Garner and Bemis, 1982; Stein & Corte, 2006). It has been suggested that patients who are able to engage in their values and acknowledge the negative impact of anorexia on following these values may be more motivated to engage in treatment (Lamoureux & Bottorff, 2005; Mulkerrin et al., 2016). Consequently, and in line with previous findings within the psychosis literature, it is difficult to disentangle the specific mechanisms by which engagement in recovery for these patients occurred (Cockell et al., 2003; Stuen et al., 2005).

Limitations of the study

Several methodological issues must be considered when interpreting the findings. Research suggests that the timing of interviews can influence participant responses, depending on the stage of their journey (Luckstead & Coursey, 1995). For this study, all participants were able to reflect back on their experiences of the CTO and talk about these difficult periods in their life. However, several patients who were invited to take part declined, as they felt that it would be too difficult to talk about their experiences. This meant that some

of the emotional aspects of these experiences may not have been as strongly captured, as participants were reflecting back on experiences that had occurred over at least a year ago. In this process, some details may have been lost, and they may have also described viewpoints that may have differed to their experiences earlier in the CTO.

In terms of the recruitment process, patients may have been more likely to engage in the study if they had strong views about the CTO that they wanted to express. Conversely, they may have been less likely to volunteer if they felt disengaged from the process (Corring et al., 2017). Recruitment was predominantly conducted through staff who identified potential participants. This may have further influenced the findings, as staff may have had their own ideas about which patients would be most suitable for the study. For example, participants who expressed their strong opinions, or patients who staff felt more positive towards may have been more likely to have been chosen. Consequently, a subset of individuals on CTOs may have been inadvertently excluded from the recruitment process.

Size and sampling methods could also be considered limitations. Though recruitment was pre-agreed to six participants per group, it was further limited by COVID-19. This meant that the final two carers were not able to be recruited. Though this is unfortunate, the number of participants recruited were within the acceptable sample size range for IPA studies (Creswell, 1999), and the representativeness was strengthened by recruitment from four separate NHS Trusts. All patients were also female within this population. It is unclear whether findings would have differed if the male experience had been included. Research suggests that males can present with different weight and body image concerns (Strother et al., 2012). However, this is a limitation that is reflective of the eating disorder field, where men are significantly under-represented as patients and in research (Weltzin, 2005).

A further limitation of this study was that a wholly IPA approach may not have been possible. This was due to the joint nature of the project with a trainee who undertook a thematic analysis which focussed more on the implementation of CTOs and led to several more factual interview questions. This was also to allow both researchers to develop an initial understanding of how CTOs were used, as this had not been investigated previously .

Due to these factors, some themes within the analysis may have taken on a more factual tone that may not have reflected a purely phenomenological approach.

Clinical implications

The current findings suggest a number of clinical implications for the use of CTOs in eating disorder services. Patients and carers understood the CTO as a framework allowing for increased monitoring and risk management of an individual in the community. However, the current findings and previous psychosis literature suggest that carers and patients are often unclear about what could trigger recall which leads to uncertainty and frustration around the CTO (Canvin et al., 2014). This may reflect a lack of clear communication about the CTO process from professionals to patients and carers. Alternatively, this may have been due to patients' and carers' focus on recovery over the particulars of the CTO that were used to get that point. Given the impact of communication on the perceptions of the CTO, this suggests the need for clearer and more transparent communication with patients and carers about the CTO's structure and application.

Carers and patients both reflected on the importance of good relationships with professionals to drive engagement with the CTO. Both groups highlighted the importance of a collaborative process, where they felt heard and respected. However, many participants spoke about the experience of not feeling heard by professionals. High levels of ambivalence around recovery, and perceptions of coercion are factors that have been found to lead to disengagement from treatment. Consequently, good relationships with professionals are essential to moderate these factors and ensure that patients feel supported in the process of change (Cooper, 2005; Corring et al., 2017; Eivors et al., 2003; Light et al., 2014).

The role of carers in CTOs also varied by service, despite recommendations for their increased involvement in patient care by the Mental Health Act (2008). Carers often found themselves consulted, or informed, only at the very end of the process, or involved very minimally in the decision making. Carers often play a crucial role in a patient's life, particularly in their understanding of the illness and triggers (Glaco et al., 2017). However,

they also take on a range of conflicting roles that can have significant impacts on their relationships with patients and professionals (Rugkasa & Canvin, 2017). As such, it is important that they feel that they have clearly defined roles within the process to allow for engagement and a continuity of care between home and professionals.

Research implications

There has been no previous research into the use of CTOs in eating disorders, and as such its implementation has only been investigated in the psychosis literature. This study highlighted significant variation in patient and carer experiences of the CTO, particularly in regards to its implementation. Given the lack of guidelines and data about its use in eating disorder service, a first step would be to complete an audit to examine the extent to which CTOs are being used by services, in particular their frequency and common conditions.

Future research might also explore treatment outcomes in response to CTO use within this population. There is very little evidence for their efficacy in the psychosis literature which has brought into question their necessity and helpfulness (Barnett et al., 2018). It would be of interest to not only investigate rates of recall, hospital admission length and engagement with services, but also to consider the weight at which patients are admitted to hospital. Though it may seem that patients are often recalled, admissions at a higher weight could be seen an indicator of their own motivation to seek help and engage in the recovery process.

Conclusion

This study found that experiences of CTOs varied widely, though there are some similarities across patient and carer groups, and some commonalities with previous findings within the psychosis literature. They refer to the importance of good relationships with professionals to drive perceptions and implementation, and the general impact of NHS funding on resource availability (Corring et al., 2017). However, the strong voice of anorexia and its impact on the development of shared goals between patients and professionals is important to consider as an additional factor influencing treatment outcomes. Due to the lack of literature in the field, further research should focus on understanding the way in which

CTOs are used by professionals, in addition to considering outcomes about their effectiveness.

References

- Barnett, P., Matthews, H., Lloyd-Evans, B., Mackay, E., Pilling, S. & Johnson, S. (2018). Compulsory community treatment to reduce readmission to hospital and increase engagement with community care in people with mental illness: a systematic review and meta-analysis. *The Lancet Psychiatry*, 5. Doi: 10.1016/S2215-0366(18)30382-1.
- Blomqvist, M. & Ziergert, K. (2011) Family in the Waiting Room: A Swedish Study of Nurses Conceptions of Family Participation in Acute Psychiatric Inpatient Settings. *International Journal of Mental Health Nursing*, 20, 185-194.
- Burns, T., Rugkåsa, J., Molodynski, A., Dawson, J., Yeeles, K., Vazquez-Montes, M., Voysey, M., Sinclair, J., & Priebe, S. (2013). Community treatment orders for patients with psychosis (OCTET): a randomised controlled trial. *Lancet (London, England)*, 381(9878), 1627–1633. [https://doi.org/10.1016/S0140-6736\(13\)60107-5](https://doi.org/10.1016/S0140-6736(13)60107-5)
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. *International Journal of Qualitative Methods*, 1–13. <https://doi.org/10.1177/160940690300200201>
- Canvin, K., Rugkåsa, J., Sinclair, J., & Burns, T. (2014). Patient, psychiatrist and family carer experiences of community treatment orders: qualitative study. *Social psychiatry and psychiatric epidemiology*, 49(12), 1873–1882. <https://doi.org/10.1007/s00127-014-0906-0>
- Churchill, R., Gareth, O., Singh, S. & Hotopf, M. (2007), International Experiences of Using Community Treatment Orders, Department of Health, London.
- Clarke, V. (2010). Review of the book "Interpretative Phenomenological Analysis: Theory, Method and Research". *Psychology Learning & Teaching*, 9, 57-56.
- Cockell, S., Geller, J. & Linden, W. (2003). Decisional balance in Anorexia Nervosa: Capitalizing on ambivalence. *European Eating Disorders Review*, 11. 75 - 89. 10.1002/erv.493.

- Cooper, M. (2005). Cognitive theory in anorexia nervosa and bulimia nervosa: Progress, development and future directions. *Clinical psychology review*, 25, 511-31.
10.1016/j.cpr.2005.01.003.
- Corring, D., O'Reilly, R., & Sommerdyk, C. (2017). A systematic review of the views and experiences of subjects of community treatment orders. *International journal of law and psychiatry*, 52, 74–80. <https://doi.org/10.1016/j.ijlp.2017.03.002>
- Creswell, John, Taylor, Steven, Bogdan, Robert & Denzin, Norman. (1999). Qualitative Research Comes of Age. *PsycCRITIQUES*, 44, 97-100.
<https://doi.org/10.1037/001958>
- Darcy A., Katz, S., Fitzpatrick, K., Forsberg, S., Utzinger, L. & Lock, J. (2010). All better? How former anorexia nervosa patients define recovery and engaged in treatment. *European Eating Disorders Review*, 18(4), 260–270. doi:
10.1002/erv.1020.
- Dignon, A., Beardsmore, A., Spain, S. & Kuan, A. (2006). 'Why I Won't Eat' Patient Testimony from 15 Anorexics Concerning the Causes of Their Disorder. *Journal of health psychology*, 11. doi: 942-56. 10.1177/1359105306069097.
- Doody, O., Butler, M. P., Lyons, R., & Newman, D. (2017). Families' experiences of involvement in care planning in mental health services: an integrative literature review. *Journal of psychiatric and mental health nursing*, 24(6), 412–430.
<https://doi.org/10.1111/jpm.12369>
- Eassom, E., Giacco, D., Dirik, A., & Priebe, S. (2014). Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ open*, 4(10), e006108. <https://doi.org/10.1136/bmjopen-2014-006108>
- EDSECT (2012): Eating Disorder Newsletter. Retrieved from:
<https://www.rcpsych.ac.uk/members/your-faculties/eating-disorders-psychiatry/news-and-resources>

- Eivors, A., Button, E., Warner, S. & Turner, K. (2003), Understanding the experience of drop-out from treatment for anorexia nervosa. *European Eating Disorders Review*, 11: 90-107. doi:[10.1002/erv.492](https://doi.org/10.1002/erv.492)
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British journal of clinical psychology*, 38(3), 215–229. <https://doi.org/10.1348/014466599162782>
- Federici, A., & Kaplan, A. S. (2008). The patient's account of relapse and recovery in anorexia nervosa: a qualitative study. *European Eating Disorders Review: The journal of the Eating Disorders Association*, 16(1), 1–10. <https://doi.org/10.1002/erv.813>
- Fischer C. T. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy research: Journal of the Society for Psychotherapy Research*, 19(4-5), 583–590. <https://doi.org/10.1080/10503300902798375>
- Garner, D. M., & Bemis, K. M. (1982). A cognitive-behavioral approach to anorexia nervosa. *Cognitive Therapy and Research*, 6, 123–150. doi:10.1007/BF01183887
- Greenwood, N., Holley, J., Ellmers, T., Mein, G., & Cloud, G. (2016). Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors. *BMJ open*, 6(1), e009498. <https://doi.org/10.1136/bmjopen-2015-009498>
- Gregertsen, E. C., Mandy, W., & Serpell, L. (2017). The Egocentric Nature of Anorexia: An Impediment to Recovery in Anorexia Nervosa Treatment. *Frontiers in psychology*, 8, 2273. <https://doi.org/10.3389/fpsyg.2017.02273>
- Harris, E. C., & Barraclough, B. (1998). Excess mortality of mental disorder. *The British journal of psychiatry: the journal of mental science*, 173, 11–53. <https://doi.org/10.1192/bjp.173.1.11>
- HM Courts & Tribunal Service, (2014). Retrieved from: <https://www.gov.uk/guidance/community-treatment-orders>

Human Rights Act (1988), Retrieved from

<http://www.legislation.gov.uk/ukpga/1998/42/contents>

Keel, P. K., & Brown, T. A. (2010). Update on course and outcome in eating disorders. *The International journal of eating disorders*, 43(3), 195–204.

<https://doi.org/10.1002/eat.20810>

Kisely, S., & Hall, K. (2014). An updated meta-analysis of randomized controlled evidence for the effectiveness of community treatment orders. *Canadian journal of psychiatry. Revue canadienne de psychiatrie*, 59(10), 561–564.

<https://doi.org/10.1177/070674371405901010>

Lamoureux, M. & Bottorff, J. (2005). “Becoming the Real Me”: Recovering from Anorexia Nervosa. *Health care for women international*, 26, 170-88.

10.1080/07399330590905602.

Langer, D., Mooney, T., & Wills, C. (2015, November 12). Shared Decision-Making for Treatment Planning in Mental Health Care: Theory, Evidence, and Tools. *Oxford Handbooks Online*. Retrieved 8 Jul. 2020, from

<https://www.oxfordhandbooks.com/view/10.1093/oxfordhb/9780199935291.001.0001/oxfordhb-9780199935291-e-7>.

Lidz C.W. (1998). Coercion in psychiatric care: what have we learned from research? *The journal of the American Academy of Psychiatry and the Law*, 26(4), 631–637.

Light, E.M., Robertson, M.D., Boyce, P., Carney, T., Rosen, A., Cleary, M., Hunt, G.E., O'Connor, N., Ryan, C. & Kerridge, I. H. (2014). The lived experience of involuntary community treatment: a qualitative study of mental health consumers and carers. *Australasian Psychiatry*, 22(4), 345–

351. <https://doi.org/10.1177/1039856214540759>

Löwe, B., Zipfel, S., Buchholz, C., Dupont, Y., Reas, D. L., & Herzog, W. (2001). Long-term outcome of anorexia nervosa in a prospective 21-year follow-up study. *Psychological Medicine*, 31(5), 881–890. <https://doi.org/10.1017/s003329170100407x>

- Lucksted, A., & Coursey, R. D. (1995). Consumer perceptions of pressure and force in psychiatric treatments. *Psychiatric Services*, 46(2), 146–152. <https://doi.org/10.1176/ps.46.2.146>
- Lund, B.C., Hernandez, E.R., Yates, W.R., Mitchell, J.R., McKee, P.A., Johnson, C.L. (2009). Rate of inpatient weight restoration predicts outcome in anorexia nervosa. *International Journal of Eating Disorders*, 42(4), 301–5.
- McKenna, B. G., Simpson, A. I. F., & Coverdale, J. H. (2000). What is the Role of Procedural Justice in Civil Commitment? *Australian & New Zealand Journal of Psychiatry*, 34(4), 671–676. <https://doi.org/10.1080/j.1440-1614.2000.00744.x>
- McMillan, J., Lawn, S., & Delany-Crowe, T. (2019). Trust and Community Treatment Orders. *Frontiers in psychiatry*, 10, 349. <https://doi.org/10.3389/fpsy.2019.00349>
- Mental Health Act (2007), Chapter 4. Retrieved from: http://www.opsi.gov.uk/acts/acts2007/ukpga_20070012_en_1
- Mental Health Act Code of Practice (2007). Retrieved from: <https://www.gov.uk/government/news/new-mental-health-act-code-of-practice>
- Mulkerrin, Ú., Bamford, B., & Serpell, L. (2016). How well does Anorexia Nervosa fit with personal values? An exploratory study. *Journal of Eating Disorders*, 4, 20. <https://doi.org/10.1186/s40337-016-0109-z>
- Newton-Howes, G., & Mullen, R. (2011). Coercion in psychiatric care: systematic review of correlates and themes. *Psychiatric services (Washington, D.C.)*, 62(5), 465–470. https://doi.org/10.1176/ps.62.5.pss6205_0465
- O'brien, A., Farrell, S. & Faulkner, S. (2009). Community Treatment Orders: Beyond Hospital Utilization Rates Examining the Association of Community Treatment Orders with Community Engagement and Supportive Housing. *Community Mental Health Journal*. 45, 415-9. 10.1007/s10597-009-9203-x.
- Papadopoulos, F. C., Ekblom, A., Brandt, L., & Ekselius, L. (2009). Excess mortality, causes of death and prognostic factors in anorexia nervosa. *The British journal of psychiatry*:

the journal of mental science, 194(1), 10–17.

<https://doi.org/10.1192/bjp.bp.108.054742>

Pridham, K. M., Berntson, A., Simpson, A. I., Law, S. F., Stergiopoulos, V., & Nakhost, A.

(2016). Perception of Coercion Among Patients With a Psychiatric Community

Treatment Order: A Literature Review. *Psychiatric services (Washington,*

D.C.), 67(1), 16–28. <https://doi.org/10.1176/appi.ps.201400538>

Pugh, M., & Waller, G. (2016). The anorexic voice and severity of eating pathology in

anorexia nervosa. *The International journal of eating disorders*, 49(6), 622–625.

<https://doi.org/10.1002/eat.22499>

Pugh, M., & Waller, G. (2017) Understanding the ‘Anorexic Voice’ in Anorexia

Nervosa. *Clinical Psychology & Psychotherapy*, 24: 670– 676.

doi: [10.1002/cpp.2034](https://doi.org/10.1002/cpp.2034).

Richard, M. (2005). Care provision for patients with eating disorders in Europe: what patients

get what treatment where? *European Eating Disorder Review*, 13(3):159–68.

Rugkåsa, J., & Canvin, K. (2017). Carer involvement in compulsory out-patient psychiatric

care in England. *BMC health services research*, 17(1), 762.

<https://doi.org/10.1186/s12913-017-2716-z>

Rugkåsa, J., Yeeles, K., Koshiaris, C., & Burns, T. (2017). What does being on a community

treatment orders entail? A 3-year follow-up of the OCTET CTO cohort. *Social*

psychiatry and psychiatric epidemiology, 52(4), 465–472.

<https://doi.org/10.1007/s00127-016-1304-6>

Rusner, M., Carlsson, G., Brunt, D. A., & Nystrom, M. (2012). The paradox of being both

needed and rejected: The existential meaning of being closely related to a person

with bipolar disorder. *Issues in Mental Health Nursing*, 33(4), 200–208. [https://doi-](https://doi.org/libproxy.ucl.ac.uk/10.3109/01612840.2011.653037)

[org.libproxy.ucl.ac.uk/10.3109/01612840.2011.653037](https://doi.org/libproxy.ucl.ac.uk/10.3109/01612840.2011.653037)

Serpell, L., Treasure, J., Teasdale, J., & Sullivan, V. (1999). Anorexia nervosa: friend or

foe? *The International journal of eating disorders*, 25(2), 177–186.

[https://doi.org/10.1002/\(sici\)1098-108x\(199903\)25:2<177::aid-eat7>3.0.co;2-d](https://doi.org/10.1002/(sici)1098-108x(199903)25:2<177::aid-eat7>3.0.co;2-d)

- Smith, J.A. (1995). Semi structured interviewing and qualitative analysis. In: Smith, J. A., Harre, R. & Van Langenhove, L. (eds.) *Rethinking Methods in Psychology*. Sage Publications, pp. 9-26. ISBN 9780803977334.
- Smith, J.A., Flower, P. & Larkin, M. (2009), *Interpretative Phenomenological Analysis: Theory, Method and Research.*, *Qualitative Research in Psychology*, 6:4, 346-347, DOI: [10.1080/14780880903340091](https://doi.org/10.1080/14780880903340091)
- Steadman, H.J., Gounis, K., Dennis, D., Hopper, K., Roche, B., Swartz, M. & Robbins, P.C. (2001). Assessing the New York City involuntary outpatient commitment pilot program. *Psychiatric Services*, 52, 330–336
- Stein, K.F., & Corte, C. (2007). Identity impairment and the eating disorders: content and organization of the self-concept in women with anorexia nervosa and bulimia nervosa. *European eating disorders review: The journal of the Eating Disorders Association*, 15(1), 58–69. <https://doi.org/10.1002/erv.726>
- Steinhausen, H.C., Grigoriu-Serbanescu, M., Boyadjieva, S., Neumarker, K.J. & Winkler Metzke, C. (2008) Course and predictors of rehospitalization in adolescent anorexia nervosa in a multisite study. *International Journal of Eating Disorders*, 41(1), 29–36.
- Stensrud, B., Høyer, G., Granerud., A & Landheim, A.S. (2015) “Life on Hold”: A Qualitative Study of Patient Experiences with Outpatient Commitment in Two Norwegian Counties, *Issues in Mental Health Nursing*, 36(3), 209-216, DOI: 10.3109/01612840.2014.955933
- Stroud, J., Banks, L., & Doughty, K. (2015). Community treatment orders: learning from experiences of service users, practitioners and nearest relatives. *Journal of mental health*, 24(2), 88–92. <https://doi.org/10.3109/09638237.2014.998809>
- Stuen, H.K., Rugkåsa, J., Landheim, A., & Wynn, R. (2015). Increased influence and collaboration: a qualitative study of patients' experiences of community treatment orders within an assertive community treatment setting. *BMC health services research*, 15, 409. <https://doi.org/10.1186/s12913-015-1083-x>

- Swartz, M.S., & Swanson, J.W. (2004). Involuntary Outpatient Commitment, Community Treatment Orders, and Assisted Outpatient Treatment: What's in the Data? *The Canadian Journal of Psychiatry*, 49(9), 585–591
<https://doi.org/10.1177/070674370404900903>
- Swartz, M., Wilder, C., Swanson J., Van Dorn, R.A., Robbins, P.C., Steadman, H.J., Moser, L.L., Gilbert, A.R. & Monahan, J. (2010). Assessing outcomes for consumers in New York's assisted outpatient treatment program. *Psychiatric Services*. 61(10), 976–981.
doi: 10.1176/ps.2010.61.10.976
- Tierney, S. & Fox, J.R.E. (2010). Living with the anorexic voice: A thematic analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 83, 243-254.
doi:[10.1348/147608309X480172](https://doi.org/10.1348/147608309X480172)
- Vitousek, K., Watson, S., & Wilson, G. T. (1998). Enhancing motivation for change in treatment-resistant eating disorders. *Clinical psychology review*, 18(4), 391–420.
[https://doi.org/10.1016/s0272-7358\(98\)00012-9](https://doi.org/10.1016/s0272-7358(98)00012-9)
- Williams, Sarah & Reid, Marie. (2011). 'It's like there are two people in my head': A phenomenological exploration of anorexia nervosa and its relationship to the self. *Psychology & health*. 27, 798-815. doi:10.1080/08870446.2011.595488.

Part 3: Critical Appraisal

This critical appraisal contains some of my reflections on the process of conducting the major research project. I will begin by discussing the initial decision-making process, including how my previous experiences impacted on my views about this project. I will then reflect on the process of recruitment and interviews, and how I managed my own assumptions and biases. Finally, I will reflect on my experiences of qualitative analysis.

Background

The path settling on this project took 9 months. I wanted to try qualitative research, as I had only conducted quantitative research before, and I was interested in the field of eating disorders. However, I eventually settled on a secondary data analysis project in another area. After a few months this project fell through, but thankfully my now research partner offered for me to join her project as there was room for expansion. Though this initial process had been quite stressful and difficult, I was happy to have been able to settle on an area of research that I was initially interested in.

I had not had previous experience of working within eating disorder services. However, I have always been curious about this area, as I have noticed eating difficulties in many of the patient groups I have worked with. My assumptions and beliefs were consequently derived from what I had heard from others. This was that this is an extremely difficult field to work in due to high levels of ambivalence to treatment. However, given my position as a trainee psychologist, and the value I place in person-centred care, I was keen to develop a greater understanding about the perspectives of patients and carers.

My knowledge about CTOs was also limited at the start of this project. I had heard about their use in my first placement in a Community Mental Health Team. My understanding from this experience was from the professional's perspective, where they were considered necessary to manage risk in the community. I remember one patient in this service, a male diagnosed with Bipolar, who was on a CTO. There had been a lot of uncertainty about whether he should be recalled, and professionals were extremely concerned about his safety. When they made the decision, there was also a difficulty in this process due to bed shortages. During this time, I also found myself wondering about the

patient's experience. Particularly as, in this team, it often felt that the patient voice was often left out.

As I had joined the project later than my colleague, much of my understanding about the project was based on what she had already discussed with our supervisor. My role was to consider the additional role of carers in CTOs, and how we could bring their voice into our data collection. My experience before training had been in CAMHS services, and several of my placements implemented systemic principles. Consequently, this aspect of the research felt in line with my own values and beliefs about working with both the individual and the people around them. It was extremely helpful having another person to work alongside and share ideas with. Despite the initial stress of changing projects, I ended up feeling quite excited about this project.

Conducting research in eating disorders

Coming from a quantitative background, I spent a lot of time learning and developing my understanding of qualitative methodology. Given that I had come from a field where objectivity was aimed for, I had to adapt my expectations of what qualitative research. I learned how researchers strive to manage and embrace subjectivity by explicitly identifying implicit personal biases and assumptions. The concept of 'bracketing' was one method I used. It is the process of identifying and attempting to step aside from one's preconceptions in order to limit their influence on the research (Fischer, 2009; Hill et al., 2005). Though the extent to which complete bracketing is possible has been debated, researchers argue that this process encourages thoughtful and reflective engagement with the data (Fischer, 2009; Tufford & Newman, 2010).

Self-reflexivity

At the start of this process, I noticed that some of my assumptions were drawn from information I had gained from other people and then adopted as my own. Qualitative guidelines discuss the impact that these assumptions may have on objectivity in data collection and analysis and recommend management of these assumptions through 'self-reflexivity'. This is the process of reflecting upon how one's experiences, beliefs and identity

have shaped our research (Malterud, 2001; Willig, 2001). Researchers have suggested several ways in which to foster reflexivity in research, including using multiple investigators on a project and maintaining a reflexive journal (Lincoln & Guba, 1982).

As this was a joint project, we found it incredibly helpful to have ongoing conversations about our assumptions and reflect, in particular, on interviews. Though we never sat down for a formal bracketing discussion we spent time reflecting on our own views of CTOs and eating disorders. Some of the important conversations we had close to the start of the project were around the development of the semi-structured interview. The development of interview questions was a lengthy process. We initially based our questions on information we had gained from the literature, as well as our own understanding of the mental health system. We also drew on our experiences as psychologists to consider how we could engage participants in a topic that could be highly emotive. After we had developed a draft, we consulted with our supervisor, a psychologist with experience working with eating disorders, and a service user representative to ensure that our questions were relevant. Unfortunately, we were not able to consult with a carer due to time restrictions. Upon reflection, this may have been an oversight on my part. After my first carer interview, I realised that, as the questions mirrored the patient interview, there was a focus on how carers perceived the CTO impacted patients rather than themselves. After further consultation with my colleague and supervisors, I adapted the questions to ensure that questions about carer experiences were included in the remaining interviews.

Following the interviews, we spent time discussing what had come up during the interview, our responses and how our assumptions may have influenced our responses. This was to ensure that we weren't just focusing on areas that agreed with our own biases. We also considered how our roles as psychologists could conflict with the role of a researcher. Often, we would find ourselves wanting to be empathic and use interpretations to guide discussions. However, we had to find a balance that would ensure that patients felt able to describe their experiences in their own words, but also felt understood. Though we

never found the perfect solution, we were able to talk through and adapt our interview styles to ensure that participant experience was in clear focus.

Recruitment and interview process

As we had both initially planned to complete our analysis using IPA, we agreed on a sample size of 6 participants per group. This is generally considered as an appropriate size for IPA studies (Creswell, 1999). It also felt achievable given the small number of patients on CTOs. During recruitment, we noticed a trickle-down effect on numbers, which led to difficulties in finding participants towards the end of the study. It was easiest to recruit professionals as they were our key point of contact within services. They were then able to provide us with a number of patients to follow-up. However, as we already had a more limited sample of patients, this meant that it was harder to recruit carers.

I hypothesise that these difficulties may have been caused by a combination of factors. Overall there is only a small number of patients on CTOs, which would have meant we were initially recruiting from a very small sample pool. We found that several patients did not want to burden their family members with reliving the CTO, leading to a further reduction in the pool of carers we could recruit from. We also had to end recruitment early, due to the onset of COVID-19.

Additionally, the ongoing strain on the NHS and staff meant that many professionals may have been too busy to help with recruitment. Due to ethics, we required professionals to contact patients before we were able to talk to them. Given constraints on services, this could have been an extremely time-consuming task for professionals. Professionals' views of CTOs may have influenced their enthusiasm and motivation to help us. Those services where CTOs were felt to be helpful, or where they were used more often were more likely to aid our recruitment drives as they were keen for more research in this area.

Through discussions with my colleague and my own reflective notes, I considered my position as a professional and how it impacted my stance. There were times in interviews where I found myself considering professionals' perspectives, though my focus was on patients and carers. For example, when patients spoke about the CTO as being

unnecessary, I thought about how there must have been significant concern from professionals to place them on a CTO. I noted how this view could lead to me pushing participants to talk about the ways in which the CTO had been beneficial, even when this was not their view. Discussing these biases with my research colleague enhanced my reflexivity and allowed me to consider how this could also further influence my data analysis. I ensured that throughout interviews I was able to maintain a more neutral and curious stance towards participants' experiences.

I also considered my preference for systemic working and how it may have influenced interviews. I have always felt strongly about the importance of carer involvement in treatment. For example, in CAMHS services, parents are most often involved in that child's care, and when they are younger it is helpful to involve them in the therapy itself. When questions about family involvement came up, I found myself wanting to explore this area in more depth. I was also particularly curious about how carers experienced their relationship with the patient and the eating disorder, despite this not being fully relevant to the research. Having identified these biases, I ensured that I did not push participants to talk about areas which I found myself pulled towards, unless the discussion was led by them. I also tried to make sure that I was able to relate any questions directly back to the CTO.

As I interviewed some patients and carers who were related to one another, I also had to be mindful that my experience of the other person's interview did not affect my assumptions and questioning. This came up when there was a contrast in the information I was given by the patient and carer about how the CTO was implemented. I was mindful that I was there to understand the participants' experiences, not to report on the precise details of the CTO. However, upon reflection after the interview I noticed myself thinking about which perspective could have been 'the right one'. As I considered how this was not relevant to the research, I attempted to shelve this assumption. I also ensured that I was able to focus on the individual experiences being presented during data analysis so that my interpretations matched their experiences.

Qualitative analysis

IPA is completed on homogenous samples where all participants are assumed to have had similar experiences (Banister et al., 2011). Throughout the project I found myself questioning whether to treat patients and carers as one homogenous sample, or two distinct groups. I spent time discussing this question with my colleague and supervisors, as well as tutors within the qualitative field. We considered how the analysis would depend on the research question being investigated, for example how CTOs were experienced vs what the similarities and differences in experiences were between groups. As I have a more quantitative background, I reflected on how differences are often the key point of focus, and how this may have influenced my thinking. However, throughout the interviews, it also became apparent that, though there were some similarities between groups, each group had their own experiences. I felt that it would be helpful to present the data in two separate groups to allow for a greater understanding and exploration of these experiences.

During the interviews, I also considered how interviewing two individuals, that is a patient and their carer, could have impacted on the data analysis. In qualitative research, bias is usually managed by using correlation analyses. After consideration with my supervisors, we agreed that though the groups may have had a shared key experience, what we were trying to investigate was how they interpreted this experience. I felt that it would have been interesting to examine these shared experiences through analysis of patient-carer pairs. However, there were only three matched pairs, which we felt may have been too few. Additionally, though patients and carers knew the other would be interviewed, we had not asked for consent from either group to share their interviews with the other. Consequently, we felt that it was important to keep interviews separate for reasons of confidentiality.

Another difficulty I had, particularly towards the start of the analysis, was considering how to synthesise the data into themes. I was worried about moving too far from the details of participants' words and over-interpreting their meaning. This meant that I coded quite literally to begin with. One of the most helpful aspects of this process was talking to others about the analysis. Myself and my research colleague co-coded four patient interviews. As

she had changed her analysis, this meant that I considered the dataset from a thematic analysis perspective, whilst she considered it from an IPA perspective. This allowed me to take a step back from the data set and consider it from a different framework. It also allowed us to bounce ideas off of each other and consider how our assumptions and interpretations impacted on our analysis. Through this process, and with further analysis, I began to strike a more effective balance between my interpretations and participant details. This also allowed me to more effectively condense the vast amounts of information from the transcripts into usable themes.

To further entrench this process in participant data, I constantly referred back to the initial transcripts. As I had only conducted a proportion of the patient interviews, I was aware that I may have been drawn to and remember quotes more easily from these. Consequently, I ran the risk of privileging some voices over others. I managed this by spending more time listening through, and re-reading interviews I had not completed to ensure I was fully immersed in the data. At the theme amalgamation stages, I organised the data in many different ways. I checked with transcripts for examples that fit or did not fit with each organisation. I also spent time discussing these themes with my supervisor who had knowledge of eating disorder services. We considered different ways of organising the themes to check if they were also consistent with her clinical experiences of working with both patients and carers.

Overall, working on this project allowed me to undertake an in-depth exploration of patient and carer experiences. Listening to participant's experiences of services emphasised the importance of the therapeutic relationship. It highlighted how perceptions of professionals and a lack of patient voice can impact on recovery. I am appreciative for this perspective, as it has heightened the value I place in the contributions of patients and carers to their own care. I can also see how this could be easily overlooked in busy service environments and hope that I will be able to take this forward with me across my career.

References

- Banister, P., Dunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., Lawthom, R., Parker, I., Runswick-Cole, K., Sixsmith, J., Smailes, S., Tindall, C. & Whelan, P. (2011). *Qualitative methods in psychology: A research guide*. 2nd edition. Maidenhead: Open University Press/ McGraw Hill.
- Creswell, John, Taylor, Steven, Bogdan, Robert & Denzin, Norman. (1999). Qualitative Research Comes of Age. *PsycCRITIQUES*, 44, 97-100.
<https://doi.org/10.1037/001958>
- Fischer C. T. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy research: journal of the Society for Psychotherapy Research*, 19(4-5), 583–590. <https://doi.org/10.1080/10503300902798375>
- Guba, E.G. & Lincoln, Y.S. (1982). Epistemological and methodological bases of naturalistic inquiry. *ECTJ* 30, 233–252. <https://doi.org/10.1007/BF02765185>
- Hill, C., Knox, S., Thompson, B., Williams, E., Hess, S. & Ladany, N. (2005). Consensual Qualitative Research: An Update. *Education Faculty Research and Publications*, 52. 10.1037/0022-0167.52.2.196.
- Malterud, K. (2001). Qualitative Research: Standards, Challenges, and Guidelines. *Lancet*, 358, 483-8. 10.1016/S0140-6736(01)05627-6.
- Tufford, L., & Newman, P. (2012). Bracketing in Qualitative Research. *Qualitative Social Work*, 11(1), 80–96. <https://doi.org/10.1177/1473325010368316>
- Willig, C. (2001). *Introducing qualitative research in psychology*. Buckingham, UK: Open University Press.

Appendix A: Adapted Qualsyst Tool

Criteria	Yes (2)	Partial (1)	No (0)	N/A
1. Question / objective sufficiently described?				
2. Study design evident and appropriate?				
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4. Subject (and comparison group, if applicable) characteristics sufficiently described?				
5. If interventional and random allocation was possible, was it described?				
6. If interventional and blinding of investigators was possible, was it reported?				
7. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
8. Sample size appropriate?				
9. Analytic methods described/justified and appropriate?				
10. Some estimate of variance is reported for the main results?				
11. Intervention adherence reported and robust?				
12. Controlled for confounding variables?				
13. Follow-up conducted and reported?				
14. Results reported in sufficient detail?				
15. Conclusions supported by the results?				

Appendix B: Flyer for patients

UCL Research Department of Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



UCL

Are you currently on a CTO or have been on one previously?

Are you interested in talking to someone about
these experiences?

We are hoping to understand your views on CTOs,
especially in terms of their advantages and
disadvantages in the treatment of Eating Disorders.

Participation will involve an interview lasting between
1-2 hours at your local Eating Disorder Service, or over
skype/the telephone. You will be paid **£10 an hour** and
given up to **£5 for travel expenses**.

Your participation will be valuable to a research study based
at University College, London, and will shape the use of
CTOs in the near future. If you are interested in
participating, please contact Vall on
vallabhi.khurana.13@ucl.ac.uk or 07473664636

21/03/2019, v1.0

Appendix C: Patient information sheet

UCL Research Department of Clinical, Educational &
Health Psychology
1-19 Torrington Place
University College London
London



Information Sheet (Version 1.1)

12/06/2019

We are inviting you to take part in a research project. We want to find out about the use of Community Treatment Orders (CTOs) in the treatment of Eating Disorders; specifically looking at your experiences of being under a CTO presently or in the past.

This study is being carried out by two trainee clinical psychologists undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

Title of Project:	Exploring the Psychological Impact of Community Treatment Orders in the Treatment of Eating Disorders
Project ID No:	120817
Student Researchers:	Vallabhi Khurana (Trainee Clinical Psychologist) Kim Mihaljevic (Trainee Clinical Psychologist) UCL Clinical Psychology Doctoral Programme
Supervisors:	Dr Lucy Serpell (Clinical Psychologist and Senior Lecturer) UCL Research Department of Clinical, Educational & Health Psychology

This study has been approved by the Clinical, Educational and Health Psychology Research Department's Ethics Chair.

What is the purpose of this study?

This study aims to explore the impact that CTOs have on the treatment of Eating Disorders, mainly assessing their associated advantages and disadvantages. We are not holding a particular view in mind, but rather are interested in your experiences of being under a CTO.

The study's main purpose is to understand whether CTOs might help or get in the way of recovery. We hope to assess this by understanding the perspectives from both patients, clinicians and carers and are interested in whether they have different views. Therefore, we are interested in understanding your experiences of being under a CTO, whilst getting treatment for an eating disorder.

Why have I been invited?

You have been invited to participate in this study as you are/have previously been under a CTO, whilst getting treatment for an eating disorder.

Do I have to take part?

No. You are under no obligation to take part in this study.

What will I be asked to do?

Your participation will involve taking part in a one-to-one interview with one of the student researchers (Vallabhi Khurana & Kim Mihaljevic, trainee clinical psychologists currently undertaking the UCL Clinical Psychology Doctorate programme).

Interviews will last up to 2 hours depending on your availability. You will be compensated for up to 2 hours of your time, at £10 per hour. You are also entitled to flat rate of £5 as travel allowance. Payments will be given in cash.

Participation in this study is voluntary and you will be asked to give your written consent. You will be given the opportunity to ask the investigator any questions you may have, before being asked to read and sign the consent form if you are willing to take part in the subsequent interview. If you decide to take part you are still free to withdraw at any time during the process and without giving a reason.

What is the role of my carer in this study?

We hope to also recruit carers of patients, to gain an understanding of their views and opinions on CTOs. For the purpose of this study, a carer is defined as someone who is actively engaged and involved in your care whilst you are/have been receiving treatment for an Eating Disorder.

Your carer's participation will involve also taking part in a one-to-one interview with the student researchers (Vallabhi Khurana & Kim Mihaljevic). Interviews will also last up to 120 minutes depending on their availability.

If your carer is recruited for this study, you will be asked to give your written consent for them to participate and undergo the interview. You and your carer will be given the opportunity to ask the investigator any questions you may have, before being asked to read and sign the consent form.

What are the benefits of participating in this study?

Participating in this study will give you the opportunity to reflect on your experiences of being under a CTO. You will also get the opportunity to voice your opinions about the use of CTOs in the treatment of eating disorders.

It is anticipated that the findings from this study will be used to improve the way that CTOs are used in Eating Disorder services in the U.K. to better support patients in their recovery.

What are the risks of participating in this study?

Discussing your experiences of being under a CTO can be distressing. If you feel distressed, you will be advised to speak to your clinical team at your eating disorder service. Additionally, you are encouraged to speak to the Chief Investigator of this study (see below) who will provide any additional support.

What if I no longer want to take part in this study?

If you no longer want to take part in this study, please let the researcher know. Any data collected will be removed from the study. You do not need to give a reason for withdrawing from the study.

Who will have access to my information and how will my information be kept confidential?

We respect your privacy and are committed to protecting your personal data.

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider [UCL privacy notice\(s\)](#):

- [General privacy notice](#) when you visit UCL's website
- [Research participants for health and care purposes privacy notice](#)

Interviews will be audio recorded using a Dictaphone. All data will be kept confidential and only the student researchers (Vallabhi Khurana & Kim Mihaljevic) will have access to the raw data collected in this study. The student researchers will transcribe the data and are the only people who will be able to identify you.

Anonymised data containing no identifiable information (e.g. name, email) will be analysed by the research team (student researchers, chief investigator).

Audio recordings will be transferred at the earliest opportunity to a password-protected laptop or UCL computer and then deleted from the Dictaphone. Data will be stored electronically on password protected computers. All data will be handled according to the Data Protection Act 1998 and will be kept confidential. Audio recordings will be destroyed following study completion, and any personal identifiable data will be destroyed 12 months after the study ends.

Who is the Sponsor for this Study?

University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep anonymised information from the study for 20 years after the study has finished.

What Happens to the information that I provide?

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at:

<https://www.ucl.ac.uk/legal-services/privacy>

UCL will collect information from you for this research study in accordance with our instructions.

UCL will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your student researchers will pass these details to UCL along with the information collected from you. The only people in UCL who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

How will my information be used on research databases?

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

What will happen with the results of this study?

Once the study has been completed the results will be published in a report as part of two thesis projects. The results will also be submitted to peer review journals and you will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a copy of the final thesis report. Confidentiality and anonymity will be maintained, and it will not be possible to identify you from any publications.

Who is organising the funding of this study?

The study is funded by UCL's Research Department of Clinical, Educational and Health Psychology. The student researchers will be liaising with UCL to organise funding for the study

Who has reviewed the study?

The study has been peer-reviewed by Dr Georgina Charlesworth, a Senior Lecturer within UCL's Research Department of Clinical, Educational and Health Psychology.

This study has also been reviewed by (*insert name of ethics committee*) on (*date*).

What if there is a problem?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the University College London or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Dr Lucy Serpell who is the Chief Investigator for the research and is based at UCL (please find details below). The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

You are encouraged to ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

Appendix D: Carer information sheet

UCL Research Department of Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



Information Sheet (Version 1.1)

12/06/2019

We are inviting you to take part in a research project. We want to find out about the use of Community Treatment Orders (CTOs) in the treatment of Eating Disorders; specifically looking at your experiences of being a carer of a patient under a CTO presently or in the past.

This study is being carried out by two trainee clinical psychologists undertaking the Doctorate in Clinical Psychology (DClinPsy) at University College London (UCL). Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

Title of Project:	Exploring the Psychological Impact of Community Treatment Orders in the Treatment of Eating Disorders
Project ID No:	120817
Student Researchers:	Vallabhi Khurana (Trainee Clinical Psychologist) Kim Mihaljevic (Trainee Clinical Psychologist) UCL Clinical Psychology Doctoral Programme
Supervisors:	Dr Lucy Serpell (Clinical Psychologist and Senior Lecturer) UCL Research Department of Clinical, Educational & Health Psychology

This study has been approved by the Clinical, Educational and Health Psychology Research Department's Ethics Chair.

What is the purpose of this study?

This study aims to explore the impact that CTOs have on the treatment of Eating Disorders, mainly assessing their associated advantages and disadvantages. We are not holding a particular view in mind, but rather are interested in your experiences of being a carer of a patient under a CTO.

The study's main purpose is to understand whether CTOs might help or get in the way of recovery. We hope to assess this by understanding the perspectives from patients, carers and clinicians, and are interested in whether they have different views.

Why have I been invited?

You have been invited to participate in this study as you are a carer of a patient who is or has previously been under a CTO, whilst getting treatment for an eating disorder. The patient has also consented to us approaching you about his project.

Do I have to take part?

No. You are under no obligation to take part in this study.

What will I be asked to do?

Your participation will involve taking part in a one-to-one interview with one of the student researchers (Vallabhi Khurana & Kim Mihaljevic, trainee clinical psychologists currently undertaking the UCL Clinical Psychology Doctorate programme).

Interviews will last up to 2 hours depending on your availability. You will be compensated for up to 2 hours of your time, at £10 per hour. You are also entitled to a flat rate of £5 as travel allowance. Payments will be given in cash.

Participation in this study is voluntary and you will be asked to give your written consent. You will be given the opportunity to ask the investigator or student researchers any questions you may have, before being asked to read and sign the consent form if you are willing to take part in the subsequent interview. If you decide to take part you are still free to withdraw at any time during the process and without giving a reason.

What will the person you are caring for be asked for do?

The person that you are caring for will be asked to give their written consent for you to participate in this study.

The person you are caring for has the right to withdraw their consent to participate in the study, and their consent for you to participate in the study. If they withdraw their consent, we will ask them if they are happy for you to continue your participation. This will not impact on treatment within the Eating Disorder Service.

What are the benefits of participating in this study?

Participating in this study will give you the opportunity to reflect on your experiences of being a carer of a patient under a CTO. You will also get the opportunity to voice your opinions about the use of CTOs in the treatment of eating disorders.

It is anticipated that the findings from this study will be used to improve the way that CTOs are used in Eating Disorder services in the U.K. to better support patients in their recovery.

What are the risks of participating in this study?

Discussing your experiences of being a carer of a patient under a CTO can be distressing. If you feel distressed, you will be advised to speak to the Chief Investigator of this study (see below) who will provide any additional support.

What if I no longer want to take part in this study?

If you no longer want to take part in this study, please let the researcher know. Any data collected will be removed from the study. You do not need to give a reason for withdrawing from the study.

Who will have access to my information and how will my information be kept confidential?

We respect your privacy and are committed to protecting your personal data.

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider [UCL privacy notice\(s\)](#):

- [General privacy notice](#) when you visit UCL's website
- [Research participants for health and care purposes privacy notice](#)

Interviews will be audio recorded using a Dictaphone. All data will be kept confidential and only the student researchers (Vallabhi Khurana & Kim Mihaljevic) will have access to the raw data collected in this study. The student researchers will transcribe the data and are the only people who will be able to identify you. Anonymised data containing no identifiable information (e.g. name, email) will be analysed by the research team (student researchers, chief investigator).

Audio recordings will be transferred at the earliest opportunity to a password-protected laptop or UCL computer and then deleted from the Dictaphone. Data will be stored electronically on password protected computers. All data will be handled according to the Data Protection Act 1998 and will be kept confidential. Audio recordings will be destroyed following study completion, and any personal identifiable data will be destroyed 12 months after the study ends.

Who is the Sponsor for this Study?

University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep anonymised information from the study for 20 years after the study has finished.

What Happens to the information that I provide?

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at:

<https://www.ucl.ac.uk/legal-services/privacy>

UCL will collect information from you for this research study in accordance with our instructions.

UCL will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your student researchers will pass these details to UCL along with the information collected from you. The only people in UCL who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

How will my information be used on research databases?

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

What will happen with the results of this study?

Once the study has been completed the results will be published in a report as part of two thesis projects. The results will also be submitted to peer review journals and you will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a copy of the final thesis report. Confidentiality and anonymity will be maintained, and it will not be possible to identify you from any publications.

Who is organising the funding of this study?

The study is funded by UCL's Research Department of Clinical, Educational and Health Psychology. The student researchers will be liaising with UCL to organise funding for the study

Who has reviewed the study?

The study has been peer-reviewed by Dr Georgina Charlesworth, a Senior Lecturer within UCL's Research Department of Clinical, Educational and Health Psychology.

This study has also been reviewed by *(insert name of ethics committee)* on *(date)*.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the University College London or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Dr Lucy Serpell who is the Chief Investigator for the research and is based at UCL (please find details below). The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

You are encouraged to ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

Thank you for your interest in this project.
The Research Team

Appendix E: Joint trainee contributions

The main research project was conducted jointly with another trainee, Vallabhi Khurana. The research paper presents the experiences of patients and carers, whereas the fellow trainee's study explores patient and professional perspectives.

The following tasks were completed in collaboration:

1. Ethics proposal
2. Development of the interview schedule
3. Consultation with service user representative
4. Recruitment of participants (professionals, patients and carers)
5. Patient interviews and transcription (each researcher completed three interviews each)

The following tasks were completed independently:

1. Carer interviews and transcription
2. Data analysis
3. Write-up of empirical paper

Appendix F: Letters of Approval (REC and HRA)



London - Riverside Research Ethics Committee

Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

20 June 2019

Dr Lucy Serpell
UCL Department of Clinical, Educational and Health Psychology
1-19 Torrington Place, London
WC1E 7HB

Dear Dr Serpell

Study title: Exploring the psychological impact of Community Treatment Orders in the treatment of Eating Disorders
REC reference: 19/LO/0806
Protocol number: 120817
IRAS project ID: 255552

Thank you for your letter of 17 June 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised](#), subject to the conditions specified below.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

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

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

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate from UCL]		25 July 2018
Interview schedules or topic guides for participants [Interview Schedule]	v1.0	21 March 2019
IRAS Application Form [IRAS_Form_15042019]		15 April 2019
IRAS Checklist XML [Checklist_17062019]		17 June 2019
Letter from funder [Letter from UCL confirming funding]		21 March 2019
Letters of invitation to participant [Invitation Leaflet for Patients]	v1.0	21 March 2019
Letters of invitation to participant [Invitation Leaflet for Carers]	v1.0	21 March 2019
Other [Data Phhttps://www.harp.org.uk/member/Default?refresh_user=1#applications_tab_tabrotection Impact Assessment through UCL]		08 February 2019
Other [Evidence of Peer Review from UCL]		04 February 2019
Other [Statement Of Activities]	v1.1	12 June 2019
Participant consent form [Consent form for Clinicians]	v1.0	21 March 2019
Participant consent form [Consent form for Patients]	v1.1	12 June 2019
Participant consent form [Consent form for Carers]	v1.1	12 June 2019
Participant information sheet (PIS) [PIS for Patients]	v1.1	12 June 2019
Participant information sheet (PIS) [PIS for Clinicians]	v1.1	12 June 2019
Participant information sheet (PIS) [PIS for Carers]	v1.1	12 June 2019
Research protocol or project proposal [Protocol]	v1.0	21 March 2019
Research protocol or project proposal [Protocol]	v1.1	12 June 2019
Response to Request for Further Information		17 June 2019
Schedule of Events or SoECAT [Schedule of Events]	v1.1	19 June 2019
Summary CV for Chief Investigator (CI) [CV for CI]		18 August 2018
Summary CV for student [CV for Vallabhi Khurana]		04 February 2019
Summary CV for student [CV for Kim Mihaljevic]		04 February 2019
Summary CV for supervisor (student research) [CV for Lucy Serpell]		18 August 2018



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Dr Lucy Serpell
UCL Department of Clinical, Educational and Health
Psychology
1-19 Torrington Place, London
WC1E 7HB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

20 June 2019

Dear Dr Serpell

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Exploring the psychological impact of Community
Treatment Orders in the treatment of Eating Disorders
IRAS project ID: 255552
Protocol number: 120817
REC reference: 19/LO/0806
Sponsor University College London

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **255552**. Please quote this on all correspondence.

Yours sincerely,

Thomas Fairman
HRA Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Ms Suzanne Emerton, University College London, (Sponsor Contact)*

Appendix G: Consent form for patients

UCL Research Department of Clinical,
Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



CONSENT FORM - Patients

Project Title: Exploring the Psychological Impact of Community Treatment Orders in the Treatment of Eating Disorders

Please initial box

1. I confirm that I have read and understand the information sheet version 1.1, dated 12/06/2019 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason
3. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project.
4. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained and it will not be possible for others to identify me.
5. I give permission for my carer/family member to take part in this study.
6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix H: Consent form for carers

UCL Research Department of Clinical,
Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



CONSENT FORM – Family Members

Project Title: Exploring the Psychological Impact of Community Treatment Orders in the Treatment of Eating Disorders

Please initial box

1. I confirm that I have read and understand the information sheet version 1.1, dated 12/06/2019 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason
3. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project.
4. I consent to the use of ~~anonymised~~ quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained and it will not be possible for others to identify me.
5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix I: Interview Schedule for Patients



RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH
PSYCHOLOGY

Experiences of Community Treatment Orders in Individuals with Eating Disorders Service User version

Semi-Structured Interview Schedule

Introduction

The following points will be discussed with participants:

- Informed Consent.
- The structure and length of the interview.
- Note taking and use of recording device.
- Confidentiality and data storage.
- Compensation

1. Can you tell me a little bit about yourself?

2. What is your understanding of your CTO?

Prompts/Follow-up questions

- *Why do you think you were put on the CTO?*
- *What were the conditions of your CTO?*
- *Who explained the CTO to you? What did they tell you?*
- *What do you understand about recall and how it works?*
- *Were you ever recalled?*
- *Have you ever gone into hospital voluntarily to avoid recall?*
- *In what circumstances do you think your CTO will come to an end/what led to it ending?*

3. How did you feel about being on the CTO?

Prompts/Follow-Up questions

- *Were you in agreement with being put on a CTO?*
- *What was helpful about it?*
- *What was unhelpful about it?*
- *How did it affect how you see/saw yourself?*
- *What do you think about the possibility you might be recalled?*
- *What would you have liked to be different about the CTO?*

- *Do you think it reduced admission rates/risk of admission rates?*
- *Has your CTO been renewed? Were you involved in the renewal of the conditions?*

4. How did you feel about the conditions on your CTO?

Prompts/Follow Up questions

- *Who decided on the conditions and how clear were they?*
- *Were your views of the conditions of the CTO considered? If yes, by whom?*
- *Did you agree with them?*
- *Did you think they were fair?*
- *Do you think there would have been better/more appropriate conditions?*
- *How did you feel about the amount of control they imposed on your life?*

5. How did being put on a CTO affect your life?

Prompts/Follow-Up questions

- *Personal life*
- *Quality of your life?*
- *Relationships with family*
- *Relationships with friends*
- *Relationship with therapy team*

6. (Optional) You mentioned that you were recalled into hospital. Could you tell us a bit more about what happened?

Prompts/Follow-Up questions

- *What led to the recall? What was happening before you were recalled?*
- *Who made this decision?*
- *Were you recalled to the same hospital you were discharged from?*
- *Would it have made a difference if you were recalled to a different hospital?*
- *How many times were you recalled? How many times were you fully readmitted under Section 3?*
- *How did this affect you?*
- *Do you agree with the decision around recall?*
- *Did you believe this decision was fair at the time? How do you feel about it now, looking back on it?*
- *Did you think recall changed how you feel about CTOs?*
- *Was the recall helpful/unhelpful?*
- *Was it made clear to you that you could avoid compulsory recall under the CTO by agreeing to go in voluntarily?*

7. How did the CTO affect your eating disorder and treatment?

Prompts/Follow-Up questions

- *Weight gain/Weight management*
- *Attempts to lose weight*
- *How do you think your CTO affected your ideal weight goal?*
- *Cognitions*
- *Eating Schedule*
- *Compliance with treatment (e.g. attending appointments psychological therapies, medication)*
- *Goals for life – any aspects helpful*
- *Overall care plan*
- *Readmission rate*
- *Length of initial admission (before put on a CTO)*
- *In what ways did it help you manage your ED*
- *In what ways did it make managing your ED Harder?*
- *If you weren't placed on a CTO, what do you think might have happened?*

8. How much freedom did you feel you have whilst on the CTO?

Prompts/Follow-Up questions

- *What about the CTO made you feel this way? (i.e. recall, threat, conditions, living at home opposed to hospital, restrictive, coercive)*
- *Did you feel able to disagree with the terms/conditions on your CTO (specifics about disagreements, if any)*
- *Were you aware that you had the right to appeal your CTO*
- *Did you see/know that you could see an advocate or ask for a tribunal/managers meeting?*

9. In your opinion, what are the general advantages/disadvantages of CTOs?

Prompts/Follow-Up questions

- *Should CTOs be used in the treatment of eating disorders?*
- *What type of person do you think a CTO is most suited towards?*

10. Are there any recommendations that you would like to suggest about the use of CTOs in the treatment of eating disorders?

We have now come to the end of the interview. I would now like to ask you if there is anything else you would like to tell me about your experiences of being on a CTO.

Thank you again for sharing your experiences and talking with me today.

Appendix J: Interview schedule for carers



RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Experiences of Community Treatment Orders in Individuals with Eating Disorders: Carer/Family Member version

Semi-Structured Interview Schedule

Introduction

The following points will be discussed with participants:

- Informed Consent.
- The structure and length of the interview.
- Note taking and use of recording device.
- Confidentiality and data storage.
- Compensation

1. Can you tell me a little bit about yourself and the person you are caring for?

Prompts/Follow-up questions

- *Your relationship with them*
- *How involved were you in X's care, personally and with professionals?*

2. What do you understand about CTOs and how they work?

Prompts/Follow-up questions

- *Why do you think X was put on the CTO?*
- *What were the conditions of the CTO?*
- *Who explained the CTO to you and what did they tell you?*
- *Were you involved in the decision-making process around the CTO?*
 - *If yes, how were you involved?*
- *What were you told about your role during the CTO?*
- *What do you think was expected of you during the CTO?*
- *What is your understanding of recall and how it works?*
- *Did X ever recalled?*
- *Did X ever go into hospital voluntarily to avoid recall?*
- *In what circumstances do you think X's CTO will come to an end/what led to it coming to an end?*

3. How did you feel about X being on the CTO?

Prompts/Follow-Up questions

- *What do you feel was helpful about it?*
- *What do you feel was unhelpful about it?*
- *Did it make you see x differently?*
- *What would you have liked to be different about the CTO*

4. How did you feel about the conditions of the CTO?

Prompts/Follow Up questions

- *Who decided on the conditions and how clear were they?*
- *Were your views of the conditions of the CTO considered? If yes, by whom?*
- *Did you think the conditions were fair?*

5. How do you think being put on a CTO affected X's life?

Prompts/Follow-Up questions

- *Personal life*
- *Eating Disorder/Recovery/Weight Gain*
- *Quality of your life?*
- *Relationships with family*
- *Relationships with friends*
- *Relationship with therapy team*

6. (Optional) You mentioned that X was recalled into hospital. Could you tell us a bit more about what happened?

Prompts/Follow-Up questions

(Keep in mind whether they were recalled for 72hrs or Section 3)

- *What led to the recall? What was happening before X was recalled?*
- *Who made this decision?*
- *Was X recalled to the same hospital you were discharged from?*
- *Do you think it have made a difference if X were recalled to a different hospital?*
- *How many times was X recalled? How many times was X fully readmitted under Section 3?*
- *How did this affect X? How did this affect you?*
- *Do you agree with the decision around recall?*
- *Did you believe this decision was fair at the time? How do you feel about it now, looking back on it?*
- *Did you think recall changed how you and X feel about CTOs?*
- *Was the recall helpful/unhelpful?*

7. What effect do you think the CTO had on X's eating disorder/treatment?

Prompts/Follow-Up questions

- *Weight gain/Weight management*
- *Attempts to lose weight*

- *Cognitions*
- *Eating Schedule*
- *Compliance with treatment (e.g. attending appointments psychological therapies, medication)*
- *Overall care plan*
- *Readmission rate*
- *Length of initial admission (before put on a CTO)*
- *How did it help manage their eating disorder/make it harder to manage their eating disorder?*

8. How did X's CTO impact on your life?

Prompts/Follow-up questions:

- *On your own time?*
- *On your relationship with X?*
- *On your relationship with the rest of your family?*

9. How much freedom did you feel X had whilst on the CTO?

Prompts/Follow-Up questions

- *What about the CTO made you feel this way? (i.e. recall, threat, conditions, living at home opposed to hospital, restrictive, coercive)*
- *Where there any disagreements with the terms/conditions of the CTO? Were you involved with this?*
- *Did you know that X could see an advocate/ask for a tribunal/managers meeting? If this occurred, what was your experience/where you involved with this?*
- *Were you aware the X had the right to appeal the CTO? If so, how involved were you with this?*
- *Did you feel that you could express your views about the CTO?*

10. In your opinion, what are the general advantages/disadvantages of CTOs?

Prompts/Follow-Up questions

- *Should CTOs be used in the treatment of eating disorders*
- *What type of person do you think a CTO is most suited for?*

11. Are there any recommendations that you would like to suggest about the use of CTOs in the treatment of eating disorders?

We have now come to the end of the interview. I would now like to ask you if there is anything else you would like to tell me about your experiences of being on a CTO.

Thank you again for sharing your experiences and talking with me today.

Appendix K: Example of initial coding stage

[00:56:39] Yeah.

KM [00:56:42] And you feel that the CTO is actually part of that as well, it sounds like. *cope = become ill again.*

[00:56:47] Yeah. Now I recognise that is part of the provision and the safety and the slow release to freedom rather than when there's sort of- like through different people you know, like the doctors recognised that I wouldn't have been able to cope not being on a CTO and all these things, so, even if we resisted it, and did prevent it sometimes. *change*
change in perception over time
worked against it
- they stuck to their guns + it was helpful in the end - grateful?
↳ not able to cope

KM [00:57:25] It's a very mixed thing, by the sounds of it.

[00:57:28] Yeah.

KM [00:57:29] So I guess generally, actually what do you think are the general advantages and disadvantages of using the CTOs in eating disorders?

[00:57:40] I think the advantages are that it provides boundaries. And I think people with eating disorders, with severe and enduring eating disorders need boundaries. Because like, for example, like me, I can't- I couldn't set myself a boundary about maintaining my weight, no way. There's no way in hell I would do it. The disadvantage, I would say, is if the CTO is done like a Section 3, because then you are achieving nothing more than a Section 3. A Section 3 just made me worse, it ruined like- it's made my life, it made my life so much worse, no freedom, treated like an animal. No one listening to you- no one listening to you at all. The CTO, if it's used correctly, should be done to an extent with the decision of the person. So, when I went to JT and I said, look, J, I cannot cope with gaining weight, she'd put this condition on which said she will gain 0.2 every two months and I said, I can't cope with it. I can't, I'm not ready for it. And she was like, well ideally that's what would happen. But you just- we're going to say that you need to maintain. And I wasn't at a weight that I felt comfortable maintaining. I mean, if it was my decision, I would have maintained 10 kilos lower. But the thing is that I see that in a way she did compromise. It was a collaborative thing in a way. And I think the advantage- what other advantages do, I think. The disadvantages I think as I said, I think lack of understanding. *clarification of severity - at what point are you not able to function? - it for a certain boundaries*
emphasis on impossibility
restrictive
sect 3 - worse
emphasis on horrendous experience + loss of self
- ignored + no say
vs CTO where

KM [00:59:23] Yes.

[00:59:24] People that are not for me from my home team, but I think, for example in tribunals even the judges my understanding really. And as you guys have said, disadvantage, there's not really a lot of evidence base for it. You don't really have an idea about what it is like to be on it. I think if it is used as a blunt tool and a threat, it's restrictive and is doing nothing better than a Section 3 is. But yeah advantages, I guess, enabling a little bit more of a buffer zone, psychologically and I guess a little bit physically for people to try and move out of hospital when they've been in like a really long hospital admission. Or are just used to going in and out, in and out really quickly. It's just like a deterrent really I suppose. We all need boundaries, don't we? *lots of people*
not tested
how can you understand it? - don't know
room to fail?
bringing me into
do I understand it?

KM [01:00:35] Are there any people, do you think that it suits more than others?

[01:00:42] Um, I mean, I don't know how it would work, really, how well it works if you don't have like specialists' input. Because really if you're only going for like a weekly outpatient appointment, I don't know. I can't say for myself but... *most helpful*
is increased level of input? →

KM [01:01:17] So do you think for you worked in collaboration with the specialist input and the community team and that all were necessary rather than just one? *alot of questioning*
reluctance
about ED speciality

[01:01:40] I mean, yeah, I say it through gritted teeth about this specialist input thing because there's certain elements of this place that is not specialist. It demonstrates a massive lack of understanding. But in a sense, it's been a necessary- it's the only place that would take me and therefore what's happened here has been sort of a necessary place for which I need to *nowhere else would take her - last option*
question of
rationalising
stops from saying

Appendix L: Example of coding emerging themes

obtained from, who might get it, where it was stored, etc. So, all that detail, there was a restriction on it. There were also restrictions on whether she could prepare her own hot drinks or anything like that, which were inhibiting. There was also, you know, sort of restrictions on when she could go out, when she had to come back, who she had with her how much time she was due to be away, given that she was on a rehabilitation program. Except part of that was social rehabilitation so they were limiting the rehabilitation program by imposing restrictions, which they said were in her CTO, which actually weren't in the CTO at all.

KM [00:36:51] Okay so the house was imposing more restrictions than was listed, but I guess in terms of the actual CTO, because I think it was the conditions that are around there were about not dropping below a certain weight, maintaining physical stability, attending appointments. And those are the main ones, I think.

[REDACTED] [00:37:17] And being a resident at the [REDACTED]

KM [00:37:19] Yes. and the main one being that. Yes. What were your thoughts about those the conditions set out initially by the psychiatrist and the team?

[REDACTED] [00:37:28] Absolutely fair and reasonable. I thought, you know, I thought the CTO was as it should be. I mean it was very clear, it was very factual. It didn't have any extra detail that would make it difficult for anyone to adhere to.

KM [00:37:51] Do you think there should have been anything different or additional to it?

[REDACTED] [00:37:57] I mean, I would have liked to have seen something like a timeline to progress to maybe having a different oral intake or...but actually probably more sensibly having- engaging with and having access to a dietician, especially an eating disorder dietician and a psychologist. I think those two things could have been added in because that's when she had to negotiate more of that herself from [REDACTED] and CCG, because they were not being offered to the right people at the WH when she was initially there.

KM [00:38:52] So there was some input from dietetics and psychology, but that was through the [REDACTED] rather than through someone more in touch with eating disorders, was that right?

[REDACTED] [00:39:04] No there was a psychologist and the dietician are specialist eating disorder. But she was only allowed access to them once a month- I think it was sort of like once a month or once every three to six weeks sometimes, whereas actually the recommendation was that she should see the dietician weekly and the psychologist at least fortnightly, if not weekly. And the [REDACTED] was saying that was additional funding requirement because that wasn't set out in the original plan of care. But [REDACTED] agreed to add those extra sessions. Had those originally been in the CTO, that would have been part of the initial package.

KM [00:39:58] Okay.

RW [00:39:59] So they would have been helpful.

Mihaljevic, Kim

Life outside of ED also heavily monitored
CTO implementation similar to sectioning

Mihaljevic, Kim

Overly restrictive to the point of impacting on rehabilitation
Care home restrictions beyond CTO conditions

Mihaljevic, Kim

Conditions around weight, medical stability, appointments and resident at WH (vague)

Mihaljevic, Kim

Conditions as fair and reasonable, straightforward and easy to follow
CTO met expectations of care - did what it was meant to in keeping P safe
Lack of emotion discussing conditions

Mihaljevic, Kim

Wanted consideration of timeline for future and progress with ED

Mihaljevic, Kim

Adaptation of CTO over time to increase support
Specialist ED support
Impact of funding on level of support
Formality of process to make changes
Changes coming from patient

Mihaljevic, Kim

Recommendations from professionals vs care given
Importance of specialism in ED

Mihaljevic, Kim

Formality of change process
Impact of funding on support
Frustration regarding things missed in the initial care plan

Mark-up Area

Appendix M: Example of table grouping themes

+ Professionals as decision makers		
Team making decision about her ED	The consultant at Vincent Square...	8:01
Professionals deciding voluntary/involuntary stay	Well it's like you can go to hospital and be assessed for like 72 hours and they decide if you can stay voluntary or if they want to revoke you and be back into hospital under a section...	8:47
Consultant as decision maker (listened to by panel)	Well because whenever you say you don't want it, the panel, which basically always go with what the consultant is saying.	31:57
Team decision she can't travel	Quite a few times she's asked me to come with her. And I would say, "can I go?" and they will say "no you are not allowed".	38:20
At what point are points listened to, and at what point are they ignored – Consultants decision what to listen to	Well, they [consultants] are the ones who said that I couldn't go and travel that long.	39:06
Team as main decision maker	They said that I was declining and that they didn't like to see that, that's what the consultant told me.	44:06
Power from consultants to make decision	I was seeing the <u>team</u> but I didn't keep some of my appointments. <u>So</u> they wrote all these recall papers. I think they just heighten it up sometimes	50:37
Consultant as decision maker	I was recalled earlier, before that. But I didn't actually go to hospital. My consultant let that slip.	54:54
Team as changing the goal posts	And then when I went <u>in</u> they were like we need to wait for ward round for the bloods, even though I had had my weights.	56:21
Consultants monitoring drops in weight	So umm like when I was like on a downward trend, they were like don't lose too much in a week. I was trying to stick to that, you know that sort of thing.	1:01:25
Fixation of team on weight	But then like, say if you were having like a fluid issue. Like someone with stage 5 renal disease and heart failure, I can just imagine the scenario... that would be my first priority, but they wouldn't take that into account, its only about weight.	1:02:06
Power of professionals even without formal measures	I don't know, I mean if I was to go off the CTO and see my GP and if she was concerned, I might still go to hospital. So, it really doesn't seem to be any different really.	5:45
Power of consultant to make final decision	But the other panel weren't that nice... its really up to the consultant and it's not worth challenging it.	32:23
Consultants threatening to increase weight	Because they said that they would revoke the CTO and I would be back on a section if I didn't.	52:31
Introduction of concept by consultant	She just said that it would give the team some confidence.	8:01
Heightened power difference	<u>It</u> kind of picks on people who may be having the hardest time and they are scared and they are put on it and they find it difficult	13:51
Catch-22 – no choice but to talk to people even if she doesn't want to	Well I was told to go and talk about it in a clinic and I think I had to go and see the AMPHs, but say if I don't want to and I didn't turn up to the appointment then you see I'm breaking the conditions	33:11

Appendix N: Master and subthemes developed for carers

Carer 1	Carer 2	Carer 3	Carer 4
<p>CTO as a framework</p> <ul style="list-style-type: none"> a. Framework for guiding care <ul style="list-style-type: none"> → Key concepts of CTO, view/expectations of CTO, expectations of professionals, lack of flexibility inherent to process b. Professional power in implementation <ul style="list-style-type: none"> → CTO reliance on implementation, professional power, variations in implementation: restrictiveness, carer involvement in professional care, questioning patient focus c. Patient engagement for change <ul style="list-style-type: none"> → Patient shift in engagement with CTO, adaptation of CTO 	<p>CTO as framework</p> <ul style="list-style-type: none"> a. Framework guiding care <ul style="list-style-type: none"> → Expectations of CTO/CTO principles b. Professional power <ul style="list-style-type: none"> → Professionals as decision makers, carer involvement with professionals, carer as expert in patient but not heard, patient voice as priority over family, c. Implementation <ul style="list-style-type: none"> → Recall as an empty threat, monitoring as necessary and unrestrictive, carer misunderstanding around CTO processes d. Patient engagement for change <ul style="list-style-type: none"> → Failure in CTO process leading to shift in patient responsibility, ending of CTO 	<p>CTO as framework for care</p> <ul style="list-style-type: none"> a. Framework guiding care <ul style="list-style-type: none"> → Expectations of professionals, CTO hope, recall as threat b. Professionals driving implementation/deferment to professionals <ul style="list-style-type: none"> → Expectation vs reality, parental reality of CTO, professional failure, external barriers, questioning patient focus c. Patient/ED power through lack of engagement 	<p>CTO as framework dependent on implementation</p> <ul style="list-style-type: none"> a. CTO principles: guidelines and restrictions <ul style="list-style-type: none"> → Framework as helpful, formality of CTO b. Agreement leading to effective implementation <ul style="list-style-type: none"> → Carer active involvement, carer advocate, professional role, patient involvement
<p>CTO as necessary but not sufficient for change</p> <ul style="list-style-type: none"> a. CTO as driving patient engagement in development of identity <ul style="list-style-type: none"> → CTO as driving engagement, shifting identity b. Risk management <ul style="list-style-type: none"> → Mum as not able to support needs, reliance on 	<p>Ambivalence around CTO and change</p> <ul style="list-style-type: none"> a. Disagreement with CTO and professionals <ul style="list-style-type: none"> → Scepticism around CTO b. Focus on progress <ul style="list-style-type: none"> → Food as indicator of recovery, ambivalence around CTO outcome c. CTO as necessary for community risk management 	<p>CTO as necessary but not sufficient</p> <ul style="list-style-type: none"> a. CTO as risk management <ul style="list-style-type: none"> → Parental inability to monitor ED, reliance on professionals, complex history of AN b. Consideration of future steps <ul style="list-style-type: none"> → Consideration of future steps 	<p>CTO as necessary but not sufficient</p> <ul style="list-style-type: none"> a. Risk management <ul style="list-style-type: none"> → Inability to meet care needs, CTO as shifting relationship, motivations for CTO b. Interaction between CTO and care

<p>professional team, history of risk in ED and difficulties in engagement</p>	<p>→ CTO rationale, carer difficulty managing ED behaviour, reliance on professionals to manage ED/CTO</p>		<p>→ Interaction between CTO and care to aid progress</p>
<p>Carer involvement with patient</p> <ul style="list-style-type: none"> a. Navigation of conflictual roles <ul style="list-style-type: none"> → Mum as advocate, hope for progress, carer role, navigating discussion of opinions with patient, shift associated with acceptance of CTO b. Wider impact of ED on carer compared to CTO <ul style="list-style-type: none"> → Difficulty separating ED vs CTO, burden of ED on carer, ED impact on relationship/carers 	<p>Shift in carer relationship</p> <ul style="list-style-type: none"> a. Wider impact of ED on relationship <ul style="list-style-type: none"> → Wider impact of ED on carer b. CTO aiding navigation of relationship <ul style="list-style-type: none"> → Step back in involvement, CTO use as a tool to help manage 	<p>Parent relationship with patient</p> <ul style="list-style-type: none"> a. Distancing from professionals <ul style="list-style-type: none"> → Carer lack of understanding, Lack of professional involvement, uncertainty about timelines b. Priority as parents <ul style="list-style-type: none"> → Parenting priorities 	<p>Parental priorities</p> <ul style="list-style-type: none"> a. CTO impact on relationship <ul style="list-style-type: none"> → ED impact, CTO impact on relationship b. Focus on progress <ul style="list-style-type: none"> → General parents understanding, importance of progress/hopes for future

