# The Use of Community Treatment Orders in Eating Disorder Services: Clinician and Patient Perspectives

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## **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.



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#### Overview

This thesis is comprised of three parts and explores inpatient and compulsory community treatment options for patients diagnosed with Eating Disorders (EDs), in particular Anorexia Nervosa (AN).

Part One is a systematic review of twenty-six research papers. It explores and summarises the current qualitative evidence on patient experiences of receiving inpatient treatment for AN.

Part Two is an empirical research paper on Community Treatment Orders (CTOs). CTOs provide supervised mental health treatment to patients in the community as opposed to being detained in hospital. The study aims to explore and gain an in-depth understanding of the use and impact of CTOs in ED services. It is a qualitative study utilising twelve semi-structured interviews with clinicians and patients. This study is conducted jointly with another trainee; this research paper presents a narrative on clinician and patient perspectives whereas the fellow trainee's study explores carer and patient accounts.

Part Three presents a critical appraisal which summarises a process of reflections after undertaking an empirical research project. It emphasises the importance of choosing an appropriate research methodology and the use of reflexivity in qualitative research to minimise potential biases on the findings of a study. It concludes with demonstrating the value of including Experts by Experience in research to ensure that research is developed and carried out in a way that is relevant and meaningful to both researchers and participants.

#### **Impact Statement**

This thesis explores patient experiences of receiving treatment for an Eating Disorder (ED), in particular Anorexia Nervosa (AN). By using a qualitative methodology, this thesis focuses on developing a deeper understanding of both inpatient treatment and Community Treatment Orders (CTOs) for individuals diagnosed with EDs. It is hoped that the findings of this thesis will be disseminated via various platforms, to direct further research, enhance clinical practice, impact training delivered to mental health professionals and influence public policy design.

There is currently limited evidence for the effectiveness of inpatient treatment for AN and on the use of CTOs; the majority of research is focused on quantitative studies. Therefore, the findings from this thesis offers a unique and different perspective after understanding and interpreting lived experiences provided by participants. In particular, the use of CTOs has not been investigated in ED populations and the findings provide novel insights into the differences in using CTOs with EDs and other mental health conditions. It is hoped that such findings will be published in academic journals and presented at international ED conferences; this would be valuable not only to enhance knowledge in this area but to also inform further research which is required. This may also promote interest and encourage researchers to use qualitative methodologies and include Experts by Experience in research, to contribute to and direct any further research in this field.

Additionally, the findings from this thesis provide clinical recommendations that can be applied by a range of child and adult mental health services in the U.K. The results will be shared with all participants and clinicians involved in the study, as well as with members of the Royal College of Psychiatrists. This will be conducted with the overarching aim of improving and enhancing the treatment delivered to individuals with EDs. Ultimately, this highlights the importance of using qualitative research to improve health care and demonstrates how this particular approach can lead to research that is more relevant to benefit the lives of individuals affected by its outcomes.

Furthermore, the recommendations from his study can be included to develop and/or amend existing training opportunities for clinicians working with patients diagnosed with EDs. Upon dissemination to a range of mental health services and professional study boards, it is hoped that the suggestions can be incorporated into training modules. Given that CTOs were recently introduced in the Mental Health Act (MHA), it is an exciting prospect that the findings from this study could be used to inform the training delivered to a range of clinicians from various clinical backgrounds.

Lastly, and on a broader level, the findings from this thesis contribute to the evidence base for the MHA. The MHA is currently under review and amendments introduced in 2007 (such as CTOs) are being carefully considered and evaluated. The findings can be disseminated to provide evidence for such reviews. Subsequently, this would lead to the findings having the potential to refine and shape existing public health policies and impact on how some sections of the MHA are used in practice.

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Part 1: Literature Review

**Inpatient Treatment for Anorexia Nervosa:** A Systematic Review of Qualitative Studies

#### Abstract

**Aims:** The primary objective of this review is to synthesise the qualitative research on patient experiences of receiving inpatient treatment for Anorexia Nervosa (AN). **Method:** A systematic review of the literature was conducted; studies were identified through searching three electronic databases. A total of 26 studies met the inclusion criteria and were included in this review.

**Results:** The synthesis yielded seven core themes; all of which were considered as important when understanding the experience of inpatient treatment through a patient's perspective. These included the inpatient setting, the role and influence of control and interactions with peers and clinicians on inpatient wards. Additionally, the themes outlined the desire for patients to be seen as separate from their AN, feeling that treatment focused on physical health as opposed to providing psychological support and the perceived advantages and disadvantages of the interventions offered in inpatient settings.

**Conclusions:** This review provided a deeper understanding of the factors which impacted the way in which inpatient treatment was perceived by patients. The findings and recommendations from this review can be used to improve and enhance the quality of care delivered on inpatient treatment settings for patients with AN.

#### Introduction

### Anorexia Nervosa

Anorexia Nervosa (AN) is characterised by the restriction of energy intake leading to significantly low body weight, the intense fear of gaining weight and/or the disturbance in the way in which one's body weight or shape is experienced. In addition to food restriction, individuals with AN may also binge, engage in self-induced vomiting and excessively exercise (American Psychiatric Association, 2013).

AN is a serious and life-threatening condition and has been documented to have the highest mortality rate of any psychiatric condition (Arcelus et al., 2011; Attia, 2010). It is associated with severe physical and psychological consequences (Meczekalski et al., 2013) and significant impairment to one's physical, emotional, cognitive and social development (Bohn et al., 2008; Su & Birmingham, 2013). It is therefore vital that any treatment offered is carefully considered.

#### **Treatment for AN**

A wide range of treatment options exist; the majority occurring in outpatient, day-patient and inpatient treatment settings. Within such settings, a variety of interventions are delivered by multidisciplinary teams (MDTs), involving pharmacology, psychology and nursing care (Fairburn, 2005). The choice of treatment setting is generally dependent on the overall severity of AN symptoms; hospitalisation is necessary for patients who are medically unstable and are at high physical risk to themselves, due to detrimental effects of starvation on the body (Andersen et al., 1997).

## Inpatient Treatment

Inpatient treatment is considered when patients present with a significantly low Body Mass Index (BMI), rapid weight loss, the refusal to eat and/or drink, medical complications, severe psychiatric co-morbidity and an insufficient response to outpatient treatment settings (Herpertz-Dahlmann & Salbach-Andrae, 2009). It allows clinicians to closely monitor an individual's health and weight and to provide the support for weight gain in a safe and stable manner.

In general, inpatient treatment for AN can be categorised into two phases; firstly, a period of medical stabilisation and weight restoration and secondly targeting behavioural and/or cognitive change (Guarda, 2008). Therefore, patients are exposed to a wide range of interventions, including nasogastric tube feeding, supported mealtimes, dietician input, psychoeducation, pharmacology and individual, family, or group therapies. These interventions are delivered with the overarching aim of gradually discharging patients to receive outpatient support (Andersen et al., 1997).

It is important to note that 'inpatient treatment' is an umbrella term and encompasses a wide range of settings and treatment modalities. For example, the length of stay in hospital can range from a few days to months and patients may be admitted to specialised eating disorder units, general psychiatric hospitals or medical wards. Services may also differ in terms of their referral and discharge criteria and goals for inpatient treatment. Furthermore, some patients may be admitted voluntarily whereas others may be receiving compulsory treatment after being detained in hospital under a legal framework (Vandereycken, 2003). These differences are important to note especially when reviewing and comparing the literature on inpatient treatment for AN.

### **Evidence Base for Inpatient Treatment**

There is limited evidence for the effectiveness of inpatient treatment for AN. Several studies have demonstrated that inpatient treatment is effective in achieving weight gain at discharge and decreasing AN symptoms (Castro-Fornieles et al., 2007; Dalle Grave et al., 2014, Goddard et al., 2013; Lock & Lit, 2004; Morris et al., 2013).

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However, the research has also shown that relapse rates for successfully weightrestored patients are high, at approximately 30-50% within one year of discharge (Carter et al., 2004; Eckert et al., 1996; Pike, 1998).

It is important to consider the methodological shortcomings that exist within the literature. Firstly, the large variance in inpatient treatment presents a challenge when extrapolating and generalising findings. There is currently no consensus on factors such as when patients should be admitted, a target weight at discharge, the optimal length of stay or whether psychological interventions (i.e. family or individual therapy) should be delivered alongside medical treatment (i.e. re-feeding) (Vandereycken, 2013).

There is also a lack of 'gold-standard' research, including systematic reviews and Randomised Controlled Trials (RCTs). Systematic reviews and RCTs on the treatment of AN generally include a range of treatment settings and none have focused solely on inpatient treatment. Additionally, given the severity of the physical risks associated with AN, randomisation to control groups such as waiting lists or placebo control groups is at best challenging and at worst unethical. On the occasions where randomisation is possible, clinical trials are often too small, suffer from high attrition rates and are underpowered to detect differences (Guarda, 2008; Watson & Bulik, 2013).

#### **Qualitative Studies**

Qualitative research in this field can add a unique perspective by exploring lived experiences of inpatient treatment for AN. Qualitative research contributes to the evidence base and can be a valuable tool to guide clinical practice.

Qualitative studies have interpreted individual experiences of receiving inpatient treatment (Colton & Pistrang, 2004), the causes of treatment dropout (Eivors

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et al., 2003), factors impacting relapse (Federici & Kaplan, 2008) and discharge readiness (Turell et al., 2005). Studies have also focused on the therapeutic relationship between patients and clinicians and how this influences recovery from AN (Ramjan, 2004; Sly et al., 2014). It can be argued that the richness provided in these accounts target underlying processes and extract meanings that would not be adequately represented by numbers.

### **Previous Qualitative Reviews**

Although most current methods for synthesising research focus on quantitative methods, there is a growing recognition of the value of synthesising qualitative research (Thomas & Harden, 2008). To the knowledge of the researcher, there have been no previous qualitative systematic reviews solely focusing on the experience of inpatient treatment for AN. Previous qualitative reviews have been conducted on patient experiences of AN, often combining all types of treatment settings (i.e. inpatient, outpatient and day-patient settings).

Stockford et al. (2019) aimed to understand the factors influencing recovery from AN after treatment, including both inpatient and outpatient settings. Their findings suggested that initially patients have a diminished sense of self, but may reach a 'turning point' and develop insight into the function and consequences of AN. The findings also emphasised the importance of developing supportive relationships during treatment with the overall aim of facilitating recovery.

Bezance & Holliday (2013) conducted a systematic review that focused on adolescent perspectives of treatment and recovery. Participants provided accounts of their treatment experiences and received either inpatient, day patient and/or outpatient input. The authors identified that the influence of peers, family members and clinicians, the treatment setting and an emphasis on physical versus psychological aspects were crucial aspects when considering treatment and recovery from AN in this population group.

The above demonstrates how qualitative systematic reviews are emerging in the literature. However, including a combination of treatment modalities for AN poses challenges when trying to obtain an in-depth understanding of participant experiences pertinent to one treatment setting. It can be assumed that one's experience will likely differ based on the type of treatment setting and the research currently does not account for such differences.

### **The Current Review**

There is a lack of qualitative systematic reviews exclusively focusing on the experience of inpatient treatment for AN. Therefore, this paper aims to synthesise the most recent qualitative research on patient experiences of inpatient treatment for AN.

This review will include studies documenting any phenomenon falling under the 'inpatient treatment' umbrella bracket. Additionally, it is deemed important to include the perspectives of adolescents and adults, given the chronic nature of AN (Pike, 1998).

Specifically, this review aims to answer the following questions:

- 1) How have patients (adults and adolescents diagnosed with AN) experienced inpatient treatment?
- 2) Which are the factors which help or hinder individuals receiving treatment for their AN in inpatient settings?
- 3) How can inpatient treatment experience be enhanced?

#### Method

The review process consisted of three stages:

- 1) Systematic literature search (as presented in Figure 1)
- 2) Quality Appraisal
- 3) Thematic Synthesis

### Search Strategy

An electronic literature search was conducted using three online databases: Medline, PsycINFO and Web Of Science. Key search terms included combinations of Anorexia Nervosa, Inpatient Treatment, Hospitalisation, Compulsory Treatment, Experience and Qualitative. Search limits were also applied such that all articles had to be published in peer-reviewed journals. Table 1 displays all the search terms used.

### Table 1

Search Terms

	Search Terms Used								
Eating Disorders	Inpatient Treatment	Qualitative							
Anorexia Nervosa	Inpatient Unit	Experience							
	Specialised Inpatient Unit	Belief							
	Psychiatric Unit	View							
	Hospitalisation	Perception							
	Ward	Perspective							
	Compulsory Treatment	Opinion							
	Involuntary Treatment	Attitude							

A manual search was further conducted by identifying relevant papers from the reference lists in selected key articles. Two such articles (Colton & Pistrang, 2004; Halse et al., 2005) were identified through this process. This literature search was last carried out in October 2019.

### **Study Selection**

After the removal of duplicate papers (n=359), the initial search produced 929 articles. All papers were initially screened for relevance based on titles and were then further assessed by reading abstracts. This elimination process yielded a total of 183 articles. Their full texts were retrieved, individually evaluated and selected if they met the following inclusion and exclusion criteria:

## **Inclusion Criteria**

- Explicitly stated the use of qualitative research methods for data collection and analysis; either on their own or as part of a mixed-methods design.
- Participants were patients receiving inpatient treatment for AN and the study focused exclusively on the experience of being an inpatient/receiving inpatient treatment.
- All participants had a formal diagnosis of AN according to DSM-IV, DSM-5, ICD-10 or ICD-11.

## **Exclusion** Criteria

- Participants had a formal diagnosis of another Eating Disorder (ED) and/or AN was not the primary diagnosis.
- Participants were receiving outpatient or day treatment and/or findings focused on outpatient or day treatment outcomes and experiences.
- Findings exclusively provided an account of the experiences of clinicians and/or family involved in the care of a patient with AN rather than the patient herself.
- 4) Not published in English.
- 5) Published pre1950.

A total of 28 articles met the inclusion criteria and did not meet the exclusion criteria. Studies were excluded because they: did not exclusively focus on inpatient settings (n=56), did not use a qualitative research design for data collection and analysis (n=55), AN was not the primary diagnosis (n=22), participants were clinicians or family members caring for a patient with an ED (n=10), articles did not report on any outcomes or were a review (n=4), were not in English (n=4) or were not accessible online (n=4).

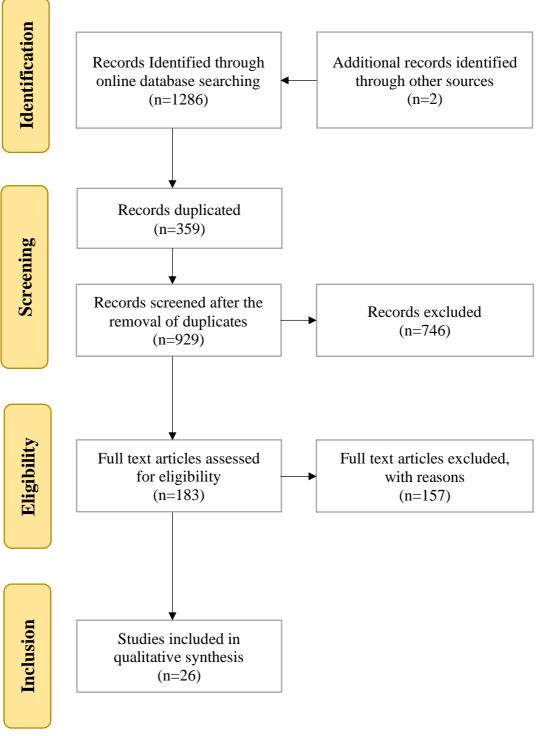
#### Further Consideration of Articles Selected

Two articles (Gorse et al., 2013; Strand et al., 2017) were further removed from this review.

Gorse et al. (2013) assessed patient motives for requesting inpatient treatment through extracting themes in a pre-admission letter. This study yielded data on the reasons why patients may want an inpatient admission and did not necessarily address subjective experiences of inpatient treatment and was therefore not considered as appropriate for this review.

Strand et al. (2017) addressed patient experiences of self-admission to an inpatient ward. 'Self-admission' enabled patients with previous inpatient admissions to return to hospital and self-admit for further treatment. This study was excluded from the current review as it was not an exploration of a patient's experience of inpatient treatment but rather was considered as an evaluation of a unique component on an ED unit.

One study carried out by Tan et al. (2003) explored patient views of involuntary treatment for AN in the U.K. and did not explicitly state that all patients were exclusively inpatients. Given that involuntary treatment in the U.K. almost always involves being detained in hospital under the Mental Health Act (MHA) it was deemed appropriate to include in this review.



# Figure 1

The Systematic Literature Search Process

## **Final Selection of Articles**

A total of 26 articles were included in the review. Table 2 provides the data extracted from each article, including information on the inpatient treatment setting, sample characteristics and methods of data collection and analysis.

# Table 2

No.	Authors &	Topic	opic Details of treatment				Sample Ch	aracteristics	Data collection – & Analysis
	Year			N	Sex	Age (years)	Ethnicity	AN Related	
1	Bravender et al. (2007)	Feeding/ Mealtimes	Primary focus of admission is the focus on physical health and safety. Usual length of stay is between 1-2	17		9 - 21 M =16.9	-	<i>BMI</i> M = 15.3	Telephone survey with open ended
			weeks, patients are fed orally, through nutritional liquid form or					<i>Duration of hosp</i> M = 8.4 days	questions
			via an NG tube					R = 2-24  days	Thematic Analysis
2	Colton &	Inpatient	Two inpatient ED units for	19	19 f	12 - 17	White	Duration of AN	Semi-structured
	Pistrang	Experience	adolescents with 10 beds. Both units			M = 15.4	British	M = 23 months,	interviews
	(2004)		were therapeutic milieus.				(18)	$\mathbf{R} = 10 - 60 \text{ months}$	
									IPA
							British	Tx Status	
							Caribbean	Involuntary = 1	
							(1)	Voluntary = 18	
								Previous Admissions	
								None $= 4$	
								Previous (paed ward) = 6	
								Previous (ED ward) =	

# Data Extracted from Individual Studies Included in this Review

No.	Authors &	Торіс	Details of treatment Sample Characteristics				Sample Characteristic		Data collection
	Year			N	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
3	Fogarty et al. (2013)	Inpatient Intervention	Patients received acupuncture, acupressure and light head massage treatments at an inpatient eating disorder programme at a private medical facility. The interventions were administered twice a week for the first three weeks, followed by weekly treatment for three weeks. During this time usual care was administered: patients were treated by an MDT team, attended group therapy daily and had meals and snacks supervised.	26	25 f 1 m	M = 22	Caucasian	Previous hospitalisation = 11 patients	Open ended questionnaire Content Analysis
4	Fox & Diab (2015)	Inpatient Experience	Two ED inpatient services providing multi-disciplinary treatment. All patients received psychological therapy	6	6 f	19 - 50 M = 27	White British	BMI R = 14-15 Duration of AN M = 7 years R = 6-23 years Length of current admission R = 4-27 months Previous admissions R = 2 - 4 Tx Status Voluntary = 4 Involuntary = 2	Semi-structured interviews IPA

No.	Authors &	Торіс	Details of treatment				Sample Characteristics			
	Year			N	Sex	Age (years)	Ethnicity	AN Related	— & Analysis	
5	Giombini et al. (2018)	Inpatient Intervention	Inpatient ward offering multi- disciplinary treatment including individual therapy, family therapy and group therapy. Group therapy consisted of psychoeducation groups on nutrition and relapse prevention. CRT was also provided to all inpatients. CRT involved exercises aiming to help young people improve their flexibility in thinking styles. It was delivered twice weekly and each session lasted 45 minutes. Patients received 8 sessions.	70	70 f	11 - 17 M = 14.8	White British (62) Asian (8)	Weight for Height M = 78.1%, R = 69.3 - 110.1	Feedback letter Thematic Analysis	
6	Gueguen et al. (2017)	Inpatient Intervention	An alternative intervention focused on grounding, relaxation exercises and positive reconnections with bodily sensations. Qigong was in a young adult psychiatric department as part of a multidimensional treatment programme for adolescents. It was a group activity, scheduled in once a week after lunch for 90 minutes.	16	16 f	13 - 19 M = 16.5	-	BMI M = 14.1 R = 11.7 - 16.9 Duration of AN M = 3.4  years R = 1 - 7  years Duration of hosp M = 4.3  months R = 1-10  months	Semi-structured interviews IPA	

No.	Authors &	Торіс	<u> </u>				Sample Characteristics		Data collection
	Year			Ν	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
7	Halse et al. (2005)	Mealtimes/ Feeding	Public, teaching hospital that treats both inpatients and outpatients. As part of inpatient care, NGF is used for medical stabilisation to support weight restoration. NGF is administered in conjunction with support meal plans and as part of a comprehensive treatment programme involving multi- disciplinary treatment delivered by both medical and mental health specialists.	23	23 f	12 - 20 M = 14.8		BMI $M = 15.6$ $R = 15.2 - 18$ $Previous Admissions$ $N = 14$	In-depth interviews Content Analysis and Thematic Analysis
8	Hedlund & Landgren (2017)	Inpatient Intervention	Locked inpatient specialist and high-intensity ED unit with 10 beds, with a focus on weight restoration. As part of a multi-disciplinary treatment approach, patients are offered acupuncture twice weekly by nurses after meals. Patients rest for 40 minutes after needles are inserted. Patients received between 1-10 acupuncture sessions.	9	9 f	22 - 55	-	BMI R = 14.1 - 18 Duration of hosp R = 0.5 - 16 weeks Previous admissions First time = 1 Two + times = 8	Narrative interviews Phenomenological Hermeneutic Method
9	Kezelman et al. (2016)	Feeding/ Mealtimes	Adolescent medical unit for medically unstable patients admitted for nutritional rehabilitation. The unit uses both NGF and standard oral feeds. Other programme components include individual, group therapy, physiotherapy, psychoeducation for families.	10	10 f	16 - 19 M= 17.5	-	Duration of hosp M = 26.90 days R = 14-66 days AN Restrictive = 9 Binge/purge = 1	Semi-structured interviews Thematic Analysis

No.	Authors &	Торіс	Details of treatment				Sample Cl	Data collection	
	Year			N	Sex	Age (years)	Ethnicity	AN Related	— & Analysis
10	Larsson et al. (2018)	Inpatient Intervention	Inpatient specialist and national ED service. Patients receive medical and nutritional input, individual therapy and group therapy. The service offered a perfectionism group, aiming to increase awareness of perfectionism and to identify and challenge perfectionist thinking and behaviours. The group size had a mean of 5 patients per session; patients were offered a total of 6		14 f	M = 27.4	-	BMI M = 15.3 Duration of AN M = 11.5 years AN Restrictive = 64% Binge/Purge = 21% Atypical = 15%	Focus groups Thematic Analysis
11	Long et al. (2012)	Feeding/ Mealtimes	<ul> <li>sessions.</li> <li>4 inpatient units, including a combination of national health services and private services. All units provided inpatient care including meals as part of treatment.</li> </ul>	12	12 f	17 - 30 M = 22	-	AN Restrictive = 100%	Semi-structured interviews Thematic Analysis
12	Money et al. (2011)	Inpatient Intervention	Those with consecutive admissions to the inpatient unit are offered the CREST intervention. This intervention is a 10-session intervention for inpatients with severe AN and targets emotional recognition and management through psychoeducation and skills- based strategies.	28	27 f 1 m	13 - 40 M = 25	-	<i>BMI</i> M = 14.6 R = 11.5 - 18.1	Open ended questionnaire Content Analysis
13	Offord et al. (2006)	Inpatient Experience		7	7 f	16 - 23	White British	-	Semi-structured interviews Grounded Theory

No.	Authors &	Topic	Details of treatment				Sample Ch	aracteristics	Data collection
	Year			N	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
14	Pemberton & Fox (2013)	Inpatient Experience	Two specialist ED inpatient services with acute wards. One service had both an acute ward and an intensive	8	7 f 1 m	< 25	-	<i>BMI</i> < 16	Semi-structured interviews
			care unit as part of the treatment setting.					Duration of hosp $R = 0.5 - 16$ months	Constructivist Grounded Theory
15	Ramjan & Gill (2012)	Inpatient Experience	A general hospital ward for adolescents with a variety of medical or surgical conditions.	10	9 f 1 m	11 - 18	-	BMI R = 15.1 – 22.2	Semi-structured Interviews
			Typically, 4/20 beds are assigned to patients with AN. Treatment components include bed rest, NG					Duration of hosp M = 33-58	Thematic Analysis
			feeding, supervised meals and individual therapy. Leave of the ward is granted when patients progress with treatment.					No of Admissions R = 1- 14	
								<i>Inpatient status</i> Current = 6 Previous = 4	
16	Ross & Green (2011)	Inpatient Experience	An ED service employing a psychodynamic and developmental approach. The therapeutic	2	2 f	>18	-	History of AN > 5	Semi-structured interviews
			programme focuses on weight gain and weight stabilisation and includes individual and group therapy						Thematic Analysis
17	Seed et al. (2016)	Involuntary Treatment	Inpatient wards in both national health services and privatised settings.	12	12 f	18 - 43	-	Time since discharge $R = 0 - 14$ years	Semi-structured interviews
									Grounded Theory
18	Sly et al. (2014)	Therapeutic Alliance	Hospitalised treatment for AN	8	8 f	15 - 24 M = 25	Caucasian	-	Semi-structured interviews
									IPA

No.	Authors & Year	Торіс	Details of treatment Specialist inpatient unit with multi- disciplinary treatment including individual therapy and dietetic management. Dietary aspects include meal supervision, nutritional education and an eating skills group. Psychological interventions were mainly based on CBT principles and providing emotional regulation skills. As part of inpatient care, joint well- being workshops were offered to both patients and the MDT. The aims of these workshops were to provide patients with new skills, provide support to the MDT and facilitate meaningful interactions on the ward. 8 workshops were delivered on the hospital ground				Sample Cl	Data collection	
				N	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
19	Smith et al. (2016)	Inpatient Experience		21	21 f	18 - 41 M = 25.2	-	BMI M = 16.6 R = 11.8 - 21.0Duration of AN M = 76.1 months R = 4 - 276 monthsLength of current admission M = 12.8 weeks R = 2 - 28 weeksTx Status Voluntary = 20 Involuntary = 1Previous Admission None = 9, >1 = 13	Semi-structured interviews Thematic Analysis
20	Smith et al. (2019)	Inpatient Intervention		34	-	16-63 M = 29	-	<i>BMI</i> M = 14.1 <i>AN</i> Restrictive = 44 Binge/Purge = 9	Open ended questionnaire and focus groups Thematic Analysis

No.	Authors &	Торіс	Details of treatment				Sample Cha	aracteristics	Data collection
	Year			Ν	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
21	Sparrow & Tchanturia (2016)	Inpatient Intervention	Adult inpatient ward offering psychotherapy groups as part of the inpatient programme. Groups included were: 1) CRT 2) CREST 3) Self-Esteem group and 4) Living with Perfectionism group. All groups involved 5-6 sessions; each session was 45 minutes	150	150 f	> 18	-	-	Open ended questionnaire Thematic Analysis
22	Tan et al. (2003)	Involuntary treatment	N/A	10	10 f	13 - 21	-	Duration of AN R = 0.2 - 6 years Tx Status Current Involuntary = 2 Previous Involuntary = 3 Voluntary = 1	Semi structured interviews Grounded Theory
23	Turrell et al. (2005)	Discharge	Inpatient programme based within a medical-psychiatric setting. Adolescents are admitted when medically unstable. Treatment is provided by a multidisciplinary team and includes a psychoeducation group. Length of admission is variable and dependent on the length of time needed for the patient to achieve sufficient weight gain.	sychiatric setting. nts are admitted when unstable. Treatment is by a multidisciplinary and includes a ucation group. Length of n is variable and dependent ugth of time needed for the		M = 14.6	Caucasian (13) Asian (1)	Duration of hosp M = 28 days Duration of AN M = 9.9 months	Open ended questionnaire Content Analysis

<b>No.</b> 24	Authors & Year	Topic	Details of treatment				Sample Cl	Data collection	
				N	Sex	Age (years)	Ethnicity	AN Related	- & Analysis
	van Ommen et al. (2009)	Therapeutic Alliance	Inpatient Unit as part of a centre providing specialised treatment for EDs, for those aged 18 or younger.	13	13 f	13 - 17 M = 15	-	<i>BMI</i> M = 13.2	Semi-structured interviews
	(2007)		The focus of treatment is to restore body weight and eating patterns and to normalise anorectic cognitions, body image and family/social functioning.					Duration of hosp M = 131 days R = 67 - 246 days	Grounded Theory
25	Wu & Harrison (2019)	Inpatient Experience	A university hospital providing treatment for AN	4	4 f	16 - 19	Chinese	<i>Duration of AN</i> M = 3.7 months	Semi-structured interviews
								<i>No of Admissions</i> First = 1 Previous = 4	IPA
26	Zugai et al.	Therapeutic	Combination of mental health	34	33 f	M = 20	-	AN Age of onset	Semi-structured
	(2018)	Alliance	inpatient units and mixed medical and mental health wards. All		1 m			M = 15.5 years	interviews
			provided specialised treatment					Age of first treatment	Thematic
			programmes for AN.					M = 17.5 years	Analysis

 $\frac{Key:}{Sex (m = Male, f = Female),}$  M = Mean R = Range Hosp = Hospitalisation IPA = Interpretative phenomenological analysis

### **Quality Appraisal**

The Critical Appraisal Skills Programme (CASP) (CASP, 2018) was employed as a tool to assess the quality of all studies included. This version takes the form of a checklist and includes ten questions on the goals/aims of the research, appropriateness of qualitative research methodology, recruitment strategy, data collection, data analysis, the extent of finding produced, considerations of the relationship between researcher and participants, ethical considerations and the overall value of the research. The following section provides a detailed account of the ten CASP items in relation to all studies included in this review. Figure 2 provides a visual summary.

		Clear Aims?	Qual Method Appropriate?	Design Appropriate?	Recruitment Strategy	Method of Data Collection	Researcher/Participant Relationship	Ethical Issues Considered?	Rigorous Data Analysis?	Clear Findings?	Value of Research?
No											
1	Bravender et al. (2007)										
2	Colton & Pistrang (2004)										
3	Fogarty et al. (2013)										
4	Fox & Diab (2015)										
5	Giombini et al. (2018)										
6	Gueguen et al. (2017)										
7	Halse et al. (2005)										
8	Hedlund & Landgren (2017)										
9	Kezelman et al. (2016)										
10	Larsson et al. (2018)										
11	Long et al. (2012)										
12	Money et al. (2011)										
13	Offord et al. (2006)										
14	Pemberton & Fox (2013)										
15	Ramjan & Gill (2012)										
16	Ross & Green (2011)										
17	Seed et al. (2016)										
18	Sly et al. (2014)										
19	Smith et al. (2016)										
20	Smith et al. (2019)										
21	Sparrow & Tchanturia (2016)										
22	Tan et al. (2003)										
23	Turrell et al. (2005)										
24	van Ommen et al. (2009)										
25	Wu & Harrison (2019)										
26	Zugai et al. (2018)										
			<u>K</u>	<u>ey:</u>							
			Rep	orted	land	consid	dered	as su	fficier	nt	
			P							-	

# Figure 2

Quality Assessment Ratings as per the CASP checklist

Not reported

Partially reported or ambiguous

#### Aims/Goals of Research

All studies described the aims of the research. It was deemed appropriate that a qualitative research design was employed by all studies to assess their research aims.

Articles aimed to assess individual experiences of inpatient treatment through adolescent perspectives (Colton & Pistrang, 2004; Offord et al., 2006; Wu & Harrison, 2019) and adult perspectives (Fox & Diab, 2015; Ramjan & Gill, 2012; Ross & Green, 2011; Smith et al., 2016). One study (Wu & Harrison, 2019) especially aimed to understand the experience of treatment for AN in non-western cultures.

Additionally, articles investigating the delivery of psychological interventions on inpatient wards aimed to explore the perceived benefits and disadvantages of such interventions and intended to obtain feedback for improvements. There was a wide range of interventions including an intervention targeting perfectionism (Larsson et al., 2018), brief group therapy (Sparrow & Tchanturia, 2016), individual Cognitive Remediation Therapy (CRT) (Giombini et al., 2018), Cognitive Remediation and Emotional Skills Training (CREST) (Money et al., 2011), acupuncture and acupressure (Fogarty et al., 2013; Hedlung & Landgren, 2017), Qigong (Gueguen et al., 2017) and well-being workshops (Smith et al., 2019).

Studies which focused on the experience of the therapeutic alliance between clinicians and patients aimed to obtain a deeper understanding on the factors contributing to a stronger therapeutic alliance (Pemberton & Fox, 2014; Sly et al., 2014; van Ommen et al., 2009; Zugai et al., 2018).

The articles on experiences associated with feeding stated aims on the experience of re-feeding and Nasogastric Feeding (NGF) (Halse et al., 2005; Kezelman et al., 2016), to understand the experience of mealtimes given its importance

in inpatient settings (Long et al., 2012) and to explore individual experiences of medical stabilisation (Bravender et al., 2017).

The papers included on involuntary treatment (Seed et al., 2016; Tan et al., 2003) aimed to explore patient perspectives on compulsory treatment and the MHA, specifically looking at the role of control in patients with AN.

Lastly, the article on discharge readiness (Turrell et al., 2005) aimed to explore the conditions necessary for one to be discharged from an inpatient setting.

#### Participants and Recruitment

All studies identified and recruited participants using slightly different methods. Interestingly, none reported any details on how the research was explained to the participants.

The majority of studies identified participants based on whether they had undergone an intervention and/or inpatient treatment within a particular time period (Bravender et al., 2017; Colton & Pistrang, 2004; Fox & Diab, 2015; Giombini et al., 2018; Halse et al., 2005; Hedlung & Landgren, 2017; Larsson et al., 2018; Money et al., 2011; Sly et al., 2014; Smith et al., 2019; Turrell et al., 2005). One study contacted patients who had received inpatient treatment in the past to understand their retrospective views of treatment (Offord et al., 2006). Another study formed part of an RCT and a subgroup of participants from the RCT sample were invited to share their experiences (Fogarty et al., 2013). Only ten studies (Fogarty et al., 2013; Fox & Diab, 2015; Kezelman et al., 2016; Long et al., 2012; Seed et al., 2016; Smith et al., 2016; Turrell et al., 2005; van Ommen et al., 2009; Wu & Harrison, 2019; Zugai et al., 2018) indicated that they had used explicit inclusion or exclusion criteria.

It appeared that the majority of the studies employed the method of purposive sampling; however, only five studies explicitly reported using this sampling technique (Gueguen et al., 2017; Ramjan & Gill, 2012; Seed et al., 2016; Sly et al., 2014; Wu & Harrison, 2019).

Four studies reported employing a volunteer or opt-in sampling method to recruit participants (Long et al., 2012; Offord et al., 2006; Pemberton & Fox, 2014; Ross & Green, 2011) and one study stated using a convenience sampling method (van Ommen et al., 2009).

In qualitative methodologies, it is common to provide information about recruitment and participation, for example, the discrepancies between how many participants were invited to take part in the study and how many chose to take part. This information was reported by six studies (Bravender et al., 2017; Colton & Pistrang, 2004; Gueguen et al., 2017; Offord et al., 2006; Seed et al., 2016; Zugai et al., 2018). Additionally, few studies provided reasons for participants declining to take part, such as no longer being interested in the study (van Ommen et al., 2009), unsure as what to write in feedback forms (Giombini et al., 2018), lack of desire to take part (Forgarty et al., 2013; Sly et al., 2014) and not wanting to share personal experiences (Colton & Pistrang, 2004; Smith et al., 2016).

# Data Collection

There was a variation in the methods of data collection in all studies selected in this review, as reviewed in Table 2. Only two studies selected provided details on the saturation of data. Ramjan & Gill (2012) described that saturation occurred when responses ceased to reveal any new information. Sly et al. (2014) stated that saturation was not considered due to the concept of data saturation not being in accordance with the principles of the methodology chosen.

#### Data Analysis

As per the inclusion criteria, all studies included used a form of qualitative analysis. The majority of the studies included gave an account of the different stages of the analysis and how categories were organised and/or derived. However, the amount of detail and information on this process varied from paper to paper.

A variety of papers included a section discussing the credibility of results. The most common strategy to enhance credibility was the use of independent co-coding of transcripts with two or more researchers, who would frequently compare codes (Colton & Pistrang, 2004; Giombini et al., 2018; Kezelman et al., 2016; Larsson et al., 2018; Long et al., 2012; Money et al., 2011; Offord et al., 2006; Seed et al., 2016; Smith et al., 2016; van Ommen et al., 2009; Wu & Harrison, 2019). Additionally, some studies reported on having 'consensus discussions' between members of a research team where discrepancies on the coding process were negotiated (Colton & Pistrang, 2004; Gueguen et al., 2017; Larsson et al., 2018; Long et al., 2012; Pemberton & Fox, 2014; Seed et al., 2016; van Ommen et al., 2009; Wu & Harrison, 2019).

One study noted that a random number of transcripts were re-read and coded by various members of a research team (Sly et al., 2014), whereas another reported that themes were compared and confirmed by other researchers investigating similar phenomena (Zugai et al., 2018). Only one study explicitly stated the percentages of agreement between raters on codes and themes (Turrell et al., 2005).

Furthermore, member checks, where results are presented back to participants to check for accuracy and resonance with their experiences, were employed by six studies (Fox & Diab, 2015; Offord et al., 2006; Ramjan & Gill, 2012; Ross & Green, 2011; Smith et al., 2016; van Ommen et al., 2009). These papers conducted member

checks with the participants of the study apart from Smith et al. (2016) who undertook member checks with a separate group of patients diagnosed with AN.

### Findings and Value of Research

All studies included in this review either provided a deeper understanding or novel insights into the phenomenon being explored. The majority of the studies provided an account of how their findings led to a wide range of clinical implications, further emphasising the value of the research. The clinical implications suggested ways to improve interventions (Money et al., 2011), improve inpatient care offered to patients (Offord et al., 2006), aspects to consider at discharge (Turrell et al., 2005), factors influencing mealtimes (Long et al., 2012), enhancing practice when using NGF (Halse et al., 2005), improving the therapeutic alliance between staff and patients (Fogarty et al., 2013; Ramjan & Gill, 2012; Sly et al., 2014; Zugai et al., 2018), improving nursing care (van Ommen et al., 2009) and cultural differences in the understanding and treatment of AN (Wu & Harrison, 2019). A further two studies provided insight into how the MHA is used within this population group (Seed et al., 2016; Tan et al., 2003).

#### **Relationships and Reflexivity**

Only a minority of studies adequately considered the relationship between the researcher and participants. This is considered essential in qualitative research and provides researchers with the opportunity to recognise and/or mitigate potential biases and assumptions that interfere with a range of research processes (e.g. recruitment, data collection and analysis). Only a few studies noted that the researchers were separate to and independent of professionals who were actively involved in providing inpatient care or delivering an intervention in an inpatient setting (Colton & Pistrang, 2004; Giombini et al., 2018; Hedlung & Landgren, 2017; Money et al., 2011; Ross &

Green, 2011). Smith et al. (2016) acknowledged that their results may be biased due to the clinical role of the researchers and that this was addressed with participants; however, no explicit account of this process was presented. Furthermore, Ramjan & Gill (2012) stated that researchers worked part-time on the ward but there was no account of how this may have influenced the results.

Five studies either included a reflexivity section or stated that a reflexive diary was used, to highlight the potential influence of researchers' perspectives on data collection or the analysis process (Fox & Diab, 2015; Gueguen et al., 2017; Offord et al., 2006; Pemberton & Fox, 2014; Seed et al., 2016).

#### Ethical Considerations

The majority of the studies provided an account of the ethical considerations undertaken during the research process. This included gaining ethical approval from an ethical review board, informed consent, written consent, confidentiality and a written information sheet containing study information. Notably, only half of the studies included in this review reported both obtaining ethical approval and employing specific procedures (e.g. consent, confidentiality, etc).

Moreover, three studies described informing participants that participating was voluntary and they had the right to withdraw at any time during the study (Ramjan & Gill, 2012; Wu & Harrison, 2019; Zugai et al., 2018). Three studies made it explicit that participants were told that participating would not have an impact on any treatment received (Long et al., 2012; Smith et al., 2016; Wu & Harrison, 2019). Two studies reported on providing details of a staff member to speak to, should participants encounter distress after participating (Long et al., 2012; Wu & Harrison, 2019) and one study provided a debrief after the study (Wu & Harrison, 2019).

Other ethical considerations that were described were: providing participants with the identity details of the researchers (Gueguen et al., 2017), providing participants with the option to change the wordings in the final article (Ross & Green, 2011) and verifications from doctors that it was medically safe for participants to take part (Zugai et al., 2018).

# **Conclusions**

Although all 26 studies varied in quality on all the above-mentioned aspects, they were considered to be satisfactory and suitable to be included for this review.

#### **Thematic Synthesis**

The results section from each selected article was extracted and uploaded onto the qualitative software 'NVivo 12'. A thematic synthesis, as informed by Thomas & Harden (2008), was performed on this data to identify key themes. This approach is recommended for reviewing qualitative studies and involves three stages of analysis, allowing for the systematic coding of data and the generation of descriptive and analytic themes.

Stages one and two of the analysis involved coding the individual data extracts from each article and developing descriptive themes. Firstly, each line of text was freely coded according to its meaning and content. Coding was conducted comparatively between studies, leading to a bank of codes being created. As the researcher continued to freely code the data extracts, new codes were added and/or codes were developed. To enhance the credibility of the results, 50% of the articles were co-coded by an independent researcher. Codes were then discussed, negotiated and modified in light of any apparent discrepancies. The first two stages of the analysis therefore allowed for the translation of concepts from one study to another and led to the formation of descriptive themes. Stage three of the analysis involved a process of translation, whereby descriptive themes were developed into analytic themes. Analytic themes are equivalent to 'third-order interpretations' and go beyond the original findings reported in the articles included. The research questions of this systematic review were used as a guide when translating descriptive themes to analytic themes, subsequently leading to the generation of concepts addressing the aims of the review.

#### Results

Seven themes were identified through the thematic synthesis. These were 'The Inpatient Setting', 'Control and Freedom', 'Peer Dynamics', 'Interactions with Clinicians', 'Eating Disordered versus being a person with an Eating Disorder', 'Discrepancies between Physical and Psychological Aspects' and 'Interventions Offered'. Table 3 presents these themes and subthemes. Table 4 shows the prevalence of themes across the reviewed studies.

# Table 3

Theme	Subtheme								
The Inpatient Setting	A hostile, isolated bubble								
	Dependency and attachment								
	The structure								
	Influence on discharge								
Control & Freedom	The lack of control & choice								
	Handing over control								
	Regaining control and								
	responsibility								
Peer Dynamics	Support								
	Perceived difficulties								
	Competition								
Interactions with Clinicians	Helpful dynamics								
	Difficult dynamics								
	Valued characteristics								
Eating Disordered versus being a	The power of AN								
person with an Eating Disorder	Treated as a person								
Discrepancies between Physical and	Fattened up								
Psychological Aspects	Holistic approach								
Interventions Offered	Positive aspects								
	Negative aspects								

Themes and Subthemes Extracted across all Studies

# Table 4

# Prevalence of Subthemes across Reviewed Studies

Subtheme	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26
A Hostile Isolated Bubble	•	•	•	•		•			•		•		•	•	•	•	•		•					•	•	
Dependency/Attachment	•						•	•					•			•	•		•					•		
The Structure		•		•				•	•		•		•		•	•	•		•				•	•	•	•
Influence on Discharge				•				•	•				•		•	•	•		•				•	•		
Lack of Control/Choice	•			•			•		•		•		•	•		•	•	•	•				•	•		•
Handing Over Control	•		•	•			•		•		•		•	•		•	•	•	•					•		•
Regaining Control		•						•					•			•	•		•					•		
Support		•				•		•	•	•			•		•		•		•	•	•			•	•	
Perceived Difficulties		•		•			•			•	•		•	•					•						•	
Competition		•				•	•				•		•				•		•						•	
Helpful Dynamics		•	•	•		•						•	•	•				•		•				•	•	•
Difficult Dynamics		•				•	•				•	•	•	•		•	•	•	•					•	•	•
Valued Characteristics		•	•	•		•					•	•	•	•		•	•	•	•			•		•	•	•
The Power of AN		•		•		•	•				•						•						•			
Treated as a Person		•	•	•	•	•			•				•	•	•		•		•	•				•		•
Fattened Up		•					•		•														•		•	
Holistic Approach		•			•				•			•	•			•	•		•						•	
Positive Aspects					•	•		•		•	•	•								•	•					
Negative Aspects					•	•		•		•	•	•								•	•					
Suggestions		•			•	•		•		•		•			1				1	•	•					<u> </u>
Note: Colours indicate the main	themes; a	is belo	w																							
The Inpatient Setting	Control & Freedom Peer Dynamics						á	Eating Disordered versus being a person with an Eating Disorder								etween rcholog		Interventions Offered								

# **The Inpatient Setting**

This theme referred to the unique inpatient setting and how it influenced one's experience of treatment. Participants<sup>1</sup> who provided retrospective views on inpatient treatment spoke about how it *"saved* [their] *life"* (25) especially given high physical risks. Additionally, participants spoke about the ethos and environment on a ward and a process of adjustment from being at home to living in hospital which differed significantly in structure. Lastly, participants spoke about being dependent on a unit and how the unique setting of inpatient treatment influenced experiences of discharge.

## A Hostile, Isolated Bubble

Some participants experienced the inpatient environment to be hostile and punitive leading to feelings of not being cared for. Participants described they felt trapped and locked up on a ward and that this impacted their hopes for recovery. The lack of privacy, withdrawal of consent for involuntary patients, restrictive interventions (i.e. 'force-feeding', NGF) and being closely watched were other factors that contributed to the experience of a hostile environment.

"It's a place for hell ... you're stuck in here and you can't get out, you can't do anything." (2)

Participants spoke about being removed from the outside world and feeling lonely on inpatient wards. Some studies reported on how patients were unable to see friends and family members and that the rules for leave did not appear to be realistic nor consistent.

"being unable to see friends or go outside made [patient] feel quite cooped up, like being in jail in a way." (16)

<sup>&</sup>lt;sup>1</sup> For the purpose of this review, 'participants' refers to any participant who was referenced in the results section of included papers. Likewise, quotes have been directly extrapolated from the results sections of included papers.

Participants felt removed from normality on inpatient wards and described the setting to be artificial. Participants spoke about how their lives had come to a standstill whilst being inpatients and that there was a stark difference between home and hospital life.

"A pervasive sense of being removed from the outside world and the normality of adolescent life... it was just like a void." (13)

# The Structure

Participants shared their experiences of being in an environment that was highly structured and regulated. To some, the high level of structure induced a sense of relief, was containing, and provided a safe place to express emotions. Similarly, a structured environment also provided participants with stability, control and a sense of familiarity. One study also reported that patients would lose weight over the weekends during home-leave and attributed this to the structures of a hospital not being in place (24).

"In the close environment of the hospital, although it's very artificial, you sort of have a place...the structured programme provided holding and containment." (16)

On the other hand, participants also experienced the structure of inpatient wards as punishing, restrictive and disempowering. Participants discussed limited options to make individual choices and a lack of patient control over treatment. Moreover, participants shared that at times a unit could be too safe, preventing individuals from learning the skills and gaining confidence to be able to eat in less structured environments.

"All adolescents within the program described their daily routine in the same way - as highly structured, with little or no variability." (15)

#### **Dependency and Attachment**

Participants spoke about how the inpatient setting fostered a sense of dependency and that they felt attached to the treatment environment. This was explained by a sense of security provided by the inpatient setting and how it was experienced as a safe and containing space. Participants felt a sense of belonging to inpatient wards and described how other patients had become "family." (26)

"You become dependent on it ... you feel it is your safe place almost. I am almost afraid to be here now because I have become quite attached." (19)

# Influence on Discharge

There was a sense of the inpatient setting being too safe and artificial, which created challenges when being discharged. Participants spoke about finding the transition from inpatient treatment to outpatient treatment difficult given the differences in the amount of support available. Participants experienced difficulties of adjusting to the absence of a structured routine that they had become familiar with during their admission. Participants also experienced a fear of the adjustment to real life, which was experienced as temporarily suspended when receiving inpatient treatment. One study reported on how patients wanted a high level of support post-discharge to cope with the above-mentioned difficulties (23).

"Participants frequently commented on the extreme difference between the high level of structure and support found in the unit and that found in the world outside. This often led to strong attachments to unit life and painful emotions on discharge." (13)

#### **Control and Freedom**

This theme referred to the level of control existing on an inpatient unit, for example, meal plans, rules for exercising and leave off the unit. Participants expressed a lack of control over treatment options and not being given the opportunity to make decisions associated with their treatment. A contradictory experience included patients handing over control to clinicians and feeling the need for others to take over. Participants then spoke about the sense of regaining this control and responsibility as treatment progressed.

# Lack of Control and Choice

Participants spoke about how they felt a lack of control when receiving inpatient treatment, how this undermined their autonomy and agency in recovery and became a predominant source of distress. This further contributed to feelings of being punished and restricted on inpatient wards. Additionally, the perception of clinicians holding all the control appeared to impact treatment decision making, as participants expressed the lack of choice over treatment options, especially with pre-set targets for weight gain.

"Like they just put the tube in...you don't have any say in treatment at all."

(7)

#### Handing Over Control

There appeared to be some ambivalence with the concept of control as participants acknowledged the importance of giving the responsibility and control to clinicians, despite this being particularly difficult. This included giving responsibility to staff for meal plans, preparation and limiting exercise. Participants shared that often handing over this control permitted them to move towards recovery. One participant described that it provided "*relief and comfort*" (19) after knowing that services were in control and had the responsibility for treatment decisions.

"when you don't have a choice there comes a point where you stop worrying about it." (9) Another view expressed was that participants felt overcontrolled in a restrictive environment. One study reported on patient experiences of being overcontrolled on aspects not related to food and gave the example of not being able to use the telephone and feeling *"powerless."* (13)

"at admission, she told me what to do, told me 'no' in a way that gave me no choice, [about] what I was going to do or needed to do. All I did from then was resist, [and] fight her, even if she made sense." (18)

### **Regaining Control and Responsibility**

Participants spoke about experiencing a shift in control as treatment progressed, as responsibilities were slowly given back to patients at different stages. This was described as a process that was built up gradually and often through a step by step plan. Participants expressed how they were slowly allowed to make and evaluate their own choices, enabling them to have more control over the decisions about treatment. Some participants reported how taking more responsibility was only possible during the later stages of treatment and that regaining this control was helpful when working towards discharge.

"It just felt nice that I could show that I could do everything by myself again ... and that I did not have to be told everything I had to do." (24)

#### **Peer Dynamics**

This theme highlighted the influence of other patients on an individual's treatment experience, both on general psychiatric wards and specialised ED units. Participants expressed positive influences, such as a sense of connectivity and a source of support, as well as negative experiences, such as distress and an increase in AN symptomatology. For specialised ED settings, competition between patients was particularly pertinent.

#### A Source of Support

Participants spoke about feeling understood, accepted and supported by peers on inpatient wards. They described the value of having peers who might have had similar experiences and the importance of verbal, non-verbal, emotional and practical support available. The development of friendships on wards led to participants feeling less alone, able to talk about their difficulties without being judged and having their experiences normalised. Moreover, participants spoke a strong sense of connection that developed with peers and how they often became role-models for recovery. Lastly, participants spoke about the importance of being with others in times of distress and learning coping skills from one another.

"Other people kind of like reassured us and said we have it too, you are not alone in this ... It generated almost a kind of feeling of community in the group as well." (10)

# Perceived Difficulties

In contrast, participants spoke about the struggles of establishing and maintaining relationships whilst being an inpatient. Difficult group dynamics, such as bullying, teasing and alienation, were experiences described by some during inpatient treatment. Some participants also described finding it difficult to see other patients in a distressed state and feeling responsible for helping them through a crisis. Patients also had experiences of being negatively influenced by others on the ward, by learning maladaptive coping strategies from other patients, such as head-banging and self-harming, or by picking up new ED behaviours, such as bingeing and purging.

"They [other patients] are all exploding at some point ... it is something I feel I do not have to be dealing with. I would rather be focussing on my treatment." (19)

## Competition

On ED units, a shared focus on food and weight often meant that patients made comparisons amongst one another. Participants spoke about spending a significant amount of time talking about weight gain and calories and competing about who would be the thinnest on the ward. This existing competition about appearance and ED behaviours was described as toxic and participants reported fears of being seen as greedy or overweight, subsequently leading to the desire for further weight loss. Moreover, the competition between patients induced feelings of guilt, enhanced insecurities and fear associated with being with peers.

"It made me uncomfortable that there were other people... I was looking at them for how they were compared to me, mainly... when they were thinner, that made me feel bad." (6)

# **Interactions with Clinicians**

This theme emphasised the importance of a clinician's role on inpatient wards and captured the patient-clinician relationship. Studies reported patient desires to be cared for and validated by clinicians. Participants spoke about helpful and unhelpful dynamics with clinicians, ranging from experiencing unconditional positive regard to not feeling understood or heard. Participants also described the valued characteristics of clinicians which contributed to a strong therapeutic relationship.

# Helpful Dynamics

Participants spoke about the experience of receiving unconditional positive regard from clinicians and feeling safe, supported and contained. As a result, this provided "*comfort and relief*" (21) and enabled participants to use key-working spaces effectively. Participants spoke about the importance of creating and maintaining trust and equality in relationships with clinicians. They also expressed the value in concise,

consistent and predictable nursing care and being told about what was expected of them. Participants noted how this had an impact on the dynamics between clinicians and patients; mainly improving communication and enabling participants to speak openly about difficulties. Participants also described how the behaviour of clinicians during mealtimes modelled healthy eating behaviours and made these situations less stressful.

"Give and take, absolutely. It felt like an even, like we were even in things...they'd do the same - like what they expected of me and that, it was good." (18)

# Difficult Dynamics

At times, participants experienced interactions with staff to be punitive, demoralising, controlling and restrictive. They reported feeling rejected and not understood by clinicians and described a sense of abandonment from professionals. Interactions with clinicians were described as "battles" (11), with high levels of distrust, evoking a sense of anger towards clinicians. Participants also spoke about the lack of consistency and communication with staff members especially regarding rules on treatment protocols and processes. Lastly, participants did not feel that clinicians were doing their jobs effectively as there was a lack of staff knowledge on AN and often clinicians had "given up" (4) on patients.

"I get the impression that they don't want to be here ... it's just... it's a job and I think that's sad in this environment that you get staff like that – they're more concerned about how long their nails are." (14)

# Valued Characteristics

Participants highlighted that consistent caregiving, the use of humour and employing a firm but supportive stance were all valued characteristics in clinicians working in inpatient settings. Participants spoke about appreciating when clinicians set boundaries and maintained their authority, whilst balancing this with a supportive and non-judgmental approach. Participants valued clinicians who were easily available and accessible and who were attuned with their state of mind and needs, leading to patients feeling understood and cared for. Participants also described that clinicians were the most valued when they showed their willingness to make a conscious effort to listen and get to know the patient.

"There's a few others [nurses] who actually treat you like family and they actually make you feel welcome and loved, and it makes the experience a lot easier." (26)

# Eating Disordered versus Being a Person with an Eating Disorder

This theme referred to participant's experiences of deindividualised treatment and being viewed as their ED. It highlighted how participants had a disintegration of their own identity and how they were only able to identify with their AN. Similarly, participants felt that clinicians also held this identity for patients and only viewed them through their ED.

# The Power of AN

Participants spoke about a sense of being consumed by their AN and that it was experienced as a protector and a threat. For example, it was described as both a "monster" (16) but also a "friend" (2) which was difficult to give up. Whilst participants did not make explicit links between their strong anorexic identity and their experience of inpatient treatment, they expressed perspectives on how they did not wish to give up their AN as it played a significant role in their lives, hence questioning their motivation towards change and treatment. "Their strong anorexic identity reinforced the participants' rebellion as an attempt to hold onto being a 'good anorexic' and 'not a textbook case'." (17)

#### Not Treated as a Person

Participants often felt that clinicians held views and assumptions about anorexic patients and that their identities were further reduced to *"just another anorexic"* (19). Participants expressed the desire to be viewed as an individual in their own right and wished for professionals to discover the person behind the ED.

"...if you get upset about anything, you're treated as a walking, talking illness. You're not a human being. Everything you say and do or anything you get upset about, it's the illness, it's the illness, it's the illness." (14)

# **Discrepancies between Physical and Psychological Aspects**

This theme highlighted how participants felt that inpatient treatment largely had a medical focus, with the sole aim of improving physical health and achieving weight gain. Therefore, there was a desire from participants for more psychological interventions alongside physical interventions. Nonetheless, some participants often spoke about accepting the need for inpatient treatment with a medical focus, to decrease the risks to their physical health, such as cardiac complications.

# Fattened Up

Participants described that treatment primarily focused on weight gain, nutrition and the prevention of weight loss behaviours and felt that this was at the expense of their psychological well-being. Participants reported that this narrow focus for treatment meant that their AN was reduced into one component and that other factors, which may have been important in the development or maintenance of their AN, were not addressed. This often led to the view that the only way to be discharged was to "*eat* [their] *way out*" (25) of inpatient treatment.

"The unit's main aim was to 'fatten them up' and restore their weight, with little attention paid to their psychological well-being. This, they believed, missed the whole point of their illness and was ineffective, especially in terms of long-term recovery." (1)

Some patients spoke about the internal conflict experienced after weight gain and did not feel that adequate support was provided to address the emotional impact of weight gain.

"you put weight on and then you're told you can go when you're struggling the most with your weight." (16)

Lastly, participants expressed that the focus on medical stabilisation and weight gain led to boredom in hospitals, with "nothing to do other than eat." (1)

# Lack of a Holistic Approach

There appeared to be a lack of psychological interventions during inpatient treatment (e.g. individual and group therapy). This was linked to the view that the treatment offered was depersonalised and not tailored to an individual's needs or situations. A desire for individual therapy was also expressed, with some patients wanting the skills to cope with distress and intolerable emotional experiences.

"I don't think it's individualised in here...they have their formula and they just put everyone on it ... everyone's problems here are completely different." (9)

## **Interventions Offered**

This theme referred to the range of interventions delivered in inpatient settings. The content of such interventions ranged from cognitive skills training, emotionfocused, perfectionism and well-being workshops. Studies reported on the use of contemporary and alternative interventions such as acupuncture and Qigong. Participants spoke about both positive and negative aspects of such interventions and also suggested improvements for their use in inpatient settings.

## **Positive Aspects**

Participants appeared to have valued the interventions offered on inpatient settings and acknowledged their positive impact. The interventions were viewed as a distraction from AN symptoms, provided the opportunity to relax and reduced distress. Participants also spoke about the social and enjoyable component of such interventions and how they provided another opportunity to connect with peers on the ward. This therefore decreased isolation levels and increased social contact.

*"Focusing on something pleasurable for no reason other than it's something that makes you happy." (20)* 

Participants also spoke about the skills learnt from such interventions, in particular the psychological interventions targeting cognitive change, perfectionism and labelling and expressing emotions. Participants articulated that the tasks in these groups were stimulating and thought-provoking. Additionally, they provided psychoeducation and helped patients to develop deeper insights, for example recognising the impact of bottling up emotions and of perfectionism. Participants also spoke about learning new skills on emotional communication and thinking styles and that this increased awareness and self-reflection.

"I think the most helpful things was working on my ability to block things out as I have been able to put that into practical use, such as blocking out unhelpful things at the table and focusing on one thing." (5)

Participants were also open to contemporary and alternative interventions and spoke about how these interventions forced individuals to switch off from AN related thoughts. *"acupuncture offered a soothing pause in a stressful period of life when they suffered from inner turmoil."*(8)

Lastly, participants spoke about the practical aspects of these interventions which contributed to their positive experiences. Some interventions were delivered on separate sections of the ward, providing a sense of freedom and separateness from being an inpatient. Additionally, participants reported on how the interventions were often delivered immediately after mealtimes, which was noted as a period of high anxiety, and therefore was considered as a good distraction technique to reduce distress levels.

"The whole interactive, practical side of doing things was really helpful. It's really boring when you're sitting in a group and there's just talking. But we actually played games...it meant that you were able to kind of completely immerse yourself in the group." (10)

# Negative Aspects

Participants also expressed that the competition existing between peers often played out in the group interventions, inhibiting participants from taking part completely. Furthermore, the interventions were sometimes viewed as challenging and demanding; this appeared to be the case for when participants were not familiar with the content being discussed. Participants also discussed that interventions were not personalised and that it was sometimes difficult to see how the content/tasks were relevant to their AN, for example cognitive inhibition tasks. Lastly, some participants felt that they were unable to use or apply the skills taught in these sessions in the longterm and therefore they had time-limited effects.

*"being forced to move slowly or to relax can be experienced as gruelling" (6)* 

"manualized nature of the intervention...[was] too structured...it was not personal enough." (12)

#### Suggested Improvements

In all studies focused on interventions, participants expressed the desire for more frequent and longer sessions. Participants also would have liked support with applying the skills to real-life situations and strategies to be able to implement what was learnt in groups.

"I think you should carry on doing it regularly with everyone not just four weeks for it have more of an impact." (5)

#### Discussion

This review synthesised 26 papers containing qualitative data on individuals' experiences of inpatient treatment for AN. It aimed to develop a greater understanding of the factors which impacted how inpatient care was perceived. Overall, the synthesis yielded seven core themes; all of which were considered as crucial when understanding the experience of inpatient treatment through a patient's perspective.

The findings highlighted how the unique inpatient setting was often experienced as hostile, isolating and restrictive, with particular power dynamics unfolding and patients feeling confined and punished. On the other hand, this environment and its structure also led to increased feelings of containment and safety and fostered a sense of belonging. This conflicting experience of inpatient wards may be linked to the role of ambivalence in AN; mainly due to the egosyntonic nature of the disorder (Gregertsen et al., 2017). Research has documented that individuals value their AN, consider it as a protector or friend and do not perceive the symptoms as problematic (Serpell et al., 1999). Therefore, those with AN often feel ambivalent about whether they wish to maintain or recover from their ED (Williams & Read, 2010). It is plausible that this ambivalence is extended to inpatient settings and that how a setting is perceived is dependent on the way in which ambivalence is experienced.

In addition to the above, the conflicting experience of inpatient settings is also consistent with the research which suggests that AN symptomatology is associated with an insecure attachment style (Ward et al., 2000; Zachrisson & Skårderud, 2010). An insecure attachment style is often associated with contradictions and ambivalence in relationships, leading to difficulties in establishing and maintaining relationships. The findings from this study contribute to the evidence and demonstrate that such patterns may also manifest in an individual's relationship to an inpatient setting, further influencing the way in which treatment is perceived and experienced.

The findings from this study also support the research which explains that AN is a means of asserting control (Lawrence, 1979; Surgenor et al., 2003) and that inpatient treatment can be experienced as a threat to an individual's sense of control. On the other hand, the findings are also consistent with the research suggesting that for some, placing a level of control and responsibility about treatment decisions onto an external source (i.e. inpatient settings) provides relief (Tiller et al., 1993). Notably, this review found that there appeared to be a shift in control as patients gradually regained control and responsibility as treatment progressed. There is a need for further qualitative research on whether there is an 'optimal' time period to enable patients to regain control and responsibility.

Moreover, the role of the therapeutic relationship and its importance in facilitating recovery on inpatient wards has been widely documented in the literature (Gilbert et al., 2008; Moreno-Poyato; 2016) and the findings from this study further emphasise its value. It is concerning that in some studies, participants described poor

therapeutic relationships with inpatient staff. This review supports the research which conveys that employing a non-judgmental approach, unconditional positive regard and actively listening to individuals are all factors that contribute to a positive therapeutic alliance (Lambert & Barley, 2001).

Furthermore, the findings portrayed the severity of AN symptoms and how both patients and clinicians held onto a strong anorexic identity. Participants felt that clinicians made sense of their AN through a medicalised discourse, which took precedence over all other factors, therefore leading participants to be viewed by their AN and its symptoms. This phenomenon has been previously described as a barrier to treatment and change (Rich; 2006). In the studies reviewed, there was a desire for patients to be viewed as separate to their AN symptoms and for interventions to be tailored to individual needs. Treatment was often experienced to be solely focused on physical health components, with a lack of psychological or emotional support. This suggests that AN is a complex phenomenon that involves more than weight gain and provides support for the biopsychosocial model for AN (Smolack & Levine, 2015). Ultimately this finding further highlights a fundamental existing dilemma regarding the aims for inpatient treatment (e.g. physical vs psychological) and how this has not yet been established in the field (Vandereycken, 2013). It is plausible that clinicians perceive the aim of inpatient treatment to be associated with weight restoration so that any psychological work can be carried out after discharge in outpatient sessions. However, patients may not see this as a helpful division.

Lastly, the findings provide an insight into the wide range of interventions that were offered in inpatient settings, such as Cognitive Behavioural Therapy groups, well-being workshops and alternative and contemporary interventions. These interventions gave patients a distraction and also provided enjoyment after increased

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interactions with peers. On the other hand, their long-term effectiveness and the applicability of skills were questioned. The findings also provided suggestions as to how interventions could be improved, primarily based on the desire to have more frequent and regular sessions.

## **Clinical Implications**

The findings from this review can be used to improve the quality of care delivered on inpatient settings for individuals diagnosed with AN. The following recommendations have been developed after gaining a deeper understanding of individual experiences of inpatient treatment, based on the current qualitative evidence. These suggestions can therefore be implemented by services with the broader aim to enhance inpatient treatment for AN, creating the potential to improve clinical outcomes for this population group.

The findings from this review highlight the importance of the relationships formed and maintained in inpatient settings, both with clinicians and other patients. Firstly, clinicians can take an active role to support patients to adjust to life on inpatient wards. It is suggested that a safe space is created early on in one's admission, perhaps in key working, where the uniqueness of the setting, perceived lack of normality and rules of the unit can be openly addressed. Secondly, services can use avenues such as staff support groups or reflective practice sessions, whereby complexities in the therapeutic alliance can be discussed and thought through. Such reflective practice sessions may also be helpful to identify and understand the conflicting and ambivalent views held by patients regarding the desire to be cared for but also feeling punished and threatened when this care is provided. Lastly, services can be guided by attachment-based models when thinking about promoting positive interactions in inpatient settings; primarily by providing patients with a secure base, especially as the inpatient environment can be experienced as uncontaining and removed from reality. It is also worthwhile to consider reducing the sense of dependency on units by empowering patients to have a more active role in their recovery, with the overall aim of promoting self-autonomy.

The findings from this review also suggest that the relationships formed with peers in inpatient settings should be closely monitored and assessed regarding whether they are helping or hindering patients' recovery. This appears to be especially pertinent on specialised ED wards. Whilst competition on ED units and influences from peers are inevitable, services can employ a proactive approach to detect when some relationships become particularly unhelpful for patients. Difficulties with peer dynamics can be addressed within group settings, for example in community meetings. Therapeutic community meetings (Kennard & Lees, 2001) have the aim of improving the social climate on inpatient wards and provide the opportunity for staff and patients to jointly work together on various tasks and to discuss group dynamics. Therefore, through the use of such settings, clinicians may want to promote the peer group as a source of support and to discuss difficult group dynamics and processes.

The findings also convey the importance of control in AN and suggest the need for all clinicians to undergo staff-training on how control and a strong anorexic identity may link to an individual's presenting difficulties. Professionals can consider how they might want to create a balance between the removal of control in the initial stages of treatment and enabling patients to regain responsibility as treatment progresses. This will likely vary based on individual needs and the findings have emphasised how this should be considered in a manner that is not threatening or disempowering but rather promotes autonomy.

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Finally, the findings highlight the need to follow integrative models of care as it appears that individuals with AN may relate best to a biopsychosocial approach when understanding their difficulties. A collaborative approach, which addresses the psychological and social elements of AN, contrary to the dominant medical view of AN, may also benefit the therapeutic relationship. Services and commissioners may also consider investing in providing regular and frequent interventions that address the emotional and psychological aspects of AN.

#### **Limitations & Suggestions**

Firstly, one must consider the shortcomings of a thematic synthesis. This method of analysis relies on translating, combining and condensing concepts across studies into a theme. Given that the studies included in this review varied significantly concerning their topic of focus, it is plausible that the findings only present the dominant and/or extreme views expressed by participants. Additionally, some themes may not be relevant to all samples included in this review, for example, the difference between voluntary and involuntary patients, adults and adolescents, or those who have been admitted for the first time in comparison to those who have had multiple admissions. Additionally, whilst efforts were made to enhance the credibility of results (e.g. cross coding and reflective discussions), it is important to note that the data analysis process is highly dependent on the judgement and insights of the researchers.

Secondly, the studies included in this review did not report on or differentiate between a patient's stage in recovery from AN. The samples likely included patients in different phases of their recovery, including being in the precontemplation, preparation and maintenance phases when thinking about change. It can be assumed that this would have an impact on one's perceptions, experiences and ambivalence towards inpatient treatment; however, this was not accounted or controlled for by any of the studies included. There is a need for further research to explore how an individual's motivation level influences perceptions of inpatient treatment.

Thirdly, whilst the clinical implications in this study can be of value to services, they are solely based on the views and experiences described in the articles included in this review. It can be assumed that there are other experiences of inpatient treatment for AN which have been missed or overlooked. Therefore, the recommendations developed from this review should be considered as tentative.

Lastly, there are significant limitations regarding the study samples. Samples were predominantly White Female Western women and therefore this review primarily investigates experiences of a subset of those receiving inpatient treatment for AN. This means that other factors, such as gender, culture, religion, socioeconomic status or racism, which may impact one's experience of inpatient experience, have unfortunately not been represented in this review.

## Conclusions

This qualitative review provides a thorough account of patient experiences of inpatient treatment. It demonstrates how rich and meaningful data can be gained by listening to patients' stories and highlights the value of using this information to understand and enhance the treatments that can be offered for this population group.

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Part 2: Empirical Paper

The Use of Community Treatment Orders in Eating Disorder Services: Clinician and Patient Perspectives

#### Abstract

**Background:** The Mental Health Act (MHA), (U.K.) was amended in 2007 to include Community Treatment Orders (CTOs). CTOs aim to provide supervised mental health treatment in the community as opposed to being detained in hospital. **Aims:** This study aims to explore the use, advantages and disadvantages of CTOs in Eating Disorder (ED) services.

**Method:** Twelve semi-structured interviews with clinicians and patients were conducted about their experiences of CTOs. Their responses were analysed using a Thematic Analysis.

**Results:** Ten key themes were identified. CTOs were described as safety nets and had the potential to be used therapeutically with the 'right patient'. Advantages included supporting patients to remain in the community, providing patients with the permission to eat and being of value to family members. Disadvantages included patients feeling powerless, CTOs reinforcing dependency, increased workloads for professionals and clinicians being able to achieve similar outcomes without using the MHA. Lastly, clinicians and patients described difficulties and dilemmas associated with the weight condition on CTOs and the recall component.

**Conclusions:** This study emphasises the importance of multidisciplinary team working, clinician training and patient selection when using CTOs in ED services. In particular, the clinical implications highlight how patient motivation and the interaction between ED symptomatology and CTO mechanisms need to be carefully considered. Further research is required on the impact of CTOs on the therapeutic relationship and the use of CTOs in supported accommodation settings.

#### Introduction

#### **Community Treatment Orders**

Community Treatment Orders (CTOs) exist in mental health legislation in more than 75 jurisdictions worldwide, most notably in North America, Australasia and Europe (Rugkåsa, 2016). Whilst all jurisdictions differ, CTOs typically involve a framework that mandates enforceable treatment in a community setting. Three types of CTOs have been identified in the literature, including 1) preventative orders (aiming to prevent deterioration in one's mental state), 2) least restrictive orders (conceptualised as a means of avoiding hospitalisation and receiving community treatment), and 3) orders that combine preventative and restrictive features (Churchill et al., 2007).

#### **CTOs in England & Wales**

CTOs were introduced in England and Wales under the amended Mental Health Act 2007 (MHA) (Mental Health Act, 2007). They are proposed as leastrestrictive alternatives to hospital provision, in conjunction with preventing patients with severe and enduring mental health difficulties from deteriorating in the community. CTOs specifically intend to prevent repeated relapses leading to hospital readmissions, thus targeting 'revolving door patients.' Therefore, the use of CTOs includes both preventative and restrictive features with the overall aim of supporting patients to maintain stability in the community, promoting medication adherence and simultaneously minimising the risk of harm to self and/or others. Information on the components and mechanisms of CTOs in England and Wales is presented in Figure 1.

# **AUTHORISATION**

- Can only be authorised following a period of involuntary hospital treatment, where individuals are detained under a section of the MHA.
- Authorised by the Responsible Clinician (RC) and an Approved Mental Health Professional (AMPH).
- The RC is usually the psychiatrist in charge of a patient's treatment whilst under the MHA.

# **CONDITIONS**

- Two mandatory conditions form part of a CTO.
- Patients must make themselves available 1) to be assessed by a psychiatrist regarding treatment without consent, and 2) for an assessment concerning the renewal of a CTO.
- RC's and AMPH's may specify a range of discretionary conditions to which a patient agrees to adhere to.
- All discretionary conditions must ensure that individuals get access to medical treatment, prevent risk to their health and safety and/or protect other people.
- Discretionary conditions are often based on clinician knowledge about the patient and their diagnoses and subsequently, these conditions can vary given individual circumstances, service structures and community resources.
- Common examples include adherence to medication, attending appointments, maintaining frequent contact with health care professionals (i.e. GPs, liaison nurses, care-coordinators) and living in supported accommodation.
- According to the Mental Health Code of Practice, it is suggested that patients and families should be consulted about conditions and that they should be made in agreement, where possible (Department of Health, 2008).

# RECALL

- The RC has the authority to recall patients to hospital if they fail to comply with the mandatory conditions.
- Patients can be recalled to hospital if they do not adhere to the discretionary conditions and as a result show early signs of a relapse or pose an increased risk of harm to themselves/other people.
- The recall period lasts for up to 72 hours; after an assessment, it is decided whether a patient returns to the community under the CTO, remains detained in hospital under the MHA for involuntary treatment or is discharged from the MHA all together.

# Figure 1

The CTO Regime for England & Wales

#### **The Evidence Base**

The evidence on the effectiveness of CTOs is scarce, with findings from systematic reviews demonstrating that CTOs are not effective in reducing admission rates, length of admissions or contact with services (Churchill et al., 2007; Kisely et al., 2017; Maughan et al., 2014; Rugkåsa, 2016). Additionally, these reviews have not found any evidence to suggest that CTOs improve medication adherence, social functioning or quality of life.

It has been documented that the evidence is consistent despite evaluating the use of CTOs in different jurisdictions, all of which have a variation in legislation and mental health service provision (Maughan et al., 2014). However, methodological limitations must be taken into account, e.g. small sample sizes, difficulties with randomisation and high attrition rates. Similarly, the research does not account for variances in different mental health diagnoses, age and race.

Qualitative studies have been conducted to explore mental health clinicians' and patients' experiences of CTOs.

#### **Clinician Perspectives**

Clinicians have described various advantages of using CTOs in mental health treatment, such as enabling early identification of relapses, increasing medication compliance, decreasing readmissions, promoting engagement with services, providing structure to a patient's life and reducing family anxiety (Atkinson et al., 2002; Canvin et al., 2014; Coyle et al., 2013; DeRidder et al., 2016; Romans et al., 2004; Stroud et al., 2015).

Clinicians acknowledged how processes associated with recall could be perceived as coercive by patients. However, they believed that such mechanisms allowed CTOs to be effective to reduce readmissions to hospital (Canvin et al., 2014). Additionally, clinicians believed that the long-term benefits outweighed the potential harm caused by coercion in the short-term (Mullen et al., 2006; Romans et al., 2004).

Subsequently, this meant that clinicians held mixed views on the impact of CTOs on therapeutic relationships, with some experiencing CTOs to be both helpful and a hindrance (Atkinson et al., 2002; Coyle et al., 2013; DeRidder, et al., 2016; Gibbs et al., 2006).

CTOs have been described as safety nets, which provide clinicians with a framework to work within (Coyle et al., 2013; Lawn et al., 2016; Mullen et al., 2016; O'Reilly et al., 2006; Stroud et al., 2015). However, some clinicians reported a lack of clarity on some processes (i.e. initiating conditions, recall), leading to uncertainties about using CTOs (Canvin et al., 2014).

Furthermore, clinicians have emphasised the importance of Multidisciplinary Team (MDT) working and interagency liaison when using CTOs (Coyle et al., 2013). However, barriers have also been identified, such as the pressures to find hospital beds after a recall (DeRidder et al., 2016) and increased paperwork (O'Reilly et al., 2006). Clinicians have also described the use of CTOs to be time-consuming, especially when liaising with community teams (Canvin et al., 2014; Mullen et al., 2006).

Additionally, clinicians have identified how CTOs signal messages to patients, including the severity of one's condition as well as a message of being looked after (DeRidder et al., 2016). In contrast, some clinicians have also reported that CTOs enhanced dependency on services and patient beliefs about not being able to take responsibility for their care (Mullen et al., 2006).

#### **Patient Perspectives**

Research shows that patients hold contradictory and ambivalent views about being on CTOs (Canvin et al., 2014; Corring et al., 2017; Gibbs, 2010). Associated advantages include an increased sense of containment, structure and stability in the community (Gibbs, 2010; O'Reily et al., 2006). CTOs have also often been described as safety nets by patients, which allow for services to detect and prevent relapses (Corring et al., 2017; Gibbs et al., 2006; Lawn et al., 2016; Stuen et al., 2015).

Additionally, patients have attributed clinical improvements to being under a CTO, citing the benefits of improved mental state and psychosocial functioning (Dawson & Romans, 2001; O'Reilly et al., 2006). Patients have also identified that CTOs increased access to services, improved quality of life and provided greater freedom as compared to being in hospital (Gibbs et al., 2006; Light et al., 2014; Rawala & Gupta, 2018; Stroud et al., 2015).

On the other hand, the literature from patient perspectives has provided insights into the disadvantages of CTOs; these are often in conjunction with the benefits described above. A common theme is associated with CTOs being considered as coercive, based on threat, pressure and persuasion (Corring et al., 2017; Gibbs et al., 2006; Gibbs, 2010; Lawn et al., 2016; Newton-Howes & Banks, 2013, Stuen et al., 2015). This is especially pertinent to the impending threat of being recalled to hospital and feeling controlled in the community (Light et al., 2014). Nevertheless, patients recognised that the threat of recall prevented further admissions to hospital (Stuen et al., 2015).

Similarly, patients have reported that CTOs impose restrictions on freedom and can be stigmatising. Whilst close monitoring was often perceived as an advantage, patients also expressed that it interfered with living life freely in the community (Atkinson et al., 2002; Light et al., 2014; Rawala & Gupta, 2018; Stuen et al., 2015).

#### Limitations of the Current Evidence Base

The current evidence base, both quantitative and qualitative, is largely based on the use of CTOs with patients diagnosed with schizophrenia, psychotic, affective and personality disorders (Churchill et al., 2007). Additionally, research samples include an overrepresentation of black male subjects diagnosed with psychotic illnesses (Rawala & Gupta, 2018). This poses difficulties when generalising findings to the use of CTOs for other mental health conditions.

Although CTOs are standardised and their mechanisms (e.g. authorisation, conditions and recall) remain unchanged regardless of mental health diagnoses, it can be argued that their aims and usage may differ across mental health conditions. For example, for patients with Eating Disorders (EDs), the aims of CTOs may target weight gain/weight maintenance and subsequently discretionary conditions may include a target weight. This may not be relevant for those with psychotic illnesses and therefore the aims and conditions will differ significantly. Unfortunately, these differences are not controlled for in the research nor captured in patient or clinician views.

#### **CTOs and Eating Disorders**

In England and Wales, CTOs are being used gradually yet increasingly with patients diagnosed with EDs (Vize, 2012); anecdotal data suggests that approximately 17 patients with EDs in London were under CTOs in 2017. However, to the knowledge of the researcher, there is currently a lack of evidence that evaluates the use of CTOs in the treatment of EDs. Given how CTOs may be used slightly differently with this population, it is especially important to understand and investigate their use within an ED context.

Therefore, the primary objective of this study is to explore, describe and ultimately gain an in-depth understanding of the use and impact of CTOs in ED services. To develop this understanding, this study sought to qualitatively make sense of both clinician and patient experiences, allowing for the reflections and comparisons to be made.

This study also aimed to address the following secondary research questions:

- What are the perceived advantages and disadvantages of CTOs in the treatment of ED?
- 2) How are CTOs used differently with an ED population?
- 3) How can CTOs be used effectively in ED services?

# Method

#### Design

A qualitative approach was employed to address the primary objective of this study: to explore, describe and ultimately gain an in-depth understanding of the use and impact of CTOs in ED services. The rationale to employ a qualitative design was driven by its ability to understand lived experiences, subsequently leading to deeper understandings about a phenomenon, its characteristics and processes (Marshall & Rossman, 2006).

This study was designed using an overarching phenomenological framework, with a focus on participant clinician and patient experiences of CTOs and the meanings assigned to such experiences. It was jointly designed and conducted with another trainee clinical psychologist (see Appendix A for an outline of the contributions to the joint study).

## Setting

Participants were recruited from four NHS trusts in the U.K. These trusts had adult ED services including inpatient, outpatient and day-patient settings. The final sample comprised of twelve participants; six mental health clinicians and six patients diagnosed with an ED.

# Recruitment

A purposive and volunteer sampling strategy was employed to identify participants who had experiences of CTOs in ED settings. Clinicians were provided with information sheets about the study and were asked if they might wish to participate.

Clinicians were also requested to identify and contact patients under their service who were either 1) on a CTO at the time, or 2) had an experience of being under a CTO previously. Clinicians were provided with a leaflet to give to patients (see Appendix B) and sought permission for the researchers to contact patients if they expressed interest in participating.

All participants were informed that taking part would involve undergoing an interview where they would be invited to share their experiences of CTOs. They were notified that the researchers were clinical psychologists in training and that the study formed part of their doctoral thesis projects. It was emphasised that the researchers were interested in gaining a deeper understanding of their experiences as opposed to leaning towards one view in particular.

In addition, patient-participants were informed that it was a paid study to compensate and thank them for their time. It was emphasised that participating in the study would not have any impact on treatment received and that the researchers were not associated with their ED service in any way.

#### **Participants**

# Clinicians

Participants were eligible to take part if they had an experience of working with at least one patient who had been on a CTO whilst receiving treatment for an ED. Ten mental health clinicians were contacted about the study. Six clinicians agreed to take part and were recruited from all four NHS trusts registered for the study. Clinicians were from a range of backgrounds, including psychiatry (n=4), nursing (n=1) and social care (n=1). Clinicians were either working at inpatient settings (n=2), outpatient settings (n=3) or day-patient settings (n=1).

## Patients

Participants were eligible to take part if they were receiving/had received treatment for an ED with the use of a CTO. Fourteen patients were approached about the study; six agreed to take part. Common reasons for declining to participate were not feeling comfortable to discuss past experiences or finding the topic distressing. Participants were recruited from three NHS trusts registered for the study. All participants were female and identified as White British (n=4), British Asian (n=1) or Black British (n=1). Their ages ranged from 22 - 59 years old (mean = 39 years). Table 1 provides further information on patient diagnoses.

## Table 1

Patient Diagnoses

Patient	Diagnoses
1	Anorexia Nervosa
2	Anorexia Nervosa, Autism Spectrum Disorder
3	Anorexia Nervosa, Autism Spectrum Disorder, Anxiety, Depression
4	Anorexia Nervosa, Obsessive Compulsive Disorder, Depression,
5	Anorexia Nervosa, Obsessive Compulsive Disorder
6	Anorexia Nervosa

#### **Ethical Considerations**

This study received ethical approval from the Riverside Research Ethics Committee, London, under the Health Research Authority (Ref: 19/LO/0806) (see Appendix C). The researcher also obtained a research passport to gain access to each ED service and all study tasks were conducted in agreement with service research policies.

All participants were provided with an information sheet before participation, which included the aims of the study, confidentiality procedures and methods of data protection (see Appendix D). Participants were informed of their right to withdraw at any time of the study. They were assured of their anonymity and that any identifiable information would be removed from transcripts. Participants were given the opportunity to ask any outstanding questions about the study before providing verbal or signed consent (see Appendix E).

## Procedure

All participants underwent a semi-structured interview lasting between 52 and 112 minutes. The interviews were conducted by the researchers of the study, either via telephone or at their local ED service.

A semi-structured interview was selected due to its flexibility and ability to allow for a range of ideas to emerge naturally. In line with a phenomenological framework, the semi-structured interview allowed participants to determine the direction of the interview, according to individual experiences.

The interview schedule was co-created with an Expert by Experience and designed for this study (see Appendix F). It consisted of open-ended questions and prompts which covered a broad range of topics informed by the existing literature and is presented in Figure 2. Patient and clinician versions were similar; the primary difference was how the questions were worded.

All interviews were audiotaped and transcribed verbatim through Trint, an AI online transcription software. This was followed by the researchers carefully checking and correcting each transcript prior to the analysis.

- 1) Individual understanding of CTOs
- 2) Views on the conditions
- 3) Views and/or experience of recall
- 4) Impact on ED symptoms and treatment
- 5) Impact on quality of life and relationship
- 6) Perceived advantages and disadvantages
- 7) Perspectives on autonomy on CTOs.

## Figure 2

#### Topics Covered in the Interview Schedule

#### **Data Analysis**

# Rationale

A thematic analysis, as informed by Braun and Clarke (2006), was performed on the transcripts. This method was chosen given its theoretical freedom and flexibility to systematically analyse data both inductively (allowing for themes to emerge from the data) and deductively (driven by the study's research objectives) (Terry et al., 2017).

Additionally, the decision to use a thematic analysis was further influenced by its ability to focus on themes across data sets (Braun & Clarke, 2006). This enabled the researcher to make sense of collective experiences for each participant group, as well as extrapolating similarities and differences between clinician and patient accounts.

Lastly, a thematic analysis was considered as more suitable to alternate phenomenological methods, e.g. Interpretative Phenomenological Analysis. This was due to the study's aims to develop an understanding of the use and impact of CTOs in the treatment of EDs, as opposed to identifying the personal and idiosyncratic experiences that individuals had encountered with CTOs (Larkin et al., 2006).

Nonetheless, a phenomenological orientation was still held by the researcher during the data analysis process. This was deemed essential, as the subjective accounts of using or being placed under a CTO, and the meanings assigned to these experiences were then interpreted to address the broader question on the use and impact of CTOs in ED services.

#### **Description of Analysis**

The analysis consisted of four main steps: familiarisation, initial coding, generating themes and reviewing themes. These steps were performed separately on clinician and patient transcripts, as informed by Lindsey (2019).

Firstly, the researcher re-read the dataset to become immersed in the content and to search for initial patterns. Secondly, the researcher manually assigned codes to the dataset, at semantic (based on explicit content) and latent (based on interpretations and assumptions) levels. Thirdly, codes were examined to identify significant patterns of meanings across the dataset, to initial themes. Lastly, the initial themes were reviewed to see whether they accurately represented the dataset as a whole. This process involved combining themes similar in nature, discarding themes that did not appear relevant and cross-checking themes with transcripts. Final themes were named, and visually represented in a theme map. This process of the analysis is presented in Appendices G, H and I.

# Credibility

Measures to enhance the credibility of analysis were employed as described by Elliott et al. (1999). Firstly, triangulation was perused by understanding the research question from both clinician and patient perspectives. Secondly, a quarter of the transcripts were co-coded by the joint researcher of the study and subsequently, codes were discussed and amended after discrepancies were reflected upon. Thirdly, discussions were held with the researcher's supervisor and feedback was incorporated into the data analysis process. This led to the development of the final theme maps to ensure that the analysis was grounded in the data. Lastly, the researcher endeavoured to maintain a stance of reflexivity at all stages by reflecting on her position as a researcher and psychology trainee (Jootun et al., 2009). Additionally, discussions after each interview were maintained to attempt to minimise any potential effects of the researcher's experiences and beliefs on the findings of this study.

### Results

# **Information on CTOs**

Information relevant to CTOs was extracted from all transcripts. Table 2 displays the types of CTO conditions that clinicians described using across patients. Table 3 provides information related to CTO status, renewal, recall and types of conditions for each patient.

# Table 2

		Types of Conditions											
		Weight Maintenance (Stay within range/ cannot go below a weight)	Physical Monitoring (Weight & bloods)	Engagement: With Care Plan	Engagement: Care-coordinator	Engagement: Therapy	Medication Adherence	Taking Supplements	Laxative Screenings	Frequent ECG	Have 2 Meals on Ward per week	Present at $A\&E$ when required	Live in Supported Accommodation
	1	•	٠	•		•		•				•	
	2	•	•	•	•	•		•			•		
cian	3	•	•	•									
Clinician	4	•	•	•		•	•		•				•
	5	•	٠	•	•	•							
	6	•	٠	•			•			•			

Types of Conditions Used Across a Range of Patients, as described by Clinicians

# Table 3

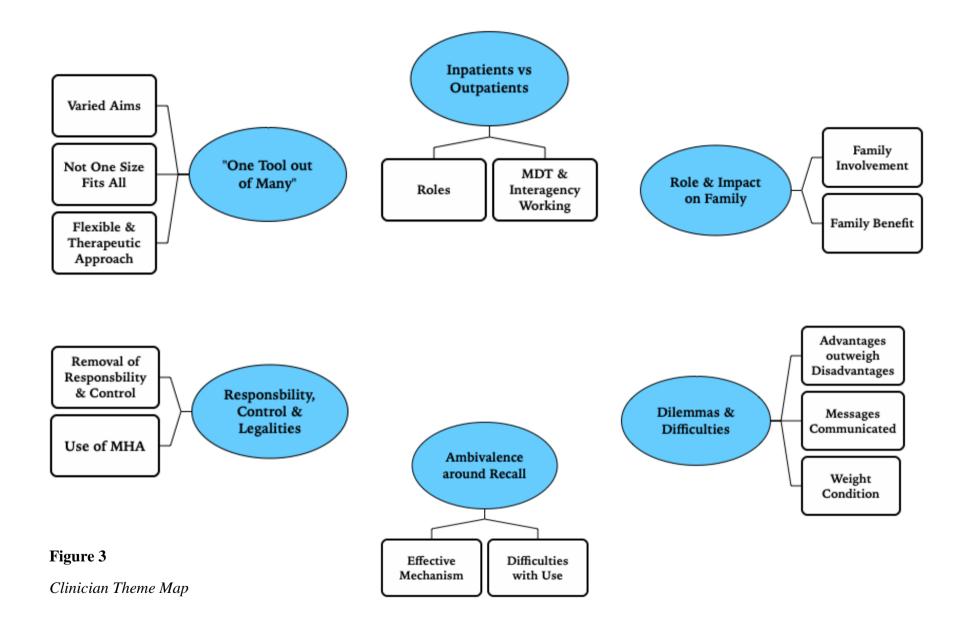
Information on Status, Renewal, Recall and Types of Conditions as described by

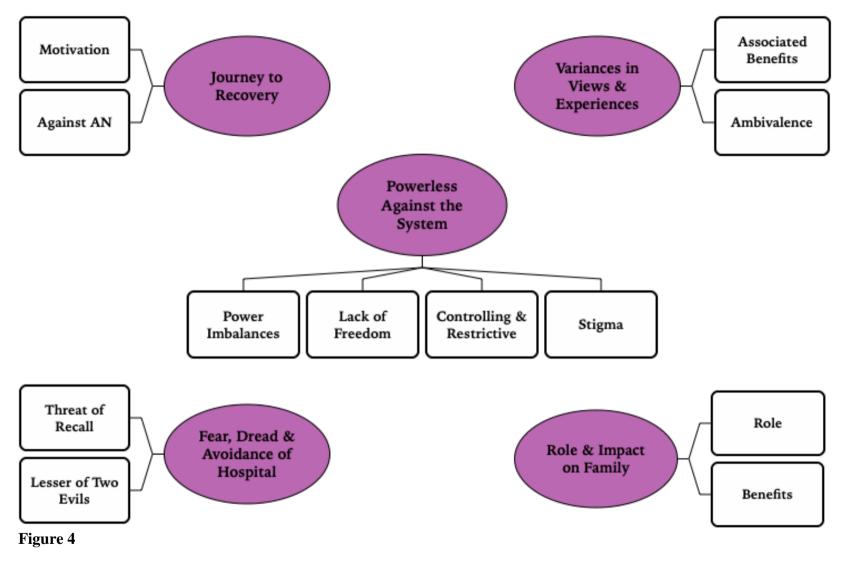
# Patients

Patient	Status	Renewed	Recalled	Types of Conditions on CTOs
1	Current	Y	N	Stay above a trigger weight Meet with consultant once every three months Meet with liaison nurse Weighed and bloods done at GP Surger Meet with care-coordinator once a month
				Take medication
				Have three supplement drinks per day
2	Current	Y	Y	Stay above a BMI of 14
				Stick to a weight band
				Meet with team
				Meet with care coordinator
				Maintain medical stability
3	Current	Ν	Ν	Stay above a BMI of 15
				Comply with supported accommodation
				Comply with meal plan
5	Current Discharged	Y Y Y	Y	Stay above a BMI of 13 Maintain weight above a minimum threshold (only allowed to drop for two weeks) Maintain physical stability Reside in care home Remain compliant with treatment package at care home Attend appointments with responsible clinician Remain compliant with medication Attend outpatient service
				Get weighed weekly Attend therapy groups Not allowed to exercise
6	Current	Y	Y	Keep weight above 52kg/BMI of 18 Keep exercise to 20 minutes per day Take medication Attending appointments Regular blood tests

# **Theme Maps**

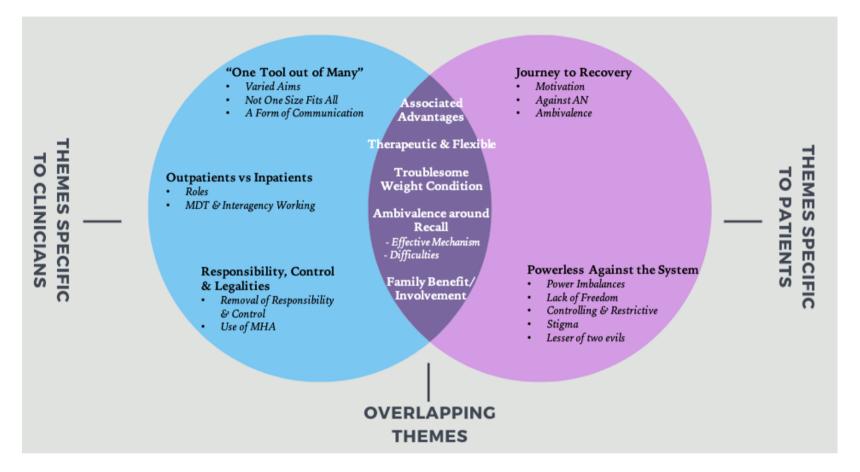
The thematic analysis revealed several themes and subthemes relevant to each participant group, as presented in Figures 3 and 4.





Patient Theme Map

These themes were further condensed and allocated to one of three categories: 1) Themes Specific to Clinicians 2) Themes Specific to Patients and 3) Overlapping Themes. A visual representation of the themes and subthemes in each category is presented in Figure 5; the prevalence of subthemes for each participant is shown in Table 4.



# Figure 5

A Visual Representation of Categories; Highlighting Themes and Subthemes

# Table 4

# Subtheme Occurrence for Each Participant

			Clinicians							Patients					
			1	2	3	4	5	6	1	2	3	4	5	6	
Theme Subthemes						<u> </u>	<u> </u>		<u> </u>						
6	One Tool	Varied Aims	•	•	•	•	•	•							
cian		Not One Size Fits	•	•	•	•	•	•							
lini		All A Form of	-												
to C		Communication		•	•	•	•	•							
Themes Specific to Clinicians	Outpatients vs Inpatients	Roles	•	•	•	•	•	•							
Spee	1	MDT &	•	•	•	•	•	•							
mes	Responsibility,	Interagency Removal													
The	Control & Legalities			•	•	•	•	•							
		Use of MHA	•	•		•	•	•							
	Journey to Recovery	Motivation							•		•	•	•	•	
S		Against AN							•	•	•	•	•	•	
Themes Specific to Patients		Ambivalence							•	•	•	•	•	•	
to P	Powerless to the	Power Imbalances	<u> </u>						•	•	•	•	•	•	
scific	System	Lack of Freedom							-	_	_		_	_	
s Spe									•	•		•	•	•	
emes		Controlling & Restrictive							•	•		•	•	•	
The		Stigma							•	•	•	•		•	
		Lesser of the Two Evils							•	•		•	•	•	
	Associated Advantages	-	•	•	•	•		•	•		•	•	•	•	
nes	Therapeutic &	-		•	•	•		•			•		•	•	
Then	Flexible Weight Condition	tion -													
Overlapping Theme		Effective Mechanism	•	•		•	•	•	•	•		•	•	•	
	Ambivalence around Recall		•	•	•	•	•	•	•			•	•	•	
		Difficulties				•	•	•	•	•	•	•	•	•	
	Family Benefit	-	•	•	•	•	•	•	•	•	•	•	•	•	

The following section describes the subthemes illustrated with quotes. Clinician quotes are denoted by C (e.g. Clinician 1 = C1) and patients by P (e.g. Patient 1 = P1).

#### **Themes Specific to Clinicians**

#### "One Tool out of Many"

**Varied Aims.** Clinicians used CTOs to "tolerate and manage risks" (C6) and support patients as they transitioned from inpatient to outpatient services. Clinicians also reported using CTOs as safety nets, to closely monitor patients and ensure that mechanisms were in place should they relapse. Some clinicians reported that CTOs were often used with the intent to "contain professional and family anxiety" (C5). Other aims included using CTOs to facilitate physical health treatment, avoid initiating new MHA assessments and to try a treatment option that had not yet been considered.

**Not one size fits all.** CTOs were used for high-risk patients with a history of repeated admissions. Nonetheless, clinicians reported that CTOs were inappropriate for all patients displaying such characteristics.

Clinicians believed that CTOs were particularly helpful for those who respected rules, had a diagnosis of Autism and were motivated to stay out of hospital. CTOs were not considered suitable for patients who did not respond to informal treatment or wanted to remain in control of their ED. Furthermore, clinicians described experiences of CTOs clashing with patients presenting with Borderline Personality Disorder traits, with such patients "*rebelling against conditions*" (*C4*).

Clinicians identified that positive outcomes were not achieved for all patients under CTOs, as some patients deteriorated further or did not make significant changes. Some clinicians felt that CTOs reinforced unhelpful behaviour patterns and created a "*push and pull dynamic*" (*C2*), where patients fought against the conditions set. Ultimately, this led to clinicians emphasising the importance of patient selection and finding a "*fit between the CTO, the patient and the way in which their ED expresses itself*" (C6).

**A Form of Communication.** CTOs were a way to demonstrate that patients were being held in mind:

"it's something that says look, we're not abandoning you by discharging you...if you need us you can always come back... for them its reassurance, it's recognising that we are here to care for them." (C3)

This meant that upon discharge, CTOs unintentionally signalled unhelpful messages:

"What did that mean for her...We don't care for her anymore, and she was really quite upset and angry with me." (C5)

CTOs also conveyed the severity of EDs to patients but also had the potential to be perceived as *"badge of honours" (C6)* which patients could hold onto, subsequently validating and strengthening their EDs.

# **Outpatients verses Inpatients**

**Roles.** Clinicians identified that their involvement in CTOs was dependent on their service setting. Inpatient clinicians spoke about "*running the thinking behind*" (*C2*) and initiating CTOs, whereas outpatient clinicians described "*taking over*" (*C1*) and managing CTOs. Clinicians held mixed opinions as to whether this divide was helpful; it created a "good vs bad cop dynamic" (*C6*) to motivate patients to stay out of hospital but also increased opportunities for splitting between teams. Additionally, it led to a lack of continuity in care:

"The difficulty is I loose touch with patients... I only see them when it's not worked and they come in...maybe you could consider no news as good news." (C4)

Despite having different responsibilities, all clinicians were required to complete paperwork. This was described as a "*nightmare*" (*C1*) and clinicians shared the experience of finding the forms non-user friendly and time-consuming.

**MDT & Interagency Working.** All clinicians described experiences of working with other teams, mainly at the stage of initiating CTOs:

"The other services set up the CTO but we had input and it was all agreed together...it made us all feel on the same page and that consistency really helped [patient]." (C3)

The majority experienced this communication as collaborative and emphasised

its value:

"It was between us, the inpatient team, the GP and nurses. We had to adopt an approach of positive and intense risk-taking. But in order to do that, we have to have everybody on board. Everyone has to understand why we're doing this. Everyone has to some extent agree and be happy with it." (C6)

However, clinicians encountered disagreements as outpatient consultants felt

that conditions were often unrealistic for patients to achieve in outpatient settings. A

difference in perspective was a barrier to interagency working:

"I really didn't want her to be on the CTO in the first place, but I had to because the inpatient consultant wanted it so much and she knew [patient] so much better at that point... I think inpatients consultants are very keen on CTOs, outpatient consultants aren't. That's sort of it in a nutshell." (C5)

Lastly, a few clinicians also spoke about disagreements with child and adolescent clinicians and felt that CTOs were used as safety nets for patients transitioning from child to adult mental health services.

#### **Responsibility, Control & Legalities**

**Removal of Responsibility and Control.** Clinicians described that CTOs removed the responsibility and control from patients and placed this onto services

instead. Some clinicians expressed how this removal was essential, given its link to the role of control in ED symptomatology. Clinicians felt that holding this control over decisions gave patients the "*permission to eat*" (*C6*).

However, clinicians had experiences of patients feeling angry at the loss of control and that it had the potential to reinforce dependency:

"It kept the responsibility on us.... which can be helpful initially. But as time goes on, it means we still hold the responsibility. So if she loses weight, we need to think about what we should do, instead of handing over the responsibility to [patient] to think about what she is going to do about it... rather than us rescuing her." (C3)

Overall, clinicians did not perceive the CTO as something which impacted the

therapeutic relationships with their patients. However, they acknowledged the need to

consider how patients responded to feeling controlled:

"I think that they probably would have used me as sort of a prison guard in some ways as they weren't doing anything voluntarily and I held all the control over their Anorexia." (C2)

Use of the MHA. Clinicians described the benefits of working under a legal

framework. CTOs were referenced as a third-party document with its mechanisms clearly outlined:

"People with eating disorders live in a delusional fantasy...they think they can loose weight and nothing will happen because they feel ok. But we can say you feel okay but you have signed this and we have this law which says that you need to come back into hospital." (C4)

However, some clinicians believed that similar results could be achieved without using a legal framework, e.g.co-creating contracts with patients with preset agreements. Outpatient clinicians also described how outpatient ways of working were very similar to the mechanisms of a CTO, though was more collaborative:

> "There's always the option of hospital in the back of your mind... We keep a threshold and make it clear to patients that if they drop below a weight then we'll arrange an admission. Essentially it's the same

thing as a CTO... but the CTO comes in between us and the model of care." (C5)

Lastly, some clinicians spoke briefly about the differences when using CTOs for EDs and other conditions, reflecting on how their use may be more appropriate to promote medication compliance. Clinicians also questioned patient motivations to consent to CTOs and attributed this to patients agreeing *with "everything and anything" (C6)* to get out of hospital. This led to some apprehension about using CTOs with EDs:

"I feel it would be more relevant and probably came from working with different client groups for where the risks escalate very quickly if something isn't there...we wouldn't let patients be on their own in the community at such a high risk anyway... Whether it fits with eating disorders... I don't know." (C3)

# **Themes Specific to Patients**

#### Journey to Recovery

**Motivation.** All patients described being at different stages of recovery; ranging from not perceiving their ED as problematic to actively working towards recovery.

Patients varied on the extent to which they perceived CTOs as part of their recovery journey. One patient felt they could manage "*independently*" (*P2*) and experienced a mismatch between their goals and those of the CTO. Similarly, another patient mentioned that the "*CTO kept [her] alive*" (*P1*) as opposed to being helpful towards recovery.

Alternatively, other patients felt that CTOs played an important part in their journey and helped envision a life out of hospital:

"I don't know why but having rules and strict regulations makes it better for me to cope with... it was needed for the next step in recovery." (P3) Patients also spoke about additional motivators, such as faith in religion, spending time with family and employment. Therefore, patients acknowledged that CTOs were often just one piece of a larger puzzle.

**Against AN.** To some, CTOs were conceptualised as an external force which allowed patients to go against their Anorexia Nervosa (AN), by reducing the temptation to engage in ED behaviours:

"A lot of the time you do need the rigidity and solid framework that says you can't go below this weight, because otherwise anorexia is always going to want you to be the lowest that you can be...There are times when I've come to get weighed and my weight's jumped up...all I want to do is just run, book myself into a hotel, not eat anything. But I know like because of the CTO...I can't." (P6)

To others, CTOs went against their ED in an unhelpful manner. Patients described that the conditions interfered with their hopes to loose weight and this triggered an internal battle between wishing to lose weight but being unable to.

Likewise, patients associated the lack of freedom with "the lack of freedom to loose weight." (C4). In such situations, patients were unable to see any associated benefits:

"Well it's gotten in the way of losing weight... I don't really see it as a good thing. I'm going against some of my natural things that I would do with my eating disorder, so that's what makes it more stressful... I would like to be a lot smaller and it just gives me so much stress because I am eating more." (P2)

**Ambivalence.** Patients described CTOs as "*conflicting but helpful*" (*P5*) and spoke about a range of ambivalent experiences at different stages of CTOs. Patients described an ongoing conflict between feeling unable to manage without CTOs but simultaneously desiring to be independent. Similarly, patients expressed their hopes

to not be under the MHA, but not feeling that this was feasible. For patients who were recalled, they described relief, fused with the fear of another hospital admission.

Patients reported that they dealt with this ambivalence by reminding themselves of the benefits:

"I can describe it like I'm constantly playing tug of war. One part of me that's pulling me to one side saying, what the bloody hell are you doing? Why are you doing what you're doing? And then obviously there's another side which is saying, you are doing the right thing, you're not going to be in hospital. You are going to be able to do things, like be a part of the family." (P1)

Patients also had mixed feelings when thinking about discharge or after being discharged from CTOs. Patients described feeling relieved, but simultaneously a sense of panic due to the loss of support. This contributed to a further paradox of patients feeling dependent on CTOs whilst trying to regain independence.

#### Powerless Against the System

**Power Imbalances.** All patients described experiences of clinicians holding some form of power on CTOs; however, this did not appear to have an impact on their relationships with services.

Patients described that CTOs were punitive and were often used as excuses by clinicians when they were forced or denied doing things. Specifically, one patient provided an example of CTOs being used *"unlawfully"*, with staff members in supported accommodation settings purposely restricting their freedom:

"I wasn't allowed to go out unless I was in a car, I wasn't allowed to go on a bus...And they kept saying, oh, it's because of your CTO, we're keeping you safe." (P4)

Additionally, patients described that clinicians had the power to recall on "anything and everything", even if patients were only "struggling a little bit" (P3).

Some felt that reasons for recall, such as disengagement, were not justified, especially if they were maintaining weight in the community.

A common experience was associated with undergoing the appeal process. Patients described a process of learned helplessness, whereby they chose not to appeal based on previous experiences. Specifically, patients perceived a lack of ED knowledge amongst appeal panels and felt that decisions were previously agreed by professionals and had little scope for change:

"It always went against me, so I thought, what is the point? Why am I going to put myself through that, when really they're going to listen more to the professionals". (P1)

Lack of Freedom. There was a variance in views regarding the amount of freedom patients perceived to have on CTOs. CTOs were described as police-like interventions where patients felt overly monitored:

"[I wasn't] able to go and do what I wanted to do. I feel like I had a tag on me all the time. Like they were watching me, like what time I came home... You know, like you have a tag and have to be home at a certain time." (P5)

Alternatively, others believed that the option of recall was the component on

the CTO which impacted their freedom:

"I don't think being on it completely takes away my freedom. But I suppose maybe in another breath it kind of does, because obviously, they can still recall me anytime and then my freedom would be taken away." (P1)

On the other hand, some patients perceived adhering to conditions as manageable, subsequently feeling that CTOs did not interfere with their freedom. The following metaphor was used to describe the experience of "*forced freedom*":

"It's kind of like a dog being on a lead. You know, one of those leads that you can change so that its very long, and I've been let out on the long lead, but I'm still on the lead. So obviously I get to do more and have a bit more of a time out of it but it's not ultimately free." (P4) Lastly, some patients acknowledged that the lack of freedom and close monitoring was necessary for recovery.

**Controlling and Restrictive.** The majority of patients described how they felt that the CTO was used in a prescriptive manner, which imposed control on various aspects of their lives:

"I think sometimes it freaks me out like that my body is under someone else's control... So that does freak me out sometimes because I feel a bit trapped." (P6)

Due to the demands placed on patients to adhere to conditions, some patients reported that they stopped seeing friends and were unable to manage any additional physical health conditions. Some patients also spoke about feeling restricted concerning what they could and could not do (e.g. travel to other countries and having gym memberships taken away).

**Stigma.** A common experience was associated with choosing to not openly discuss being under a CTO with friends or colleagues. Patients noted feelings of embarrassment and described the fear of being judged, for requiring extra support in the community or when police were involved at a recall. Additionally, some patients described being stigmatised due to being under the MHA:

"They think that people on CTOs lack capacity over more things than just eating. So they think that because you lack capacity in that area, you therefore lack capacity in all of your decisions and therefore you get treated like you're irrational." (P4)

Lesser of Two Evils. Patients frequently made comparisons between CTOs, involuntary and voluntary treatment options. The majority of patients admitted consenting to CTOs based on their aversion and dread of inpatient treatment, describing this as *"forced agreement"* (P2). Nonetheless, CTOs were considered as preferable to being sectioned in hospital:

"They can't technically stop me walking out the door. Section 3 they'll hold you on the floor to stop you getting out. Not going out for months and months and years and it's just horrific...On a Section 3 you just feel animal, you just get anything done to you. I mean the CTO is freedom compared to that." (P4)

However, the majority of patients also reflected on the difference in freedom between CTOs and standard outpatient treatment:

> "I know if I didn't go home one night, like they would have grounds to get someone out to come and look for me. Whereas if I was like a free person, they'd be like, well there's absolutely nothing we can do...She can do whatever she wants, she can go wherever she wants." (P6)

# **Overlapping Themes**

#### Associated Advantages

Clinicians and patients spoke about a range of benefits associated with CTOs. These included providing patients with a structure to adhere to, breaking previous cycles of multiple hospital admissions and being able to remain out of hospital. Other advantages included re-engagement with community activities and spending time with family. Clinicians and patients felt that CTOs reduced the length of any subsequent admissions; this was attributed to patients being monitored and brought back to hospital at a higher weight. In particular, patients also expressed a sense of gratefulness towards CTOs for keeping them alive.

Clinicians and patients hypothesised about the differences with or without the use of CTOs. There was a range of views represented from both participant groups; further emphasising the previous theme of 'not one size fits all'. Nonetheless, both provided accounts of the significant changes caused by CTOs:

"My life has massively improved... It's just completely turned around like psychologically...I've gone from being really absolutely not able to do anything to having a lot to do. I was basically dead before and the CTO has been part of the journey... it's been a safety net...you know however horrible and painful it's been, it wouldn't have happened without CTO." (P4)

Specifically, some patients in supported accommodation spoke about how the setting facilitated CTO processes and provided extra support to prevent hospital admissions:

"It's just the continued support you get every single day, 24/7 there is always support. If you wake up in the middle of the night, there's someone there that will just sit and talk to you. The CTO was helpful, but I do think the supported accommodation is more helpful than the CTO itself." (P3)

Additionally, whilst clinicians acknowledged that CTOs were perceived as threatening, restrictive and patronising by patients, the majority were under the impression that the advantages outweighed the disadvantages:

> "Ultimately you want the right thing for your patient...bottom line is that it's not punitive...it's necessary. And on balance, if it allows them to stay of out hospital and be functioning for longer, it's valuable." (C1)

Lastly, patients who had been on CTOs for long periods or had been discharged

from CTOs noted that it was easier to acknowledge the benefits retrospectively:

"But then looking back... now I understand why they put me on it. I'm glad that they did in a way put me on a CTO. I did hate it but then it was worth it." (P5)

#### Therapeutic & Flexible Approach

Clinicians and some patients shared accounts of how CTOs were explained positively to patients; emphasising its value to keep patients safe. Furthermore, they described situations where they were able to have open, honest and transparent conversations and highlighted the importance of collaboration.

Additionally, clinicians described employing a patient-led approach by including patient views on conditions where possible and purposely wording some conditions to be vague to account for change. Patients noted how this collaboration ensured that there was a level of agreement on conditions and that their voice was heard:

> "There actually weren't any disagreements, they basically just asked me what rules I wanted to put in place. And I kind of came up with them and said, "what do you think"? and they kind of agreed with it." (P3)

However, some clinicians and patients spoke about how conditions regarding medication adherence were added on CTOs, despite being irrelevant to patient presentations.

Clinicians also made efforts to avoid using CTOs as tick-box exercises, especially at recall. Clinicians and patients both described how pre-warnings were given before recall and reasons for deterioration were formulated. This led to patients being given the opportunity to "*turn things around*" (*C2*) before being recalled back to hospital. Clinicians acknowledged the consequences of using CTOs rigidly:

"It impacts working collaboratively and thinking about what's best for them...If it's essentially just a list of conditions that you have to meet, and you say "if you don't meet them, you're back in"... that limits the therapeutic benefits... it's the grey areas where the therapeutic process happens." (C3)

# "Troublesome" Weight Condition

Clinicians and patients encountered discrepancies when initiating the weight condition. This was usually due to the differences between the weight set on the condition and a patient's ideal weight:

> "It was probably the most troublesome condition... her argument was "I can only maintain a weight I'm comfortable at". We wanted it that she needed to maintain the weight she was discharged at. And she had absolutely no desire to reach that." (C1) "My ideal conditions could be no weight at all whatsoever." (P2)

Clinicians and patients described a process of negotiation to set a target weight

which was both achievable and safe:

"She'd put this condition which said I will gain 0.2 kg every two months and I said, I can't cope with it. I'm not ready for it. And she was like, well ideally that's what would happen. But we're just going to say that you need to maintain. 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 I see that in a way she did compromise." (P3)

However, this often meant that patients were somewhat forced to agree to the

weight condition:

"We try to involve patients in absolutely everything, but probably less so with the weight condition. My concerns would be that they would not agree with the conditions, and that's kinda the whole point of the CTO." (C2)

# Ambivalence around Recall

An Effective Mechanism. Clinicians and patients described that the threat of

recall helped patients remain out of hospital. For clinicians, recall was also perceived

as a way of managing risk:

"We were worried that she will imminently drop-down dead and we didn't have the luxury of time to do a new Mental Health Act assessment. So actually, recall made it so much easier...We were alerted to concerns by her mom and within 24 hours she's on the ward...it's like do not pass go, do not collect money and head straight in." (C6)

For patients, recall was a deterrent, given their fears of inpatient admissions

and dread associated with being sectioned at a hospital which they may have had

previous negative experiences:

"You'll go wherever they've got a bed and you're going to be under some absolutely egotistical, horrible consultant, who's just going to say "well, I'm going to push your weight up from the tube to this BMI and then I'm going to send you out again." That's a huge deterrent for me to not comply." (P4)

In addition, patients experienced increased anxiety by being under a "*looming threat*" (*P3*) and believed that recalls inevitably led to being detained under the MHA. However, this threat was also associated with police involvement and other losses, further motivating adherence to conditions:

> "I know if I'd carried on losing weight, I would have been recalled, I would have lost my job, I would have lost my therapy and probably lost my house." (P6)

**Difficulties.** Clinicians and patients experienced difficulties with recalls; clinicians and patients both reported attempts to avoid a recall. This was often done by encouraging or accepting a brief and voluntary hospital admission, as opposed to being formally reassessed under the MHA.

Clinicians and patients also spoke about the lack of inpatient beds after a recall,

resulting in admission delays and weakening the legal power of CTOs:

"Usually they can't even get beds... that's an issue. By the time an admission has been planned and a bed has been found, the patient has gained the weight and everybody needs to think... Should we continue with the recall?" (C4) "I'm technically being recalled right now, there's nowhere for me to go! So it defeats the purpose." (P2)

Additionally, clinicians and patients spoke about the uncertainties associated

with recall. Clinicians reported a lack of clarity around when and why to recall patients

and often felt forced to recall patients due to it being part of a legal framework:

"So say they need to come in seven days a week and one day [patient] says "I'm not coming in. I don't feel well". What do we do? Do we recall her instantly into hospital or do we work with it in a way and try and engage her to come in? The CTO ties you into "nope you've gone under the weight and you have to come back in" and actually, is that the best thing?" (C3)

Patients associated the uncertainty with not knowing when they might be recalled, despite having a thorough understanding of the reasons which could lead to a recall:

"I feel like I'm on death row. I know it might seem dramatic or whatever, but there's no other way I can really describe it... Ummm, like in real life, people could be on death row for ten or fifteen years. Because obviously, it is in your conditions that you can be recalled back to hospital but you never know what's going to happen... it could just happen at any time, I could be in hospital whenever really... And it could happen quite fast or it could take ages." (P1)

Lastly, clinicians specifically described how recalls increase workloads for

clinicians, primarily those in outpatient settings:

"I had to do it all. Everything. Finding the bed. Finding the AMPH first. I sent the letter, bought the stamp, put it on. First-class stamps!! It all adds up - phoning the patient and letting them know. And on top of all that, arranging the transport." (C5)

## Family Benefit/Involvement

All clinicians and patients acknowledged how CTOs benefited families, predominantly by providing a safety net. The option of immediate treatment was perceived to be relieving to families and CTOs appeared to remove responsibilities from parents:

> "Her parents felt reassured knowing that [patient] could access intensive treatment if needed. I also think that once they knew we were monitoring her deterioration, they could worry less about that and enjoy the bits that were working well... it allowed their relationship to repair." (C1)

> "My mom doesn't need to worry that she needs to go and knock on someone's door and tell them they need to take me back into hospital because the CTO does that." (P4)

Additionally, clinicians felt that families benefited from the legalities, which

prevented the opportunity for patients to fall through mental health systems:

"I think the CTO gives them power. They can say "hang on, we have this legal document ratified by everybody, this should happen, why is it not happening?... As opposed to them worrying about bed availabilities or not being able to get in touch with services." (C6)

Patients also noted how overall, this had a positive impact on family relationships by reducing conflict:

"Yeah, definitely, it changed our relationship for the better. Basically the arguments just stopped because there was no reason to argue anymore. They knew that I was eating...my mom was so happy... she was really proud." (P6)

Lastly, clinicians spoke about involving families and including their perspectives whilst developing conditions. They highlighted the value in collaborating with families and some attributed the success of CTOs to the extent of involvement:

> "Certainly, we wouldn't do it if families didn't agree with it because it would undermine it. If they aren't on board then nothing works really." (C4)

#### Discussion

This study endeavored to explore the use and impact of CTOs in ED services. Given that all participants spoke about their experiences of CTOs with AN, the findings and clinical implications from this study are pertinent to this subtype.

This study found that clinicians and patients encountered diverse experiences with CTOs. The following section will discuss the findings of this study in relation to its main research questions:

## Use of CTOs

CTOs were used in a largely structural fashion to monitor deterioration and facilitate contact with patients. The findings conveyed how CTOs had the potential of being used therapeutically through a collaborative and patient-led approach. CTOs were often described as safety nets for clinicians, patients and their families, to ease the transition from inpatient to outpatient settings; posing further questions about the intent of CTOs and whom they benefit the most. These findings are consistent with the existing literature on CTOs (Canvin et al., 2014; Coyle et al., 2013) and suggest that their use in the treatment of EDs is similar to that of other mental health conditions.

There appeared to be a discrepancy between understandings of CTOs and their use in reality. This was relevant to the recall component, where a recall was not enforced, either due to clinician uncertainty about recall criteria, clinician efforts to support patients to avoid recall or insufficient bed provision. The difficulties with recall have been documented in the research, further emphasising the dilemmas faced by clinicians when using CTOs (Mullen et al., 2006).

Additionally, the above suggests how the presence of a structured framework may in itself be more beneficial than the individual components of a CTO. This finding provides further support for the arguments suggesting that CTOs are used as safety nets and that similar outcomes can be achieved through standard outpatient ways of working (Stroud et al., 2015).

Moreover, the importance of MDT and interagency working was emphasised, as consistent with the literature (Coyle et al., 2013; DeRidder et al., 2016). The findings further highlighted the divide between inpatient and outpatient settings, with clinicians from each having unique roles in their involvement in CTOs. This presented challenges for those in outpatient settings, who needed to adapt to new ways of working and resolve any discrepancies in views, given they were implementing plans initiated by other teams. The impact on patients was also considered, such as splitting between teams and the lack of continuity of care.

CTOs were used for three patients who were residing in supported accommodation, where arguably extra support was provided. It is unclear from the

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results of this study whether the benefits achieved were due to the characteristics of such settings or exclusively due to the CTO. An interaction between CTOs, supported accommodation settings and patients likely influenced the experiences and effectiveness of CTOs, though further research is required in this area.

Furthermore, the findings were consistent with the literature suggesting that the use of CTOs is paradoxical regarding removing a patient's autonomy to advance it at a later stage (Mullen et al., 2015; Stuen et al., 2015). The removal of control was often seen as essential and communicated a variety of messages to patients, but was also seen as a way to reinforce dependency on services. This finding further demonstrates how interpretations and responses to CTOs vary across patients and emphasises the many considerations which need to be thought through, to avoid undesirable outcomes.

Lastly, CTOs were considered as effective and helpful when used with the 'right' patient, typically characterised as individuals who would benefit from a structure and respected authority. These findings build on the current literature (Canvin et al., 2014; Corring et al., 2017) and suggest that the characteristics of a 'right' patient are not disorder specific. Ultimately, this also highlights the importance of patient selection to assess suitability for CTOs.

## **Advantages and Disadvantages**

The diversity in experiences further highlights how clinicians and patients held contradictory and ambivalent perspectives about CTOs. The advantages and disadvantages identified in this study were strikingly similar to those highlighted in the current evidence base, implying that the outcomes of CTOs are somewhat standardised and do not vary across different mental health conditions. The findings further demonstrate the effectiveness of CTOs, as described by Canvin et al. (2015), Coyle et al. (2013), Lawn et al. (2006) and Stroud et al. (2015). CTOs prevented previous and repeated cycles of hospital admissions, enabled patients to re-engage in community activities and provided relief and reassurance to family members. Additionally, the advantages of a legal framework were identified for all stakeholders involved; for clinicians, it enhanced their confidence to manage risk, for patients, it provided a clear structure to follow and for families, it reduced worries associated with the loss of support.

The threat of recall specifically targeted patients' fears of hospital and the belief that nonadherence would inevitably lead to an admission. This supports the research which suggests that this threat is considered as an important and essential factor in the overall processes (Canvin et al., 2014; Stroud et al., 2015).

On the other hand, the findings from this study also echo the literature on the concerns associated with CTOs being coercive interventions, based on threat, imposed control and punishment (Lawn et al., 2016; Stroud et al., 2015; Stuen et al., 2015). Patients experienced feeling powerless and stigmatised and associated CTOs with the lack of freedom. Additionally, the looming threat of recall and being constantly monitored further contributed to negative and disempowering experiences.

Clinicians were aware of their role in using legal mechanisms to control and monitor patients, though often felt that this was a necessity. However, it is less clear whether clinicians understood the extent to which patients felt powerless as a result of the legal strictures, given that this finding was mainly interpreted from patient accounts. A potential explanation could be due to clinicians being familiar with working with legal frameworks, where their use is justified to minimise patient risk to self or others. Therefore, it is possible that clinicians may be desensitised to the potential impact of power and control on patients.

It appeared that how CTOs were perceived as positive or negative was dependent on a variety of factors, e.g. clinician opinions on CTOs, a patient's stage of recovery and the severity of AN symptoms. Ultimately, this finding provides support to the research which identifies the existing dilemmas for clinicians to be using CTOs in a balanced manner, where the advantages (an improvement in psychosocial function and increased engagement with services) outweigh the disadvantages of a coercive and controlling intervention.

#### Findings specific to AN & EDs

The findings of this study provide novel insights about the specific factors which may need to be considered when using CTOs for EDs.

CTOs were used with the aim of weight maintenance as opposed to medication adherence. This is understandably different from the previous research, which suggests that CTOs are mainly used to promote medication compliance (Churchill et al., 2017; DeRidder et al., 2016). The current study provides evidence for how CTOs can be used flexibly and how they can be adapted for different mental health conditions.

However, the findings from this study emphasised some of the difficulties encountered with the weight condition, primarily due to the differences between a clinician's and patient's opinions on the target weight set. This discrepancy appeared to be larger when patients perceived the CTO as something which restricted their freedom to lose weight, as opposed to an intervention that may be helpful towards recovery.

Clinicians and patients described a process of negotiation to agree on an acceptable weight for the CTO condition. This was achieved collaboratively at times

but had the potential to reinforce power imbalances. This process of compromise has not yet been explored in the literature with other mental health conditions and therefore can be assumed that it is unique to the use of CTOs with ED patients. Specifically, it identifies an additional challenge for clinicians to develop conditions which are realistic and minimise risks to self, whilst simultaneously including patient views.

The results also highlighted the interactions between ED symptoms and the mechanisms of CTOs. For some, CTOs clashed with their EDs and, for these patients, CTOs were perceived as threatening interventions, which prevented them from making choices about their ED. For others, CTOs helped patients to go against their ED and allowed them to feel that they had the permission to eat. It appeared that the way in which the CTO was perceived as negative or positive depended on the patient's stage in recovery and their responses to having some level of control placed on them.

Notably, both EDs (in particular AN) and CTOs share themes of control. Issues of control have been proposed to play a central role in the aetiology and maintenance of AN, where AN symptoms (such as food restriction or over-exercising) have been understood as an attempt to compensate for an underlying sense of lack of control (Froreich et al., 2016). Regarding CTOs, the findings of this study demonstrate that control and responsibility are further removed from patients when they are placed on CTOs. It is therefore likely that the ways in which CTOs were experienced by patients was dependent on how patients perceived this loss of control and how this interacted with the role of control in their AN symptomatology.

Lastly, whilst uncertainties around recall have been documented in the literature, the findings of this study identified further challenges for clinicians in ED services. When patients had lost weight, clinicians were faced with the additional dilemma of when to recall - should this be done immediately when patients had gone

slightly under the target weight versus when their weight had dropped on three consecutive occasions, or when a patient's weight was at a level which caused an increased risk to self, or when the patient had been given a chance to restore the lost weight but was unable to? The vague criteria for discretionary conditions likely contributed to these uncertainties. Furthermore, these findings also pose questions as to whether clinicians involved with CTOs have received sufficient training on their use in ED settings.

#### **Clinical Implications**

The findings of this study, in conjunction with suggestions from clinicians and patients (see Appendix J), provide some tentative recommendations for the use of CTOs in the treatment of EDs, to be evaluated in future research:

## Preplanning

1) Clinicians can undertake thorough assessments to examine patient suitability for CTOs, including patient characteristics, history and responses to previous inpatient treatment. Clinicians could also assess patient motivation, the intent to consent to CTOs and the presence of ED symptoms.

2) Clinicians may wish to develop a formulation based on how ED symptomatology (i.e. the role of control) may influence the ways in which CTOs are interpreted by patients.

3) Collaboration between inpatient and outpatient services is strongly recommended. Frequent communication between teams can provide the opportunity for clinicians to discuss and resolve any discrepancies in views. It also provides the opportunity to question the intent behind using CTOs (i.e. for professionals, patients or families) and whether similar outcomes can be achieved without using a legal framework.

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4) Services can ensure that clinicians undergo training on CTOs to reduce the uncertainties associated with the reasons to recall patients back to hospital.

#### Initiating & Maintaining CTOs

1) CTOs can be explained positively; emphasising how their use is in a patient's best interest. Clinicians are encouraged to have open conversations about how CTOs may feel restrictive and punitive at times and encourage patients to express any concerns about this with their ED service.

2) A collaborative stance should be employed when initiating conditions, including liaison with all services involved and family members. Patients should also be actively encouraged to be involved in setting up conditions, where possible.

3) If difficulties are encountered with the weight condition, motivational interviewing techniques can be used to help patients understand the rationale for a higher weight target.

4) Recall should not be explained as an automatic and inevitable process (i.e. recall inevitably leading to hospital admissions). Likewise, the threat of recall can be conceptualised as a framework to keep patients safe.

5) Where possible, conditions should be individualised and relevant to patient difficulties. Medical adherence is usually the dominant condition on most CTOs; however, this may be irrelevant for this patient group so it should not be included for the sake of inclusion.

6) Clinicians can consider the extent to which patients may feel dependent on CTOs and monitor this throughout, as this could impact patient autonomy and attitudes towards recovery.

## Appeal

1) Patients should be actively encouraged and supported to appeal their CTO. Clinicians should increase patient access to any information regarding patient rights on CTOs and advocacy services.

## **Strengths and Limitations**

To the knowledge of the researcher, this is the first study to explore the use of CTOs within an ED population. This has allowed for comparisons to be made with the current evidence base, which is primarily focused on the use of CTOs in acute mental health services. These comparisons provide evidence for the generalisability of the current research, but also suggest further insights into the disorder-specific aspects of CTOs.

This study included a diverse sample, with a range of clinician backgrounds, patient ages and ethnicities. Additionally, findings and clinical recommendations have been developed from both clinician and patients accounts and it is hoped that these suggestions can improve how CTOs are used in ED services.

It is important to consider the limitations of this study. Firstly, one must acknowledge the shortcomings of a volunteer sample. The results of this study are purely based on those who were willing to share their experiences with CTOs; views may have been expressed based on participants speaking about something they strongly believed in or wanted to change. There was a proportion of participants who did not participate and gave reasons such as not feeling comfortable to share experiences or finding the topic distressing. This in itself is important information and indicates that a full range of experiences has not been represented.

Secondly, the use of a thematic analysis meant that individual experiences were excluded from this study. Therefore, it should be noted that the findings and recommendations are solely based on majority experiences and may not be true to all clinicians and patients who have had experiences of CTOs in ED services.

Thirdly, the findings from this study have failed to provide a detailed account of whether CTOs impacted the therapeutic relationship between clinicians and patients. This is a well-documented finding in the current evidence base on CTOs and therefore it is somewhat surprising that it was missing from clinician and patient accounts. A possible explanation could be due to the fact that the analysis was narrowly focused on the impact of CTOs on therapeutic relationships; it is plausible that the existing relationship between clinicians and patients in itself influenced how CTOs were perceived (i.e. a stronger alliance could have led patients to view the CTO as less coercive, or perceive the approach to be more collaborative and therapeutic).

It is also unclear as to whether the semi-structured interview did not allow for this topic to be discussed in-depth or if participants did not consider the impact on relationships as an important aspect when discussing their experiences of CTOs.

## **Further Research**

It will be of interest to obtain quantitative research on the effectiveness of CTOs in the treatment of ED. This would provide evidence to support the notion that the advantages achieved in the long-term outweigh the disadvantages in the short-term and could justify the use of a coercive intervention.

Additionally, further research could focus on the role of supported accommodation when using CTOs and whether CTOs are more effective in these settings in comparison to those living in the community.

Lastly, whilst this study compared the experiences of patients and clinicians, matched dyads were not included. It would be of interest to directly compare these views to assess the extent of agreement between perspectives on a shared experience.

## Conclusions

In conclusion, this study described and explored the use of CTOs in ED services, demonstrating how CTOs were able to be used therapeutically and with multifaceted aims. The findings of this study suggest that experiences from both clinicians and patients were diverse, subsequently leading to the identification of a range of advantages, disadvantages and dilemmas associated with CTOs. The results also provided novel insights into the use of CTOs in an ED context and highlighted how ED symptomatology could interact with CTO mechanisms. Lastly, clinical implications are suggested to improve the use of CTOs in ED services and enhance patient treatment and care.

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Part 3: Critical Appraisal

## Introduction

This critical appraisal focuses on a series of challenges and reflections which arose after completing a study on the use of Community Treatment Orders (CTOs) in Eating Disorders (ED) services. Firstly, it describes how the methodology of the study was amended to better suit the nature of the data collected. Secondly, it discusses and attempts to understand the discrepancy found between participant accounts on their experiences of CTOs. Thirdly, a section on reflexivity is presented to explore how the researcher's background, interests and identity may have impacted the various stages of the research process. Lastly, this appraisal also reflects on the advantages of consulting with Experts By Experience when developing a research study.

## **Change in Methodology**

This project aimed to understand the use and impact of CTOs in ED services and was specifically designed with a focus on eliciting and understanding participant experiences. The original chosen method of data analysis was Interpretive Phenomenological Analysis (IPA). IPA is committed to the examination of a personal lived experience, by exploring a person's relatedness to, or involvement in, a particular event or process. It is idiographic and concerned with a detailed exploration of what an experience for 'one' person is like and what sense this particular person is making of their experiences (Smith et al., 2008). Therefore, it was originally hoped that the primary research objective of this study could be addressed through the interpretation of in-depth accounts provided by participants on their experiences with CTOs.

As I was completing the data collection process I realised that IPA may not be the best-suited approach for this study. Firstly, by including both clinician and patient accounts, I recognised that the analysis would not yield itself to be idiographic. I was no longer focusing on an experience of 'one' person but rather comparing similarities

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and differences across and within two heterogeneous groups. Secondly, although the design of this study was pertinent to a focus on understandings and experiences of a particular phenomenon, the primary research question was specific and concerned with generating knowledge on how CTOs were used. Therefore, the aims of the study were explanatory instead of exploratory, which is not in line with the theoretical underpinnings of an IPA approach (Biggerstaff & Thompson, 2008). Lastly, there appeared to be a discrepancy between the level of detail in clinician and patient transcripts. Transcripts from patient interviews provided in-depth descriptions of patient experiences of being under a CTO and the wide range of meanings attached to these experiences (e.g. feeling controlled, being given permission to eat, CTOs interfering with recovery, etc.). On the other hand, despite using similar interview schedules, this level of detail was missing from clinician transcripts.

After discussions with my research supervisor, I decided to change the method of data analysis to a Thematic Analysis, as informed by Braun and Clarke (2006). Given that this study was designed with a phenomenological framework from the onset, it was deemed essential that this continued throughout and therefore I chose to code the data at both semantic and latent levels during the analysis.

When reflecting on the planning stages of the project, I could have developed a better understanding of the various qualitative methods available to use, to assess which approach would best suit the aims of the research project. I have particularly resonated with the idea of 'identifying what the job is' instead of 'choosing a tool for the job' (Smith et al., 2008) when selecting an appropriate methodology for qualitative research. Looking back, I was certainly identifying the 'tool' (i.e. IPA) without having a thorough understanding of the 'job' (e.g. the research aims and purpose of the study). This has made me recognise the value of investing time and consideration into such decisions from the onset of a research project and the importance of alignment between the theoretical underpinnings of a research methodology and the research questions being studied.

## **Difference between Patient and Clinician Accounts**

It is of interest to reflect on the discrepancies between patient and clinician transcripts to further enrich our understandings of the use and impact of CTOs in ED services. Ultimately, it can be assumed that this discrepancy is due to the different roles and experiences held by both participant groups - clinicians were describing a phenomenon which they were exerting onto patients whereas patients were providing accounts of something which they were subjected to. This may explain why the theme '*Powerless Against the System*' was only extracted from patient accounts in this study.

Clinicians shared the ways in which they were working under a legal framework whilst using CTOs. It can be assumed that clinician backgrounds in mental health and their expertise influenced how they shared their accounts of how CTOs were used. Clinicians appeared to be holding patients' best interests in mind throughout the interviews and often used medicalised language to describe their experiences. Subsequently, this meant that the content was largely focused on the core components and mechanisms of CTOs (e.g. conditions and recall). Interestingly, narratives around power imbalances, oppression and stigma were somewhat missing from such accounts.

On the other hand, patients provided first-hand experiences that focused less on the specific components of CTOs but rather on the impact that CTOs had on themselves, their EDs and their world. Patients did not seem to conceptualise CTOs as something which was solely part of their treatment for ED but instead considered its impact and influence on personal, social and cultural domains. These discrepancies between patient and clinician interviews have made me reflect on the concept of power in mental health treatment. I have become more aware of the power differentials between clinicians and patients and how this is further exacerbated with compulsory treatment.

The literature on compulsory treatment tends to focus more on its ability to enhance medication compliance and adherence (Cutcliffe & Happell, 2009). A frequent finding, as mirrored in this study as well, is associated with how involuntary treatment is used with the best intentions and highest motives (Chan, 2002; Fennell, 2008). However, the idea of power, both in terms of psychiatric and legal power, which can be assumed to underly these mechanisms, is not openly addressed or reported. From a researcher's perspective, this has made me more interested in how studies can be designed so that powerful and often uncomfortable narratives can be discussed openly.

Lastly, the findings from this study, in conjunction with the current literature, has left me concerned about who we may need to rely on to share experiences of power imbalances and oppression (Sofear, 1999). A significant limitation of this study was associated with the final sample, as there was a proportion of patient participants who did not feel able to undergo the interview and expressed that they would find the experience of discussing their CTOs too distressing. This makes me wonder about whose voice research is able to capture in qualitative research and more importantly, whose voices are silenced?

## Reflexivity

Reflexivity refers to the close attention of the researcher's role in all stages of qualitative research (Fontana, 2004). It involves a continuous process of reflection on the researcher's values, preconceptions, assumptions and experiences and how these

may influence the findings of a study, either intentionally or unintentionally (Jootun et al., 2009).

From the beginning of this project, I have attempted to recognise how my background, role and interests may have impacted the data collection and analysis processes. This has mainly been conducted through bracketing, a method used in qualitative research in the attempt to mitigate the effects of the close relationship between the researcher and the research topic (Tufford & Newman, 2009). Additionally, through engaging in various reflective conversations with the joint researcher of this project, we have both been able to identify and acknowledge our own beliefs, emotions and theories as separate from each other and of the participants.

## **Researcher's Background & Interests**

I grew up in a country whereby mental health jurisdictions or legalities were not spoken about or openly used. When I moved to the U.K., I remember my reactions of surprise when I first heard about the concept of involuntary treatment and being detained under the Mental Health Act (MHA). I noticed that this disbelief soon turned into a sense of confusion, highlighting a core ethical dilemma for myself as a trainee clinical psychologist - is it justifiable to treat patients against their will or should patients be forced or coerced into treatment?

I recognised that my curiosity and ambivalence attracted me towards undergoing this project on CTOs. However, I also was aware of how this could make me more susceptible to focusing the project on the ethical dilemmas of CTOs, as opposed to their use in ED services. I appreciated the multiple conversations I had with the joint researcher of the project; we were able to discuss our wide range of experiences and unique perspectives and were somewhat able to hold each other accountable when planning and carrying out the study so that these processes were conducted in a way which fit with the original aims of the project.

### **Researcher's Role**

I became aware of my dual role of being a researcher and trainee clinical psychologist throughout all stages of the study. As a researcher, I felt determined to remain as 'neutral' and 'objective' as possible when conducting the interviews; trying to understand the experience of CTOs from each participant group and refraining from asking leading questions. I endeavored to conduct the interviews in a manner that enabled participants to share their stories in the way in which they would have liked their voice to be heard, and this meant allowing participants to determine the direction of the interview and speak about aspects which were most important to them.

At times, I noted when my role as a researcher conflicted with my identity as a trainee clinical psychologist, where for the last three years I have had the privilege of working with a wide range of clients from all walks of life. My role as a trainee has taught me the importance of remaining curious and compassionate, being a 'present listener' in a non-judgmental manner and the power of empathy. Arguably, these are all core skills that can be transferred to a research setting, especially in qualitative research.

However, I was mindful of the possibility where my trainee identity could take precedence over my researcher role and how this could complicate the research process. Therefore, in collaboration with the joint researcher of this project, we decided to undertake 'mock' interviews with other trainee clinical psychologists. Pilot interviews are strongly recommended (Doody & Noonan, 2013; Griffee, 2005) as they provide the opportunity for researchers to be comfortable with using the interview schedule and prompts and refines their interviewing skills.

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This mock interview presented me with an opportunity to practice the ways in which I would keep a narrative going in a research interview and avoid asking closed questions which could potentially dampen a discourse or prematurely terminate a narrative. Additionally, it let me practice how I could re-direct the flow of the interview so that its content was deeply rooted in the phenomenon being studied.

When reflecting on this mock interview, I noted my tendency to provide reassurance and express my empathy for participants. I realised that I frequently summarised and paraphrased the content described by participants – this is a core skill taught in clinical training and is also in line with my values and aspirations of wanting to make sure that individuals feel understood and heard. Moreover, I became more aware of how I unintentionally asked questions in a way that guided participants to perceive a situation through multiple perspectives.

The above were all significant learning points and I believe that practicing the interview schedule before-hand gave me the confidence to undertake the interviews with research participants. As I was conducting the interviews, I was actively aware of when my role and identity as a trainee clinical psychologist and a researcher could interact with each other and how this could interfere with the interview process. This increased awareness enabled me to change my position and stance when needed.

#### Working with Experts By Experience

I was fortunate to be contacted by an Expert By Experience (EBE) who expressed interest to be an advocate on the project. The literature has demonstrated the various advantages of including EBEs in research, as lived experiences and first-hand accounts can enhance the relevance and enrich the quality of research findings (Braye & Preston-Shoot, 2005; Telford & Faulkner, 2004). Additionally, input by EBEs can help guide a study towards focusing on aspects that are meaningful and important to those in the population being researched (Barber et al., 2011; Caron- Flinterman et al., 2005). The literature has also highlighted how stigma reduction and a provision of education and knowledge for researchers are additional beneficial outcomes when including EBEs in research (Rhodes et al., 2002).

In early consultations with the EBE, I was able to reflect on some of my ethical dilemmas which I held about involuntary mental health treatment. These conversations gave me a deeper understanding of a patient's perspective on such dilemmas and I noticed how my background had led me more towards aligning and potentially overidentifying with clinicians who used CTOs.

Furthermore, I had requested the EBE to review the interview schedule designed for the study. The feedback that was provided was extremely valuable; I was struck by how I had not thought about including questions on some of the core components on CTOs. For example, the EBE brought my attention to the different outcomes after a recall (72-hour recall versus an inpatient admission under the MHA), the possibility for being recalled to a different hospital based on bed availability and the options for patients to appeal their CTOs at any given time. All of this information was extremely relevant and the original interview schedule was amended to include this.

Similarly, the EBE also helped me to gain a better understanding of how ED symptoms may interact with CTO processes. I was grateful that the EBE was able to share her personal experiences with me and together we thought about how patients may view the CTO differently depending on their ideal weight and their attempts to loose weight. To reflect this, additional questions were added to the interview schedule to help patients think about their stage of recovery and whether the CTO had an impact or influence on this, either negatively or positively.

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Lastly, together with the EBE, we discussed how some patients may interpret questions differently and how this could have an impact on the responses provided. The EBE helpfully described that patients could "clam up" if they were to discuss components that were not necessarily "acceptable" to mental health professionals, such as water loading or wearing weights in attempts to avoid a recall. We agreed that it was more helpful to think about the reasons behind avoiding a recall as opposed to the actual ways in which this was done.

Upon reflection, I am extremely grateful for this input by the EBE. A difficulty that I encountered with this project was that there was no existing literature on the use of CTOs in ED services. Therefore, by hearing first handed accounts, I myself gained a deeper understanding of some of the differences when using CTOs for EDs and other mental health conditions. I was then able to use this preliminary information to further formulate the research questions under study. Additionally, through these consultations, I believe that the study was designed in a manner that was much more relevant to the population group. Lastly, I noticed how the feedback received from the EBE helped the interview schedule to be more balanced and ensured that it was not guided purely based on my own perspectives, background and interests. This process has ultimately taught me the utmost value of including EBEs in research projects to eliminate some of the research.

## Conclusions

This critical appraisal has summarised a process of reflections after undertaking a qualitative research study. It shows the importance of carefully choosing a research methodology from the onset of the study and demonstrates the need for research to be able to capture uncomfortable yet important perspectives. Additionally, it emphasises how a researcher's background and role can interreact with various research processes and subsequently highlights the usefulness of reflexivity to reduce such biases. Lastly, this appraisal demonstrates the value of including EBEs in research, to ensure that research is developed and carried out in a way that is relevant and meaningful to both researchers and participants.

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## Appendix A

## Joint Project Contributions

The empirical research project was conducted jointly with another trainee clinical psychologist. This research paper presents a narrative on clinician and patient perspectives whereas the fellow trainee's study explores carer and patient accounts.

The following tasks were completed in collaboration with the joint researcher of the study:

- 1) Obtaining ethical approval
- 2) Developing and designing the interview schedule
- 3) Consultations with the Expert by Experience
- 4) Recruiting participants (clinicians and patients)
- 5) Dividing patient interviews and transcription (There were 6 patient interviews in total; we both completed and transcribed three interviews each)

The following tasks were completed independently:

- 1) Conducting all clinician interviews
- 2) Transcription of clinician interviews
- 3) Data analysis
- 4) Writing up the empirical research paper

## Appendix B

## Patient Recruitment Leaflet



# 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. 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 talk to Dr Lucy Serpell at Orchard Centre Eating Disorder Service

21/03/2019, v1.0

## Appendix C

## Letter of Ethical Approval



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



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 <u>HRA and Health and Care Research Wales (HCRW) Approval</u> 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, <u>in</u> 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 <u>IRAS Help</u> 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 <u>obtain local agreement</u> 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 <u>HRA website</u> 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,

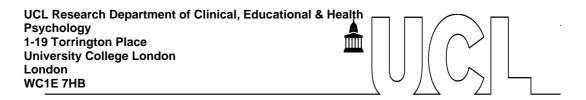
Thomas Fairman HRA Approvals Manager

Email: hra.approval@nhs.net

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

## Appendix D

## Participant Information Sheets



## Information Sheet (Version 1.1) - Clinicians

## 12/06/2019

We are inviting you to take part in a research project. We are interested in investigating the use of Community Treatment Orders (CTOs) in the treatment of Eating Disorders.

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 working with patients who are/have been under a CTO.

The study's main purpose is to understand whether CTOs are considered as facilitators or barriers to recovery in ED patients. We hope to assess this by understanding the perspectives from both patients, clinicians and carers and are interested in whether discrepancies exist. Therefore, we are interested in

understanding your experiences of working with clients who have been or are under a CTO as part of their ED treatment.

## Why have I been invited?

You have been invited to participate in this study as you are working/have worked with clients who are on/have been under a CTO.

## 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 the student researchers (Vallabhi Khurana & Kim Mihaljevic, two trainee clinical psychologists currently undertaking the UCL Clinical Psychology Doctorate programme). Interviews will last up to 120 minutes depending on your availability.

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 are the benefits of participating in this study?

Participating in this study will give you the opportunity to reflect on your experiences of working with clients who are on/have been under a CTO. You will also get the opportunity to voice your opinions about their use in the treatment of EDs. It is anticipated that the findings from this will be used to improve the way that CTOs are used in ED services in the U.K. to better support patients in their recovery.

## What are the risks of participating in this study?

Discussing experiences of patients being under CTOs can be distressing. If you feel distressed, you will be advised to speak to your supervisor. 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 <u>UCL privacy notice(s)</u>:

- <u>General privacy notice</u> 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 Mlhaljevic) will have access to the raw data collected in this study. The student researchers will transcribe the data and are the only person 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 passwordprotected 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: <u>https://www.ucl.ac.uk/legal-services/privacy</u>

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 <u>UK Policy Framework for Health and Social Care Research</u>.

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 the Riverside Research Ethics Committee, London, under the Health Research Authority on 20<sup>th</sup> June 2019.

#### 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

#### If you have any questions about this study, please contact:

Vallabhi Khurana Student Researcher UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>Vallabhi.khurana.13@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

#### Kim Mihaljevic Student Researcher

UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>Kim.mihaljevic.17@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

# Dr Lucy Serpell

Chief Investigator UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>I.serpell@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

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

#### Information Sheet (Version 1.1) - Patients

#### 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  $\pounds$ 10 per hour. You are also entitled to flat rate of  $\pounds$ 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.

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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

#### If you have any questions about this study, please contact:

# Vallabhi Khurana

Student Researcher UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>Vallabhi.khurana.13@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

#### Kim Mihaljevic Student Researcher

UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>Kim.mihaljevic.17@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

#### Dr Lucy Serpell Chief Investigator

UCL Research Department of Clinical, Educational & Health Psychology 1-19 Torrington Place University College London London WC1E 7HB Email: <u>I.serpell@ucl.ac.uk</u> Tel: +44 (0)020 7679 1897

# Appendix E

#### **Consent Forms**

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

# **CONSENT FORM - Clinicians**

# 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

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UCL Research Department of Clinical, Educational & Health			
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1-19 Torrington Place			
University College London			
London			
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### **CONSENT FORM - Patients**

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

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

Please initial box

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# Appendix F

### Interview Schedules

### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY



## Experiences of Community Treatment Orders in Individuals with Eating Disorders Semi-Structured Interview Schedule: CLINICIANS

#### 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
- Clarification  $\rightarrow$  There will be a discussion with each professional regarding the number of patients they have had on CTOs and how they would like to discuss these.

#### 1. Can you tell me a little bit about your role in the services?

#### Prompts/Follow up questions

- How confident do you feel in your understanding of CTOs?
- How often have you used them?
- Have you used CTOS in other services? Make explicit that only talking about ED

# 2. Thank you for giving me a list of your patients on CTOS. Can we talk a bit about them and their CTOS?

#### *Prompts/Follow up questions*

- What led to X being on the CTO/What led to it ending?
- What were the reasons for putting X on a CTO?
- How many CTOs has X been on and why?
- If they have previously been on a CTO, what was the duration and what led to it ending?
- Did you have a specific time frame in mind for X to be on the CTO?
- Were they recalled?
- Has the CTO been renewed?

#### 3. What was your role in the CTO?

#### *Prompts/Follow-up questions*

• How did you explain what a CTO is to your patient?

- What was your role in the decision-making process of putting your patient on a CTO
- Who else was involved?
- What is your understanding of the conditions for making a recall?
- What is your understanding of the duration of a recall?
- What are your views on the concept of a recall?

#### 4. When thinking about your patient on a CTO, what was helpful/unhelpful about it?

#### Prompts/Follow Up questions

- Views on the conditions set
- What was the extent of your involvement in the decision-making process in the setting of conditions?
- How were the conditions on the CTO justified?
- How clearly defined were the conditions? By whom?
- Did you think they were fair?
- Who else was involved in deciding the conditions of the CTO?
- What would have you liked to be different with the CTO
- 5. In your opinion, what was the impact of your patient being put on a CTO?

#### Prompts/Follow-Up questions

- How did it impact their personal life?
- How did it impact their treatment for their eating disorder (adherence, weight gain)
- How did it impact their quality of life?
- How did it impact their relationships with friends and family?
- How did it impact their relationships with your yourself/the service?
- How do you think your patient experience of the CTO was?

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

Prompts/Follow-Up questions

- What led to the recall?
- Did you use the 72 hour recall only, or did you reinstate Section 3?
- Who made this decision?
- How many times was your patient recalled?
- What was helpful about this?
- What was unhelpful about this?
- What impact did this have on their treatment?
- Did you believe this decision was fair?
- Did you think recall changed your perception of CTOs?
- How do you think your patient experienced recall?
- Was there ever a time where your patient avoided compulsory recall by agreeing to go in voluntarily?

# 7. What effect did you think the CTO had in terms of your patient's treatment/their eating disorder in general?

#### Prompts/Follow-Up questions

- Weight gain/Weight management
- Attempts to loose weight
- Cognitions
- Eating Schedule
- Compliance with treatment (e.g. attending appointments therapies, medication)
- Overall care plan
- Readmission rate
- Length of admission (as they are no longer on a section 2/3)
- What ways did it help with recovery/make recovery harder?

#### 8. How restrictive do you feel the CTO was?

Prompts/Follow-Up questions

- How much freedom did you think your patients felt they had?
- Were there any disagreements around the CTO?
- What about the CTO made you feel this way? (i.e. recall, threat, conditions, living at home opposed to hospital)
- What are your views on CTOs being used as a coercive intervention?
- What are your views on the legal use of CTOs?
- Do you consider CTOs to be ethical?
- Did any of your patients see/know that they could see an advocate or ask for a tribunal/managers meeting? What is your experience with these?

#### 9. In your opinion, Should CTOs be used in the treatment of ED?

Prompts/Follow-Up questions

- What type of patient do you think a CTO is most suited towards?
- Do you think that they can be used in a standardised manner?
- What are the general advantages/disadvantages?
- Do you consider a CTO with every sectioned patient?

# **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 using CTOs.

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

# RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY



### Experiences of Community Treatment Orders in Individuals with Eating Disorders Semi-Structured Interview Schedule: PATIENTS

#### 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

#### 11. Can you tell me a little bit about yourself?

12. 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?

#### 13. How did you feel about being 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

#### 14. 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?

#### 15. 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

# 16. (Optional) You mentioned that you were 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 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?

#### 17. 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 manging your ED Harder?
- If you weren't placed on a CTO, what do you think might have happened?

### 18. 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?

### **19.** 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?
- 20. 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 G

# Examples of Coding

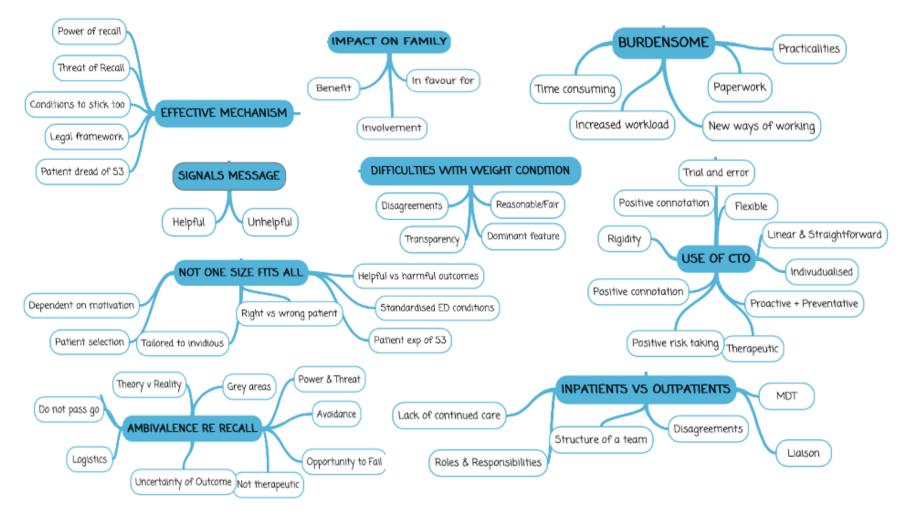
Clinician: umm I was consulted beforehand by the inpatient consultant about	Collaboration between inpatient and outpatient consultant
what I thought about them because they were the ones who were considering it and	Inpatient consultant initiates CTO, outpatient takes over
setting it all up. And I mean, I think it was a relatively informal discussion. And I	Clinician views taken into account
thought it was it was a good idea. Umm So, yeah, it wasn't much of a thing really. It	Informal collaboration
was more led by the inpatient team and then I took over when she came out to	Agreement between services
outpatients.	Different roles of inpatient + outpatient
	MDT approach required when setting up CTO
VK And thinking back or maybe thinking about the conditions now, do you think	Easy process when liaising
you would have liked anything to be different with the conditions?	
Clinician: ummI don't think so. I don't think they were overly restrictive. I think	Not restrictive
there were things that she was able to agree with when it happened. You know,	Appropriate conditions
there were all things that she identified that she would want going forward. You	Patient able to agree with conditions
know, from her discharge CPA. So I think it worked for everyone.	Patient voice/view concerned
	Discharge CPA guides conditions
	Restrictive to an extent but not at a level which is not
	acceptable
	Patient voice/view attributed to success
VK And just thinking about PATIENT in general and how do you think the CTO	Level of satisfaction for all parties involved to work?
impacted her personal life? I think we've touched a little bit on this already, but If	A team approach involving services and patients
there was anything else that you thought, in terms of her treatment but also her	
quality of life outside?	Original use of S3 sets up Cto
	Patient difficulties of S3
Clinician: I mean, I think that the original use of the section was done correctly	Value of MHA
because you know, when she came onto the ward, she was very reluctantshe	Previous experience of MHA
reluctantly came in for an admission and she was stuck for a while in terms of	Severe AN interfering with processes
progressing with her treatment. I think if she wasn't put under the section under the	Benefits of working under MHA; safety net for
mental health act, she would have probably discharged herself before reaching	professionals and patient

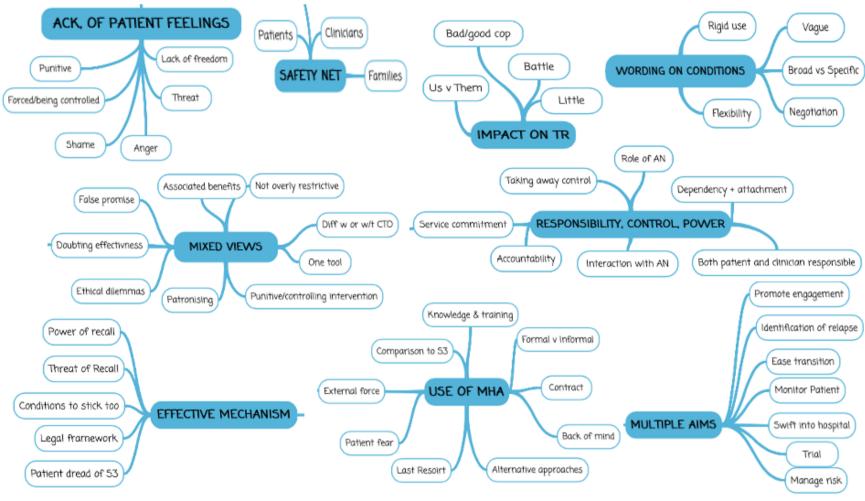
<b>Patient:</b> Uhh, it could be sort of like a relief, but then at the same time, if the logic was there long enough, it could also probably cause panic because, you know, as I said things would be different.	Relief at thought of not being under a CTO CTO perceived as negative initially Patient recognised value despite being bard to follow Differences W and W/O CTO Not wanted but needed Panic associated with increased anxiety, ED gets worse, Family worries. CTO providing some sort of safety and security
VK: And what might be different, do you think?	
Patient: Well obviously I wouldn't be taking the drinks. I probably wouldn't take the antidepressants and stuff. I would take my pain killers because my threshold for pain is not good. But I definitely wouldn't be taking the drinks, I wouldn't have any of the food items, like the yogurts and stuff. I wouldn't have the cereal with milk and stuff like that. Things would be a whole lot different. I also wouldn't go and see the nurses and have my weight checked and my bloods done and stuff like that. VK: So kind of that mix between relief but also panic when things may be spiralling?	Differences W/O CTO Advantages of CTOs CTOs enabling patients to do things otherwise would not have done or does not want to do Patient Ambivalence to CTOs Significant impact on patient; making significant changes in patients life
Patient: Yeah. Yeah. And you know they probably would spiral quite quickly	Anticipated deterioration of CTO CTO prevents a downwards spiral
<b>VK:</b> And I'm just thinking about our conversation on recall and when you were first put on the CTO, how was the concept of recall explained to you?	CTO maintains things
<b>Patient:</b> I think it was explained properly. They didn't like not explain it well, I did understand why they use it. It was explained very well.	Understanding of recall principals Clear and good communication between patient and clinicians

### Latent Codes/Semantic Codes

### Appendix H

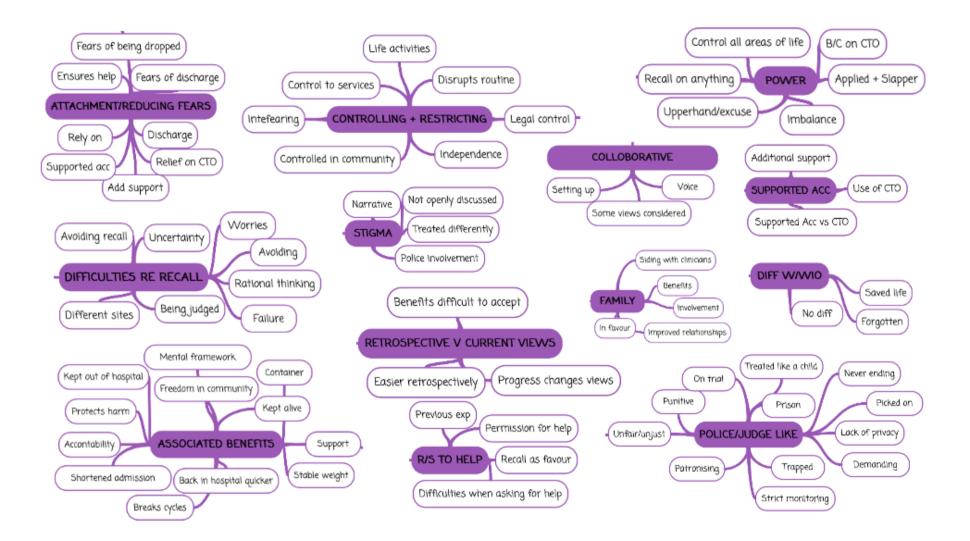
Initial Themes from Clinician and Patient Transcripts

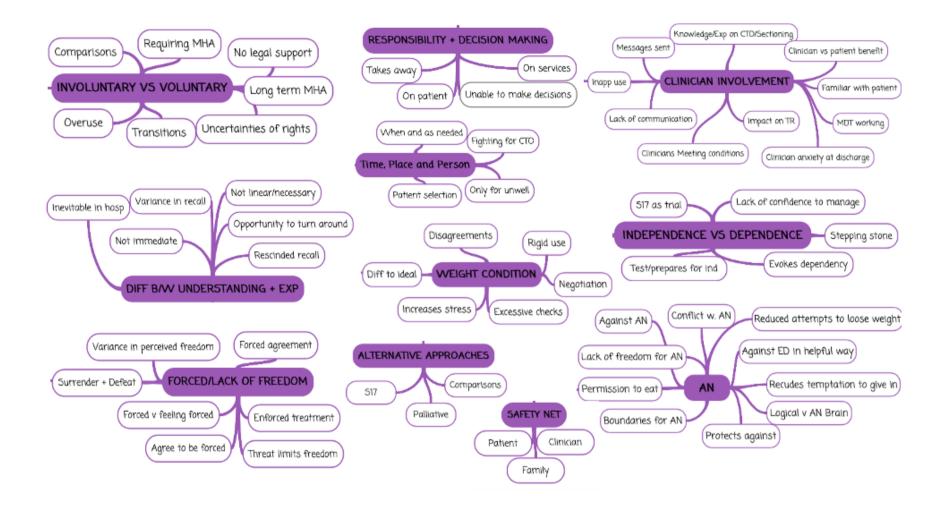




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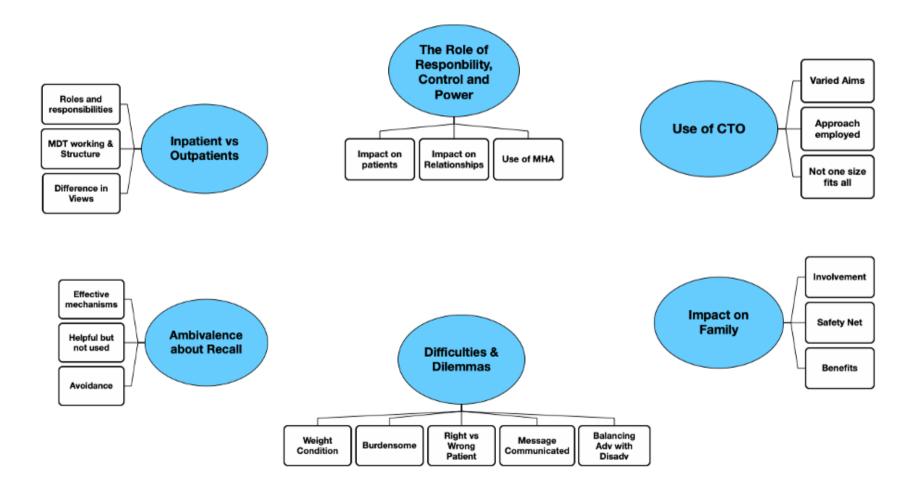


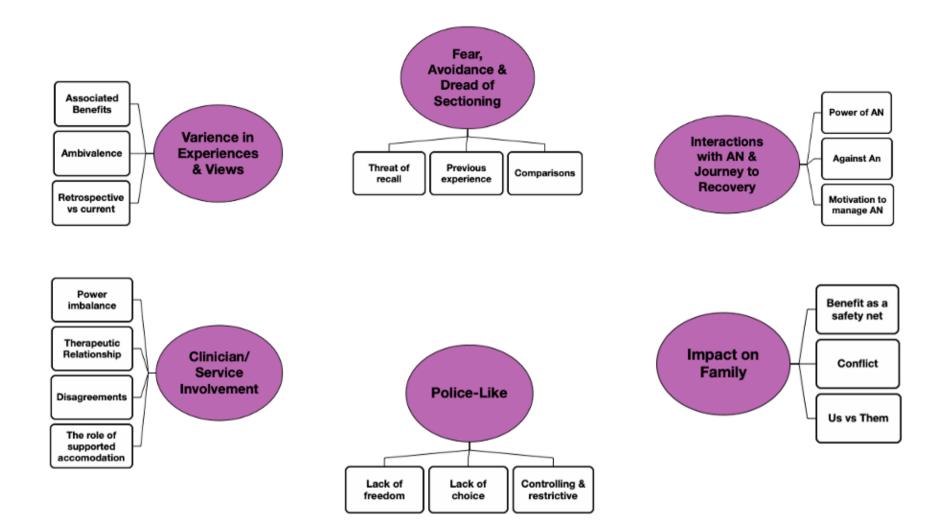




# Appendix I

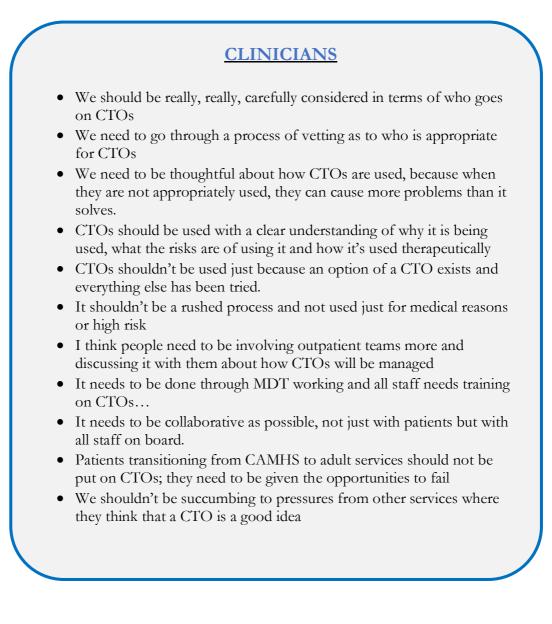
Initial Theme Maps (Prior to any feedback obtained from the researcher's research supervisor)





### Appendix J

Recommendations as described by Clinicians and Patients



# **PATIENTS**

- They need to make sure it's tailored to the individual and not used in black and white ways, like if you loose weight, you will be recalled.
- The conditions need to be appropriate, the weight one is kind of the obvious one for eating disorders.
- It should be used as a stepping-stone between inpatients and outpatients
- It should be reviewed more regularly, not only every 6 or 12 months.
- It shouldn't be used as a threat, that if you don't do very well, we can put you back into hospital. I think that can be quite dangerous and quite scary to the person actually.
- I tell my friends, you need to work with the CTO, it's not going to work on its own.
- I think it is a good way to use CTOs as a safety net. And it does sound quite positive to do that.
- It needs to be more of a collaborative approach with everyone involved (patient, consultant, AMPH)
- CTOs should be used properly with younger people or maybe a bit earlier in their treatment
- I would have liked more information on my rights
- There needs to be an understanding of eating disorder specific CTOs, so that conditions like taking medicine which are not relevant aren't put on a CTO. There should be specific seminars for at eating disorder conferences
- All professionals involved need more awareness, education and training on using CTOs
- Advocates should be actively involved. In some ways you should have this allocated as aftercare, like that actively outreaches to you, to talk about the CTO.