UNIVERSITY OF OXFORD DOCTORATE IN CLINICAL PSYCHOLOGY

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A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology (DClinPsych), comprising:

Critical Review of the Literature*:* Systematic review of prospective mental health outcomes following affirmative interventions for gender dysphoria.

Service Improvement Project: Feasibility and implementation of a brief distress tolerance intervention in Community Eating Disorder CAMHS.

Main Research Project*:* Pathways to heightened responsibility for self vs others in OCD.

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Abstracts

Critical Review of the Literature

Many trans* people experience high levels of mental health difficulties. Different gender-affirmative interventions exist which aim to alleviate gender dysphoria, with the hope that this in turn will improve the mental health and quality of life of trans* people. This systematic review aims to examine the effectiveness of affirmative dysphoria-focused interventions in improving mental health outcomes. Only studies with pre- and post-intervention measurements were included. Database searches were conducted from Medline, PsycInfo, Web of Science, Scopus and Embase with additional hand-searching (database inception to May 2022). Quality assessment of studies used the EPHPP Quality Assessment Tool. Twenty-six studies were identified that quantitatively assessed, via prospective pre- and post-test design, mental health outcomes (including depression, anxiety and self-esteem) following hormone, surgical and/or psychotherapeutic interventions. The majority of studies of hormone treatments found that mental health significantly improved following intervention and at follow-up. There was no significant change following surgical interventions at post-test to 6-month follow-up, although improvements were reported at longer follow-up time points. The majority of psychological interventions reported improvements in various mental health outcomes. The quality of the majority of included studies was assessed as being 'medium' or 'weak'. There were no found qualitative pre- and post-intervention research or research examining voice and communication therapy or hair removal/electrolysis. This review indicates that interventions for gender dysphoria, especially hormone and psychological treatments, may have mental health benefits for

trans* people. Further research is required to examine the relationship between mental health post-intervention and minority stressors, visual congruity with one's gender and intersectional factors.

Service Improvement Project

Adolescents with eating disorders experience higher levels of psychological distress compared to the general population. Distress is particularly pronounced during the first stage of the Family Based Treatment due to the focus on refeeding and weight restoration. It is feasible that equipping adolescents to manage distress early on in treatment may positively impact on later engagement and recovery. This service improvement project describes the feasibility and implementation of a brief distress-tolerance intervention delivered alongside the first phase of FBT in a community Child and Adolescent Eating Disorder Service. This study was approved by the service NHS Research and Development team (ID: 286525). 15 adolescents (aged 11-18) in the first phase of FBT received two fortnightly 1-1 sessions with an Assistant Psychologist. Intervention content was based on distress tolerance dialectical-behavioural strategies. The Distress Tolerance Inventory (DTI) was administered at pre-test and two-week follow-up. Participants were interviewed about their experience and usefulness of the intervention sessions. Paired sample t-tests indicated tentative effectiveness of the intervention. Thematic analysis identified key superordinate themes: 'Empowerment and Skilling Up', 'Delivery and Relevance' and 'Connection and Psychological Support'. The intervention was seen as highly acceptable and empowering for participants starting FBT. More sessions may be needed to ensure consolidation of

newly learnt skills. Next steps regarding wider service implementation and empirically evaluating impact (e.g. on crisis referrals) are discussed.

Theoretically Driven Research Project

Individuals suffering from OCD experience a heightened sense of responsibility compared to community sample and anxious controls. This responsibility may vary depending on the subject of potential harm (e.g. I am responsible for my own safety vs I am responsible for other people's safety). 5 causal factors or 'pathways' to the development of heightened responsibility have been proposed. This study aims to examine the relationship between the pathways to heightened responsibility towards oneself vs towards others. 60 participants with OCD and 60 community controls completed an online questionnaire measuring childhood and early adulthood experiences and responsibility dimensions. Regression analyses established the predictive value of each pathway. 'Responsibility for oneself', 'responsibility for others' and four of the five pathway subscales were significantly higher for the OCD group. The extent that participants had acted to influence misfortune was a significant predictor of heightened responsibility for oneself. Increased responsibility as a child and experience of overprotective parenting significantly predicted responsibility for others. This study indicates that heightened responsibility for oneself vs others may develop via separate pathways. Prospective studies are needed to understand how responsibility and other OCD-related beliefs develop in adolescence and early adulthood.

Critical Review of the Literature

Systematic review of prospective mental health outcomes following affirmative interventions for gender dysphoria

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Word count: 6118 (excluding references and appendices)

Internal supervisor: Dr Matthew Knight

External supervisor: Dr Sue Cotton

Target journal: This paper is targeted towards the journal Clinical Psychology Review as this accepts integrative literature reviews on diverse issues relating to community mental health and psychopathology.

Embedded Abstract

Many trans people experience high levels of mental health difficulties. Different gender-affirmative interventions exist which aim to alleviate gender dysphoria, with the hope that this in turn will improve the mental health and quality of life of trans* people. This systematic review aims to examine the effectiveness of affirmative dysphoria-focused interventions in improving mental health outcomes. Only studies with pre- and post-intervention measurements were included. Database searches were conducted from Medline, PsycInfo, Web of Science, Scopus and Embase with additional hand-searching (database inception to May 2022). Quality assessment of studies used the EPHPP Quality Assessment Tool. Twenty-six studies were identified that quantitatively assessed, via prospective pre- and post-test design, mental health outcomes (including depression, anxiety and self-esteem) following hormone, surgical and/or psychotherapeutic interventions. The majority of studies of hormone treatments found that mental health significantly improved following intervention and at follow-up. There was no significant change following surgical interventions at post-test to 6-month follow-up, although improvements were reported at longer follow-up time points. The majority of psychological interventions reported improvements in various mental health outcomes. The quality of the majority of included studies was assessed as being 'medium' or 'weak'. There were no found qualitative pre- and post-intervention research or research examining voice and communication therapy or hair removal/electrolysis. This review indicates that interventions for gender dysphoria, especially hormone and psychological treatments, may have mental health benefits for trans* people. Further research is required to examine the relationship between mental health post-intervention and minority stressors, visual congruity with one's gender and intersectional factors.*

Introduction

Note: For the purposes of this review, the term trans will be used to refer to individuals who have experienced gender dysphoria and who may have sought gender-affirming intervention. This is an umbrella term that aims to encompass the diverse spectrum of individuals with identities that do not include being a cisgender man or woman (Killermann, 2018). The majority of studies discussed in this review refer to trans* people as transgender and/or non-binary. 'Cisgender' will be used to refer to individuals who are not experiencing gender dysphoria and have the same gender identity as their gender assigned at birth.*

Trans* people are at higher risk of developing mental health difficulties compared to cisgender people (Auer et al., 2013; Davey et al., 2014; Heylens et al., 2014b). At the point of assessment within gender clinics, transgender people have significantly higher levels of mental ill health than the cisgender population, with the most common presentations being depression and anxiety (Dhejne et al., 2016; Millet, Longworth, & Arcelus, 2017; Newfield, Hart, Dibble, & Kohler, 2006). Bachmann and Gooch (2017) found that 46% of transgender people had thought about ending their own life – a significantly larger proportion compared to cisgender lesbian, gay and bisexual participants (31%). The survey reported that two-thirds of transgender participants had experienced depression in the past year, with 12% of participants having made an attempt to end their life (Bachmann & Gooch, 2017). These results are supported by a range of studies indicating high levels of mental health difficulties for trans* people (Jones, Pierre Bouman, Haycraft, & Emma, 2019; Newfield et al., 2006; Nobili, Glazebrook, Arcelus, et al., 2018). It is critical that trans* people access effective and useful mental health support. This systematic review aims to understand the

effectiveness of gender dysphoria interventions on the mental health of trans* people. The review will build on existing research on trans* mental health and explore different types of existing gender-affirmative interventions.

Predictors of mental health difficulties

There are four theorised contributors to distress and mental health difficulties in trans* people: 1) gender dysphoria, 2) minority stressors, 3) reduced social support and 4) reduced access to healthcare services (Carmel & Erickson-Schroth, 2016; Riggs, Ansara, & Treharne, 2015). Gender dysphoria describes the sense of feeling unhappy, uncomfortable and unaligned with one's sex assigned at birth. This sensation is persistent for many trans* people and is often present from early childhood. The term 'gender dysphoria' is used by the American Psychological Association (DSM-V; APA, 2013) and has also been known as transsexualism (ICD-10; WHO, 2004) or gender incongruence (ICD-11). The term is conceptualised as an independent diagnostic identity that is not necessarily associated with comorbid psychiatric conditions. The dysphoria may cause clinical distress and impairment in functioning (Sohn & Bosinski, 2007).

Minority stress theory describes how minority stressors (e.g. bullying, discrimination, internalised anti-trans attitudes and microaggressions) are strong predictors of suicidality and mental health difficulties for gender minorities (Tebbe & Moradi, 2016). Trans* people experience high rates of discrimination, harassment, abuse and violence based on their gender identity (Bachmann & Gooch, 2017; McNeil, Bailey, Ellis, Morton, & Regan, 2012). Trans* people experience inequality or discrimination

regarding housing, education, crime, employment, economic status, citizenship, health and social care (Mitchell & Howarth, 2009). Compared to cisgender people, trans* people are less likely to have perceived family and social support, with this directly predicting higher levels of psychological distress (Bariola et al., 2015; Basar et al., 2016; Davey, Bouman, Arcelus, & Meyer, 2014; Tebbe & Moradi, 2016). Trans* people experience significant barriers to accessing mental health services, with common reported factors including care services not being knowledgeable about trans* health and issues, financial barriers and discrimination (Safer et al., 2016). This lack of access to mental health services in turn impacts on mental health treatment and recovery (McCann & Sharek, 2016).

Gender-affirming interventions for gender dysphoria

A number of interventions exist that aim to directly reduce gender dysphoria experienced by individuals. These interventions introduce physical, psychological, social and behavioural changes to reduce the individual's experienced discrepancy between their gender assigned at birth (or biological sex) and their gender identity (Byne et al., 2012). These include medical interventions that alter the biological and/or physical appearance of an individual, psychological/psychosocial interventions and adaptive methods to address physical appearance and internal congruity. The theory behind these interventions is that alleviating the gender dysphoria-related distress may improve an individual's discomfort, self-identity, self-esteem and interaction with minority stressors which may in turn lead to mental health benefits (Wylie et al., 2014). For the purpose of this review, the focus will be solely on gender-affirmative interventions, meaning that the purpose of the intervention is to alleviate gender

dysphoria and not attempt to change or convert an individual's perceived gender identity to a cisgender identity.

Medical interventions are characterised as gender reassignment/realignment surgical procedures (GRS; often referred to as sex reassignment surgery; SRS) and hormonal procedures and are increasingly available for adults experiencing gender dysphoria. Examples of gender-affirming surgical/GRS interventions for transgender women include vaginoplasties, augmentation mammoplasty and facial feminisation surgery. Examples of gender-affirming surgical/GRS interventions for transgender men include chest masculinisation surgery, phalloplasty and scrotoplasty, amongst others. Common hormonal treatments for trans* people include hormonal replacement therapy (HRT) and administration of estrogens, testosterone, hormone blockers and androgens. These interventions often follow rigorous assessment and can be offered alongside psychotherapeutic and social support.

There is a growing body of evidence to suggest that medical interventions may improve the quality of life for trans* people. Several reviews have found that hormonal treatment is closely linked to an improvement in anxiety (Costa & Colizzi, 2016), depression and quality of life (Nguyen et al., 2018; Rowniak et al., 2019). Reviews of surgical interventions have found improvements in quality of life for transgender men (Defreyne, Motmans, & T'sjoen, 2017; Passos, Teixeira, & Almeida-Santos, 2020) and women (Zagami, Roudsari, & Sadeghi, 2019). One review found that the majority of studies reported significant improvements in psychological symptoms following co-occurring hormonal and surgical intervention (Murad et al., 2010). Previous reviews have commented on the poor overall study quality and inconsistencies in outcomes

between studies. There has not been a comparison of different mental health outcomes for both surgical and hormonal interventions. This may be useful in expanding our understanding of the respective and relative benefits of each of the interventions.

For some trans* people, medical interventions may not be available or necessary in reducing feelings of gender dysphoria. Many other interventions are utilised prior to, alongside or alternatively to medical procedures (Nieder, Eyssel, & Köhler, 2019). Gender-affirming psychological therapies and peer-support initiatives have been developed to explore the dysphoria in an affirming and supportive environment (Austin & Craig, 2015). Other, more adaptive interventions are used such as breast binding, genital tucking and voice and communication therapy. Despite the many different interventions that exist, little research has been conducted into the impact of such methods on mental health. There are no known reviews of research on non-medical interventions designed to alleviate gender dysphoria.

Whilst previous reviews have examined cross-sectional and longitudinal outcomes for medical interventions, there has not been a review of existing research of all types of intervention, including medical, psychotherapeutic, social and adaptive. There has been little study of the differences between these types of interventions and their respective impact on the mental health outcomes of participants.

The present study

This systematic review aims to analyse and synthesize studies of gender affirmative interventions designed to affirm gender identity and alleviate gender dysphoria in

adults. The study aims to build on previous systematic literature reviews by conducting an analysis of existing pre- and post-test prospective longitudinal research to better understand the temporality and effectiveness of interventions on mental health outcomes. It will examine:

a) The effectiveness of gender-affirming interventions for adults experiencing gender dysphoria in improving mental health outcomes for participants
b) Whether specific factors such as type of intervention and length of time post-intervention impact on different mental health outcomes
c) The quality and areas of existing research to identify new areas of study

The review will examine only studies that include a pre- and post-intervention outcome measure of subjective mental health. We also intend to examine the presence of qualitative research that captures changes in mental health pre- and post-intervention.

This review will provide important information about whether gender-affirmative interventions that aim to reduce gender dysphoria are effective in improving the mental health of trans* adults. Furthermore this review will identify ways to optimise the focus, design and reporting of future research.

Method

Protocol and registration

This systematic review method follows the guidelines from the AMSTAR checklist for systematic review quality (Shea et al., 2017). The search terms and study inclusion

criteria were developed under consultation with a research librarian and experts-by-experience from a NHS Gender Identity Clinic. Two expert-by-experience groups were used in this consultation with transgender men and transgender women to ensure that a range of interventions and search terms were considered. A research protocol for the review was devised on the basis of the existing literature and PROSPERO records prior to starting the review data search. The protocol and search strategy were registered on PROSPERO; registration number CRD42021241800.

Search strategy

An electronic search was conducted in May 2022 using the following electronic databases: Medline (PubMed), PsycInfo, Web of Science, Scopus and Embase. Additional hand-searching was conducted in GenderWatch (ProQuest) and LGBT Life with Full Text (EBSCO). The search terms used were formed of three main terms, using the keywords (transgender OR transsexual OR "gender dysphori*" OR "gender incongruen*") AND (interven* OR program* OR treatment OR therapy OR medicat* OR surg* OR group*) AND ("mental health" OR depress* OR anxi* OR trauma OR PTSD OR mood OR "quality of life" OR emotion*). These search terms were based on multiple scoping searches. The aim of these terms was to generate a large database of gender dysphoria interventions measuring mental health outcomes to ensure a comprehensive and inclusive list of possible articles. Secondary searches were also conducted via hand-searching, using the reference lists of included articles and exploring grey literature online. Search terms were used to search databases that contained articles with these terms in the abstract or title. All eligible studies based on

the abstract and title were added to an EndNote database and transferred into Microsoft Excel. These were de-duplicated automatically.

Screening criteria

Eligible studies in the present review had to fulfil the following inclusion criteria: (1) published within a peer reviewed journal or as a doctoral dissertation; (2) published in the English language, due to a lack of resources for accurate translation; (3) the intervention must be gender-affirmative; (4) the intervention must have a prospective pre- and post-intervention measure of outcomes; (5) the study participants are adults over the age of 18. Studies that had an age range of participants of 16+ were included if the mean age was above 21; (6) the main function of the intervention was to help with alleviating gender dysphoria-related distress or mental health difficulties. Studies where the focus of the intervention was on physical health, HIV/AIDS or substance misuse prevention were not included; (7) there was recorded outcome data for at least one DSM-5 internalising disorder (depression, anxiety and related disorders, psychotic disorders, PTSD and OCD) (American Psychiatric Association, 2013) or measures of psychopathology, emotional functioning, distress and self-esteem that took the form of either clinical diagnoses or relevant symptoms from a validated symptom rating scale.

Studies that included a measure of sexual distress, body image, body dysmorphia or quality of life without a mental health related outcome (e.g. income, stigma and social support) were not included. Quantitative, qualitative and mixed-method research were included in the search. Single-person case studies were not included due to difficulties

in making generalisable conclusions. Any length of follow-up for longitudinal studies was included.

Screening procedure

A pilot screening was first conducted to ensure inter-coder reliability. The first stage of selection involved the lead researcher independently screening the papers' abstracts and titles based on the inclusion criteria. A research assistant was a second rater during this screening stage for 600 studies. Outcomes between researchers were compared and Cohen's kappa (κ) statistics were calculated for categorical screening codes and found to be strong (κ = .81; % of agreement: 98%; McHugh, 2012). In the second stage the same researchers screened the full text of 25% of the remaining papers. Reliability between raters was checked and found to be excellent (κ = .89%; % of agreement: 98%). Discrepancies between researchers were resolved through discussion with the second and third authors.

The screening procedure and number of articles screened and accepted at each stage can be seen in Figure 1.

Data extraction and review synthesis

The data were extracted from the studies by the lead researcher. A pilot data extraction was conducted with 10 studies with a research assistant and excellent inter-coder reliability was found (κ= 95%; McHugh, 2012). Discrepancies were resolved via discussion with the co-authors. A data extraction form recorded details about study

characteristics, intervention design, the results and measures of outcomes. The standardized form for data extraction recorded (a) study design; (b) study location; (c) recorded demographic information including participant ethnicity, socio-economic status, sexuality and relationship status; (d) number of transgender male, transgender female and non-binary participants; (e) mean age of participants and age range; (f) type of intervention (e.g. surgical, hormonal, psychological, adaptive) and description of intervention procedure; (g) follow-up time points; (h) internalising disorder/symptom measures used; (i) summary of relevant outcomes; (j) background and biases of authors, where possible to record.

Further data was requested from several authors of papers and this was included, if provided. The study characteristics and outcomes were extracted and synthesized as a review.

Risk of bias

All studies were systematically evaluated for risk of bias using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (EPHPP, 1998; Silverman, Schertz, Yuen, Lowman, & Bickel, 2012). This standardized assessment tool allows classification of studies based on quality of design and measures (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection methods, (6) withdrawals and dropouts, (7) intervention integrity and (8) analyses. Total scores were generated, with 1 indicating the highest quality level, and 3 being the lowest. A score of 3 on two or more of the criteria would result in a ‘weak’ rating. The

assessment was conducted by the lead author and repeated by a research assistant for reliability. Discrepancies were resolved in discussion with the co-authors.

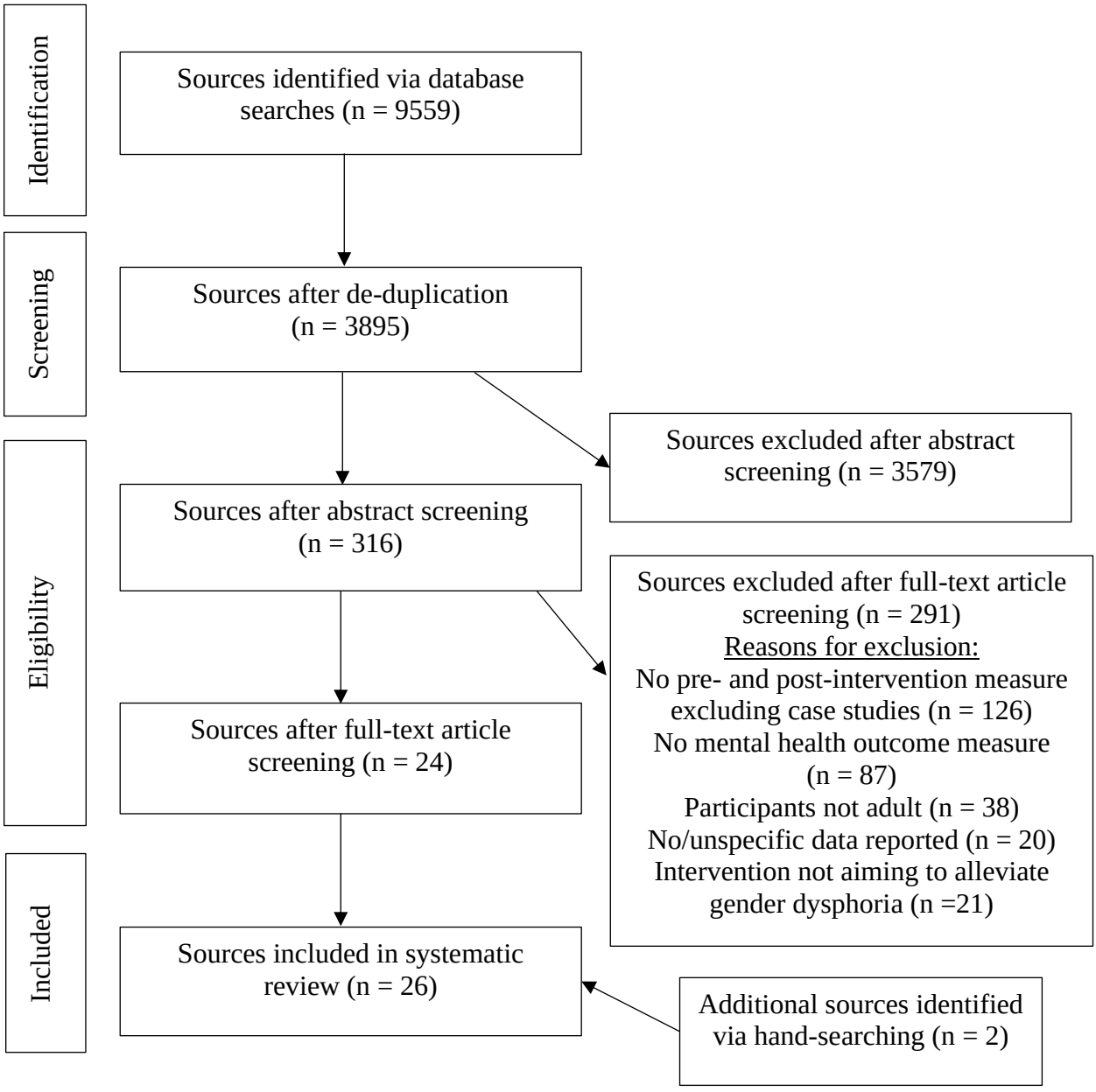


Figure 1: A PRISMA flow diagram detailing the number of papers included within each section of screening (Page et al., 2021).

Results

This section synthesises the existing literature of pre- and post- gender-dysphoria focused interventions with mental health outcomes. Given the significant differences between different intervention modalities, the findings are presented by intervention type, separately considering studies of hormone treatments, surgical interventions and psychotherapy, social and adaptive interventions. Other study-specific factors are considered when examining intervention type. The reporting quality of included studies is recorded in order to understand possible biases within the existing research literature.

Study characteristics

Twenty-six studies were included in the present review, including a total of 2627 participants at pre-test. The sample size in each study varied from eight to 873 participants. All but seven (27%) of the studies included medical interventions (hormonal or surgical). Further details about the factors relating to intervention content and study delivery can be found in Table 1. The most common study location was the UK (n = 6, 23%) and Italy (n = 6, 23%), followed by the USA (n = 4, 15%), Germany (n = 2, 8%), Sweden (n = 2, 8%), Belgium (n = 2, 8%) and the Netherlands (n = 2, 8%). One multisite study was conducted in Netherlands, Belgium, Norway and Italy (Matthys et al., 2021). Single studies were also conducted in Switzerland, Japan, Brazil and Iran.

All of the studies used a pre- and post-test design and collected self-reported outcome data. Eight of the studies (31%) also recorded cross-sectional or experimental outcome data, comparing post-test outcomes with previously collected population data

(Lindqvist et al., 2017; Papadopulos et al., 2017), cisgender participants (Keo-Meier et al., 2015; Meier, 2014; Metzger & Boettger, 2019; van de Grift et al., 2016) or participants who had experienced gender dysphoria who had not received the intervention (Fisher et al., 2016; Nobili, Glazebrook, Bouman, et al., 2018). There were no qualitative studies that captured the mental health experiences of participants pre and post-intervention.

The mean age of participants across the studies ranged from 22.0 (Matthys et al., 2021) to 47.3 (Udeze, Abdelmawla, Khoosal, & Terry, 2008). Six studies (23%) described interventions for people who were assigned female at birth (AFAB), six (23%) for people who were assigned male at birth (AMAB) and 15 (58%) for both. Three studies (12%) reported the inclusion of non-binary participants. No study reported the inclusion of intersex participants.

Sixteen studies (62%) measured depression outcomes, 12 studies (46%) measured anxiety outcomes, four studies (15%) measured self-esteem outcomes and nine studies (35%) measured generic mental health, mental wellbeing, distress and negative affect. Studies also included measures of dissociation, psychoticism, obsessive-compulsive disorder symptoms and stress.

Thirteen studies (50%) measured outcomes at additional follow-up time-points beyond the post-test. Post-test and follow-up time points ranged from immediately post-surgery (Megeri & Khoosal, 2007) to 60 months (Lindqvist et al., 2017).

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Aldridge et al. (2020) UK	178 95 AMAB 83 AFAB	23	1	Gender-affirming hormone treatment	18	HADS-D HADS-A	Depression: Sig. lower after intervention Anxiety: Lower scores but not significantly different after intervention.	2
Briggs et al. (2018) USA	8 MtF, FtM, Non-binary, Gender-fluid	"Adult"	3	Psychotherapy (10 weekly 90-minute group sessions based on Somatic Experiencing Informed Psychotherapy)	2.5	PHQ-9 GAD-7 WHOQoL	Depression: No change Anxiety: No change Psychological wellbeing: Sig. lower after intervention	3
Budge et al. (2021) USA	17 Non-binary, trans-feminine and trans-masculine	Two groups: 27.5 and 31.1	3	Transgender Affirmative Psychotherapy (12 weekly sessions) and psychoeducation session (Building Awareness of Minority Related Stressors)	3, 9	OQ-45	Distress: Significant reduction at post-test but no difference between baseline and follow-up	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Cardoso da Silva et al. (2016) Brazil	48 MtF	31.2	2, 3	Surgery (penile inversion vaginoplasty, urethroplasty). Participants also attended "supportive group therapy sessions" weekly or fortnightly	At least 12 months	WHOQoL	Mental health/negative feelings: Sig. improvement after intervention Self-esteem: No change after intervention	2
Colizzi et al. (2013) Italy	70 45 MtF 25 FtM	MtF: 29.3 FtM: 26.8	1	Hormone treatment (MtF: transdermal estradiol gel, FtM: intramuscular testosterone injections)	12	PSS	Stress: Sig. lower after intervention	2
Colizzi et al. (2014) Italy	107 78 MtF 29 FtM	29.2 MtF: 29.3 FtM: 29.1	1	Hormone treatment (MtF: transdermal estradiol gel, FtM: intramuscular testosterone injections)	12	SDS SAS SCL-90-R	Depression: Sig. lower after intervention Anxiety: Sig. lower after intervention Obsessive-Compulsive Disorder: Sig. lower after intervention Psychoticism: Sig. lower after intervention	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Colizzi et al. (2015) Italy	118 82 MtF 36 FtM	30.2 MtF: 30.4 FtM: 29.8	1, 2	Hormone treatment (MtF: transdermal estradiol gel, FtM: intramuscular testosterone injections) 22 participants also received sex reassignment surgery (mammoplasty, vaginoplasty, phalloplasty)	Post-HT: 12 Post GRS: 24	DDIS DES	Dissociation: Sig. lower for both intervention groups after intervention	1
Costantino et al. (2013) Italy	50 FtM	29.8	1, 2	Hormone treatment for 12 months and then surgery (Testosterone under various preparation and routes, hysteroannexiectomy and reductive mammoplasty)	Post-HT: 12 Post-GRS: 18	Measure designed for study	Depression: No change	3
Cotton & Wood (2019) UK	8 7 AMAB 1 AFAB	45	3	Psychotherapy (6 two-hour fortnightly group sessions using a CBT approach)	3	WEMWBS	Mental wellbeing: Statistical analysis not conducted due to small sample size. Authors describe change as	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
							"meaningful increase" in wellbeing	
Drydakis (2016) UK	40 23 MtF 17 FtM	MtF: 35.8 FtM: 34.1	2	Sex reassignment surgery (vaginoplasty or phalloplasty)	24	CES-D	Depression: Sig. lower after intervention for both MtF and FtM groups	3
Fisher et al. (2016) Italy	54 28 MtF 26 FtM	MtF: 32.5 FtM: 26.3	1	Hormone treatment (MtF: oral or transdermal estradiol treatment, FtM: intramuscular testosterone injections)	3, 6, 12, 24	BDI-II SCL-90-R	Depression: Sig. lower after intervention at all time-points for both groups. Overall distress: Sig. lower at all time points for MtF group. Sig. lower for FtM group only at time points 3 and 4	2
Heylens et al. (2014) Belgium	57 46 MtF 11 FtM	"Adult"	1, 2	Hormone treatment and surgery (genital surgery, breast augmentation/removal, facial hair removal, female feminization surgery). 11 participants did not receive surgery	3-6 after HT, 1-12 after GRS Mean length at follow-up = 39	SCL-90-R	Depression: Sig. lower after hormone treatment. No further change following surgery Anxiety: Sig. lower after hormone treatment. No further change following surgery Psychoticism: Sig. lower after hormone treatment. No	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
							further change following surgery	
Isung et al. (2017) Sweden	10 MtF	44	2	Surgery (facial feminisation surgery)	6	HADS-D HADS-A	Depression: No change Anxiety: No change	2
Knutson et al. (2020) USA	14 5 AMAB 9 AFAB	31.6	3	Psychotherapy (text-message based treatment based on cognitive-behavioural therapy (CBT))	1.5, 4.5	PROMIS	Depression: Sig. lower after intervention. No change at follow-up compared to pre-test Anxiety: Sig. lower at post-intervention and follow-up	2
Lingqvist et al. (2017) Sweden	146 MtF	36	2	Surgery (gender reassignment surgery)	12, 36, 60	SF-36	Mental health: No change	3
Matthys et al. (2021) Netherlands, Belgium, Norway, Italy	451 MtF 422 FtM	MtF:27.0 FtM:22.0	1	Hormone treatment (range of interventions)	3, 6, 9, 12, 18, 24, 36	PANAS	Negative affect: No change in both groups in median score at 36-month follow-up	3
Megeri and Khoosal	40 MtF	41.8	2	Surgery (gender realignment surgery)	Post-surgery	HADS BDI	Depression: No change Anxiety: No change	3

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
(2007) UK						STAI GHQ		
Meier (2014) USA	79 FtM	26.6	1	Hormone treatment (administration of testosterone)	3-4, 10-12	DASS RSES SF-36	Depression: Sig. lower at post-intervention and follow-up Anxiety: Sig. lower at post-intervention and follow-up Self-esteem: No change Stress: Sig. lower at post-intervention and follow-up	2
Metzger (2019) Switzerland, Germany	26 FtM	27.2	1	Hormone treatment (subcutaneous, intramuscular or transdermal administration of testosterone)	3, 6	BDI-II NEO-PI-R	Depression: Sig. lower after intervention for both measures at both time-points Neuroticism: Sig. lower after intervention	1
Naeimi et al. (2019) Iran	42 FtM	34.2	2	Surgery (gender reassignment surgery, penile and scrotal reconstruction)	6	SF-36	Mental health: Sig. improvement after intervention	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Nobili et al. (2020) UK	118 59 AFAB 59 AMAB	27.95 AFAB: 22.5 AMAB: 33.4	1	Hormone treatment. Participants may have had surgery in that time but numbers are not reported.	12	HADS-A	Anxiety: No change	3
Oda & Kinoshita (2017) Japan	14 FtM	23.9	1, 3	Hormone treatment (cross-sex hormone treatment) and psychotherapy	12	MMPI-2	Depression: Sig. lower after intervention Anxiety subscale, also labelled as "Hysteria" in paper: Sig. lower after intervention Schizophrenia sub-scale: Sig. lower after intervention	3
Papadopulos et al. (2017) Germany	39 MtF	38.6	2, 3	Surgery (orchiectomy, penectomy and vaginoplasty). Undescribed psychotherapy ran from before the pre-test to beyond the post-test	12	PHQ-4 RSES	Depression: Sig. improvement after intervention Self-esteem: Sig. improvement after intervention	2
Udeze et al. (2008) UK	40 MtF	47.3	2	Gender reassignment surgery	6	SCL-90-R	Obsessive-compulsive disorder: No change Depression: No change	2

Author(s) Country	N and study's own description of sample	Mean age at pre-test	Category (1 = HT, 2 = surgery 3 = therapy)	Study description of intervention	Time-points from pre-test (months)	Outcome measure	Results at post-test/follow-up	Quality rating (1 = strong, 2 = moderate, 3 = weak)
							Anxiety: No change Psychoticism: No change	
van de Grift et al. (2016) Netherlands	33 Transmen	26.1	2	Surgery (mastectomy)	6	RSES	Self-esteem: No change	1
van Dijk et al. (2019) Netherlands, Belgium, Italy	398 193 Trans men 205 Trans women	Trans men: 23 Trans women: 29	1	Hormone treatment (Trans men: intramuscular or transdermal testosterone administration, Trans women: oral or transdermal estradiol treatment)	3, 6, 12	Single question on nervous-ness and anxiety	Anxiety: No change	3

Table 1: Summary of included studies. Sample: AFAB: Assigned Female at Birth; AMAB: Assigned Male at Birth; MtF: Male to Female transgender person; FtM: Female to Male transgender person. Intervention: CBT: Cognitive-Behavioural Therapy; HT: Hormone Treatment; GRS: Gender Reassignment/Realignment Surgery. Outcome measure: BDI-II Beck's Depression Inventory; CES-D: Center for Epidemiological Studies Depression; DASS: Depression Anxiety Stress Scales; DDIS: Dissociative Disorders Interview Schedule; DES: Dissociative

Experiences Scale; GAD-7: Generalised Anxiety Disorder Assessment; GHQ: General Health Questionnaire; HADS: Hospital Anxiety and Depression Scale; MMPI-2: Minnesota Multiphasic Personality Inventory; NEO-PI-R: Revised NEO Personality Inventory; OQ-45: Outcome Questionnaire 45; PANAS: Positive and Negative Affect Scale; PHQ: Patient Health Questionnaire; PROMIS: Patient-Reported Outcomes Measurement Information System; PSS: Perceived Stress Scale; RSES: Rosenberg Self-Esteem Scale; SAS: Zung Self-Rating Anxiety Scale; SCL-90-R: Symptom Checklist-90-Revised; SDS: Zung Self-Rating Depression Scale; SF-36: 36-Item Short Form Survey; STAI: The State-Trait Anxiety Inventory; WEMWBS: The Warwick-Edinburgh Mental Wellbeing Scale; WHOQoL: World Health Organization Quality of Life; Scale. Results: Sig: Statistically significant.

Hormone treatment

Hormone treatment describes the use of prescribed medication in order to change hormone levels to be consistent with a gender identity. Thirteen studies (50%) examined a hormone intervention. Almost all of these studies reported outcomes after participants had received hormonal treatment for 1 year. Two studies (8%) reported final post-test outcomes at 6 months (Heylens, Verroken, De Cock, T'Sjoen, & De Cuypere, 2014; Metzger & Boettger, 2019). The most commonly reported hormonal treatment were oral or transdermal estradiol gel and intramuscular testosterone injections. The majority of studies that measured depression outcomes reported that depression symptoms significantly decreased following hormonal treatment (n = 6, 23%), with only one study (4%) reporting no change following intervention (Costantino et al., 2013). These changes were maintained in studies that reported multiple follow-up time points. Heylens et al. (2014) reported that both depression and anxiety improved following hormonal intervention but no further change in symptoms was found after additional surgical intervention. One study (4%) reported no change in negative affect between pre-test and 36-month follow-up (Matthys et al., 2021).

Three studies found that anxiety significantly reduced and three showed no significant change after hormonal intervention (n = 6, 23%). All studies with other mental health outcome measures (stress, OCD, psychoticism, dissociative symptoms and distress) reported significant improvements following hormone intervention. There were no observed differences in findings for studies with varying follow-up time points. There were no observed differences in outcomes for participants of different genders or for other participant demographics (e.g. ethnicity, socio-economic status).

Surgical interventions

Surgical interventions describe the medical alteration of a person's physical appearance or functioning of existing genitalia to reduce dysphoria and lead to changes more closely aligned with a person's gender identity. Twelve studies (46%) involved a surgical intervention. These included reductive mammoplasty/breast augmentation (n = 4, 15%), vaginoplasty (n = 3, 12%), phalloplasty (n = 3, 12%), facial feminisation surgery (n = 2, 8%), facial hair removal (n = 1, 4%) and penectomy/orchiectomy (n = 1, 4%). Three studies did not report details of the surgery (e.g. "gender reassignment surgery").

Two studies (8%) reported a significant improvement in depression outcomes following surgical intervention. The intervention for both these studies was vaginoplasty. Five studies reported that there was no change in depression outcomes. All four studies (15%) that measured anxiety outcomes following surgery reported no significant change in outcomes compared to pre-test scores. Two studies (8%) reported improvements in overall mental health, one (4%) in self-esteem and one (4%) in dissociative symptoms. No change was reported in one study (4%) for mental health, two (8%) for self-esteem and one (4%) for psychoticism.

Four of the five surgery studies with long-term follow-up time-points of 12 months or more found significant improvements in mental health outcomes. Six of the seven studies which only collected outcomes post- to 6-months after surgery did not find any change in outcomes. There were no observed differences in outcomes for AFAB (n = 6) or AMAB (n = 9) participants or for other participant demographics (e.g. ethnicity,

socio-economic status). None of the six studies (23%; of which three were of surgical interventions) in which the average age of participants was over 40 reported statistically significant improvements in any outcomes.

Psychotherapy interventions

The majority of studies were of hormone or surgical approaches. Seven studies (27%) described interventions that used a psychotherapeutic approach. One study described Somatic Experiencing Informed Psychotherapy, a ten-session 90-minute group therapy which focuses on the autonomic nervous system and emotional regulation (Briggs, Hayes, & Changaris, 2018). This intervention placed emphasis on the "felt sense", identifying biopsychosocial elements of a gender diverse identity which contributes to gender dysphoria and providing ways of helping individuals build emotional regulation skills when distressed.

Two studies (8%) integrated Cognitive-Behavioural Therapy (CBT) principles. One of these included six two-hour group therapy sessions (Cotton & Wood, 2019) adapting an existing transgender affirmative cognitive behavioural therapy (Austin & Craig, 2015) which includes cognitive modification to negative thoughts and core beliefs (e.g. "I will never be a 'real' woman") and behavioural activation to encourage and help participants to feel more comfortable living authentically within the community. The intervention also included modules on problem solving and management of stressful social situations related to trans* experiences. Another study also adapted the transgender affirmative cognitive behavioural therapy (Austin & Craig, 2015) approach to create a six-week 24-day manualised text-message intervention alongside

psychoeducation and skill-based exercises which considered the role of gender dysphoria in distress (Knutson et al., 2020).

One study described 12 sessions of Transgender Affirmative Psychotherapy (TA) or the same intervention with an additional psychoeducation session on Building Awareness of Minority-Related Stressors (BAMS) (Budge, Sinnard, & Hoyt, 2021). There was no additional detail to the content of the intervention used in this study, as the therapists were instructed to follow their own choice of theoretical framework (one therapist provided psychodynamic psychotherapy and the other provided person-centred psychotherapy).

The remaining three studies (12%) described how psychotherapy took place alongside another intervention. One of these was a group intervention (Cardoso da Silva et al., 2016) and another had an average period of psychotherapy of 28.7 months (Papadopulos et al., 2017). However, beyond this, there was no additional information about the type, content or form of psychotherapy. All studies reported an improvement in mental health, psychological wellbeing, depression and/or anxiety symptoms, apart from one intervention which found no change in depression or anxiety symptoms (Briggs et al., 2018) and another study that found a reduction in distress at post-test but not at follow-up (Budge et al., 2021).

Social and adaptive interventions

There were no found studies of other types of gender-dysphoria focused interventions for trans* people with gender dysphoria, such as voice and communication therapy, hair

removal/electrolysis, binding, genital tucking, internet support groups, peer support and self-medicating of hormone medication (Gendered Intelligence, 2021; UCSF Transgender Care, 2021).

Quality assessment

The quality assessment classified studies into ‘strong’, ‘moderate’ and ‘weak’ based on how information was transparently presented across six domains (selection bias, study design, confounders, blinding, data collection method, withdrawals). It also considers intervention integrity and analytic methods. A summary of the quality assessment of each study can be found in Appendix A. Three studies (12%) were rated as having a ‘strong’ reporting quality, 14 (54%) with a ‘moderate’ quality and 9 (35%) with a ‘weak’ quality. The main reasons for poor quality assessment ratings were ignoring of confounders, selection bias and participant withdrawals. Fourteen studies (54%) did not discuss or examine the presence of any confounders such as age, demographics or pre-test scores on outcomes. Eight studies (31%) were assessed to have a significant level of selection bias, with the most common reason being that less than 60% of people who registered their interest or were approached for the study ended up completing the pre-test measure. Nine studies (45%) reported high drop-out rates, with over 40% of participants not completing the post-test measures. Several of these papers did not report participant drop-out rates and only described participants that completed both pre- and post- measures. There were no observed differences between studies with varying assessed quality and outcomes when considering different types of intervention and participant demographics.

Discussion

This systematic review synthesises 26 studies in which mental health outcomes were measured before and after an intervention designed to alleviate gender dysphoria in adults. The majority of identified studies were of medical interventions, specifically hormone treatment and surgical procedures that altered physical characteristics of individuals. For hormone treatment, the majority of studies suggested that intervention was beneficial in improving mental health outcomes, especially for depression symptoms. The majority of studies of surgical interventions reported no change in outcomes following intervention, especially at post-test follow-up time point measurements. The overall research quality of the included studies was categorised as 'medium' to 'weak'. This is consistent with reports from other reviews which suggest a high risk of bias in study designs, small sample sizes and limited consideration of confounding factors (Baker et al., 2021; Dhejne et al., 2016). There is a need for more high-quality intervention studies within this area of research.

This review highlighted the lack of qualitative research that captured the 'before and after' experience of participants undergoing hormone or surgical intervention. Qualitative research enables multi-faceted health-care interventions to be developed in a way that considers the complexities of people, procedures and context (Thirsk & Clark, 2017). An understanding of the lived experience of participants will ensure that future interventions have a thorough theoretical underpinning and are optimally adapted to ensure that individuals are supported and given appropriate post-intervention care (Duggleby et al., 2020).

Interventions aiming to alleviate the dysphoria felt by many trans* people may not be sufficient to reduce mental health difficulties experienced by this population. Whilst gender dysphoria is a key predictor of mental health outcomes for trans* people, there are still many other significant factors that may predict poor mental health that may or may not be addressed by such interventions. There is a strong evidence base emphasising that, especially for trans* people, mental health and resilience is predicted by the presence of peer-support, feeling connected to others (often referred to as trans* community connectedness; TCC) and the availability of safe spaces (Matsuno & Israel, 2018; Pflum, Testa, Balsam, Goldblum, & Bongar, 2015; Puckett, Matsuno, Dyar, Mustanski, & Newcomb, 2019; Zeeman, Aranda, Sherriff, & Cocking, 2017). For instance, one study of transgender youth found that the use of a chosen name by members of an individual's family and wider system is associated with reduced depressive symptoms and suicidal ideation (Russell, Pollitt, Li, & Grossman, 2018). Additional factors linked to mental health outcomes include having positive role models, as well as having an online internet supportive community (Matsuno & Israel, 2018; Pilecki, 2015). One study found that psychosocial wellbeing was moderated by social support for individuals following surgery (Schultz, 2002). It may be the case that many of the interventions described in this review integrated elements of peer-support, affirmative care and inclusion into a supportive community, all of which may have contributed to overall mental health outcomes. Future intervention studies should aim to examine these factors at post-intervention and follow-up (e.g. by using The Gender Minority Stress and Resilience measure; Testa, Habarth, Peta, Balsam, & Janice, 2015) and explore whether this is more closely correlated with mental health outcomes.

Hormone treatment

This review indicates that hormonal treatments are effective in improving low mood and other mental health difficulties for trans* people. These findings are consistent with similar reviews of hormone treatment finding improvements in depression (Nguyen et al., 2018; Rowniak et al., 2019). These outcomes may be explained by interventions contributing to a reduction in gender dysphoria, which in turn may decrease participants' global distress and improve their own sense of self-affirmation and self-efficacy. Hormone treatments often impact on an individual's ability to visually and aurally 'pass/blend' as their identified gender, which may result in reduced instances of discrimination and associated perceived minority stress, all of which may impact on mental health outcomes (Cohn, Casazza, & Cottrell, 2018; To et al., 2020). Other possible benefits to such interventions are that they often enable access to trans-related healthcare and the integration of healthcare services within often "closely-knit trans communities" (Fomotar, 2017, p. 1; Puckett, Barr, Wadsworth, & Thai, 2018). Undergoing hormone interventions to reduce gender dysphoria may enable individuals "to live full and authentic lives" (Fomotar, 2017, p. 1). Future research should explore whether mental health outcomes are mediated by other quality of life factors including minority stress, discrimination and self-perceived authenticity.

Surgical interventions

Whilst previous reviews have found improvements in more holistic quality of life outcomes following surgery such as sexual satisfaction, psychosocial wellbeing and physical health (Defreyne, Motmans, & T'sjoen, 2017; Passos, Teixeira, & Almeida-

Santos, 2020), there has been little systematic examination of studies measuring mental health specifically following surgery. The present findings suggest that surgical interventions may not be effective at improving the mental health of trans* people in the short term (e.g. up to 6 months after surgery).

There are many feasible explanations for these findings. It may be the case, especially when relative to long-term and gradual change that occurs during hormonal treatment, that surgical interventions can be perceived as a fast and sudden change which may require a significant amount of time for individuals to adjust to. Future research should capture the long-term mental health effects of surgery. Surgical interventions generally occur much later for most trans* people's treatment pathways, and therefore gains may have already been made from other interventions (e.g. hormone treatment) much earlier in transition. Another reason may be linked to aesthetic change. There is evidence suggesting that visual conformity with affirmed gender (VCAG) or "passing" is inversely related to depression and anxiety outcomes for transgender people (To et al., 2020). One possible reason for the discrepancy in findings between hormone treatment and surgical interventions may be that, when compared to genital surgery, long-term hormone use may be more closely linked with changes in overall visual appearance and subsequent VCAG. Facial feminisation surgery is associated with improved VCAG and satisfaction (Morrison et al., 2016) and yet the two included studies of this intervention reported no significant change in outcomes, suggesting that there may be other factors beyond VCAG that explain the lack of mental health changes following surgery. No studies examined the impact of voice and communication interventions on participant mental health. Previous studies have found that having a voice that is congruent with participants' own gender identity is associated with greater psychological wellbeing and

quality of life (Hancock et al., 2011; Watt et al., 2018). Future studies should examine whether changes in voice and perceived VCAG post-intervention mediates mental health outcomes post-surgery.

Psychotherapy interventions

This review also examined other types of non-medical interventions. All studies but one that included psychotherapeutic elements found an improvement in mental health outcomes. Two studies utilised CBT elements, drawing on recently developed trans-affirmative interventions (TA-CBT) which aim to incorporate cognitive-behavioural theory alongside addressing relevant sources of stress for trans* people (Austin & Craig, 2015). Four papers included very limited information about the type or content of the psychotherapeutic approach and occurred alongside other interventions, which makes it difficult to determine the relative effectiveness of this approach or identify hypothetical active components in treatment.

Previous qualitative research has emphasised the value of psychotherapeutic approaches in exploring the dysphoria and mental health difficulties faced by many trans* people (Mizock & Lauren, 2016; Stephens, 2019). These studies have shown the importance of affirmation from the therapist within sessions and a therapist awareness of minority stress (Stephens, 2019). Common barriers identified to successful psychological interventions include the therapist "placing the burden of education on the client", pathologizing gender and the therapist avoiding discussions about gender-related issues (Mizock, 2017; Mizock & Lauren, 2016; Stephens, 2019).

Social and adaptive interventions

There were no found appropriate studies examining social and adaptive interventions. Many studies incorporating social interventions did not meet the review's inclusion criteria and yet may provide insight into how effective interventions may be designed. A significant number of studies exist in which the primary aim is to support and educate trans* people about living with HIV/AIDS. Many of these incorporate gender dysphoria interventions, peer-led mental health/substance-misuse education and community support alongside HIV/AIDS education (e.g. Hunter-Jones et al., 2020; Nemoto et al., 2005). Similar peer-led and community projects that focus on ways to alleviate gender dysphoria should be evaluated using comparable research methods.

Strengths and limitations

This review was conducted with a high level of systematic rigour. The search for studies was exhaustive, with study selection, data extraction and quality assessment all completed with high inter-rater reliability. The method followed AMSTAR guidelines to ensure high quality reporting of findings (Shea et al., 2017).

It is important to recognise the low research quality of several included studies and the possible impact this may have on the validity of any conclusions made. The limited reporting of study characteristics and confounding factors (e.g. length of intervention, relationship between outcome and participant age) made it difficult to clearly establish the association between study factors and outcomes. There is potential for authorship bias throughout much of the research literature, as several studies were authored by

clinical staff in which interventions are routinely offered. All future intervention studies should conform to pre-established guidelines and checklists to improve the quality of the research and reporting style of studies (Shea et al., 2017).

There was a wide range in the measures used for different mental health difficulties, with many outcomes being sub-scales of larger measures of quality of life. This may have impacted on the reliability of certain measures and the validity that different measures were examining the same mental health domain.

Despite the prevalence of mental health difficulties in trans* people, many do not experience mental health difficulties. These participants may be less likely to experience any change in their mental health by post-intervention. For many of the studies, the pre-intervention mental health of participants compared to normative outcomes is not considered when measuring change. Subsequently this is not explored in this review but may be important when interpreting the effectiveness of interventions.

Reflexivity

It is important to acknowledge our own positioning and potential bias when synthesising the research findings. LS is a cisgender white male who has a gender-affirmative positioning regarding trans* care, rights and support. Whilst care was made to select and synthesise research papers in an objective and rigorous scientific method, it is feasible that the author's biases may have impacted on the analysis and presentation of research findings.

This review does not fully account for intersectional factors such as class, economic circumstances, ethnicity and age (amongst others) when exploring the research findings (Cho, Crenshaw, & McCall, 2013). Intersectional factors may have a unique impact on an individual's experience of healthcare and mental health beyond what is reported within the included studies (Bower-Brown & Zadeh, 2020; White & Fontenot, 2019) and should be included in study reporting.

Conclusion

Many trans* people experience significant mental health difficulties directly related to their gender dysphoria (Sohn & Bosinski, 2007). This review indicates that hormone and psychological interventions are effective at improving the mental health of trans* people, especially for depression outcomes. There is less conclusive evidence to suggest that surgical interventions improve mental health for trans* people, although further investigation of longer-term change is required. Future research should focus on examining other types of methods used to alleviate gender dysphoria and investigate the relationship between post-intervention mental health and gender minority stress factors.

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Service Improvement Project

Feasibility and implementation of a brief distress tolerance intervention in Community Eating Disorder CAMHS

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Embedded Abstract

Adolescents with eating disorders experience higher levels of psychological distress compared to the general population. Distress is particularly pronounced during the first stage of the Family Based Treatment due to the focus on refeeding and weight restoration. It is feasible that equipping adolescents to manage distress early on in treatment may positively impact on later engagement and recovery. This service improvement project describes the feasibility and implementation of a brief distress-tolerance intervention delivered alongside the first phase of FBT in a community Child and Adolescent Eating Disorder Service. This study was approved by the service NHS Research and Development team (ID: 286525). 15 adolescents (aged 11-18) in the first phase of FBT received two fortnightly 1-1 sessions with an Assistant Psychologist. Intervention content was based on distress tolerance dialectical-behavioural strategies. The Distress Tolerance Inventory (DTI) was administered at pre-test and two-week follow-up. Participants were interviewed about their experience and usefulness of the intervention sessions. Paired sample t-tests indicated tentative effectiveness of the intervention. Thematic analysis identified key superordinate themes: 'Empowerment and Skilling Up', 'Delivery and Relevance' and 'Connection and Psychological Support'. The intervention was seen as highly acceptable and empowering for participants starting FBT. More sessions may be needed to ensure consolidation of newly learnt skills. Next steps regarding wider service implementation and empirically evaluating impact (e.g. on crisis referrals) are discussed.

Introduction

Adolescents with eating disorders experience substantially higher levels of psychological distress compared to the general population (Trompeter et al., 2021). This distress may manifest in panic attacks, screaming, angry outbursts, running off, making threats of harm, non-suicidal self-injury (NSSI) and suicidality. One prevalence study found that 40.8% of patients had self-harmed during treatment offered by community Child and Adolescent Mental Health Eating Disorder Services (CAMHS ED), with more young people expressing statements of intent to self-harm or end their life when in periods of high distress (Peebles, Wilson, & Lock, 2011). NSSI is highly prevalent for individuals with an eating disorder, with some prevalence rate estimates rising to 72% (Anderson, Carter, McIntosh, Joyce, & Bulik, 2002; Claes, Klonsky, Muehlenkamp, Kuppens, & Vandereycken, 2010).

There are many possible reasons why adolescents with an eating disorder experience high levels of distress. Prior to self-harm adolescents often report overwhelming and uncontrollable feelings of sadness, anger and guilt (Chapman, Gratz, & Brown, 2006; Nock, Prinstein, & Sterba, 2009). The distress behaviours may serve as self-punishment for allowing oneself to eat and break dietary behaviours, to communicate dissatisfaction and despair, to be anxiety relieving, or to increase parents' anxiety in the hope that they will stop monitoring their eating (Lock & Le Grange, 2015). The behaviours can become ritualistic or associated with dissociative thinking. Individuals with eating disorders who self-harm often report feeling calm and relaxed afterwards (Claes et al., 2010).

Distress often rises during treatment in response to increased supervision and challenges to the young person's disordered eating (Wufong, Rhodes, & Conti, 2019). Caregivers may feel more challenged by the elevated distress from the young person and subsequently become more avoidant or ambivalent of distress-inducing interventions (e.g. mealtimes; Whitney et al., 2005). Furthermore, risk of serious physical consequences following high distress behaviours (e.g. NSSI) is particularly heightened for many adolescents with eating disorders due to their low-weight and other health-related concerns (Wufong et al., 2019).

There is an unmet need for psychological distress-focused interventions for adolescents with eating disorders (Trompeter et al., 2021). A common intervention delivered to adolescents and their caregivers by CAMHS ED services is Family-Based Treatment (FBT), an outpatient treatment that places emphasis on the role of the parents/carers in supporting the young person to gain weight and normalise eating patterns (Lock & Le Grange, 2015). The first phase of FBT usually lasts between 8-10 weeks and prioritises weight restoration and engaging and assisting the caregivers in providing support for the young person. At the start of treatment the young person may have limited cognitive capacity and experience difficulty in making decisions for their care and wellbeing. As such, in the early stages of treatment the main focus of intervention is on mobilising and supporting parents with refeeding, and there is less emphasis on the young person having direct 1-1 support.

A possible limitation of the FBT intervention model is that it does not address the high levels of distress that adolescents likely may experience in the early stages of treatment. One qualitative study explored the experiences of adolescents in services where the

primary focus of early treatment is on weight gain and the prevention of weight loss. The service users described how the limited input of psychological support at the start of treatment can be perceived as 'punishing', 'scary' and failing to address psychological issues that contributed to the illness (Offord, Turner, & Cooper, 2006). It is hypothesised that helping the adolescent to feel better equipped to manage distress may positively impact on treatment engagement and recovery. Furthermore, CAMHS ED services providing distress-focused interventions 'in-house' may reduce the number of referrals to other teams (such as CAMHS Crisis services) and mean that distress-related concerns are addressed by clinical teams who already have a pre-existing relationship with the adolescent. However, it is critical that these interventions can be integrated into existing treatment plans and take into consideration the reduced cognitive capacity of adolescents with an eating disorder at the start of treatment.

One intervention that has shown to be effective at reducing distress-related behaviours is Dialectical Behavioural Therapy (DBT; Miller, Rathus, DuBose, Dexter-Mazza, & Goldklang, 2007; Walsh & Eaton, 2014). DBT is an intervention guided by cognitive-behavioural and mindfulness principles. It was developed as a treatment for women with Borderline Personality Disorder who presented with emotional dysregulation, NSSI and suicidal intentions (Linehan, 2014). A crucial component of DBT is 'distress tolerance' which assists individuals in sitting with difficult emotions without using NSSI or other unhelpful behaviours to neutralise the distress. Skills are taught to enable individuals to manage crises and reduce the automatic behaviours of NSSI. This is typically achieved via self-soothing, distraction techniques, calming, relaxation and using pros and cons to rationalise the use of NSSI. There is a small evidence base to suggest that brief DBT informed distress tolerance interventions can feasibly be

delivered to adolescents in school settings (Zapolski & Smith, 2017) and as part of an intensive treatment for eating disorders (Rockwell, Boutelle, Trunko, Jacobs, & Kaye, 2011).

This paper describes the implementation and assessment of feasibility of a brief distress-tolerance intervention delivered alongside the first phase of FBT in a community CAMHS ED service. This service improvement project examines the acceptability and usefulness of the intervention for adolescents and explores preliminary evidence for its' effectiveness in reducing distress.

Method

Design and Ethics

This is a feasibility service improvement project using a Plan-Do-Study-Act quality improvement and clinical audit paradigm (NHS Improving Quality, 2014). A mixed methods design was used. The qualitative elements were conducted following established criteria for rigour in qualitative research (Denzin & Lincoln, 1994). This study was approved by the Oxford Health Foundation Trust Research and Development office (PID 286525). Information sheets were shared with families and informed consent was gained. Further information on study protocol and ethical considerations can be found in Appendix B.

Participants

Study recruitment took place between September – December 2021 within the Oxfordshire and Buckinghamshire community CAMHS ED services. Adolescents between the ages of 11-18 who at the time of recruitment had received up to 3 sessions of the first phase of FBT were invited by the clinical care team to take part in the study. Adolescents who were receiving psychiatric or inpatient treatment from other services concurrently with FBT were not eligible to be included in the study. Two adolescents declined to take part as they felt they were not experiencing difficulties managing distress. Three adolescents completed pre-testing but did not complete the post-test due to an inpatient admission or being unable to be contacted. Fifteen adolescents (age range: 13-17, mean age: 14.9) participated and completed both pre- and post-testing. Participant characteristics are summarised in Appendix C. Whilst the study was open to patients in the service with any eating disorder, all of the participants had an eating disorder diagnosis of anorexia nervosa only.

Procedure

A two-session intervention protocol was developed by the lead author with feedback/input from service-users and supervisors (Appendix D). A 1-hour training session was delivered by the lead author to four Assistant Psychologists (APs) working in the service. The session focused on delivering the intervention and managing any risk that arose during sessions. The APs received regular weekly individual/group supervision as part of their standard clinical practice in which any issues raised in intervention delivery could be discussed. The lead author was available throughout the study for ad-hoc supervision on request. Any risk or safeguarding issues that arose were discussed with the clinical care coordinator of the participant and relevant notes were made on the service's clinical record management system.

The APs met one-to-one with the participants either in-person at the CAMHS service or online via Microsoft Teams. Informed signed consent to take part was gained at the start of the first session from both the participant and, if aged below 16, their parent/carers. A pre-test questionnaire (Distress Tolerance Scale, DTS; Simons & Gaher, 2005) was administered by the APs at the start of the first session. The second session took place two weeks after the first session.

Two weeks after the end of the intervention, the lead author contacted the participant via telephone to conduct a semi-structured interview and administer the post-test DTS questionnaire. The interviewer had no prior contact with the participants before the study. A semi-structured topic guide (Appendix E) was used to direct the interviews which focused on utility and usefulness of the intervention. The topic guide was reviewed by one service-user prior to the study commencing to ensure clarity and validity. The interviews lasted between 14 to 24 minutes and were audio-recorded and transcribed. Data saturation was met as determined by the lead author.

Other study measures (see below) were collected by the care team at the assessment and at session 4 of FBT following standard clinical procedures.

Following the intervention implementation, the APs took part in a one-hour focus group led by the lead researcher and were asked to comment on their perceived feasibility of delivering the intervention long-term within the clinical services. Study outcomes were shared with the service leads and staff via a report and a presentation in a team meeting to inform future service implementation. A copy of the reports was shared with participants who were invited to comment on the findings.

Intervention

The brief intervention used in the present study was written by the lead author drawing on DBT-informed distress-tolerance skills and interventions. The lead author met with CAMHS ED service users to design the intervention and received feedback on the accessibility of the content. Service users highlighted the usefulness of ice in distress tolerance interventions, their previous difficulties engaging in mindfulness techniques and which skills felt more appropriate given patients' typical cognitive and attentional ability at the start of FBT. Skills that included exercise or muscle tension were removed due to this often being a target behaviour to reduce in eating disorder intervention. The skills chosen incorporated techniques from the distress tolerance and emotional regulation DBT modules, whilst also removing exercise-related and adding ice-related skills. The intervention consisted of two 45-minute fortnightly sessions delivered one-to-one by an AP with the participant. It focused on identifying alternative coping strategies when feeling distressed and follows a structured intervention protocol. Session 1 provided psychoeducation about distress tolerance and developing coping skills. A homework task was set for the participant to practice the skills in between sessions. Session 2 examined feedback from the homework task and involved making a self-soothe box with different personalised distress tolerance skills to practice. A therapy booklet was used alongside the sessions that the participant kept (Appendix F).

Measure

Distress Tolerance Scale.

The Distress Tolerance Scale (DTS) is a 15-question self-report questionnaire that examines an individual's ability to tolerate upsetting emotional states and sensations (Simons & Gaher, 2005). Participants are asked to select how much they agree with a

statement from 1 (strongly agree) to 5 (strongly disagree), with higher scores indicating better distress tolerance. The measure has shown good-to-excellent reliability in adolescent community samples (α = .74 - .84) and high discriminant validity for adolescent clinical samples (Tonarely & Ehrenreich-May, 2020).

Data analysis

The computer software package NVivo 10 (NVivo, 2014) was used to facilitate coding of the transcribed data. Data analysis followed guidelines for thematic analysis from Clarke & Braun (2013). The lead author read and re-read each transcript to ensure a high level of familiarisation with the data. Transcripts were then annotated and coded into nodes. Two of the participant transcripts were second-coded by an additional author (JA) to ensure that salient data was being accurately captured. Following this stage, nodes were grouped into key presenting themes by the lead author. A consultation with the two other authors was held to classify the nodes into more functionally distinct and independent subordinate and superordinate themes. Thus, the analysis was conducted, compared and contrasted by several different researchers whose varying background and experience will have informed their opinions and beliefs about the usefulness of the intervention. When acknowledging potential biases and subjectivity in interpretation (Denzin & Lincoln, 1994), it is important to acknowledge the researcher's positioning. The lead author is a male trainee clinical psychologist with a PhD incorporating qualitative methods. The lead author designed the intervention and believes that brief one-to-one support for a young person at the start of treatment is likely to be beneficial for their wellbeing.

Change between pre- and post-intervention quantitative outcomes was assessed using a paired samples t-test.

Results

Data Analysis

Whilst the statistical analysis was not powered enough to make generalisable conclusions regarding effectiveness, a one-sided paired samples t-test comparing pre-test (M = 32.4, SD = 8.5) and post-test (M = 43.1, SD = 11.5) DTS scores indicated that participants experienced an improvement in distress tolerance, $t(14) = 3.96$, $p < .001$.

Thematic Analysis

Three superordinate themes were generated via analysis and are presented in Table 2. The first theme describes how the content and skills learnt from the intervention equipped the participants when facing high distress. The second theme discusses how the intervention was received by the participants and changes that could have been made. The third theme highlights the therapeutic process factors that participants noticed when taking part in the intervention.

	Superordinate Themes		
	Empowerment and skilling up	Delivery and relevance	Connection and psychological support
Subordinate themes	Strategies used in real-world contexts	Timing right with FBT	Protected space to talk about feelings
	Ease of implementing strategies	Well-pitched and structured	Connection with a relatable therapist
	Fostering autonomy and control	More support in practicing skills	Normalising distress

Table 2: A summary of superordinate themes and subordinate themes that arose via thematic analysis

Empowerment and skilling up.

Participants highlighted the impact of the sessions in equipping them with strategies that could be easily implemented in a variety of real-world contexts. This 'skilling up' may have improved participants' sense of control and autonomy in the management of their own distress.

Strategies used in real-world contexts.

All participants identified at least one strategy learnt from the intervention that they regularly used to help manage their distress. The primary use of the strategies was that they functioned as an effective distraction from distressing stimuli.

> *"…it just really surprised me how much I could take my mind off everything else and just focus on the breathing." (P05)*

Several participants described the positive effect of the learnt strategies in helping manage anticipation or guilt around mealtimes and refeeding.

> *"I mostly used them after meals when I felt guilty or stressed in general or just when I felt overwhelmed about body image." (P10)*

Participants also shared the utility of the strategies in other contexts unrelated to mealtimes, such as when going into school or trying to sleep.

> *"When I had to go to school for the first time when I was feeling really scared, they really helped me cause mostly why I was feeling anxious was going back to school and those helped me to calm myself down." (P09)*

Ease of implementing strategies.

Many participants described how one of the benefits of the strategies were that they could easily be accessed and used in daily life, without drawing attention to themselves. For some participants, it helped them to feel integrated into family/community life without having their distress become the focus of other people's attention

> *"They gave me another way to cope … it's helpful as a different way to cope in front of other people. It's more subtle if I'm feeling distressed." (P10)*

Some participants felt that having tangible objects helped them feel able to focus on something other than their distress.

> *"Like immediately my brain and my body just relaxed. I thought the box was much easier to use because you didn't have to look for things or tell yourself to do stuff you just had to breathe and it was kind of simple and structured to give yourself." (P07)*

Fostering autonomy and control.

A theme emerged of participants developing more personal autonomy over their own ability to cope when distressed. Participants described how at the start of FBT much of their control is taken away. It may be that the intervention helped the participants value their own ability to cope and improve confidence, mastery and self-efficacy.

> *"I think I did become very reliant on other people and that was kind of the only coping strategy I had and so it kind of gave me [skills] that I could use on my own, so in the future when I would be on my own I could use them and it would be ok" (P13)*

The majority of participants described how the sessions helped them feel hopeful and equipped in addressing overwhelming feelings of distress.

> *"It's quite scary when I don't want to feel a certain way … but I have no idea what to do about it and I think that the sessions sort of made me feel like there was something to do about it which it quite calming. You can just acknowledge that you can try something." (P15)*

At the end of one interview, a participant's mother joined and shared her perspective, describing how having an intervention that encourages participants to regain control of their emotions has potential to be empowering.

> *"When they're diagnosed a lot of the independence they were just starting to get is taken away and that's really hard I think for them. She was just starting to go out with her friends a bit more and being left alone in the house a bit more and then all of a sudden it totally changes and the parent has to be back in charge like when they were little so having this makes them feel more empowered in order to help themselves." (P09)*

Delivery and relevance.

This theme describes how the intervention was received by participants and what could have been changed. The majority of participants felt that the structure of the intervention was appropriate given their stage in treatment and cognitive capacity, with the content being especially useful given how distressing the first phase of FBT could be. Often participants described that it would have been helpful to receive greater support in learning how to effectively implement the learnt strategies in different situations.

Timing right with FBT.

Almost all participants acknowledged how distressing phase one of FBT is and felt that the sessions should be delivered early on in treatment in order to improve their ability to tolerate this particularly intense and difficult part of recovery.

> *"If I'd had those methods … and kind of had this in place before treatment then maybe it would have helped me to be able to use those methods a bit more so when it does get more difficult and the mealtimes start to come into place they might be easier to use." (P11)*

Well-pitched and structured.

Almost all participants mentioned how the content was well-balanced and had a good session length. Several participants commented on liking how the intervention was simple, structured and skills-focused, especially at a time when they might be feeling overwhelmed or unable to engage with cognitively demanding interventions.

> *"I preferred that because it wasn't all just sitting and talking. I feel like the sessions had a bit more of an objective to them and I think the tasks and activities guided the sessions. And I think sometimes I can find it quite hard to describe how I'm feeling or find what to say but I found having specific tasks helped me kind of figure out what to say." (P02)*

Participants differed in whether they preferred face-to-face or online. One participant suggested that two different booklets be produced for different age groups as at times the content may have felt too simplistic.

> *"Maybe you could have two different sorts of work booklets for a younger age and an older age. You could add more and put slightly more complex things in the older booklets." (P05)*

More support in practicing skills.

Several participants described how they found it difficult to use the strategies when feeling highly distressed or angry and spoke about how they would have liked the opportunity to discuss how to overcome this obstacle. The majority of participants described that it would have been useful to have either an extra session or additional time within the sessions to focus on how to implement the skills in different contexts and situations.

> *"[I want] to know when best to use the strategies, whether you should use the strategies before you get distressed or afterwards, and kind of to see how at what times they work the best." (P15)*

The majority of participants suggested that a third follow-up session could be used to 'problem-solve' and establish how and when the strategies can be implemented.

> *"I think maybe one more could help. I think maybe like just to cause obviously after the first session there's a gap then there's a second one … where I made the box so I think it would be helpful to have another session to see how the skills and soothing box has gone and see what can be done to make it better." (P03)*

Connection and psychological support.

This theme highlights the positive impact of having a safe protective space, even if short-term, for participants to talk about psychological issues at the start of their eating disorder treatment. Many participants highlighted the additional benefit of the sessions in normalising their distress and subsequent negative cognitions around their personal capacity to cope.

Protected space to talk about feelings.

The majority of participants mentioned how useful it was to have a space outside of FBT to talk about issues that were not directly focused on their eating disorder. Some participants spoke about how this was the first time that they had ever spoke about psychological issues and that this brought feelings of relief.

> *"I think I liked it because it was the first time I'd spoken to someone that was more about my brain and less about what I'm consuming and how much I'd gained … It was just really nice to have someone to talk to about the more mental part of it … it was almost, not exciting but relieving to be able to talk about some of the struggles I was having mentally." (P05)*

Many participants described how they benefited from having a one-to-one therapeutic space. Some participants compared this to FBT where they may have felt overwhelmed with multiple people within the room.

> *"The fact that my mum was in the room as well for FBT made it kind of awkward … [In the 1-1 intervention] I was finding more to talk about and get off my chest because usually when I had [FBT sessions] I wouldn't really have anyone to talk to about how I'm doing." (P06)*

Connection with a relatable therapist.

Several participants described that they found it easier to engage in the intervention due to the Assistant Psychologists therapists being younger than other clinicians they had previously met and subsequently felt that they were more likely to understand and relate to their experience.

> *"She was easy to talk to, she was like calm, like it also felt easier to talk to someone younger as well cause they kind of understand more like from my perspective." (P08)*

All participants commented on positive therapist qualities that they noticed during the sessions. Therapists were described as easy to talk to, resourceful and knowledgeable which facilitated a non-judgemental and positive therapeutic environment.

> *"I felt like she had a really good understanding of the illness and she was really able to logically tell me things in a nice way and give me the strategies. I found that really, really useful." (P03)*

Normalising distress.

The majority of participants emphasised the importance of the intervention normalising and destigmatising their experience of distress. For several participants, this was the main learning point from the session that had the most impact on their recovery.

> *"Teaching myself not so much the strategies but actually just that it's ok and it's normal to feel anxious was probably like the thing that was most helpful for me … because I just always thought that when I feel anxious the first thing I need to do is get to the root of the problem but it just made me realise that being anxious and things stressing you is just a part of life and it's something that happens." (P05)*

Some participants emphasised the value in knowing that other people were in similar positions to themselves and that feelings of distress are universal.

> *"It was good to know that it wasn't just me and that there are other people in a similar situation and there are ways to cope and there are ways to help yourself when it feels like you can't." (P10)*

Several participants described how this in itself positively impacted their ability to cope in distressing situations and their eating disorder treatment.

> *"It makes you feel less alone. It makes you feel like people are helping you to do it and understand that it's not going to be easy and that you can talk to someone if you have to." (P09)*

Feedback from deliverers of intervention

A one-hour focus group was held with the Assistant Psychologists to explore the feasibility of delivering the intervention. The APs shared that the brevity and use of a protocol made the intervention easy to deliver and clinically manageable. They reported needing minimal time to prepare outside of sessions. The APs spoke about finding it difficult to integrate the intervention into other service practices. They recommended including information about the intervention in induction sessions for families and on service leaflets. There was a consensus that an additional session would be more useful in helping the participants practice how to implement the skills in real-world situations, with a suggestion that the first two sessions could be one-week apart to ensure information would not be forgotten. There was also a discussion about how the content of the sessions could be integrated into other treatments such as FBT. For example, one AP suggested having an additional third session where the AP joins a family meal to help the young person practice skills in situ.

Discussion

This paper examines the feasibility of a brief distress tolerance intervention for adolescents with an eating disorder. The thematic analysis identified how participants

applied the skills learnt in different contexts and implemented their coping strategies. The method of delivery was widely perceived as acceptable, yet participants suggested further input incorporating further skills practice. Participants emphasised the importance of normalising distress and having a space to discuss psychological issues early on in eating disorder treatment.

These findings complement the existing small-scale research demonstrating the effectiveness of integrating distress tolerance modules into treatment for adolescents with eating disorders (Murray et al., 2015; Reilly et al., 2020; Rockwell et al., 2011). The present report indicates that brief, 'light-touch' interventions that can be delivered by relatively inexperienced professionals can hold significant value for young people who may a) be unfamiliar with coping strategies and techniques, b) have limited cognitive capacity at the start of treatment, c) have never had the opportunity to speak to a professional about their mental wellbeing, and d) had not had their distress and experiences normalised and de-stigmatised. This is consistent with a number of studies that suggest that short, low intensity interventions can reduce acute symptoms and are perceived as acceptable and engaging for young people with mental health difficulties (McCarthy, 2018; Wood, Harrington, & Moore, 1996; Zhang, Park, Sullivan, & Jing, 2018). Similar to the present intervention, effective brief interventions tend to use manualised protocols that are embedded in services that provide co-occurring monitoring and support of a young person's mental health (McCarthy, 2018). In an overstretched service where therapist availability is a constant concern, this finding may hold value into how interventions are delivered in the early stages of eating disorder treatment.

One emerging theme recognised the value that 'skilling-up' participants had on their sense of autonomy. This is particularly noteworthy when considering the impact of an eating disorder and phase one of FBT on the self-sufficiency of adolescents. There is relatively little literature on the developmental implications of an eating disorder for adolescents, with some research indicating the adolescents with eating disorder report deficits in social functioning and use of coping strategies in dealing with difficulties (Patel, Tchanturia, & Harrison, 2016). This theme highlights the importance of the loss of control, reliance on increased care and reduction in autonomy on the healthy social-cognitive development of adolescents with an eating disorder.

Strengths, limitations and research implications

This study has high validity in understanding the experiences of adolescents with eating disorders taking part in the intervention. The research was conducted by experienced qualitative researchers and meets the criteria of the COREQ guidelines for rigorous reporting of qualitative research (Appendix G; Tong, Sainsbury, & Craig, 2007). Triangulation and multiple perspectives were used to capture a valid understanding of the feasibility of implementing the intervention long-term. One strength is the inclusion of service-users in the design and development of the intervention to ensure that the content and method used was valid and relevant to the experiences that participants may have.

When considering the study limitations, the small sample size and lack of control group condition means it is difficult to conclude that the observed reduction in distress can be attributed to the intervention. It is feasible that the repeated exposure the feared stimuli

(e.g. food) during FBT contributes to desensitisation and increased distress tolerance. Furthermore, participants self-selected and as such may have been more biased into wanting and embracing additional support. An examination into modifying factors, such as age, previous psychological input and familiarity with distress tolerance concepts may provide insight into active mechanisms contributing to change. A future powered study with an active control condition could further explore the effectiveness of the intervention in reducing distress, alongside secondary analyses of other symptoms associated with eating disorder recovery.

To further establish the benefit of the intervention, it would be helpful to examine the impact of the intervention on frequency of distress-related behaviours such as self-harm, the number of referrals to external crisis management services and adolescent engagement in FBT. The long-term efficacy and a cost-benefit analysis might then establish the viability of such interventions, alongside parent/carer perspectives on the impact of the intervention on distress management at home.

As with all qualitative research, it is important to acknowledge that the themes presented are not intended to be generalisable but rather reflect the experiences of these particular participants. The research team's own beliefs and expectations may have impacted on any qualitative analyses and conclusions made. These biases were mitigated in part by having supervisors involved in second coding the data and respondent validation.

Service-level implications

This study suggests that a similar intervention could be implemented in the service and could feasibly be delivered by Assistant Psychologists within existing support structures. The findings suggest that one-to-one psychological support at the start of eating disorder treatment may have significant value. It is important that the intervention is offered to families as part of their induction into the service following assessment (e.g. alongside information about parent support groups). There should be consideration about whether a third additional session could be delivered and how the learnt skills can be integrated into co-occurring treatments and parent interventions.

Conclusion

To conclude, this study reports the findings from a brief distress tolerance intervention delivered to young people with an eating disorder beginning Family-Based Treatment. This intervention has shown acceptability and feasibility when implemented in a community CAMHS eating disorder setting and there is promising evidence into intervention efficacy at improving distress tolerance.

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Theoretically Driven Research Paper

Pathways to heightened responsibility for self vs others in OCD

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Embedded Abstract

Individuals suffering from OCD experience a heightened sense of responsibility compared to community sample and anxious controls. This responsibility may vary depending on the subject of potential harm (e.g. I am responsible for my own safety vs I am responsible for other people's safety). 5 causal factors or 'pathways' to the development of heightened responsibility have been proposed. This study aims to examine the relationship between the pathways to heightened responsibility towards oneself vs towards others. 60 participants with OCD and 60 community controls completed an online questionnaire measuring childhood and early adulthood experiences and responsibility dimensions. Regression analyses established the predictive value of each pathway. 'Responsibility for oneself', 'responsibility for others' and four of the five pathway subscales were significantly higher for the OCD group. The extent that participants had acted to influence misfortune was a significant predictor of heightened responsibility for oneself. Increased responsibility as a child and experience of overprotective parenting significantly predicted responsibility for others. This study indicates that heightened responsibility for oneself vs others may develop via separate pathways. Prospective studies are needed to understand how responsibility and other OCD-related beliefs develop in adolescence and early adulthood.

Introduction

Psychological treatments for mental health problems typically target factors understood to be involved in the maintenance of the problem. Whilst there is growing evidence for risk factors for mental health problems, there is little robust evidence for causal factors which subsequently hinders the development of effective primary or secondary prevention programmes. Few, if any, mental health interventions are based on an understanding of aetiological (causal factors). The present study seeks to identify potential causal and or trigger factors in Obsessive-Compulsive Disorder (OCD) which is a highly impairing mental health problem typically having its onset in adolescence and early adulthood (Brakoulias et al., 2017). The cognitive theory of obsessions asserts that beliefs of heightened personal responsibility for preventing harm increases the distress associated with negative intrusive thoughts or images (Salkovskis, 1985). Compulsions are conceptualised as safety seeking behaviours directed at preventing the harm believed to be linked to intrusions and thereby reducing the inflated sense of personal responsibility for harm to oneself or others (Rachman & Shafran, 1998; Salkovskis, 1985).

This theory is supported by significant evidence to suggest that individuals suffering from OCD have a specific inflated sense of responsibility for the safety of themselves or others compared to community sample and anxious controls (Freeston, Ladouceur, Gagnon, & Thibodeau, 1993; Niemeyer, Moritz, & Pietrowsky, 2013; Salkovskis et al., 2000; Smári, Gylfadóttir, & Halldórsdóttir, 2003; Steketee, Frost, & Cohen, 1998). These inflated responsibility beliefs have been found to have high heritability, with parental behaviours feasibly conveying messages to children about the likelihood of threat and personal responsibility for harm (Barcaccia, Tenore, & Mancini, 2015;

Pietrefesa, Schofield, Whiteside, Sochting, & Coles, 2010; Rector, Cassin, Richter, & Burroughs, 2009). The cognitive theory of OCD alongside evidence for maintenance factors offers the prospect of understanding the initial development of the disorder.

Pathways to heightened responsibility

When considering the aetiology and development of the inflated sense of responsibility characteristic of individuals with OCD, Salkovskis, Shafran, Rachman, and Freeston (1999) proposed five non-exclusive pathways or origins, as described as follows:

1) *Increased responsibility* in which as a child they had high levels of responsibility and care for others (e.g. cooking for the family or performing adult-oriented tasks). Salkovskis et al., (1999) describes how these children may be raised with the belief that they are responsible for preventing negative outcomes. One study of mother-child dyads found that children with OCD were more likely than non-clinical samples to have mothers who would designate the child as being responsible in problem-solving scenarios (Farrell, Hourigan, & Waters, 2013).

2) *Rigid rules and codes of conduct* describes how during childhood an individual may be taught to follow extreme behavioural rules and practices, with the implicit teaching that not following these rules would result in punishment, failure and blame. Rigid rules, punishment and authoritarian parenting styles have been found to be associated with increased OCD symptoms and beliefs about personal responsibility (Mariaskin, 2009; Timpano, Keough, Mahaffey, Schmidt, & Abramowitz, 2010).

3) *Overprotective and anxious parenting* describes how individuals may have been raised in an environment with high parental anxiety and constant protection from harm or danger. This may impact on the child's sensitivity to responsibility and mean that they have a disproportional understanding of appropriate levels of personal responsibility when faced with threat. There is existing evidence to suggest that parental overprotection may be linked to the development of OCD (Haciomeroglu & Karanci, 2014; Mathieu, 2019; Yoshida, Taga, Matsumoto, & Fukui, 2005).

4) *Incidents in which one's actions/inactions caused a serious misfortune* describes the acute increase in perceived responsibility following a significant event in which a person believes that they were instrumental in causing or not preventing harm to themselves or others. For example, a patient may have been the driver in a car accident in which their friend was critically hurt and subsequently feel responsible based on how they were driving.

5) *Incidents in which it appears one's actions/inactions or thoughts influenced a serious misfortune.* This pathway differs to the one previously in that the historical event and actions/inactions or thoughts of the individual are unconnected and coincidental, and the link between the two cannot be instrumentally described. For example, a patient may have been thinking about buying a new car and then found out later that day that a friend had died in a car accident. The fourth and fifth pathways have been conceptualised as one pathway (e.g. actual or imagined harm) in confirmatory factor analyses and subsequent research studies (Adams Jr, 2012; Smári, Þorsteinsdóttir, Magnúsdóttir, Smári, & Ólason, 2010).

It is important to note that the first and third pathways can be compatible and are not necessarily part of the same continuum or high vs low responsibility in childhood (e.g. a child may have increased responsibility as a young carer for their parents yet not be allowed outside due to parental anxiety of harm coming to them) (Coles & Schofield, 2008).

Empirical evidence for pathways

There have been several studies on the aetiology of OCD that support the proposed pathways to heightened responsibility beliefs. One measure, the Pathway to Inflated Responsibility Belief Scale (PIRBS) was developed and tested with student samples to identify the presence of the proposed pathways and their significant association with OCD symptoms and inflated responsibility (Coles & Schofield, 2008; Smári et al., 2010).

The PIRBS total score, and 'overprotective parenting' and 'actions that caused or influenced serious misfortune' subscales have been found to be correlated with increased responsibility in adults with OCD (Coles et al., 2015), with the other two subscales also correlating with responsibility beliefs and symptom severity for youth with OCD (Collins & Coles, 2018). Heightened sense of responsibility has been shown to mediate between the proposed pathways and OCD symptoms (Smári et al., 2010). One cross-sectional study with a non-clinical sample found that the 'increased responsibility' and 'causing or influencing serious misfortune' pathways were significantly related to specific OCD subtypes (Adams Jr, 2012). However, evidence of

the link between the pathways and OCD subtypes, and the mediating role of increased responsibility has yet to be studied in clinical samples.

Heightened responsibility for self vs others

It is unclear whether heightened responsibility in OCD differs depending on the perceived subject of harm. Whilst there has been research into the perception of one's own responsibility vs others' responsibility (e.g. I am responsible for harm vs other people are responsible for harm; Ashbaugh, Gelfand, & Radomsky, 2006; Menzies, Harris, Cumming, & Einstein, 2000), there has been limited empirical research examining attributes of responsibility for self vs others (e.g. I am responsible for *my own* safety vs I am responsible for *other people's* safety).

Such differences in the focus of OCD have been hypothesised as relating in different ways to responsibility beliefs (Obsessive Compulsive Working Group, 1997; Tolin, Brady, & Hannan, 2008). Foa, Steketee, & Young (1984) theorised that individuals with OCD are more preoccupied with harm coming to others rather than to themselves, unlike in other anxiety-related disorders where the focus is primarily on the sense of threat to their own welfare. Taking a different perspective, Rachman (2002) suggested that different subtypes of OCD were associated with different aspects of responsibility, predicting that checking behaviour was associated with the aim of protecting others from harm and contamination related behaviours related to protecting oneself from harm. This was supported by a small study showing participants with the checking OCD subtype were more likely than those with the contamination subtype to feel responsible for protecting others from harm over themselves (Rachman, 2002).

There is limited further empirical evidence to support this theory. Forbes, Bream and Salkovskis (2012) conducted a study exploring whether the two subtypes of responsibility (self vs other) was associated with different phenotypes of OCD. The researchers adapted the Responsibility Attitude Scale (Salkovskis et al., 2000) to measure responsibility for self and for others. Heightened responsibility for oneself was more strongly associated with contamination symptoms than responsibility for others. Contrary to Rachman's (2002) findings, Forbes et al. found no relationship between the responsibility types and checking behaviours, although this study was underpowered, unpublished and did not include a comparison between clinical and control samples.

Further research is needed to establish how responsibility regarding harm either to one's self or others is distinguished in OCD. It is possible that the different pathways to heightened responsibility previously identified may predict distinct responsibility dimensions (self vs other). The development and types of responsibility beliefs may differ between those with and without OCD (Coles & Schofield, 2008).

To date, almost all previous studies of inflated responsibility conflate both responsibility towards oneself and others into one measure. This study aims to examine the relationship between the pathways to heightened responsibility towards oneself vs towards others. Additionally, this study will explore whether these differences are unique for those with OCD or are replicated in a non-clinical sample.

A greater understanding of how different dimensions of inflated responsibility are developed may have implications on the cognitive and aetiological theories of OCD (Shalev, 2013).

Method

Design

This research used a between subjects experimental design to determine whether participants with OCD who have experienced different 'pathways' have different attributions of responsibility towards themselves or others, and whether this effect is consistent with participants without OCD. Additionally, a correlational design using regression analyses was used to understand the relationship between the pathways, responsibility domains and OCD subtypes. Two individuals with lived experiences of OCD were invited to be consultants on this project to help modify and shape the questionnaire measures used and method of data collection. This study received ethical approval from the University of Oxford Central University Research Ethics Committee (CUREC Reference R74411/RE001).

Participants

One hundred and twenty-five adult participants were recruited via online advertisement and community support groups and charities. Of these, 62 participants were currently experiencing OCD and were either screened via telephone/video call using the OCD sub-section of the Structured Clinical Interview for DSM-5 (SCID-5; (First, Williams,

Karg, & Spitzer, 2015) by the lead researcher or had previously completed a screening by another researcher from the Oxford Clinical Psychology Anxiety Research Group. The first 15 of the SCID screening interviews were audio-recorded and second-rated by a research assistant to ensure coder reliability which was found to be excellent (κ) = 1.00.

The remaining 63 participants formed a non-clinical control sample. The control sample were not interviewed but were instead asked to confirm at the start of the questionnaire that they had not had or currently receive or question a diagnosis of OCD. Control participants who scored both above 42 in the Obsessive-Compulsive Inventory (OCI) and 10 in the Work and Social Adjustment Scale (WSAS; see below more information about measures) were excluded from the study to prevent group contamination. Three participants were excluded in this way. Two additional participants were excluded from analyses as their responses were significant consistent outliers indicating possible data entry error, resulting in both groups having 60 participants. The sample size was determined following an a-priori power analysis using G*Power. A summary of participant demographic information collected can be found in Table 1.

Procedure

Study information was shared with potential participants via email before taking part in the study. Consent to take part in the study was taken either by the lead researcher during the screening interview or by completion of a form at the start of the questionnaire. Participants were asked to complete an online Qualtrics questionnaire at home in their own time comprising of the below measures. Online data collection was

deemed to be reliable for assessing constructs relating to anxiety (Coles, Cook, & Blake, 2007). The questionnaire took approximately 15 minutes to complete. Participants were not paid to take part in the study.

Measures

Structured Clinical Interview for DSM-5 Research Version (SCID-5; First et al., 2015). The SCID-5 is a semi-structured interview guide for DSM-5 diagnoses. It is administered by a clinician or trained mental health professional who is familiar with the DSM-5 classification and diagnostic criteria. The interview is conducted either face-to-face, over video or telephone and is used to diagnose OCD based on the DSM criteria.

Obsessive Compulsive Inventory (OCI; Foa, Kozak, Salkovskis, Coles, & Amir, 1998). The OCI is a 42-item self-report measure assessing the presence and severity of OCD symptoms and is composed of 7 subscales: Washing, Checking, Doubting, Ordering, Obsessing (i.e. having obsessional thoughts), Hoarding, and Mental Neutralising. A 5-point (0- 4) scale of symptom distress is used to rate each item. Mean scores are calculated for each of the seven subscales, and an overall mean 'distress' score Scores are totalled to form an overall mean 'distress' score and mean scores are calculated for each of the subscales. A total score of 42 or more, or a mean score of 2.5 or more in the subscales indicates the presence of OCD. The OCI shows high test-retest reliability and good internal consistency and construct validity (Foa et al., 1998).

Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002). The WSAS is a 5-item self-report measure assessing the impact of a psychological problem on different aspects of a person's life. The scale has a moderate correlation with OCD symptom severity and a good internal reliability (Mundt, Marks, Shear, & Greist, 2002)

Pathways to Inflated Responsibility Beliefs Scale (PIRBS; Coles & Schofield, 2008). The PIRBS is a 23-item instrument to measure five different pathways to inflated responsibility. The five subscales of the PIRBS are: Increased Responsibility (5 items); Rigid Rules (5 items); Overprotective Parenting (5 items); Actions Caused Misfortune (4 items); and Actions Influenced Misfortune (4 items). A 5-point (0-4) scale is used to measure the presence of each of the items ('never' to 'always'). Two changes were made to the questionnaire following service-user involvement feedback in order to improve the clarity and understandability of the measure. For the measure of the fourth subscale, the scale items were altered from 'Never; Rarely; Sometimes; Often; Always' to 'Not at all; Unlikely; Possibly; Likely; Definitely'. The item description for the fifth item included the following lines (in italics): "Sometimes it appears that something we think or do may have resulted in a serious misfortune, *even when other people might not think it was your fault*" and "We are interested in whether you have ever felt like your thoughts or actions have resulted in a serious misfortune occurring, *even if there may have been other explanations behind it*". The items are summed to form a total PIRBS score and score for each pathway. The PIRBS has good internal consistency $\alpha >$ .78 and shown positive test-retest reliability and convergent validity when compared with similar measures of beliefs, OCD and responsibility (Coles & Schofield, 2008). Prior to data analysis, the PIRBS Subscales Actions Caused Misfortune and Actions Influenced Misfortune each have 4 items and were scaled (multiplied by 1.25) to have

comparable scores with each of the other Subscales (5 items). A four subscale version of the PIRBS has been used in which the totals from the fourth and fifth subscales are combined to be named 'Actions caused/Actions influenced' (Smári et al., 2010).

Modified Responsibility Attitudes Scale – Self (MRAS-Self; Forbes, Bream, & Salkovskis, 2012; Salkovskis et al., 2000). The RAS is a 26-item scale that is designed to assess general assumptions and beliefs about responsibility. Participants are given a statement relating to responsibility and are asked to rate their agreement/disagreement with the statement by giving ratings on a seven-point scale, ranging from totally agree to totally disagree. The RAS score is the sum of the 26-item scores. Salkovskis et al. (2000) report the RAS has high reliability and internal consistency, and can discriminate between people with OCD, anxious controls and non-clinical control participants. The MRAS-Self is a modified version of the RAS developed by Forbes et al. (2012) which specifically refers to responsibility attitudes towards the self. This scale identifies participants who show excessive responsibility to protect the self from harm. Forbes et al. (2012) reported good internal consistency and showed good validity when examining correlations between the measure and the RAS and OCI.

Modified Responsibility Attitudes Scale – Others (MRAS-Others; Forbes, Bream, & Salkovskis, 2012; Salkovskis et al., 2000). The MRAS-Others is a modified version of the RAS which specifically refers to responsibility attitudes towards others. This scale identifies participants who show excessive responsibility to protect others from harm. Forbes et al. (2012) similarly reported good measure reliability and validity when comparing with existing measures.

Data analytic strategy

To assess whether there were any baseline differences between the two groups (OCD vs Control) in terms of demographic characteristics or OCI scores, independent samples t-tests and a Chi square test were used.

A general linear model repeated-measures ANOVA was used to examine differences between Groups and PIRBS and to assess whether an interaction between Group and Subscale was present. Independent sample t-tests were used to examine differences between the Groups in each of the PIRBS subscales and Responsibility scales (Coles, Schofield, & Nota, 2015).

Two hierarchical multiple regressions were used to examine the predictive power of each of the PIRBS subscales on sense of Responsibility for Oneself and for Others. The relevant assumptions for this statistical test were examined (Appendix V).

Table 2: Demographic information and measure outcomes by group

	OCD group	**Control group**	
Demographics			
n	60[b]	60[b]	
Mean age (SD)	40.1 (12.15)	49.38 (18.03)	$t(118) = 3.31$, $p < .001$[a]**
Age range	19-64	23-78	
n Female (%)	44 (73%)	40 (66%)	χ^2 (2, n = 120) = .64, p = .426
OCI mean (SD)	70.05 (24.35)	12.88 (10.54)	$t(118) = 16.69$, $p < .001$[a]**
WSAS mean (SD)	21.48 (9.40)	5.07 (6.61)	$t(118) = 11.07$, $p < .001$[a]**
PIRBS scores *Mean (SD)*			
Total	38.67 (15.44)	25.02 (12.09)	$t(118) = -5.39$, $p = <.001$**

Increased Responsibility	5.35 (5.23)	4.07 (4.28)	$t(118) = 1.47$, $p = .144$
Rigid Rules	11.55 (5.93)	9.07 (5.16)	$t(118) = 2.45$, $p = .016$*
Overprotective Parenting	9.72 (5.14)	6.17 (3.90)	$t(118) = 4.26$, $p < .001$[a]**
Actions Caused Misfortune	12.05 (8.30)	5.72 (6.08)	$t(118) = 3.88$, $p < .001$[a]**
Actions Influenced Misfortune	6.28 (5.02)	3.27 (3.33)	$t(118) = 4.95$, $p < .001$[a]**
MRAS-Self Mean (SD)	101.78 (33.35)	63.33 (31.31)	$t(118) = 6.51$, $p < .001$**
MRAS-Other Mean (SD)	91.43 (28.38)	65.48 (28.88)	$t(118) = 4.96$, $p < .001$**

[a] Unequal variances as determined by Levene's test for equality
[b] Note: Four additional participants were excluded (not reported, see Participants section for rationale).
* = $p < .05$ (two-tailed), ** = $p < .01$ (two-tailed)

Results

Demographics

The age of participants ranged from 19 to 78 years (M = 44.74, SD = 16.00). Age was non-normally distributed, with skewness of .38 (SE = 0.22) and kurtosis of -.98 (SE = 0.44). There was a significant difference in age between the control and OCD groups, $t(118) = 3.31$, $p < .001$. There was no significant difference in gender distribution between the two groups. Total OCI and WSAS scores were significantly larger in the OCD group compared to the Control group (respectively: $t(118) = 16.69$, $p < .001$; $t(118) = 11.07$, $p < .001$).

Measure reliability

The OCI was found to have a high internal consistency (42 items; α = .97), with each of the subscales also demonstrating very high reliability (Washing: 8 items, α = .95; Checking: 9 items, α = .92; Doubting: 3 items, α = .91, Ordering: 5 items, α = .90, Obsessions: 8 items, α = .92; Hoarding: 3 items, α = .85; Neutralising, 6 items, α = .85). The WSAS was found to have a high internal consistency (5 items, α = .94).

When examining the PIRBS measure, the Increased Responsibility, Rigid Rules and Overprotective Parenting subscales each consisted of 5 items (respectively α = .84, α = .92, α = .87). The Actions Caused Misfortune and Actions Influenced Misfortune subscales each consisted of 4 items (respectively α = .87, α = .85). The MRAS-Self and MRAS-Others measure each consisted of 26 items and was found to be highly reliable (respectively α = .97; α = .95).

Comparisons between OCD and Control group in PIRBS scores

A repeated measures ANOVA revealed a significant main effect of group (OCD vs Control) $F_{(1, 118)} = 29.7$, $p < .001$ and a main effect of PIRBS Subscale, $F_{(3.5, 407.5)} = 33.4$, $p < .001$ (as sphericity is violated, ε = .86, Greenhouse-Geisser corrected results are reported), yet the Group by PIRBS Subscale interaction was not significant. An independent samples t-test on the difference between PIRBS Subscale scores between the OCD and Control group found significant differences in Total score, $t(118) = -5.39$, $p < .001$; Overprotective Parenting, $t(118) = 4.26$, $p < .001$; Actions Caused Misfortune, $t(118) = 3.88$, $p < .001$; and Actions Influenced Misfortune, $t(118) = 4.95$, $p < .001$ (see Figure 1).

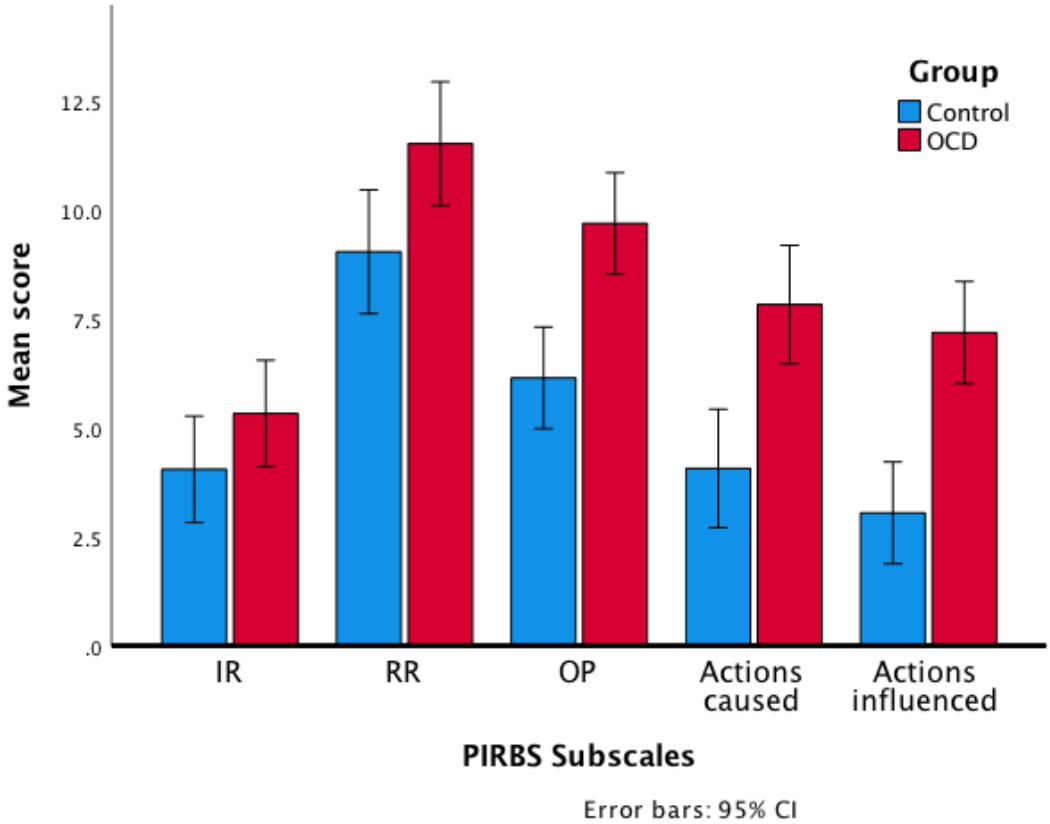


Figure 1: A bar chart showing different mean PIRBS Subscale scores for the Control and OCD groups. IR: Increased Responsibility, RR: Rigid Rules, OP: Overprotective Parenting.

Comparisons between OCD and control group in MRAS-Self and MRAS-Others scores

When examining differences in MRAS-Self and MRAS-Others outcomes between groups, a significant main effect of Group (control vs OCD) was found, $F_{(1, 118)} = 43.06$, $p < .001$). A significant group by subscale interaction effect was found; $F_{(1, 118)} = 5.57$, $p = .020$ (Figure 2).

A Bonferroni correction was used, setting $\alpha = .0125$ when investigating these differences. An independent samples t-test found that participants in the OCD group (M = 101.78, SD = 33.35) reported significantly higher Responsibility for Oneself (MRAS-

Self) compared to the Control group (M = 63.33, SD = 31.31); $t(118) = 6.51$, $p < .001$. Similarly participants in the OCD group (M = 91.43, SD = 28.38) reported significantly higher responsibility for others (MRAS-Others) than Controls (M = 65.48, SD = 28.88); $t(118) = 4.96$, $p < .001$. A paired-sample t-test found that there were no significant differences between the MRAS-Self and MRAS-Others in both the Control; $t(59) = -0.88$, $p = .383$ and OCD groups; ($t(59) = 2.20$, $p = .032$.

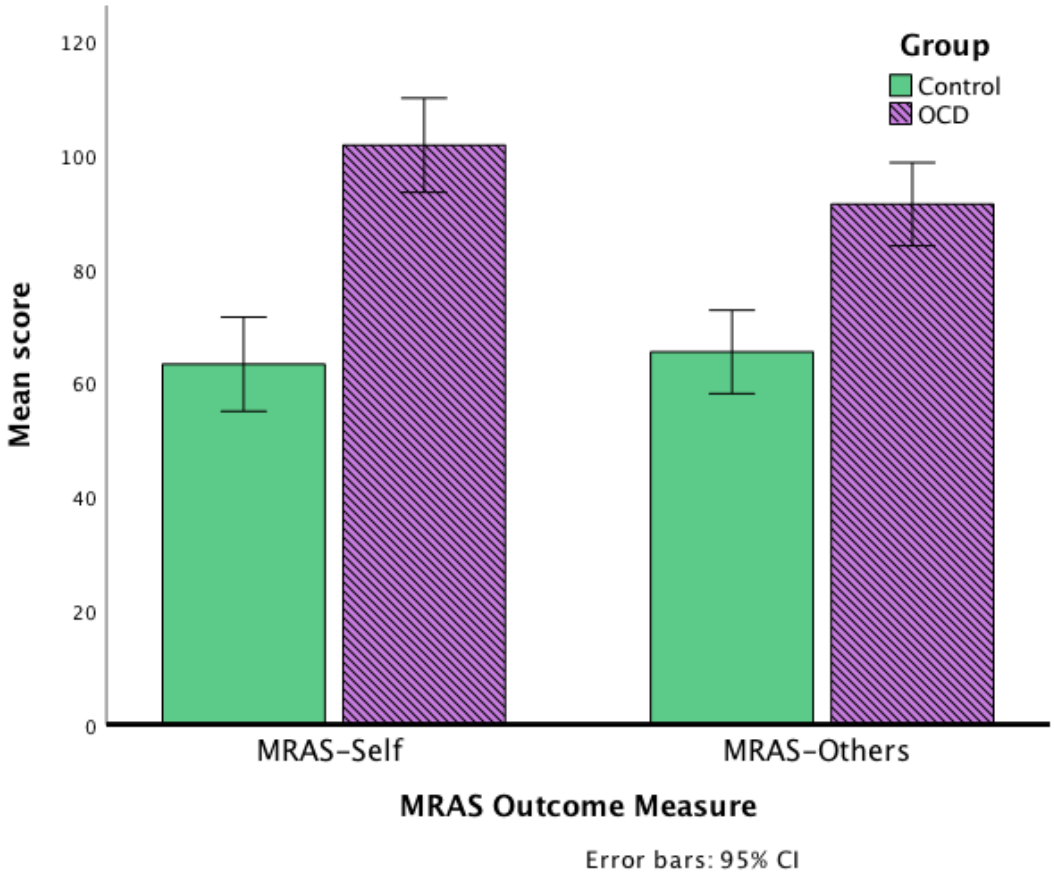


Figure 2: A bar chart showing mean Responsibility for Oneself and Responsibility for Others scores for the Control and OCD groups

Predicting Responsibility for Self from PIRBS subscales

A correlational matrix of variables can be found in Appendix X. A three-stage hierarchical multiple regression analysis was used to test if the different PIRBS

subscales significantly predicted participants' Responsibility for Oneself (MRAS-Self). Age was entered at the first stage to control for significant age differences identified between groups. The five PIRBS subscales were entered at the second stage, and the Group type (Control vs OCD) was entered in the final model to establish how much of the variance could be explained by the presence of OCD. The regression statistics are reported in Table 2. The results of the regression indicated that at the second stage, the five pathways contributed significantly to the regression model, $F_{(6, 113)} = 8.78$, $p < .001$ and accounted for 28% of the variation in Responsibility for Oneself, an addition of 24% compared to the stage where only Age was entered. The addition of Group type explained an additional 9% of the variation and this change in R^2 was significant, $F_{(1, 112)} = 15.94$, $p < .001$. In the third model, the only independent PIRBS subscale that was a significant predictor of Responsibility for Oneself was Actions Influenced Misfortune ($\beta = .33$, $p = .007$). Unlike the other subscales, the Actions Caused Misfortune had a negative β coefficient when predicting Responsibility for Oneself, although this effect was not statistically significant, and these variables do not negatively correlate (multicollinearity assumptions were not violated; VIF = 2.13), suggesting that responsibility towards oneself is not statistically dependant on prior Actions that Caused Misfortune.

Table 3: Regression Coefficients for Predicting MRAS-Self Outcomes

Predictor variables	B	95% CI	β	*t*	*p*
Model 1					
(Constant)	111.53	[92.11, 130.95]		11.37	<.001
Age	-.65	-1.06, -.24	-.28	-3.14	.002
Adjusted R^2 = .07, R^2 Change *p* = .002					
Model 2					
(Constant)	63.67	[39.46, 87.87]		5.21	<.001**
Age	-.33	[-.72, .07]	-.14	-1.64	.104
PIRBS: Increased responsibility	1.30	[.04, 2.57]	.17	2.04	.044*
PIRBS: Rigid rules	.83	[-.36, 2.02]	.13	1.39	.169
PIRBS: Overprotective Parenting	1.15	[-.18, 2.49]	.15	1.72	.089
PIRBS: Actions caused misfortune	-1.22	[-3.09, .66]	-.15	-1.29	.201
PIRBS: Actions influenced misfortune	3.76	[1.41, 6.11]	.40	3.17	.002**
Adjusted R^2 = .28, R^2 Change *p* < .001					
Model 3					
(Constant)	30.72	[2.71, 58.74]		2.17	.032*
Age	-.21	[-.59, .17]	-.09	-1.10	.274
PIRBS: Increased responsibility	1.04	[-.16, 2.24]	.13	1.72	.088
PIRBS: Rigid rules	.80	[-.32, 1.92]	.12	1.42	.159
PIRBS: Overprotective Parenting	.50	[-.79, 1.80]	.07	.77	.442
PIRBS: Actions caused misfortune	-1.41	[-3.17, .36]	-.17	-1.58	.116
PIRBS: Actions influenced misfortune	3.09	[.86, 5.33]	.33	2.74	.007**
Group (Control vs OCD)	25.37	[12.78, 37.96]	.34	3.99	<.001**
Adjusted R^2 = .37, R^2 Change *p* < .001					

Note: CI = Confidence Interval for B; * = $p < .05$ (two-tailed), ** = $p < .01$ (two-tailed)

Predicting Responsibility for Others from PIRBS subscales

The same three-stage hierarchical multiple regression analysis was replicated to instead examine how each of the variables predicted participants' Responsibility for Others (MRAS-Others). The regression statistics are reported in Table 3. Similarly at the second stage, the five pathways contributed significantly to the regression model, $F_{(6, 113)} = 8.59$, $p < .001$ and accounted for 28% of the variation in Responsibility for Others, an addition of 24% compared to the stage where only Age was entered. The addition of Group type explained an additional 3% of the variation and this change in R^2 was significant, $F_{(1, 112)} = 5.31$, $p = .023$. In the third model, Increased Responsibility ($\beta = .19$, $p = .021$) and Overprotective Parenting ($\beta = .29$, $p = .001$) were significant predictor of Responsibility for Others.

Table 4: Regression Coefficients for Predicting MRAS-Others Outcomes

Predictor variables	B	95% CI	β	*t*	*p*
Model 1					
(Constant)	101.65	[85.38, 117.91]		12.38	<.001**
Age	-.52	[-.86, -1.76]	-.27	-3.00	.003**
Adjusted R^2 = .06, R^2 Change *p* = .003					
Model 2					
(Constant)	57.54	[37.26, 77.82]		5.62	<.001**
Age	-.32	[-.65, .01]	-.16	-1.91	.059
PIRBS: Increased responsibility	1.37	[.31, 2.44]	.21	2.56	.012*
PIRBS: Rigid rules	.83	[-.16, 1.83]	.15	1.65	.101
PIRBS: Overprotective Parenting	2.22	[1.10, 3.33]	.35	3.94	<.001**
PIRBS: Actions caused misfortune	.31	[-1.27, 1.88]	.04	.39	.701
PIRBS: Actions influenced misfortune	.26	[-1.71, 2.23]	.03	.26	.793
Adjusted R^2 = .28, R^2 Change *p* < .001					
Model 3					
(Constant)	40.90	[16.39, 65.42]		3.31	.001**
Age	-.26	[-.59, .07]	-.13	-1.56	.122
PIRBS: Increased responsibility	1.24	[.19, 2.30]	.19	2.35	.021*
PIRBS: Rigid rules	.82	[-.16, 1.79]	.15	1.65	.101
PIRBS: Overprotective Parenting	1.89	[.76, 3.02]	.29	3.31	.001**
PIRBS: Actions caused misfortune	.21	[-1.34, 1.75]	.03	.27	.791
PIRBS: Actions influenced misfortune	-.08	[-2.03, 1.88]	-.01	-.08	.939
Group (Control vs OCD)	12.81	[1.80, 23.83]	.21	2.31	.023*
Adjusted R^2 = .30, R^2 Change *p* = .023					

Note: CI = Confidence Interval for B; * = $p < .05$ (two-tailed), ** = $p < .01$ (two-tailed)

Discussion

This experimental study aimed to examine how different proposed aetiological 'pathways' are related to heightened responsibility towards oneself and towards others in adults with OCD. Participants with OCD scored significantly higher than community controls in four of the five proposed pathways (Rigid rules, Overprotective parenting, Actions caused misfortune, Actions influenced misfortune), with there being no reported difference for the 'Increased responsibility' in childhood subscale. Participants with OCD had significantly higher sense of responsibility for oneself and for others compared to control participants. There were no significant differences between responsibility for oneself and for others within each group. An analysis of the predictive value of each of the pathways for each of the types of responsibility found that 'Actions influenced misfortune' was a consistent significant predictor of sense of responsibility for oneself when adjusting for group. 'Increased responsibility' and 'Overprotective parenting' were significant predictors of sense of responsibility for others, even when adjusting for differences between OCD and control groups.

This study supports the existing body of evidence that sense of responsibility is elevated for individuals with OCD compared to those without (e.g. Niemeyer et al., 2013; Salkovskis et al., 2000). Similarly, this study supports research highlighting the positive relationship between childhood responsibility experiences and the presence of OCD and heightened responsibility (Coles et al., 2015; Smári et al., 2010). Consistent with previous research, there was no difference in the PIRBS subscale 'Increased responsibility' as a child between the two groups and similarly the subscale was the least endorsed by participants with OCD, which may indicate the presence of a floor

effect (Coles & Schofield, 2008; Coles et al., 2015). Whilst the domains of responsibility beliefs (towards oneself vs towards others) differ in the same way between those with and without OCD (Coles & Schofield, 2008), the precursors to their development may be unique.

Different PIRBS subscales were significant predictors of the separate responsibility dimensions. When examining responsibility for oneself, the subscale 'Actions influenced misfortune' was the only significant predictor of responsibility for oneself (when controlling for group). This finding is comparable to one study which found that the subscale 'Actions that caused or influenced serious misfortune' (the two items were combined into one subscale) was significantly correlated with increased sense of responsibility (Coles et al. 2015). Interestingly, in this study whilst both items were positively correlated with Responsibility for Oneself, Actions that Caused Misfortune had a negatively valued predictor coefficient (although this effect was not significant) which may indicate that how previous events are interpreted (I caused vs I influenced) may have differential protective or causal effects on responsibility attributions. One difficulty with interpreting this finding is that the subscale may encapsulate a variety of experiences and life events. There is small body of evidence to suggest that adverse childhood experiences and traumatic life events contribute to the development of OCD-related dysfunctional beliefs (Briggs & Price, 2009) and symptom severity (Cromer, Schmidt, & Murphy, 2007). However, there is little research into which specific kinds of adversity or life events (e.g. betrayal) are responsible for these changes and whether these experiences are predominately acute or chronic. It would be useful for future studies to examine the qualia of these life experiences in order to understand whether

there are direct links to the development of heightened responsibility specifically for one's own safety and wellbeing.

The experience of 'overprotection' in childhood was a predictor of responsibility for others and not for oneself. Whilst there is existing evidence to suggest that many people with OCD experience overprotective parenting (e.g. Mathieu, 2019; Turgeon, O'Connor, Marchand, & Freeston, 2002), this study indicates that it may be more prevalent for individuals who experience heightened responsibility for others. Overprotective parenting may contribute to heightened perceptions of threat and increasingly avoidant behaviour, and subsequently children may learn that preventing harm to others in a dangerous world is of paramount importance (Mariaskin, 2009). Children experiencing overprotective parenting may feel less of a need to worry about their own wellbeing, and yet may also have gained a disproportionate understanding of how concerned and responsible they should feel for other people's safety, replicating their parents' own behaviour and/or anxieties. Future research may test this hypothesis by studying whether children's sense of responsibility, worry and concern for others vs themselves may differ depending on their parents' own anxiety and overprotection.

Study limitations

Prospective studies of the effects of adverse childhood experiences may not show as strong a relationship as retrospective reports (Widom, Raphael, & DuMont, 2004), suggesting a possible bias in participants attributing meaning and/or interpretation to their early experiences based on their current functioning. The retrospective reporting of childhood and early adulthood events in this study may be influenced by recall bias in part related to the current psychological wellbeing of participants. Future studies

would benefit from use of prospective or longitudinal measures in order to make conclusions around causality.

The present study may benefit from the addition of a comparison group (e.g. anxious controls) in order to establish specificity in whether the pathways predicting responsibility outcomes are unique to OCD.

Implications

This study indicates that several of the proposed developmental pathways can explain differences in sense of responsibility for oneself vs others. These may hold predictive value in heightened responsibility regardless of the presence of co-existing OCD symptomatology. There may be clinical value in exploring how experiences in which 'actions influenced misfortune' may have shaped the individual's beliefs about responsibility for oneself in order to create more effective cognitive modifications. Preventative interventions may wish to focus on reducing overprotective parenting styles and encourage children to have realistic understandings of threat and personal responsibility for harm to others.

This study highlights the value in seeking to understand the aetiological basis of mental health conditions. Future research may seek to examine the relationship between the PIRBS subscales, the responsibility dimensions and specific OCD subtypes through structural equation modelling in order to develop subtype specific interventions.

Summary

To conclude, this study explores the relationship between proposed pathways in the development of heightened responsibility towards oneself and for others in OCD. There is a difference in which pathways uniquely predict increased sense of responsibility for oneself and for others. Further research in aetiological causes and factors contributing to maladaptive beliefs may be crucial in the prevention and early intervention of anxiety disorders.

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Executive summary

Introduction

'Heightened responsibility' is the sense of feeling responsible if bad things were to happen to you or to other people. Obsessive Compulsive Disorder (OCD) is a condition in which a person has recurring thoughts and behaviours that are difficult to control. There is lots of research showing that a 'heightened responsibility' is a very common characteristic of OCD. For example, a person with OCD may have the frequent belief: 'If my child gets sick then it will be completely my fault'.

Childhood often sets the scene for the later development of anxiety difficulties and OCD. It has been proposed that there are five main causes or ***'pathways'*** to heightened responsibility in OCD. These are:

1) Increased responsibility as a child (e.g. cooking for the family regularly)
2) Rigid rules and codes of conduct in childhood (e.g. breaking strict rules would result in punishment and blame)
3) Overprotective and anxious parenting (e.g. being constantly protected by parents from harm and danger)
4) Incidents in which one's actions/inactions caused a serious misfortune (e.g. being the responsible driver in a car accident)
5) Incidents in which it appears one's actions/inactions or thoughts influenced a serious misfortune. This pathway differs to the one previously in that the event and actions/inactions of the individual are unconnected and coincidental. For example, a

patient may have been thinking about buying a new car and then found out later that day that a friend had died in a car accident.

It is not known whether these five 'pathways' affect the way people with OCD worry about themselves (e.g. it is my fault if *I* get sick) and other people (e.g. it is my fault if *my friend* gets sick).

This study aims to explore whether different childhood experiences are associated with different aspects of 'heightened responsibility' (towards oneself vs towards others). Understanding this would give clues to how we can prevent and treat OCD. We also included people in the study who are not experiencing OCD (called *community controls*) to examine whether these processes exist uniquely in OCD.

Method

This study received ethical approval from the University of Oxford Central University Research Ethics Committee (CUREC Reference R74411/RE001). Two individuals with lived experiences of OCD were invited to be consultants on this project to help modify and shape the questionnaire measures used and method of data collection.

Sixty participants who were experiencing OCD and 60 community controls took part in the study. Participants who had OCD took part in a screening interview with a researcher to ensure that they were still experiencing clinical levels of symptoms. Study information was shared with participants before they took part, and consent to take part was gained.

Participants were asked to complete an online questionnaire at their home in their own time. The questionnaire took around 15-20 minutes to complete.

There were four main measures used in the questionnaire. The first one asked about each of the five 'pathways' to capture participants' early life experiences. The second and third measures asked about participants' sense of responsibility for themselves and for others respectively. The final one asked about current OCD symptoms. Participants were not paid to take part in the study.

Results

The age of participants ranged from 19 to 78 years with a mean average of 44. Participants who had OCD scored significantly higher than community controls in both measures of responsibility (towards oneself or towards others). They also scored significantly higher in each of the 'pathway' measures apart from the one measuring heightened responsibility in childhood.

A statistical analysis was used to identify which of the 'pathways' predicted how responsible participants would feel towards themselves or others. Only the fifth pathway, 'actions influenced misfortune', predicted levels of responsibility towards oneself. Both 'heightened responsibility as a child' and 'overprotective parenting' predicted levels of responsibility towards others.

These findings did not significantly differ between the OCD and community control group, indicating that the relationship between the pathways and responsibility beliefs may not be unique to those with OCD.

Discussion

These findings support existing research showing that the sense of responsibility and the presence of the 'pathways' is higher for individuals with OCD compared to those without.

This study indicates that several of the proposed 'pathways' can explain differences in sense of responsibility for oneself vs others.

There may be clinical value in exploring how experiences in which 'actions influenced misfortune' may have shaped the individual's beliefs about responsibility for oneself in order to create more effective treatments. Preventative interventions may wish to focus on reducing overprotective parenting styles and encourage children to have realistic understandings of threat and personal responsibility for harm to others. Further research in the causes and factors contributing to unhelpful beliefs may be crucial in the prevention and early intervention of anxiety disorders.

Reflective Narrative

Below is an account of reflections, learning and challenges faced when conducting each of the three research projects.

Critical Review of the Literature (CRL)

This CRL was developed from learning about the huge disparity in mental health difficulties and access to appropriate services for trans and non-binary people compared to the general population. Following conversations with staff from the Northamptonshire Gender Identity Clinic, it became clear that there was little evidence base for the interventions being offered in regard to mental health outcomes. It was felt that a review of existing literature may hold value for services identifying how to use their resource and make a case for further commissioning.

It was important that I remained as neutral and objective as possible when analysing the research literature. There is a great ongoing public debate around what interventions should look like for people with gender dysphoria. I personally have always been very 'trans-affirmative', meaning that I believe that the feelings, choices, beliefs and personal preference of trans people should be prioritised and respected. My internal supervisor encouraged me to consistently be reflexive about my own positioning, methodological stance and process throughout the research. Within supervision we discussed ways of reducing possible bias (e.g. by making a clear protocol of analysis and write-up prior to reading the papers and committing to report on findings regardless of direction).

As always with a systemic review, the process was incredibly time intensive and exhaustive. One frustration I felt when analysing the research was the high propensity of low-quality research, and in particular the overlooking of key data in the write-up and reporting of study characteristics. This process has helped me to appreciate how to ensure that the research I disseminate is reported to a high-standard.

It was important for me to integrate the service-user voice into each of the three projects, yet this was harder to achieve for the CRL. I intend to collaborate with service-users in a revised version of the paper to comment on the findings in a collaborative discussion in order to enrichen the readers' understanding of possible explanations for the outcomes.

Service Improvement Project (SIP)

I was drawn to the idea of the project proposed by my internal supervisor as my primary research interest is in identifying ways of capitalising on existing resources and knowledge to improve service effectiveness without compromising the amount of resource that can be offered. I really enjoyed the barriers and rewards from working in a research setting that has real-world applicability and impact.

Despite the intervention being so brief and relatively simple, I was surprised to hear how positively received it was from clinicians and patients. Following a presentation of the findings at the Eating Disorder International Conference, I have had multiple clinicians contact me asking for ways to replicate the intervention in their service,

which highlighted to me the need for grounded and simple tools that can be used by overwhelmed services.

This was the first time I have attempted to gain ethical approval via the IRAS process working with NHS Trust Research and Development teams. This proved to be an incredibly stressful process, with delays attributed in part due to the Covid-19 pandemic and long waits for staff to review and offer amendments to the submitted documents. Ultimately, we were told that the project no longer required ethical approval from the Health Research Authority and instead could obtain the much less onerous approval as a clinical audit and service improvement project. Despite this change, the process taught me how to write clear and exhaustive study and intervention protocols that followed a number of best practice data management and governance guidance.

Theoretically Driven Research Project (TDRP)

The TDRP was developed after working with one client who had highly pervasive and strong convictions of responsibility of safety for her mother. This often meant that she would be in dangerous situations completing her compulsions in order to satisfy the obsessions to keep her mother safe. When asking about these dangerous situations, it became clear that she had little sense of responsibility or interest in her own safety. In conversation with my internal supervisor, it became clear that there was little research or intervention that distinguishes between different types of responsibility when working with OCD.

My supervisor then directed me towards literature on possible aetiological pathways to heightened responsibility in OCD and it struck me how little an understanding we have over the causal mechanisms behind various mental health difficulties.

One highlight of the project was the privilege of conducting screening interviews with many different individuals who had lived experience of OCD. I was amazed by the willingness of participants in wanting to take part in research and share their experiences in the hope that it would lead to more effective treatments for others.

The project was my first experience using paid social media advertisements to gain participants. This was surprisingly effective and it did not take long for the recruitment materials to reach over a thousand people. One advantage of using the Facebook advertising was that I could control certain demographic features such as age in order to try and get as closely matched groups as possible.

Onwards involvement in research

I hope that this when working in clinical settings I continue to have the time and dedicated space to integrate research, service improvement and the supervision of trainee research projects. There is still a significant discrepancy between what is offered in NHS mental health settings and what service-users want and need, and I intend to bridge this gap in my future practice.

Acknowledgements

Thank you to my course tutor Dr Reena Vohora who has helped me remain on track and navigate through all the course demands. Thank you to my research supervisors, namely Dr Matthew Knight, Dr Joanna Adams, Professor Paul Salkovskis, Dr Sonia Bues, Dr Sue Cotton, Dr Fiona McFarlane and Dr Abi Wroe (as well as the rest of the course admin and teaching staff). I have been lucky to have exceptional placement supervisors Jodie Leigh, Natalie Holmes, Dr Abi Wroe, Dr Sophie Mills, Dr Mat Lister and Simon Cornwell.

Thank you to my personal tutor Dr Ryan Nah for your wisdom and kind words when I am in times of stress.

I am endlessly grateful to my friends and family who have encouraged and supported me over the years.

Most of all, I want to thank the patients, service-users and research participants who I have worked with over the last three years.

Appendices

Appendix A: CRL Instructions to authors for nominated Clinical Psychology Review journal

Clinical Psychology Review publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.

Reviews on other topics, such as psychophysiology, learning therapy, experimental psychopathology, and social psychology often appear if they have a clear relationship to research or practice in **clinical psychology**. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies and theoretical treatises or clinical guides without an empirical base are not appropriate.



Before You Begin

Ethics in publishing

Please see our information on Ethics in publishing.

Declaration of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double anonymized) or the manuscript file (if single anonymized). If there are no interests to declare then please state this: 'Declarations of interest: none'. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to

conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's Author Services.

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Article structure

Manuscripts should be prepared according to the guidelines set forth in the most recent publication manual of the American Psychological Association. Of note, section headings should not be numbered.

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least to 3 months within date of submission) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (http://www.prisma-statement.org/) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

Corresponding author. Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address"' (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Highlights

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract

should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Graphical abstract
Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.
Authors can make use of Elsevier's Illustration Services to ensure the best presentation of their images and in accordance with all technical requirements.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations
Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements
Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources
List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources

available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

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General points

• Make sure you use uniform lettering and sizing of your original artwork.
• Embed the used fonts if the application provides that option.
• Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
• Number the illustrations according to their sequence in the text.
• Use a logical naming convention for your artwork files.
• Provide captions to illustrations separately.
• Size the illustrations close to the desired dimensions of the published version.
• Submit each illustration as a separate file.
• Ensure that color images are accessible to all, including those with impaired color vision.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the most recent publication

manual of the American Psychological Association. Information can be found at https://apastyle.apa.org/

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.

Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions.* Mendeley Data, v1. http://dx.doi.org/10.17632/xwj98nb39r.1

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To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

Appendix B: Quality review of articles using EPHPP tool

Author(s) Country	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Intervention integrity	Analyses	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Aldridge et al. (2020) UK	2	2	1	2	1	3	1	1	2
Briggs et al. (2018) USA	3	2	3	2	1	2	1	2	3
Budge et al. (2021) USA	3	2	1	2	1	1	1	2	2
Cardoso da Silva et al. (2016) Brazil	2	2	1	2	2	1	3	2	2
Colizzi et al. (2013) Italy	1	2	2	2	1	3	1	1	2

Author(s) Country	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Intervention integrity	Analyses	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Colizzi et al. (2014) Italy	2	2	3	2	1	1	1	1	2
Colizzi et al. (2015) Italy	2	2	2	2	1	1	3	1	1
Costantino et al. (2013) Italy	3	2	3	2	3	1	1	3	3
Cotton & Wood (2019) UK	2	2	3	2	1	2	1	1	2
Drydakis (2016) UK	3	2	3	2	1	2	2	1	3
Fisher et al. (2016) Italy	2	2	3	2	1	1	2	2	2
Heylens et al. (2014) Belgium	1	2	3	2	1	2	2	2	2

Author(s) Country	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Intervention integrity	Analyses	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Isung et al. (2017) Sweden	2	2	3	2	1	1	2	1	2
Knutson et al. (2020) USA	2	2	3	2	1	2	2	1	2
Lingqvist et al. (2017) Sweden	2	2	3	2	3	3	2	3	3
Matthys et al. (2021) Netherlands, Belgium, Norway, Italy	3	2	1	2	1	3	2	1	3
Megeri and Khoosal (2007) UK	2	2	3	1	2	3	3	1	3
Meier (2014) USA	3	2	2	2	2	2	3	3	2
Metzger (2019) Switzerland, Germany	1	2	2	2	1	1	2	2	1

Author(s) Country	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Intervention integrity	Analyses	Quality rating (1 = strong, 2 = moderate, 3 = weak)
Naeimi et al. (2019) Iran	2	2	1	2	1	3	2	1	2
Nobili et al. (2020) UK	2	2	3	2	2	3	2	1	3
Oda & Kinoshita (2017) Japan	3	2	3	2	3	3	3	3	3
Papadopulos et al. (2017) Germany	1	2	3	2	1	1	2	1	2
Udeze et al. (2008) UK	2	2	2	2	2	3	3	2	2
van de Grift et al. (2016) Netherlands	2	2	1	2	1	2	2	2	1
van Dijk et al. (2019) Netherlands, Belgium, Italy	3	2	2	2	3	2	1	2	3

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify _____
8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):

1 STRONG
2 MODERATE
3 WEAK

Appendix C: SIP Ethical protocols and data protection

Informed Consent

At the start of the first intervention session, the Assistant Psychologist delivering the intervention will take informed consent/assent from both the adolescent and their parent/carer. The participants will have read an information sheet detailing the procedure of the study and how any personal information will be processed and stored. Participants will have the opportunity to ask any questions during the initial telephone conversation with the CI, with the Assistant Psychologist taking consent and via email with the research team via a contact email address.

If the intervention takes place face-to-face, written informed consent will be sought. Participants aged 11-16 will complete an assent form with their parent/carers completing a consent form. Participants aged 16+ will complete a consent form. If the intervention will take place over video conferencing software, participants will be sent a copy of the consent form via email by the Assistant Psychologist in advance of the first intervention session. Participants will be asked to provide verbal consent. The oral consent script will be read by the Assistant Psychologist to the participant explaining the study. The consent statements will then be read to the participant with the Assistant Psychologist completing a paper consent form on behalf of the participant concurrently. This will then be signed by the Assistant Psychologist, scanned and a copy emailed to the participant for their records on the same day.

Withdrawal of Participants

Each participant has the right to withdraw from the study at any time. The participant and all identifiable data or tissue collected would be withdrawn from the study. Data which is not identifiable to the research team may be retained.

Data Sharing and Access to Data

The lead clinician will ask the family whether the lead researcher can contact them in the coming week to discuss the study further. The adolescent and their parent/carer will be asked to sign a form giving permission for the family's contact information to be accessed by the research team (name, telephone number, email). This signed form will be stored at the study location by the lead clinician and given to the CI within two weeks from collection. If they consent, the CI will access the potential participant's Carenotes to view their contact details (name, telephone number and email). For those that consent to being contacted, the CI will contact the family via phone once in the following week after they have received the contact information. In this conversation the CI will explain the aims and method of the study to both the adolescent and their parent/carer and allow potential participants to ask any questions that they have. If they agree to take part in the study, an appointment for the first intervention session will be arranged.

The research team and CI will have access to the data. The CI will have access to the participants' Carenotes files which will contain relevant contact information (name, email and phone number) and demographic information collected by the service.

Direct access to pseudonymous/anonymous research data will be granted to authorised representatives from the Sponsor and host institution for monitoring and/or audit of the study to ensure compliance with regulations.

The name, email address and phone number of participants will be kept on Carenotes in the participant's records. The email address and phone number of participants will remain on Carenotes and will be directly accessed by the CI using their own staff login details.

A separate password protected Microsoft Excel linkage list file will be kept on a password-protected Oxford Health computer. Only the research team and Assistant Psychologists will have access to the linkage list file.

Only the research team and Assistant Psychologists will have access to the research data file.
Audio recordings of participant interviews will be conducted by the CI and will only be accessed by the CI.

Electronic scans of consent forms will be stored by either the CI, Assistant Psychologists or care team on a password-protected folder on an Oxford Health computer and be accessible by the CI, research team and clinical care team. These will be deleted by the CI or care team 3 years after the end of the study. The CI is responsible for them remaining secure. A copy will also be uploaded to the participant's Carenotes by either the CI, Assistant Psychologists or care team. The consent form will not contain the participant numeric ID.

The process of identifying potential participants will be conducted by the service clinical team with no patient information being shared with the lead researcher or other members of the research team outside of the service. Potential participants will be asked whether they give permission for their contact details (name, telephone number and email address) to be shared with the lead researcher. A signed record of their consent will be kept by the participants with a copy kept by the service. Patient contact details will only be shared with consent from the patient.

Data Collection, Recording and Record Keeping

This study collects child-reported data. Participants will be given a numeric identifier. This identifier would be used on all data entry in place of identifiable participant information. A separate password protected Microsoft Excel linkage list file will be kept on a password-protected Oxford Health computer. The CI will copy the name of the participant from Carenotes only the linkage list alongside the unique participant numeric identifier. At the end of the participant's participation in the study, the name of the participant will be removed from the linkage list file by the CI, leaving only the participant number. The linkage list sheet will be destroyed 3 years after the end of the research study by the CI or a member of the clinical team.

The consent form to share information will be kept in a locked secure cabinet at the study site and destroyed by the CI at the end of the research study.

Following each intervention session the Assistant Psychologist will write a comprehensive clinical note on the CareNotes system as per usual practice to provide a summary of the session and document any issues that arose.

The name, email and phone number of participants will be collected by the service during standard clinical protocol and kept on Carenotes. Email addresses may be used by the CI in direct email communication with the participant. This will always be from a password-protected Oxford Health email account. At the end of the participant's participation in the study, all email communication between the research team and the participant will be deleted, with records of the email communication being copied onto Carenotes following standard clinical procedure. Phone numbers will not be copied anywhere else, and any records of this information (e.g. phone number in call records) will be deleted immediately after use. For example, the CI may access Carenotes to find the telephone number of a participant. Immediately after the CI has called them using their personal phone, the phone number will be deleted from their phone call log.

Questionnaires will be completed either by the participant completing a paper copy or questions being asked by the Assistant Psychologist/CI to the participant and their responses being recorded onto the Microsoft Excel sheet. Paper copies of questionnaire data will be immediately transferred by the Assistant Psychologist to a locked cabinet within the study site location. Once all quantitative data has been copied from the paper copy onto the datasheet it will be immediately destroyed by the Assistant Psychologist or CI by putting them in the service's confidential waste bin. All quantitative study research data will be entered onto a password-protected Microsoft Excel sheet kept on a password-protected Oxford Health computer on the Oxford Health NHS Foundation Trust OneDrive network, using the participant numeric identifier (study participant number). The name of the participant and any other identifying details will not be included in any study research data electronic file. The data will be entered by an Assistant Psychologist (who collects the quantitative data) or by the CI. Pseudonymous research data will be anonymised after the participant's completion of the study, as their name and numeric identifier will be deleted from the linkage list. The anonymous research data will be stored for 3 years after publication of research findings. After 3 years after publication of research findings the data will be destroyed by the CI or study supervisor.

Audio recordings of participant interviews will be made using an Oxford Health iPad using the Voice Memos application. Audio-recordings will be immediately uploaded to the CI Oxford Health OneDrive and then deleted from the ipad. When not in use the ipad will be kept in a locked cabinet in the home of the CI. The audio-recordings will only be accessible by the CI. Transcriptions of the audio-recordings will be completed by the CI onto a password-protected Microsoft Word document on the password-protected and encrypted Oxford Health iPad. Identifying information (names, personal details) will not be included in the transcription of the audio-recording. The participant numeric identifier will be included as part of the transcription. The audio recordings will be immediately uploaded by the CI following recording to their Oxford Health Onedrive and then be deleted from the iPad. They will be permanently deleted by the CI from the Onedrive within 3 months of data collection or once the recording has been transcribed. Pseudonymised (anonymised following participant completion of study)

research transcription data will be deleted by the CI 3 years after publication of research findings.

Personal identifiers may be used within a recording (e.g. the use of names). This will not be included within transcriptions. To prevent this from occurring, participants will be asked at the start of the interview to refrain from mentioning names or identifiable information about themselves or other people during the interview.

Appendix D: Participant characteristics

Numeric identifier	Gender	Age
P01	Female	15
P02	Female	15
P03	Female	14
P04	Female	15
P05	Female	17
P06	Female	17
P07	Female	13
P08	Female	14
P09	Male	15
P010	Female	17
P011	Female	15
P012	Male	14
P013	Female	15
P014	Female	13
P015	Female	15

Appendix E: Intervention protocol

Brief distress tolerance intervention protocol for therapist

This protocol uses materials adapted from Dialectical Behaviour Therapy practices related to distress tolerance. The intervention is very brief (2 sessions) and is intended to be a first line of treatment at the start of Family-Based Treatment.

The aim of the intervention is to equip the young person with healthy skills and strategies to use when feeling distressed.

Session 1 – Introducing distress tolerance and self-soothing – 45 minutes

Introductions (5 minutes):

- Introduce yourself and explain the focus for today. Acknowledge that the session may feel overwhelming, and that the purpose of today is to explore what can help when emotions become a bit too intense. Allow the young person to ask any questions that they may have.

- Re-establish confidentiality agreement. "What we speak about today will not be shared with people outside of the service. However, I might speak to other people in the service about what we discuss. If we talk about something where I am worried for you or someone else's safety, then this will be something that we might discuss in sessions with your parents/carers. Is this ok?"

Introduction to distress tolerance (10 minutes):

"We will start today by thinking about what 'distress tolerance' is"

- Show handout 1.

"When our emotions get too intense, sometimes we manage it in ways that aren't great. For example, sometimes when I get stressed and I feel I have too much to do I might start to shout or get snappy at people (refer to sheet and point out example). Often when emotions get really high some young people shout, scream, hurt themselves, say nasty things, threaten to hurt themselves or others, cry."

"What do you sometimes do when your emotions get strong?"

- Circle the examples on the handout that the young person identifies and add any extra examples to the bottom.

"The focus of today and our next session is to help you manage when these things are going on. It isn't about changing how you feel, but instead changing how able you are to cope when the emotions get high."

"So why is this important to do?"

- Read out loud or ask the young person to read Handout 2.

- Explore the young person's views on the handout. Allow them to ask any questions that they may have.

Complete questionnaire (5 minutes):

"As this is a new intervention we are running at the service, we would like to see whether it is useful or not for young people. To do this we have these questionnaires– would it be ok if we go through these?"

- Ask the young person to complete the DTS questionnaire. If they would prefer, you could read out the items and they can provide responses.

Identifying examples of good distress tolerance (10 minutes)

"So, let's think, we've identified times when we don't manage strong emotions so well. Can we think of any times that you do manage the strong emotions well? For example, was there a time when you felt really angry or upset but managed to stay calm? What did you find helped? What meant that you were able to stay calm?"

"What do you find relaxing or helps you unwind? We'll make a list here and come back to it at the end"

- Write down these examples on handout 3.

Deep breathing (5 minutes):

Show handout 4.

"Another thing we can practice is breathing. Why do you think deep breathing helps us to calm? This may seem obvious, but when we are anxious our heart starts beating faster because it thinks we are in danger. Why do you think this might be? Yes, it tries to prepare our muscles and body to respond, either by fighting or by running away. By doing slower breathing, we can tell our heart and body that we are safe and it helps us feel calmer."

Practice box breathing exercise together with young person.

"One deep breathing exercise that helps is called box breathing. You look around you and find a rectangle or square. When you start looking you begin to realise how many there are (e.g. windows, laptop screen). You place your finger in the bottom left of the screen and slowly trace your finger along each edge clockwise. When you go along the left and right side, you breath in through your nose and out through your mouth. When along the top and bottom, you hold your breath. Should we practice for a minute? … How are you feeling in your body now?"

54321 exercise (5 minutes):

"We're going to practice an activity now that can be really helpful when we are getting upset. When we get upset our head gets really overwhelmed and busy. This activity

helps bring us out of our heads and back to the world around us and helps calm down the brain."

- Show handout 5. Practice exercise with them. (5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell, 1 deep breath).

- When practising this try to encourage them to spend time thinking about what the senses are like (e.g. what does it feel like? Is it warm, cold, rough, soft?). If the young person says 'I can't hear anything' encourage them to continue to listen until they pick up on something. For smell, try to encourage the young person to find something that has a soft smell, like a pencil or washing detergent. Smells of food may be triggering for the young person so try to encourage them to find things that are not directly related to food.

"What was it like? How are you feeling now? Have you noticed any change to how you are feeling now compared to before?"

Finish and recap (5 minutes):

- Show handout 6.

"This week it may be helpful to practice these skills. When we practice them regularly we get better at using them when we really need them. It's important to practice these skills even when you aren't feeling upset. There are three things to practice this week: a) noticing how you manage when emotions get high, b) using my list of things I find relaxing and c) using my new calming strategies."

- Discuss with the young person the possibility of practicing these skills throughout each day in the week (e.g. breathing exercise in the morning and evening or during meals). What do they anticipate the barriers will be for practicing these? Problem solve and discuss ways that would work for them.

- Put sheets in binder/workbook for young person.

<u>Session 2: Practising distress tolerance</u>

Check in and review things to practice sheet (5 minutes):

"How have you found the past week? How were the moments where emotions got too much? Did you manage to use any of the strategies from last week?"

- Allow time for the young person to process and describe their week. It is important to not use punitive language here, but instead explore what they felt were the barriers to using the strategies, and what did found helpful. Normalising and empathy is crucial.

Self-soothe with 5 senses (10 minutes):

“We’re now going to try another exercise which can help with calming us in the moment”.

- Show handout 7. Talk through the handout, identifying things that the young person likes or finds relaxing/soothing for each of the five senses. Write these down.

Using ice (5 minutes):

“When emotional arousal is very high, you are completely caught in Emotion Mind. Emotion Mind is when your brain is not processing information and things become too much. One thing that helps with Emotion Mind is ice. Ice helps to calm us down when we are feeling overwhelmed. It can be a good substitute for some of the unhelpful behaviours that we sometimes do when we are upset”

- Show handout 8. This has information about how to use ice in helpful ways. Discuss with the young person what they might find helpful to try. Add these examples to the above list under ‘touch’.

Making a self-soothe kit (20 minutes):

“So let’s take all of these things that we know are helpful and put them into what we call a self-soothe kit. Then, when you notice that emotions are starting to get high, instead of doing the unhelpful behaviour, you can instead go to this box.”

- Think about things to include in the box (a shoebox or equivalent) based on the previous activity. Make a list with the young person of items that they can share with their parent/carer after the session.

- Discuss how they would like to decorate the box and what they need to do this.

- Try to include a mixture of tactile objects, things related to the senses, and written instructions (e.g. breathing exercise), words of encouragement (positive coping thoughts) and distraction items (e.g. music, something to read). What is something that you would like to say to a future you that is feeling overwhelmed? Encourage the young person to write this down and include it in the box. Also ask them to add the handout sheets they have worked on to the box to look at when they are feeling distressed (this could be scanned copies).

- Think about the following questions with the young person:
    - Where are you going to put this box?
    - How are you going to remember to use it?
    - When should it be used?

Finishing (5 minutes):

“What have we learnt – what one thing are you going to take away from today’s session?”

Remind young person about crisis services and options when distress cannot be managed.

At the end of each session parents may be invited to join if appropriate. The therapist or young person can then share with parents anything they have learnt from the session and any strategies that they would like to practice.

Other information:

Carenotes and outcoming appointments:

Each session should be outcomed on Carenotes as a 'Treatment' session. A clinical note should be uploaded following each session with the below template:

Purpopse: [Participant name] attended the [Session Number] DBT Distress Tolerance session [face-to-face / on Microsoft Teams] facilitated by [your name]. Topics covered were [identifying distress-related patterns, deep breathing and relaxation techniques / self-soothing techniques and creating a coping toolkit]

Mood/behaviour: [Participant name] appeared to be [brief description of presentation, e.g. settled and in a positive mood at the beginning of the session]/

Participation: [Participant name] participated [brief description of how they participated, e.g. appropriately in the session and was well engaged in several of the tasks. They felt quite tired towards the end of the session].

Risk-related information: [Insert any risk-related information here]

Plan: Next session [insert date and location].

Risk:

Any risk-related information that arises from the session should be shared with the care-coordinator for the family after the session. This can be shared via email, telephone or face-to-face. If immediate current risk is discussed within the session (e.g. current risk of self-harm), the session should be paused and the on-duty clinician or care-coordinator for the young person be contacted.

Supervision:

Reflective practice following the sessions can be discussed in regular group and individual supervision you receive. An additional ad-hoc 1-1 supervision session can be requested by emailing me at any time throughout the study.

Arranging appointments:

Once the family agree to take part in the study, either myself, Jo Adams or the care-coordinator will let you know that you can contact the family. Please arrange appointments directly with the parent/carers and young person.

Administration:

All consent forms should be scanned and uploaded to Carenotes with the title "Brief Distress Tolerance Intervention Consent Form".

There are three types of consent forms: parent/carer consent, 16-18 consent and 11-15 assent. If the young person is aged 11-15, the parent/carer should sign a consent form and the young person an assent form. If the young person is aged 16-18, the young person should sign their own consent form.

Please print the therapy booklet and give it to the young person in Session 1. The booklet should be brought by the young person to Session 2 which should occur approximately 2 weeks after Session 1. Pens should be provided.

Online appointments:

If the appointment will occur online, please arrange appointments via Microsoft Teams. Please print and send the therapy booklet and consent form in the post prior to the first session. If this cannot be done, please let me know and I can try to print/send them.

At the start of the first session, please ask the participants (and their parent/carers) for verbal consent. Please read the consent form statements and initial each box if they agree. Type yours and their name at the bottom of the consent form. Instead of the signature section please write 'oral consent gained via Microsoft Teams' and add your e-signature. At the end of the session, send a copy of the consent form to the family for their reference.

The rest of the sessions should occur similar to face-to-face appointments, following the therapy booklet. In the second session, it may be helpful for participants to be asked in advance to bring along a shoebox/box and decorating equipment (e.g. colouring pens, paper, Sellotape). For face-to-face appointments, a box of decorating things will be provided at each site.

Inclusion criteria for participants:

Adolescent between the ages of 11-18 and their parent/carer(s)
English speaking
Patient within the Oxfordshire or Buckinghamshire Child and Adolescent Mental Health (CAMHS) Eating Disorder Service.
Offered Family-Based Treatment for an eating disorder at the time of sampling.

Exclusion Criteria:

Non-English speaking.
Adolescent patient is living in an in-patient clinical setting and/or is in a hospital psychiatric setting.

Adolescent patient is unable to access or engage with intervention due to physical, neurodevelopmental or cognitive impairments.

DTS questionnaire data:

Please enter the DTS questionnaire data after Session 1 into the Excel Onedrive File that will be shared with you along with the password. The answers provided could be copied from the therapy booklet or the page can be taken out. Use the participant numeric identifier (study participant number) only. This will be shared with you by me when allocating the participant.

End of session 2:

After the second session, please arrange a time with the young person for Lucas to contact them by telephone within the next 2 weeks. This can be explained as “a brief 15-20-minute telephone call where someone from our team will ask you about how you found the sessions and will go through the same questionnaire that you did last session”.

Please let Lucas know by email the name of the young person and the time of the interview.

Appendix F: Semi-structured topic guide

Introduction

Recap study protocol on confidentiality and consent

Usefulness:

1. How did you find the two one-to-one sessions? What was most/least helpful?
2. What did you like about the sessions? What did you dislike?
3. How able were you to use the strategies outside of the sessions? How helpful were these strategies in relation to managing eating?
4. On a scale of 0-10, how helpful was the intervention? Would you recommend it to other young people beginning Family-Based Treatment?

Improvements:

1. Would you change anything about the sessions? If so, what (e.g. longer, shorter, different time/format, more of them)?
2. Was it a good time to have these sessions or would it be more helpful later/earlier on in treatment?
3. Do you think that our service should continue to offer these sessions to young people receiving family-based treatment?

Appendix G: Intervention booklet

Coping with distress workbook



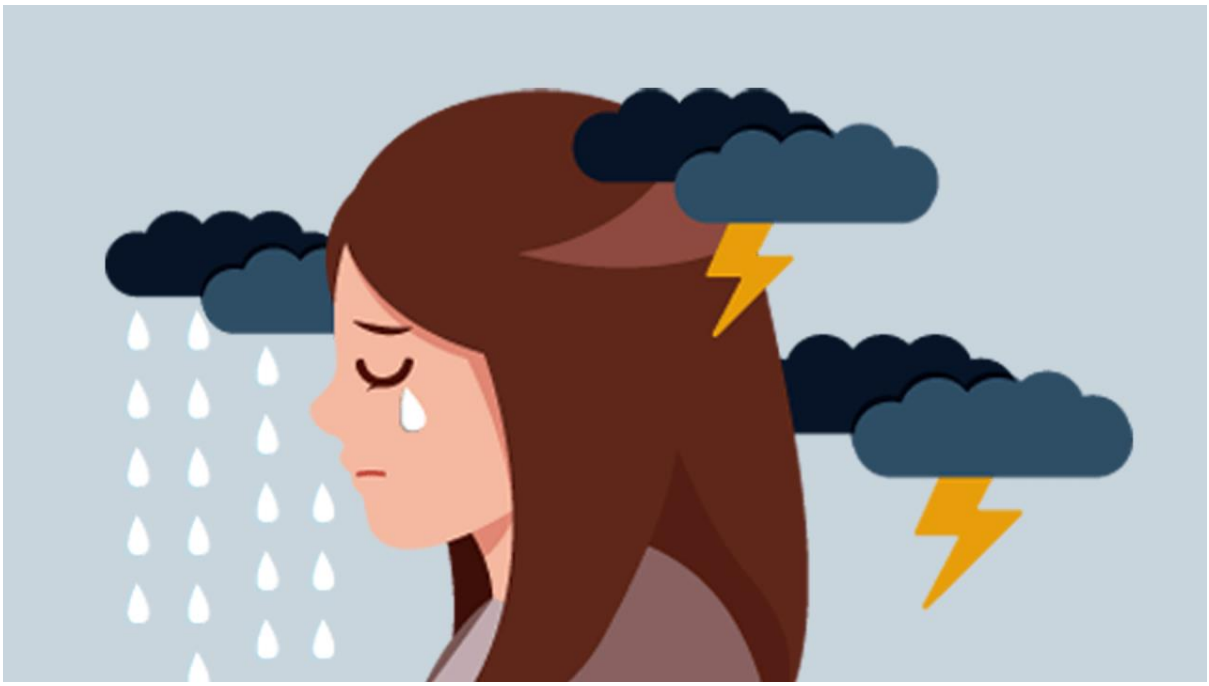
Name:……

Therapist:……..

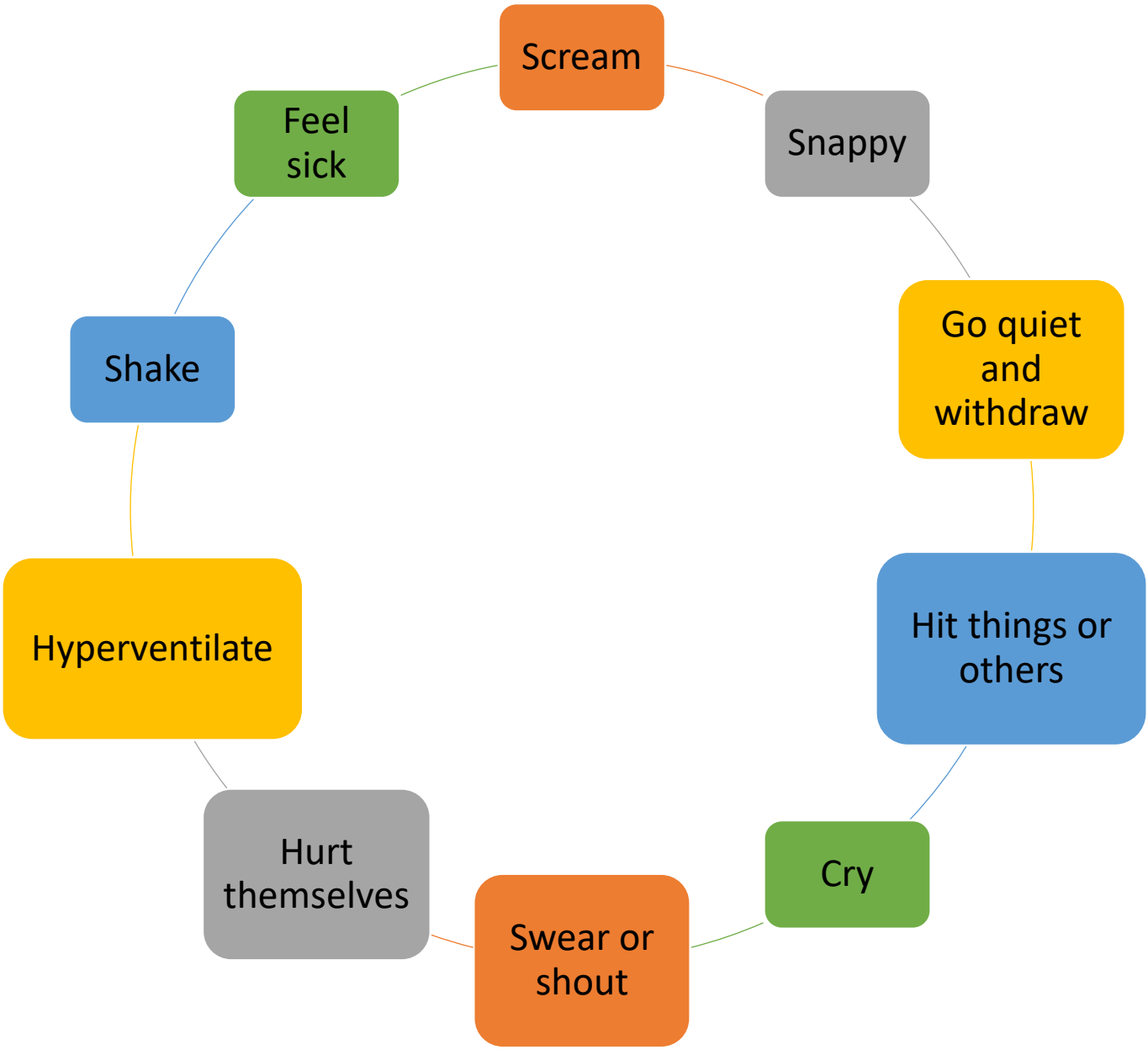
What is distress tolerance?

Distress tolerance is…

- Learning how to make it through a bad situation without feeling worse afterwards
- Being able to sit through stressful events
- Knowing how to use distraction in a crisis to think more clearly and to stay safe



People show their distress in lots of different ways…


Scream
Snappy
Go quiet and withdraw
Hit things or others
Cry
Swear or shout
Hurt themselves
Hyperventilate
Shake
Feel sick

Any others?

_____
_____
_____

Why Bother Tolerating Painful Feelings and Urges?

Because . . .

1. **Pain is part of life and can't always be avoided.**

2. **If you can't deal with your pain, you may act impulsively.**

3. **When you act impulsively, you may end up hurting yourself, hurting someone else, or not getting what you want.**

Questionnaire

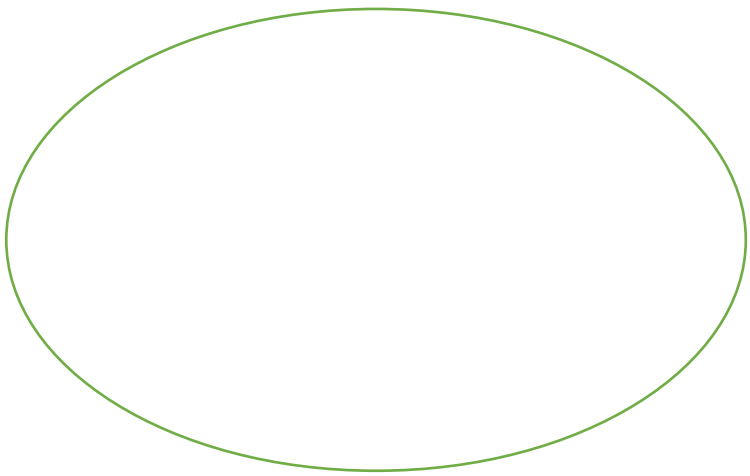
Simons, J.S. & Gaher, R.M. (2005). The Distress Tolerance Scale: Development and Validation of a Self-Report Measure. Motivation and Emotion, 29, 83-102.

Think of times related to your eating disorder that you have felt distressed or upset. Select the item from the options that best describes your beliefs about feeling distressed or upset.

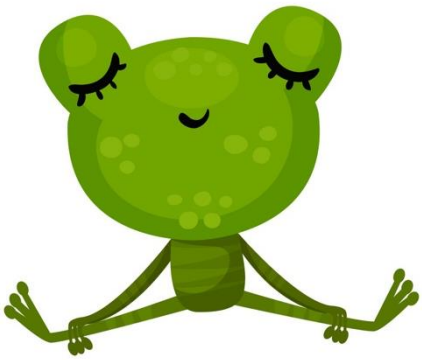
		Strongly Agree	Mildly Agree	Agree and Disagree Equally	Mildly Disagree	Strongly Disagree
1.	Feeling distressed or upset is unbearable to me.					
2.	When I feel distressed or upset, all I can think about is how bad I feel.					
3.	I can't handle feeling distressed or upset.					
4.	My feelings of distress are so intense that they completely take over.					
5.	There's nothing worse than feeling distressed or upset.					
6.	I can tolerate being distressed or upset as well as most people.					
7.	My feelings of distress or being upset are not acceptable.					
8.	I'll do anything to avoid feeling distressed or upset.					
9.	Other people seem to be able to tolerate feeling distressed or upset better than I can.					
10.	Being distressed or upset is always a major ordeal for me.					

11.	I am ashamed of myself when I feel distressed or upset.					
12.	My feelings of distress or being upset scare me.					
13.	I'll do anything to stop feeling distressed or upset.					
14.	When I feel distressed or upset, I must do something about it immediately.					
15.	When I feel distressed or upset, I cannot help but concentrate on how bad the distress actually feels.					

What do you find helps you to relax when stressed?



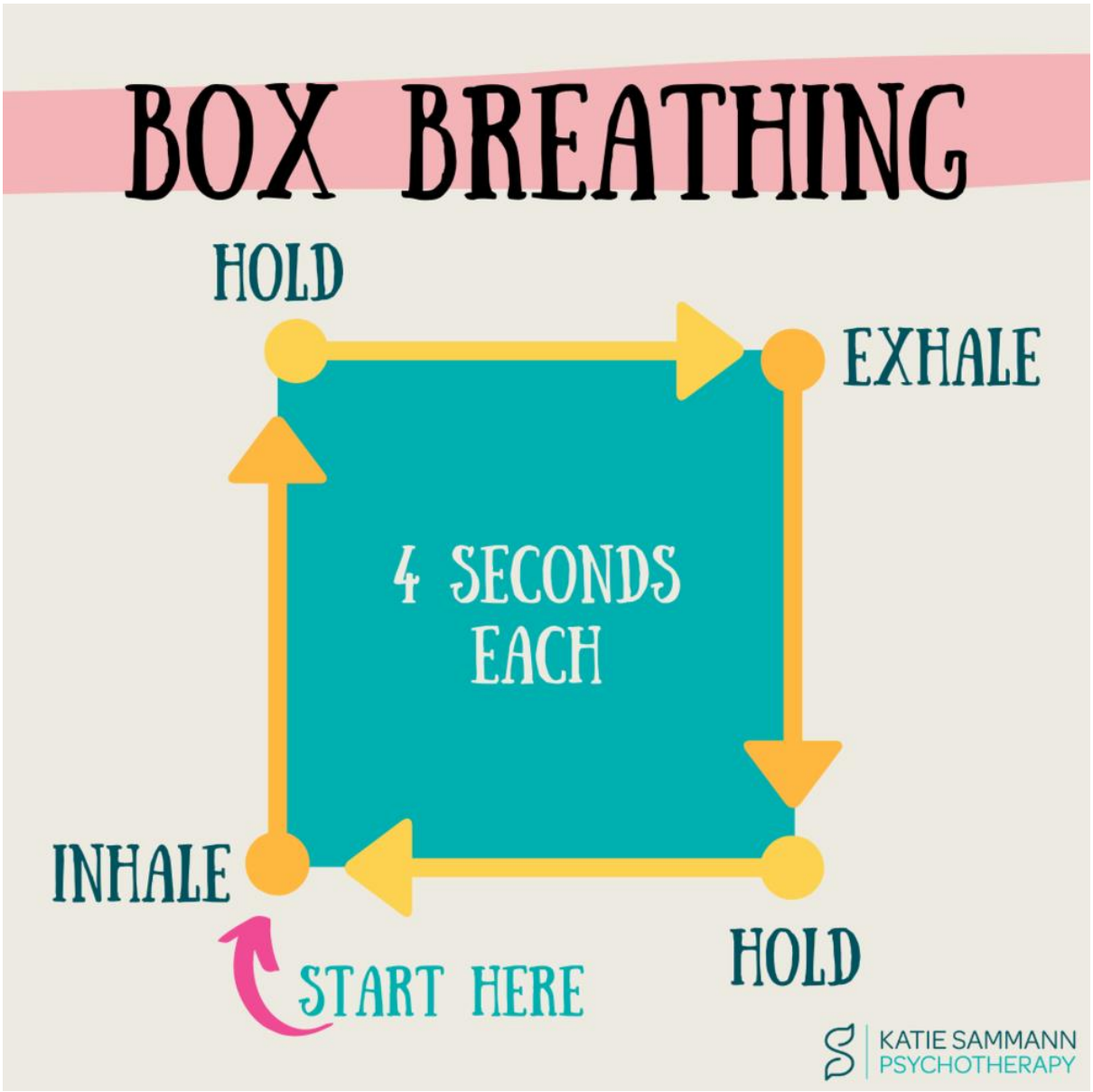






Deep breathing technique:

- Helps calm down the heart and body
- Tells our body and brain that we aren't in danger



54321 technique:

- Helps to get out of our head and focus on the world around us
- Distracts us from harmful behaviours



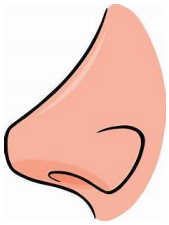
5 – Find 5 things you can see and think about how they look



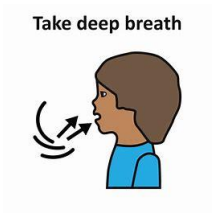
4 – Find 4 things you can touch and think about how they feel



3 – Listen slowly for 3 things you can hear and think about how they sound



2 – Find 2 things you can smell and think about what they are like



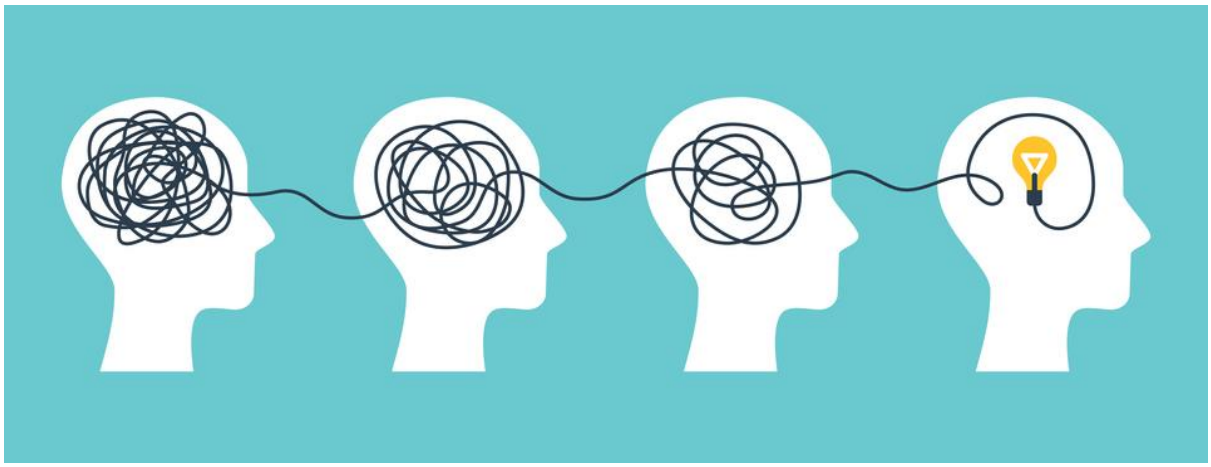
1 – Take 1 slow BIG breath

Thing to practice after Session 1:

This week it would be good to practice:

- Notice how you manage distress when you get upset (by filling out the next page)
- Practice activities on page 7
- Practice Box Breathing and 54321

Try to practice these things both when you are and aren't feeling upset. It's like learning a new skill!



Try and complete this sheet before your next session:

Briefly describe the stressful situations you were in and the specific skills you used:

1. _____

_____

_____

2. _____

_____

_____

Did using this skill help you to (1) cope with uncomfortable feelings and urges and/or (2) avoid conflict of any kind?

Circle Yes or No.

If YES, please describe how it helped: _____

_____

_____

_____

_____

If NO, please describe why you believe it did not help: _____

_____

_____

_____

_____



Session 2: Self-soothing

Write down two things for each ‘sense’ that you find soothing:

Vision:

Touch:

Listening:

Smells:

Taste:

<u>Ice is nice…</u>



When emotional arousal is very HIGH!!!!!!!!

- You are completely caught in Emotion Mind.
- Your brain is not processing information.
- You are emotionally overwhelmed.

Ice can help calm the Emotion Mind quickly

Ideas:

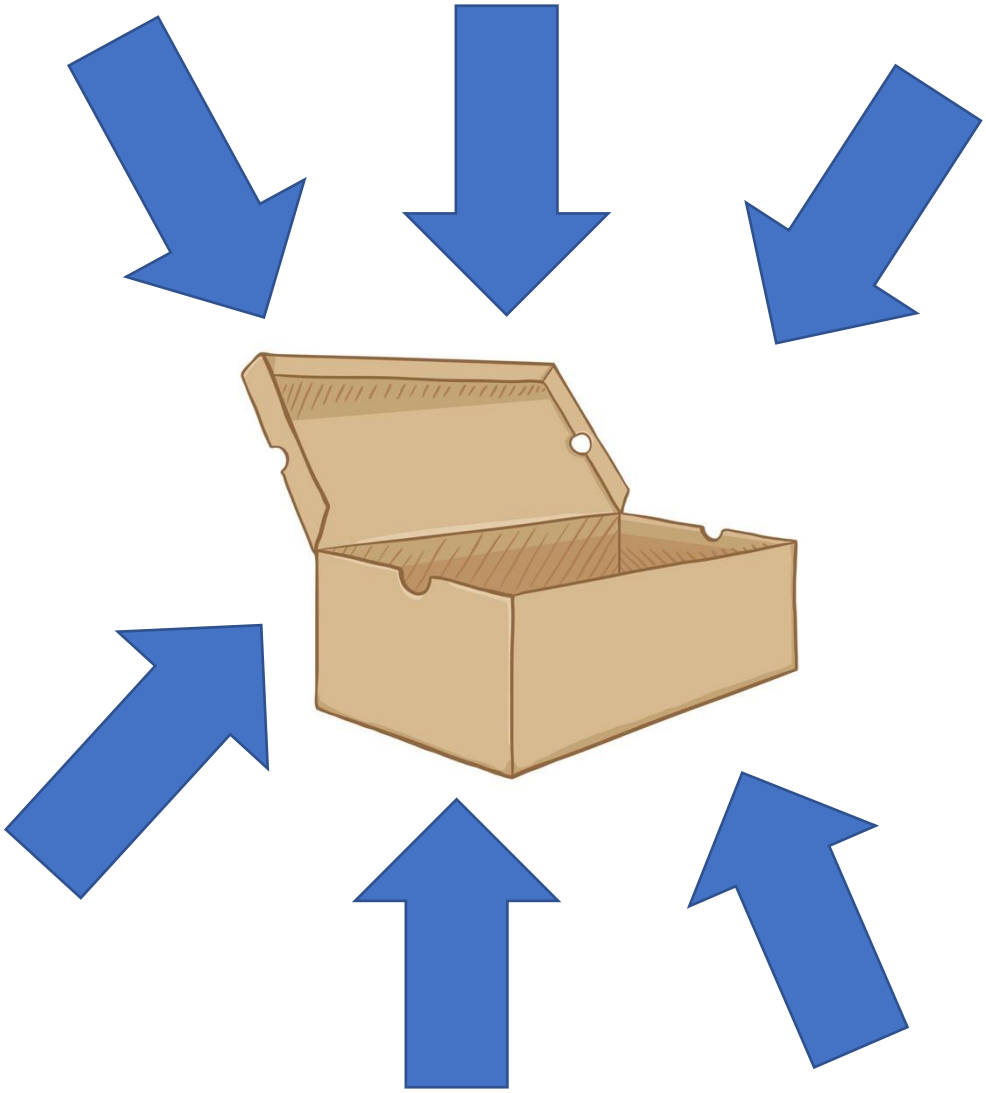
- Circle ice cubes on your palm/wrist
- Squeeze ice cubes for 10 seconds
- Put a cold pack on your eyes or cheeks
- Splash cold water on your face





Things for my self-soothe box:

Stick this inside the box to make sure it always has what you need!



Planning the self-soothe box:

- Where am I going to put this box?

- How am I going to remember to use it?

- When should it be used?

Appendix H: COREQ Checklist

Note: This will be added when submitted as the page numbers will change.

Appendix I: Parent/Carer information sheet

Oxford CAMHS Eating Disorder Service
Raglan House, 23 Between Towns Road, Oxford, OX4 3LX
01865 902 720

Bucks CAMHS Eating Disorder Service
Sue Nicholls Centre, Bierton Road, Aylesbury, Buckinghamshire, HP20 1EG

Oxford Institute of Clinical Psychology Training and Research (OXICPT)
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
01865 226 431 oxicpt-admin@hmc.ox.ac.uk





Chief investigator: Dr Lucas Shelemy
Telephone number: 01865 226 431
Email address: lucas.shelemy@oxfordhealth.nhs.uk
Study supervisor: Dr Joanna Adams; Joanna.adams@oxfordhealth.nhs.uk

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service

PARENT/CARER PARTICIPANT INFORMATION SHEET

1. *Why is this research being conducted?*

A high level of distress is common for young people undergoing treatment for an eating disorder. High levels of distress may be seen in panic attacks, screaming, angry outbursts, running off, self-harm and suicidal ideation. This behaviour can be distressing for young people and their families, impact treatment progress and put the young person at risk of harm.

One intervention that has shown to be effective at reducing distress-related behaviours is Dialectical Behavioural Therapy. One crucial component of DBT is 'distress tolerance' which helps people sit with difficult emotions without using unhelpful behaviours to neutralise the distress. Skills like self-soothing, distraction techniques, calming, relaxation and using pros and cons are often taught and practiced.

Within the Oxon/Bucks CAMHS Eating Disorder outpatient service, high levels of distress can impact on treatment engagement and recovery. In response to this difficulty faced by adolescents, their families and services, this project aims to develop, implement and evaluate a brief distress-tolerance intervention for adolescents.

The intervention may be important in reducing distress and associated behaviours in adolescents at the start of treatment for an eating disorder which may have significant positive effects on subsequent recovery.

This research is being conducted as part of a Service Improvement Project for a clinical psychology doctorate.

2. ***Why has my child been invited to take part?***

You child has been invited to take part because they are aged 11-18 and have been invited to receive Family-Based Treatment at either the Oxfordshire or Buckinghamshire CAMHS Eating Disorder service.

3. ***Does my child have to take part?***

No. You and your child can ask questions about the research before deciding whether or not to take part. Your decision whether or not to take part will not impact on your other ongoing treatment within the service. If you and your child do agree to take part, your child may withdraw from the study, without giving a reason and without negative consequences, by advising us of this decision.

4. ***What would taking part involve?***

You and your child will be invited to attend an appointment with an Assistant Psychologist (AP) from the clinical care team. This will be either within the Oxon/Bucks Eating Disorder service or online via Microsoft Teams. At the start of the appointment, you will be given the opportunity to ask any questions you may have. If you and your child are still happy to take part, you will be asked to either sign a consent form. If you are meeting online, you will be asked to give verbal consent. This will be recorded by the Assistant Psychologist and a copy will be emailed to you.

Your child's contact information (this may be your contact information), demographics (including age and gender) and answers to previously completed service questionnaires will be shared with the research team.

Immediately following this, the AP will meet with your child one-to-one and will administer a short questionnaire. This questionnaire asks about your child's current levels of distress and coping strategies and should take approximately 5 minutes to complete. The first intervention session will then take place and will focus on identifying how your child manages their distress and coming up with strategies to practice in between sessions. At the end of each session you may be invited to join and the strategies learnt will be shared.

Two weeks later your child will meet with the same clinician again for a second intervention session. This session will recap learnt techniques and identify further skills and strategies that can be used to help manage distress. Both intervention sessions will last 45 minutes. At the end of this session a time will be arranged for the lead researcher to contact your child.

Two weeks after the second session, the lead researcher will telephone you to speak to your child. The lead researcher will then administer the same questionnaire mentioned earlier and will conduct a telephone interview asking about your child's experiences of the intervention. The interview will be audio-recorded by the lead researcher and transcribed. The telephone interview should last approximately 15 minutes.

Following the interview, you will receive an email thanking you and your child for your time.

5. ***Are there any potential risks in taking part?***

It is possible that your child may experience some psychological distress when discussing their own mental health during the intervention and interview. The Assistant Psychologists conducting the intervention are all trained in safely providing psychological support. The clinical care team will be on hand at all times in case any additional distress arises during the intervention sessions. The lead researcher is a trainee clinical psychologist who will able to provide brief psychological support in the case of any distress arising during the interview. Links to available resources, helplines and charities will also be provided following participation in the study.

To reduce any potential risks of breaches of confidentiality, all personal data used in this research will be anonymised and stored on password-protected encrypted computers on the Trust network. Any personal data stored in any other way (audio recordings of the interview) will be transferred to an encrypted computer and then deleted.

6. ***What are the possible benefits in taking part?***

Your child may experience a reduction in unhealthy distress tolerance behaviours such as self-harm or threats of violence. They may experience improved distress tolerance and will use healthy strategies to manage strong emotions when upset. The skills learnt from the intervention may improve the adolescent's ability to engage with Family-Based Treatment and subsequently may result in a more effective recovery.

7. ***Expenses and payments***

There will be no payment for taking part in this study.

8. ***What happens to the data provided?***

The information provided during the study is the **research data**. Any research data from which you or your child can be identified (e.g. name, age, gender, audio recording) is known as **personal data**.

Personal / sensitive data will be stored on a password-protected encrypted computer on the Trust network and will be anonymised. After maximum 3 months after data collection the personal data will be deleted. Confidentiality may be breached in the rare case that the researcher becomes aware of a serious risk of harm to self or others and information will be shared with your clinical care team.

Other research data (including consent forms) will be stored for at least 3 years after publication or submission of the research in thesis format.

The researcher and research team will have access to the research data. Responsible members of the Oxfordshire Health NHS Foundation Trust may be given access to data for monitoring and/or audit of the research.

9. *Will the research be published?*

The research may be published in academic publications. All information presented will be anonymised. You can also request a copy via email of any published outcomes from the research team.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University of Oxford archives to facilitate its use in future research. If so, the thesis will be openly accessible.

10. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the Health Research Authority Ethics Committee (IRAS Project ID: 286525).

11. *Who do I contact if I have a concern about the study or I wish to complain?*

If you have a concern about any aspect of this study, please contact Dr Lucas Shelemy, lucas.shelemy@oxfordhealth.nhs.uk or Dr Joanna Adams, joanna.adams@oxfordhealth.nhs.uk, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Research and Development Team who will seek to resolve the matter as soon as possible:

Oxford Health NHS Foundation Trust Research and Development; Email: research@oxfordhealth.nhs.uk

12. *Further Information and Contact Details*

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Dr Lucas Shelemy
Oxford Institute of Clinical Psychology Training and Research, Oxford Health NHS Foundation Trust
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
University tel: 01865 226431
Trust email: lucas.shelemy@oxfordhealth.nhs.uk

Appendix J: Older adolescent information sheet

Oxford CAMHS Eating Disorder Service
Raglan House, 23 Between Towns Road, Oxford, OX4 3LX
01865 902 720

Bucks CAMHS Eating Disorder Service
Sue Nicholls Centre, Bierton Road, Aylesbury, Buckinghamshire, HP20 1EG

Oxford Institute of Clinical Psychology Training and Research (OXICPT)
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
01865 226 431 oxicpt-admin@hmc.ox.ac.uk





Chief investigator: Dr Lucas Shelemy
Telephone number: 01865 226 431
Email address: lucas.shelemy@oxfordhealth.nhs.uk
Study supervisor: Dr Joanna Adams; Joanna.adams@oxfordhealth.nhs.uk

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service

ADOLESCENT 16+ PARTICIPANT INFORMATION SHEET

13. *Why is this research being conducted?*

We know that some young people experience panic attacks, angry outbursts or can be really upset when having treatment for an eating disorder. This behaviour can be distressing for a young person and their family and can also impact on treatment progress and put the young person at risk of harm to themselves.

One intervention that has shown to be effective at reducing distress-related behaviours is 'distress tolerance' which helps people learn to manage difficult emotions without using unhelpful or harmful behaviours to stop the distress. Skills like self-soothing, distraction techniques, calming, relaxation and using pros and cons are often taught and practiced.

This study aims to see if a two-session distress tolerance intervention is helpful for young people being seen within the Oxon/Bucks CAMHS Eating Disorder service outpatient service. This intervention may help reduce distress at the start of eating disorder treatment and have positive effects on recovery.

This research is being conducted as part of a Service Improvement Project for a clinical psychology doctorate.

14. *Why have I been invited to take part?*

You have been invited to take part because you are aged 11-18 and have been invited to receive Family-Based Treatment at either the Oxfordshire or Buckinghamshire CAMHS Eating Disorder service.

15. ***Do I have to take part?***

No. You can ask questions about the research before deciding whether or not to take part. Your decision whether or not to take part will not affect any other treatment you are receiving. You can choose to stop taking part in the study at any time you want by letting us know.

16. ***What will happen to me if I take part in the research?***

You will be invited to an appointment with an Assistant Psychologist (AP) from the clinical care team. This will be either within the Oxon/Bucks Eating Disorder service or online via Microsoft Teams.

You will be given the opportunity to ask any questions you may have and will sign a consent form. If you are meeting online, the study information will be read to you and you will be asked to give verbal consent. This will be recorded by the Assistant Psychologist and a copy will be emailed to you.

Your contact information, demographics (including age and gender) and answers to previously completed service questionnaires will be shared with the research team.

You will then be asked to complete a questionnaire about how distressed you sometimes feel and how you manage this stress. This will take around 5 minutes to complete.

After this, you will meet one-to-one with the Assistant Psychologist to talk about how you have been feeling and to come up with new ideas of managing distress. Two weeks later you will meet with them again to come up with more skills and strategies that can help. These sessions will be 45 minutes long. Your parents may join towards the end of the session and strategies from the session will be shared with them.

Two weeks after the second session, the lead researcher will call you. They will then ask you the same questions from the questionnaire you completed at the start of the study. After this, the researcher will ask you questions about what the treatment sessions were like and what you would like to be changed. This will last around 15 minutes and will be audio-recorded.

After this interview you will be thanked for your time and you will continue to receive Family-Based Treatment as normal. Any other appointments you with the care team can continue during this study.

17. ***Are there any potential risks in taking part?***

It is possible that you may get upset when talking about your mental health during the sessions. The Assistant Psychologists conducting the intervention are all trained in safely providing psychological support. The clinical care team will be on hand at all times in case any additional distress arises during the intervention sessions or the interview. Links to available resources, helplines and charities will also be provided.

To reduce the chance of private information being shared, all information collected will be anonymised and stored on password-protected encrypted computers on the Trust network.

18. *Are there any benefits in taking part?*

You will have a range of strategies that may be helpful when feeling upset to help manage intense emotions. This might help with later treatment and recovery.

19. *Expenses and payments*

There will be no payment for taking part in this study.

20. *What happens to the data provided?*

If something is discussed with the Assistant Psychologist or the lead researcher that makes us worried about you or someone else's safety, this information may be shared with the clinical care team and your parent/carers.

Personal / sensitive information will be stored on a password-protected encrypted computer on the Trust network and will be anonymised. After maximum 3 months after data collection the personal data will be deleted.

Other research data (including consent forms) will be stored for at least 3 years after publication or submission of the research in thesis format.

The researcher and research team will have access to the research data. Responsible members of the Oxfordshire Health NHS Foundation Trust may be given access to data for monitoring purposes.

21. *Will the research be published?*

The research may be published in academic publications. All information presented will be anonymised. You can also request a copy via email of any published outcomes from the research team. The research will be written up as a student's thesis.

22. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the Health Research Authority Ethics Committee (IRAS Project ID: 286525).

23. *Who do I contact if I have a concern about the study or I wish to complain?*

If you have a concern about any aspect of this study, please contact Dr Lucas Shelemy, lucas.shelemy@oxfordhealth.nhs.uk or Dr Joanna Adams, joanna.adams@oxfordhealth.nhs.uk, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Research and Development Team who will seek to resolve the matter as soon as possible:

Oxford Health NHS Foundation Trust Research and Development; Email: research@oxfordhealth.nhs.uk

24. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Dr Lucas Shelemy
Oxford Institute of Clinical Psychology Training and Research, Oxford Health NHS Foundation Trust
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
University tel: 01865 226431
Trust email: lucas.shelemy@oxfordhealth.nhs.uk

Appendix K: Younger adolescent information sheet

Oxford CAMHS Eating Disorder Service
Raglan House, 23 Between Towns Road, Oxford, OX4 3LX
01865 902 720

Bucks CAMHS Eating Disorder Service
Sue Nicholls Centre, Bierton Road, Aylesbury, Buckinghamshire, HP20 1EG

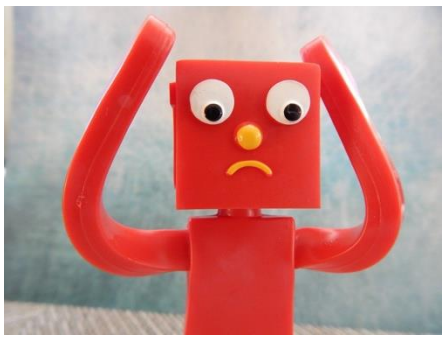
Oxford Institute of Clinical Psychology Training and Research (OXICPT)
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
01865 226 431 oxicpt-admin@hmc.ox.ac.uk

Chief investigator: Dr Lucas Shelemy
Telephone number: 01865 226 431
Email address: lucas.shelemy@oxfordhealth.nhs.uk
Study supervisor: Dr Joanna Adams; Joanna.adams@oxfordhealth.nhs.uk

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service

ADOLESCENT 11-16 PARTICIPANT INFORMATION SHEET

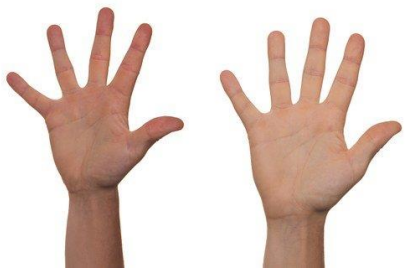
What is this research?



Lots of young people with an eating disorder feel very upset and stressed. Sometimes they can have panic attacks, get really angry or scream.

There are different things that can help young people feel better when stressed, like calming and relaxation techniques.

We want to see if a two-session intervention can help young people feel better when having intense emotions. This might help in your recovery from an eating disorder.



Why have I been invited to take part?

You are aged 11-18 and are going to receive Family-Based Treatment from our service.

Do I have to take part?

No, it is up to you. You can ask us questions you have and choose if you want to take part. You can also stop half-way if you want by telling us.

What will happen to me if I take part in the research?

We will ask you to fill out a quick questionnaire (about 5 minutes long).

Then you will meet with our Assistant Psychologist on your own to talk about how you have been feeling and find new ways of coping. You will meet with them again 2 weeks later for another session.



After the second session, the lead researcher will call your parent/carers and will interview you for 15 minutes over the phone. They will ask you about what you thought about the sessions and will go through the same questions from the first questionnaire.



What do I need to know?

Your contact information, demographics (including age and gender) and answers to previously completed service questionnaires will be shared with the research team.

You might get upset during the sessions when talking about how you are feeling – this is ok! The person you will be meeting is able to help you and give you support.

If we are worried about your safety, we will share what you tell us with your parent/carers and your care team. Otherwise everything else we speak about will be confidential, meaning it will be shared only with other people involved in your care or the study.

All information from the study will be kept on password-protected computers that only the researchers can access. The information will be made anonymous, meaning the findings can't be traced back to you. After 3 years all of the research data will be deleted.

What's in it for me?

You will have new skills to help when feeling very stressed. This might help with getting better from an eating disorder.

Who has reviewed this study?

This study has received ethical approval from the Health Research Authority Ethics Committee (IRAS Project ID: 286525). This research is being done as part of a university qualification.

Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact Dr Lucas Shelemy who's details are at the top of this sheet.

Thank you! ☺

Appendix L: Parent/carer consent form

PARENT/CARER CONSENT FORM

IRAS Project ID: 286525

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service

Please initial each box

1	I confirm that I have read and understand the information sheet version 1 dated _____ 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 the participation of my child in this study is voluntary and that I am free to withdraw at any time, without giving any reason, and without any medical care or legal rights being affected.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from Oxford Health Foundation Trust where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data.	☐
4	I understand that my child's contact details (where appropriate), demographic information (including age and gender) and previously completed service questionnaires will be shared with the research team.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand that all information will be kept strictly confidential except in rare circumstances in which it is judged that my child, or someone else is, at immediate risk of serious harm, or where information is requested by a court of law.	☐
7	I understand that this project has been reviewed by, and received ethics clearance through, the Health Research Authority Ethics Committee.	☐
8	I understand how to raise a concern or make a complaint.	☐
9	I agree for my child to take part in the above study.	☐

_____	dd / mm / yyyy	_____
Name of Parent/Carer	Date	Signature
_____	dd / mm / yyyy	_____
Name of Child	Date	Signature
_____	dd / mm / yyyy	_____
Name of person taking consent	Date	Signature

Appendix M: Older adolescent consent form

ADOLESCENT 16+ CONSENT FORM

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service
IRAS Project ID: 286525

Please initial each box

1	I confirm that I have read and understand the information sheet version 1 dated _____ 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 in this study is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from Oxford Health Foundation Trust where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data.	☐
4	I understand that my contact details (where appropriate), demographic information (including age and gender) and previously completed service questionnaires will be shared with the research team.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand that all information will be kept strictly confidential except in rare circumstances in which it is judged that I, or someone else is, at immediate risk of serious harm, or where information is requested by a court of law.	☐
7	I understand that this project has been reviewed by, and received ethics clearance through, the Health Research Authority Ethics Committee.	☐
8	I understand how to raise a concern or make a complaint.	☐
9	I agree to take part in the above study.	☐

	dd / mm / yyyy	
Name of Participant	Date	Signature
	dd / mm / yyyy	
Name of person taking consent	Date	Signature

Appendix N: Younger adolescent consent form

ADOLESCENT 11-16 ASSENT FORM

Acceptability of a brief distress tolerance intervention in a CAMHS Eating Disorder service

Please initial each box

1	I have read and understand the information sheet for the above study. I have been able to ask questions and get answers.	☐
2	I understand that I am a volunteer and I can choose to stop taking part at any time without any problems.	☐
3	I give permission for my contact details, demographic information (including age and gender) and previously collected questionnaire data to be shared by my care team with the study researchers.	☐
4	I understand who will have access to information that I give and how it will be stored.	☐
5	I understand that what I say will be kept confidential unless someone is worried about my safety.	☐
6	I understand that this project has received ethical approval from the Health Research Authority Ethics Committee.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I agree to take part in the above study.	☐

	dd / mm / yyyy	
Name of Participant	Date	Signature
	dd / mm / yyyy	
Name of person taking consent	Date	Signature

Appendix O: Approval confirmation from Oxford Health NHS Foundation Trust Research and Development

From: "Rhodes Katie (RNU) Oxford Health" <Katie.Rhodes@oxfordhealth.nhs.uk>
Date: 30 July 2021 at 09:33:47 BST
To: "Shelemy Lucas (RNU) Oxford Health" <Lucas.Shelemy@oxfordhealth.nhs.uk>
Subject: FW: Audit proposal LShelemy

Good morning lucas,

Your audit and improvement project has been approved.

Upon completion please provide us with a report of your findings.

Kind Regards

Katie Rhodes
Senior Team Administrator
Buckinghamshire Mental Health Directorate
Oxford Health NHS Foundation Trust
The Whiteleaf Centre | Bierton Road | Aylesbury | HP20 1EG

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From: Khosla Vivek (RNU) Oxford Health <Vivek.Khosla@oxfordhealth.nhs.uk>
Sent: 21 July 2021 13:16
To: Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>; Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>
Subject: RE: Audit proposal LShelemy

Happy to approve

Best wishes

Vivek
Vivek Khosla
Clinical Director | Buckinghamshire Mental Health Directorate

The Whiteleaf Centre, Bierton Road, Aylesbury, HP20 1EG | Tel: 01865 901337 (Emma Peachment)
Consultant Forensic Psychiatrist| Oxford Health NHS Foundation Trust
Oxford Clinic MSU, Littlemore Mental Health Centre, Sandford Road, Oxford, OX4 4XN
Tel: 01865 902907 (Courtney Glenn)
Mobile: 07887791621 | vivek.khosla@oxfordhealth.nhs.uk |
www.oxfordhealth.nhs.uk

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From: Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>
Sent: 21 July 2021 13:07
To: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>; Khosla Vivek (RNU) Oxford Health <Vivek.Khosla@oxfordhealth.nhs.uk>
Subject: RE: Audit proposal LShelemy

approved

Regards

Rob
Dr Rob Bale
Clinical Director and Consultant Psychiatrist, Oxford Health NHS Foundation Trust
Oxfordshire, BaNES, Swindon and Wiltshire Mental Health Directorate, Oxfordhealth NHS Foundation Trust, John Sharich House, Slade Hospital, Horsepath Driftway, Oxford OX3 7JH
Email: rob.bale@oxfordhealth.nhs.uk
PA: Ian Horwood, Phone: 01865 902759, Email: ian.horwood@oxfordhealth.nhs.uk





From: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>
Sent: 21 July 2021 10:17
To: Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>; Khosla Vivek (RNU) Oxford Health <Vivek.Khosla@oxfordhealth.nhs.uk>
Subject: FW: Audit proposal LShelemy

Good morning both,

Please see attached for your approval

Katie Rhodes
Senior Team Administrator

Appendix P: SIP Instructions to Authors for nominated Cognitive and Behavioral Practice journal

Aims and Scope

Cognitive and Behavioral Practice, published four times a year, is an international scholarly journal with the primary mission of **dissemination**: to bridge the gap between clinical research and **practice** of **cognitive** and **behavioral therapies**. The journal is a publication of the Association for Behavioral and Cognitive Therapies (ABCT).

C&BP values diversity, equity, and inclusion in science and welcomes submissions on topics that impact BIPOC communities and scholars. The journal is for practicing mental health clinicians and instructors, as well as for researchers with an interest in the clinical dissemination of their findings.

Types of Submissions

C&BP welcomes submissions on innovative assessment and treatment in all areas of cognitive and behavioral practice on topics that appeal to a broad practitioner audience. Manuscripts should address current challenges facing practitioners, both in terms of technique, process, and the content of treatment. *C&BP* publishes the following types of original contributions, with specific requirements for each (see below sections):

1. Quantitative and Qualitative Research Reports
2. Case Series
3. Case Studies
4. Clinical Commentaries
5. Multimedia Reviews
6. Treatment Development Reports
7. Reviews (theoretical and quantitative)
8. Special Features (series and issues)

1. Quantitative and Qualitative Research Reports

Innovative assessment or treatment research submissions to *C&BP* must adhere to Journal Article Reporting Standards (JARS) guidelines for reporting psychological research reports (https://www.apa.org/pubs/authors/jars.pdf), including the use of person-first language and reporting on the race and ethnicity of study participants. Checklists are available for a number of study designs, including: Randomized trials (CONSORT) and Study protocols (SPIRIT), and for Qualitative research (SRQR) and (COREQ). In addition, authors should use systems-centered language (O'Reilly, 2020) to highlight the systemic structures that maintain disparate outcomes for minoritized communities. ABCT Journals require the registration of all clinical trials in a public trials registry. These registries set standards for the uniform reporting of the minimum registration data set as determined by the World Health Organization and the International Committee of Medical Journal Editors (http://www.clinicaltrials.gov, http://www.anzctr.org.au, http://www.umin.ac.jp/ctr , http://www.isrctn.com, http://www.trialregister.nl/trialreg/index.asp/).

Community-based participatory research and mixed methods research can be submitted as research reports.

Importantly, to ensure relevance for our practitioner audience, please ensure all research reports include:

- Rich descriptions of clinical interventions, and:
- Embedded Video clips*, or:
- Examples of client-therapist dialogue, or
- Significant case descriptions that highlight how the treatment is implemented and how barriers/challenges are addressed**.

* Note - Submissions including Video clips are especially encouraged, see https://www.journals.elsevier.com/cognitive-and-behavioral-practice/videos.
** Note - *Qualitative reports require these elements in addition to results*.

2. Linked Behavior Therapy and Cognitive and Behavioral Practice submissions
Linked submissions to *C&BP* are based on research reports reviewed and approved for publication in *Behavior Therapy*. To ensure relevance for our practitioner audience, please ensure all submissions include rich descriptions of the specific clinical interventions studied in the report approved for publication in *Behavior Therapy*, and at least one other element required for research reports submitted to *Cognitive and Behavioral Practice*, such as video, client-therapist dialogue, or case descriptions (see above).

3. Case Series
Case series contain a case description with authors responding to various aspects of the innovative assessment or treatment approach. Authors are recommended to adhere to CARE guidelines for case reports. The Case Series Organizer writes up a detailed description of a case and selects four to eight Case Conference Respondents. Respondents then write 6 to 20 page manuscripts describing how they would assess and treat the patient.

Examples include:
https://www.sciencedirect.com/science/article/pii/S1077722920300274
https://www.sciencedirect.com/science/article/pii/S107772292030081X

4. Case Studies
Case studies focus on innovative assessment and treatment. Authors are recommended to adhere to CARE guidelines for case reports. *C&BP* also considers methodologically sound single-case designs (e.g., that conform to the recommendations outlined in the "What Works Clearinghouse (WWC) Single-Case Design" resources, https://ies.ed.gov/ncee/wwc/StudyReviewGuide/).

Examples include:
https://www.sciencedirect.com/science/article/pii/S1077722921000092
https://www.sciencedirect.com/science/article/pii/S1077722920300808
https://www.sciencedirect.com/science/article/pii/S1077722920300766

5. Clinical Commentaries
Clinical commentaries are brief articles in which experts in the field provide invited comment on the most up-to-date clinical topics, controversies, or discoveries within their expertise. Authors are encouraged to consult clinical practice guidelines (AGREE) and (RIGHT). Commentaries are usually associated with Special Features in the journal.

Recent examples include:
https://www.sciencedirect.com/science/article/pii/S1077722916300232
https://www.sciencedirect.com/science/article/pii/S107772291500005X
https://www.sciencedirect.com/science/article/pii/S1077722911000757
https://www.sciencedirect.com/science/article/pii/S1077722919300513

6. Multimedia Reviews
C&BP also publishes reviews of electronic resources (smartphone apps, standalone programs, etc.) for psychological practice. These reviews are commissioned by the Multimedia Review Editor, and there is a specific format for these reviews that must be adhered to. Multimedia reviews are typically published quarterly. If you are interested in writing a multimedia review or would like to have a multimedia resource reviewed, please contact the Multimedia Review Editor, Matthew Carper, at matthew_carper@williamjames.edu.

Examples include:
https://www.sciencedirect.com/science/article/pii/S107772291930029X
https://www.sciencedirect.com/science/article/pii/S1077722918300233
https://www.sciencedirect.com/science/article/pii/S1077722917301001

7. Treatment Development Reports
Reports describe the theoretical foundation and iterative process used to develop a novel intervention or describe how an established treatment is adapted to a novel population or clinical setting. Papers address issues of acceptability, feasibility, and initial outcomes. Competitive papers include a description of the structure, strategies, and techniques the treatment employs.

Examples include:
https://www.sciencedirect.com/science/article/pii/S107772291930080X
https://www.sciencedirect.com/science/article/pii/S1077722919300690

Requirements for Submissions

Length: Manuscripts should be a maximum of 35 pages, inclusive of all matter. Clinical commentaries should be a maximum of 10 manuscript pages, inclusive of all matter.

Format: Manuscripts are to be formatted in accordance with the American Psychological Association *Publication Manual* (7th edition) for all aspects, not limited to formatting of figures and figure captions. All pages should be typed double-spaced and numbered (including pages containing the title, authors' names and affiliation footnotes, abstract, acknowledgments, references, tables, and figure caption list). A title page is to be provided and should include the title

of the article, authors' names (no degrees), authors' affiliations, and suggested running head. The affiliation should comprise the department, institution (usually university or company), city, and state (or nation) and should be typed as a footnote to the author's name. The suggested running head should be less than 80 characters (including spaces) and should comprise the article title or an abbreviated version thereof. For office purposes, the title page should include the complete mailing address, telephone number, and email address of the one author designated to review proofs. An abstract is to be provided, preferably 100-200 words.

Video Content: Submit your videos online. The maximum allowable unload size for all submission files (cover letter, manuscript file, video files, etc.) is 2000 MB. Larger video files can be emailed separately as attachments or in a Zip file to bonnieb@bu.edu. If the videos are too large for emailing, then an FTP server or free online transfer service can be utilized.
Contact bonnieb@bu.edu for further information.

Highlights: Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Tables: Please submit tables as editable text and not as images.

Submission
Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Submit Your Article
Please submit your article via https://www.editorialmanager.com/candbp

Open Access
Please visit our Open Access page for more information.

Language (usage and editing services)
Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's Author Services.

Appendix Q: Ethical approval from University of Oxford CUREC

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Dr Lucas Shelemy
Oxford Institute for Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Headington, Oxford

16 March 2021

Dear Dr Shelemy,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R74411/RE001

Study title: Childhood experiences associated with heightened responsibility for self vs others in obsessive-compulsive disorder

Short title: Childhood experiences associated with feelings of responsibility in adult OCD

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for Ethical Approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on **16th March 2021**.

Approval is **subject to:**

a) **you agreeing to follow Approved Procedure 02**
b) **you following the BPS guidelines for online research**
c) **the PI agreeing to comply with the requirements for administering any tests or questionnaires and, if in doubt, to contact the publisher of those tests or questionnaires**
d) **the PI ensuring that, where new research staff are engaged, they are suitably qualified by training and/or experience.**

I would like to remind you that your study may be selected for review for the purposes of monitoring and/or audit.

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

H. Barnby-Porritt

Dr. Helen Barnby-Porritt
Research Ethics Manager, Medical Sciences

Appendix R: Information sheet

Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
01865 226 431 oxicpt-admin@hmc.ox.ac.uk



Professor Paul Salkovskis
01865 226431; paul.salkovskis@hmc.ox.ac.uk
Dr Lucas Shelemy, Trainee Clinical Psychologist
Oxford University telephone number: 01865 226431
Oxford University email address: lucas.shelemy@hmc.ox.ac.uk

Childhood experiences associated with feelings of responsibility in adult OCD

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee (CUREC) Approval Reference: **R74411/RE001**

25. *Why is this research being conducted?*

'Heightened responsibility' is the sense of feeling responsible if bad things were to happen to you or to other people. Obsessive Compulsive Disorder (OCD) is a condition in which a person has recurring thoughts and behaviours that are difficult to control. There is lots of research showing that a 'heightened responsibility' is a very common characteristic of OCD. For example, a person with OCD may have the frequent belief: 'If my child gets sick then it will be completely my fault'.

Childhood often sets the scene for the later development of anxiety difficulties and OCD. However, it is not known whether different childhood experiences affect the way people worry about themselves (e.g. it is my fault if I get sick) and other people (e.g. it is my fault if my friend gets sick).

This study aims to explore whether different childhood experiences are associated with different aspects of 'heightened responsibility'. Understanding this would give clues to how we can prevent and treat OCD. We are also recruiting people who are not experiencing OCD to examine whether these processes exist uniquely in OCD.

26. *Why have I been invited to take part?*

You have been invited because you are over the age of 18 years and are an English speaker. We are recruiting both individuals with OCD and those without OCD to compare outcomes.

27. *Do I have to take part?*

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you may withdraw yourself from the study, without giving a reason and without negative consequences, by advising us of this decision. The deadline by which you can withdraw any information you have contributed to the research is three months after data collection, as beyond this point, your responses will have been de-identified. All data collected until the point of withdrawal will be stored on a password-protected encrypted audio-recorder or computer within the University network.

28. *What will happen to me if I take part in the research?*

Over the telephone or via Microsoft Teams we will talk you through the study procedure and give you the opportunity to ask any questions you may have. If you are still happy to take part, I will read you a consent script and ask for your verbal consent to take part in the study. Your responses will be recorded by myself on a paper consent form and then a copy of this will be scanned and emailed to you on the same day.

A clinical researcher from our team will then conduct a screening interview with you. The aim of this interview is to determine whether you currently are experiencing OCD and will follow a structured guide asking about any symptoms of OCD that you may experience. This interview will last approximately 15 minutes. You can ask to pause or stop the interview at any time. If you have previously taken part in a screening interview in the last 6 months as part of a research study conducted by our research group, you will not have to take part in another screening interview.

With your consent, we will ask to audio record the screening interview so that we can accurately classify your responses.

After the screening interview you will be sent via email a link to an online questionnaire to complete in your own time on your personal computing device. The questionnaire asks questions about any symptoms of OCD that you may experience, your sense of responsibility for yourself and for others and your experiences of growing up. The questionnaire will take approximately 20-30 minutes to complete. When the questionnaire is completed your participation in the research will be complete.

We will ask whether you would like your contact details to be added to our database stored on a University password-protected computer so we can contact you about future studies. This is entirely up to you and will not affect your participation in the study. You can request to have your contact details removed from this database at any time by contacting the research team.

29. *Are there any potential risks in taking part?*

It is possible that you may experience some psychological distress when discussing your own mental health during the screening interview. All researchers conducting the screening interviews are trainee clinical psychologists who will able to provide brief

psychological support in the case of any distress arising during the screening interview. Links to available resources, helplines and charities will also be provided following the screening interview and online questionnaire.

To reduce any potential risks of breaches of confidentiality, all personal data used in this research will be de-identified and stored on password-protected encrypted computers on the University network. If you consent to be contacted for future studies from our research team, your contact details will be stored on a password-protected file on an encrypted computer on the University network.

30. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part in this research. However, your participation in this study will be useful in advancing our understanding of OCD and developing new intervention techniques which may ultimately help others.

31. Expenses and payments

There will be no payment for taking part in this study.

32. What happens to the data provided?

The information you provide during the study is the **research data**. Any research data from which you can be identified (e.g. name, age, gender, audio recording) is known as **personal data**.

Personal / sensitive data will be stored on a password-protected encrypted computer on the University network. Your name will not be stored alongside any data provided (e.g. with audio recordings). After a maximum period of 3 months after data collection, the personal data, including audio recordings, will be deleted. Your name and contact details will be stored on a password-protected database and deleted 3 months after the end of study data collection.

If you consent to be contacted by other members of our research team, your contact information will be stored on a password-protected database on an encrypted computer network for 3 years and then will be deleted by the principal investigator.

Other research data, including scanned consent forms, will be stored on a password-protected encrypted computer on the University network for at least 3 years after publication or submission of the research in thesis format.

The researcher and research team will have access to the research data. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research.

33. Will the research be published?

The research may be published in academic publications. A version of the results will be put onto our department website for you to see the results. You can also request a copy via email of any published outcomes from the research team.

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

34. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R74411/RE001).

35. *Who do I contact if I have a concern about the study or I wish to complain?*

If you have a concern about any aspect of this study, please contact Dr Lucas Shelemy, lucas.shelemy@hmc.ox.ac.uk or Professor Paul Salkovskis, 01865 226 431, paul.salkovskis@hmc.ox.ac.uk, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

36. *Data Protection*

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.
The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.
Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

37. *Further Information and Contact Details*

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Dr Lucas Shelemy

Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
University tel: 01865 226431
University email: lucas.shelemy@hmc.ox.ac.uk

Appendix S: Consent form

Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
01865 226 431 oxicpt-admin@hmc.ox.ac.uk



Professor Paul Salkovskis
01865 226431; paul.salkovskis@hmc.ox.ac.uk
Dr Lucas Shelemy, Trainee Clinical Psychologist
Oxford University telephone number: 01865 226431
Oxford University email address: lucas.shelemy@hmc.ox.ac.uk

PARTICIPANT CONSENT FORM

CUREC Approval Reference: R74411/RE001

Childhood experiences associated with feelings of responsibility in adult OCD

A study to explore the relationship between early experiences and sense of responsibility for individuals living with OCD.

Please initial each box

1	I confirm that I have read and understand the information sheet version 1 dated _____ 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, and without penalty.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data.	☐
4	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
5	I understand that all information will be kept strictly confidential except in rare circumstances in which it is judged that I am, or someone else is, at immediate risk of serious harm, or where information is requested by a court of law.	☐
6	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
7	I understand how to raise a concern or make a complaint.	☐

8	I agree to take part in the above study.	☐
Optional:	I agree for my contact details to be kept in a secure database for the purpose of contacting me about future studies.	☐
Optional:	I agree for the screening interview to be audio-recorded and I understand who will have access to this data, how the data will be stored and what will happen to the data at the end of the research project.	☐

_____	dd / mm / yyyy	_____
Name of Volunteer	Date	Signature
_____	dd / mm / yyyy	_____
Name of person taking consent	Date	Signature

Appendix T: TDRP information on data governance

SECTION H. DATA MANAGEMENT AND HANDLING

All information provided by participants is considered **research data** for the purpose of this form. Any research data from which participants can be identified is known as **personal data**; any personal data which is sensitive is considered **special category data**.

Management of personal data, either directly or via a third party, must comply with the requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, as set out in the University's Guidance on Data Protection and Research. In answering the questions below, please also consider the points raised in the Data Protection Checklist and whether, for higher-risk data processing, a separate Data Protection Impact Assessment may also be required for the research. Advice on research data management and security is available from Research Data Oxford and your local IT department. Advice on data protection is available from information.compliance@admin.ox.ac.uk.

1. Please mark 'X' against the data you will collect for your research

Screening documents	☐	Audio recordings	☒
Consent records including participant name (written consent forms, audio-recorded consent, assent forms (for research involving minors))	☒	Video recordings	☐
Online consent (may be anonymous)	☒	Transcript of audio/video recordings	☐
Opt-out forms	☐	Photographs	☐
Contact details for research purposes only (destroyed when no longer needed for this research)	☒	Information about the health of the participant (including mental health)	☒
Contact details kept for future studies	☒	Physiological test results / measurements	☐
Field notes	☐	MRI scans	☐
Questionnaire answers	☒	Other (please specify below)	☐
Task results (e.g. paper/online tasks, diary completion)	☐		

2. For each of the types of data selected above, state how this will be physically transferred from where it is collected to a secure local storage site (and backed up as necessary). This includes both paper records and data captured electronically.

Screening interviews will be transferred from a password protected encrypted audio-recorder to an encrypted computer within the University network. The audio-recorder will be kept in a locked cupboard until the data is transferred.

Scanned consent forms will be transferred to a password-protected folder on an encrypted computer within the University network. Paper and digital copies of consent forms will be destroyed.

Online questionnaire data including information about the mental health of the participant will be downloaded from the website where the information is stored onto a password-protected Excel file on an encrypted computer within the University network.

Contact details for research purposes and for future studies obtained by email or over telephone will be added to a password-protected Excel file on an encrypted computer within the University network and then previous records (e.g. via email) will be deleted.

2. How and where will <u>each type of data</u> be stored whilst the research is ongoing (until the end of all participant involvement)? Describe the arrangements for ensuring confidentiality, i.e. location of storage (e.g. Nexus 365 OneDrive for Business, SharePoint), security arrangements and de-identification of such data. Do not store unencrypted data in freely available cloud services or unprotected USB drives.

Audio recordings will be stored as a password-protected file on an encrypted computer within the University network until it has been listened to and independently rated by a member of the OCD Clinical Psychology Research Group. When this has been completed, or after a period of 3 months from data collection, the audio recording will then be destroyed by deletion. The file name will be the participants' unique participant number.

Paper consent forms will be scanned and stored as password-protected files on an encrypted computer within the University network with the paper copy being destroyed.

All other electronic data will be stored in password-protected Excel files on encrypted computers within the University network.

A linkage list (see below) with participant names, contact details, screening outcome and unique participant number will be stored on a password-protected file on the University network.

All research data will have the file name changed to the unique participant number provided to participants when sent the questionnaire link.

3. Will you use a unique participant number on research data instead of participant name?

If yes, state whether or not you will retain a list of participant names against numbers (pseudonymisation via a linkage list). Where will the list be stored, and when will it be destroyed?

Yes, there will be a linkage list with the list of participant names, contact details and screening outcome against unique participant numbers. This list will remain on the encrypted password-protected computer within the University network and will be destroyed 3 months from the end of data collection.

4. Who will have access to the research data?

The 'OCD Clinical Psychology Research Group' is a group of trainee clinical psychologists and research staff from the Oxford Institute for Clinical Psychology Training. For participants who have given their consent, recorded screening interviews will be listened to by another researcher from the OCD Clinical Research Group to independently second rate whether the potential participant meets the criteria for study inclusion or not. Any discrepancies between

the interviewer and second rater will be raised within supervision with the primary investigator. After the interviews have been second rated and all discrepancies between researchers are resolved, the recorded interview will be permanently destroyed.
If the participant consents for their contact details to be shared with other members of the OCD Clinical Psychology Research Group for other ethically approved studies, their name, email address, phone number and results from the screening interview will be entered into a password-protected database and shared with other researchers from the OCD Clinical Psychology Research Group. Participants will be able to ask for their contact details to be removed from this database at any time.
Researchers listed on this form will have access to any other research data. The MS IDREC may request to see data for the purposes of monitoring and/or audit of the study.

5. If research data is to be shared with another organisation, how will it be transferred / disclosed securely?

NA

6. When and how will identifiable data be destroyed or deleted?

Records of consent will be kept on the encrypted computer on the University network for three years after submission of the study in thesis format. The PI will delete the records of consent after this period.

Audio-recordings will be deleted once it has been second-rated by another researcher. This will occur maximum 3 months after data collection.

The linkage list file will be deleted via computer by the PI 3 months from the end of data collection. Unique participant numbers and the linked outcome from the screening will be copied into a new anonymised database kept as research data.

Specific optional consent will be gained from participants to be re-approached for future studies. If participants consent, the record of consent and contact details will be kept on a password-protected database on an encrypted computer on the University network for three years. After this point, the record of consent will be deleted by the PI and the participant contact details will be removed from the database.

8. Please confirm that you will store other research data safely for at least 3 years after final publication or public release and adhere to any additional research funder policies. For more information about the University policies, please see the University's web pages on research data management. **If 'Yes'**, please give details of who will store the data and on storage format, location and security. **If 'No'**, please provide further details.	Yes ☒	No ☐

Data management will adhere to the University research data management and information government policy. Anonymised research data will be stored by the PI on a password-protected encrypted computer on the University network at the Oxford Institute for Clinical Psychology Training for minimum 3 years after final publication of the research findings.

Appendix U: MRAS-Self and MRAS-Others questionnaire

This questionnaire lists different attitudes or beliefs which people sometimes hold. Read each statement carefully and decide how much you agree or disagree with it. For each of the attitudes, show your answer by putting a circle round the words which BEST DESCRIBE HOW YOU THINK. Be sure to choose only one answer for each attitude. Because people are different, there is no right answer or wrong answer to these statements. To decide whether a given attitude is typical of your way of looking at things, simply keep in mind what you are like MOST OF THE TIME.

Please note that these questions are to do with the way you feel about things that may happen to <u>OTHERS</u>.

1. I often feel responsible for things which go wrong for other people.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

2. If I don't act when I can foresee danger to others, then I am to blame for any consequences that happen to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

3. I am too sensitive to feeling responsible for things going wrong for others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

4. If I think bad things about others, this is as bad as <u>doing</u> bad things to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

5. I worry a great deal about the effects on others of things which I do or don't do.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

6. To me, not acting to prevent disaster to others is as bad as me making disaster happen to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

7. If I know that harm to others is possible, I should always try to prevent it, however unlikely it seems.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

8. I must always think through the consequences to others, of even the smallest actions.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

9. I often take responsibility for things that happen to others, which other people don't think are my fault.

NEUTRAL

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY		DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

10. Everything I do can cause serious problems for others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

11. I am often close to causing harm to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

12. I must protect others from harm.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

13. I should never cause even the slightest harm to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

14. I will be condemned for my actions regarding others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

15. If I can have even a slight influence on things going wrong for others, then I must act to prevent it.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

16. To me, not acting where disaster regarding others is a slight possibility is as bad as making that disaster happen.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

17. For me, even slight carelessness is inexcusable when it might affect other people.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

18. In all kinds of daily situations, my inactivity can cause as much harm to others as deliberate bad intentions.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

19. Even if harm to others is a very unlikely possibility, I should always try to prevent it at any cost.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

20. Once I think it is possible that I have caused harm to others, I can't forgive myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

21. Many of my past actions have been intended to prevent harm coming to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

22. I have to make sure other people are protected from all of the consequences of things I do when there is the possibility of harm coming to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

23. Other people should not rely on my judgement.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

24. If I cannot be <u>certain</u> I am blameless for things that happen to others, I feel that I am to blame.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

25. If I take sufficient care to protect others then I can prevent any harmful accidents happening to others.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

26. I often think that bad things will happen to others if I am not careful enough.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

Now, please note that the following questions are to do with the way you feel about things that may happen to <u>YOURSELF</u>. Read each statement carefully and decide how much you agree or disagree with it. For each of the attitudes, show your answer by putting a circle round the words which BEST DESCRIBE HOW YOU THINK.

1. I often feel responsible for things which go wrong for myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

2. If I don't act when I can foresee danger to myself, then I am to blame for any consequences that happen to me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

3. I am too sensitive to feeling responsible for things going wrong for me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

4. If I think bad things about myself, this is as bad as <u>doing</u> bad things to myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

5. I worry a great deal about the effects on myself of things which I do or don't do.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

6. To me, not acting to prevent disaster to myself is as bad as making disaster happen to me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

7. If I know that harm to myself is possible, I should always try to prevent it, however unlikely it seems.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

8. I must always think through the consequences to myself, of even the smallest actions.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

9. I often take responsibility for things that happen to me, which other people don't think are my fault.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

10. Everything I do can cause serious problems for me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

11. I am often close to causing harm to myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

12. I must protect myself from harm.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

13. I should never cause even the slightest harm to myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

14. I will be condemned for my actions regarding myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

15. If I can have even a slight influence on things going wrong for myself, then I must act to prevent it.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

16. To me, not acting where disaster regarding myself is a slight possibility is as bad as making that disaster happen.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

17. For me, even slight carelessness is inexcusable when it might affect me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

18. In all kinds of daily situations, my inactivity can cause as much harm to me as deliberate bad intentions.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

19. Even if harm to myself is a very unlikely possibility, I should always try to prevent it at any cost.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

20. Once I think it is possible that I have caused harm to myself, I can't forgive myself.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

21. Many of my past actions have been intended to prevent harm coming to me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

22. I have to make sure I am protected from all of the consequences of things I do when there is the possibility of harm coming to me.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

23. I should not rely on my judgement.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

24. If I cannot be <u>certain</u> I am blameless for things that happen to me, I feel that I am to blame.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

25. If I take sufficient care to protect myself then I can prevent any harmful accidents happening to me.

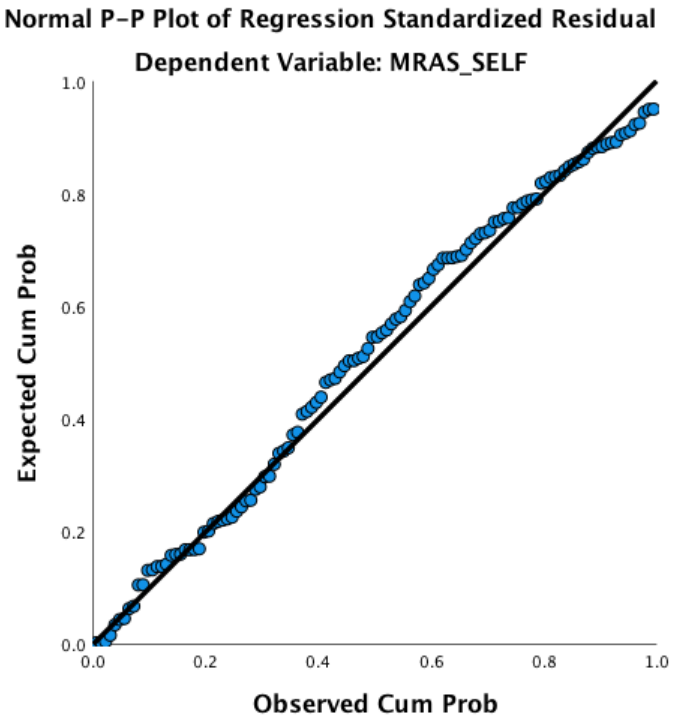
TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

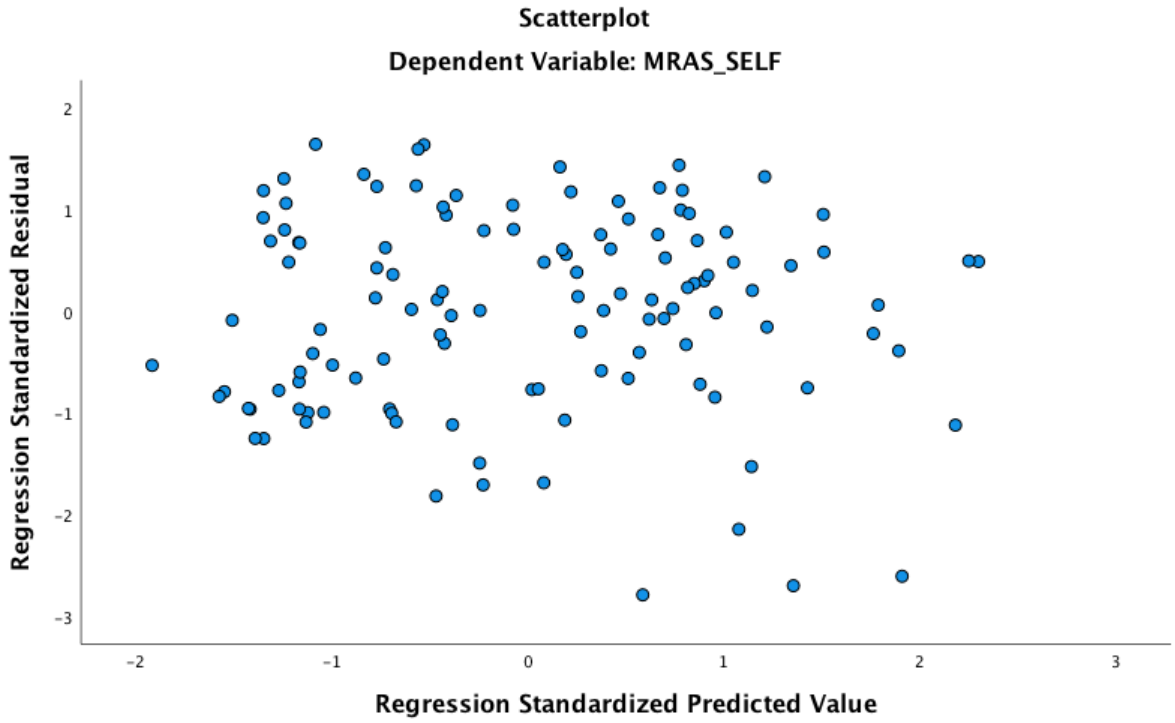
26. I often think that bad things will happen to me if I am not careful enough.

TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE

Appendix V: TDRP Graphs and table measuring linear relationship between variables, multicollinearity and homoscedasticity prior to regression analyses

Regression analyses with MRAS-Self as dependent variable:



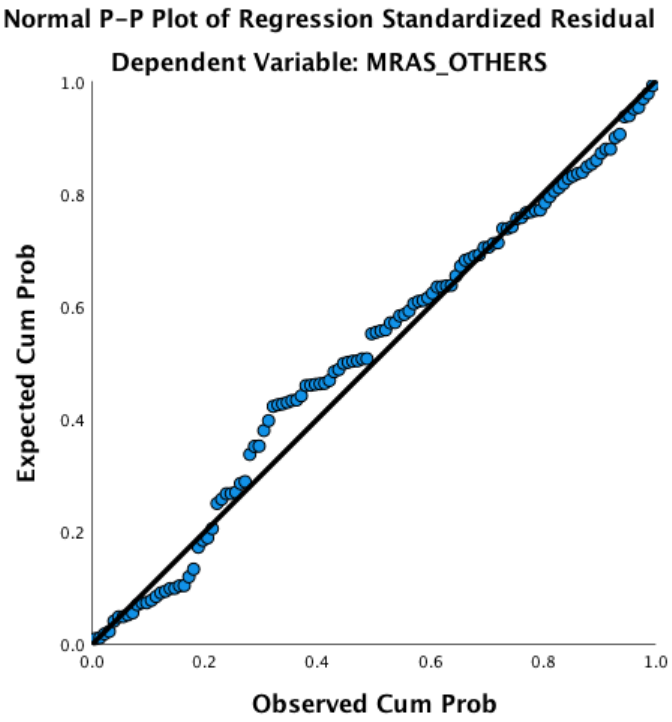


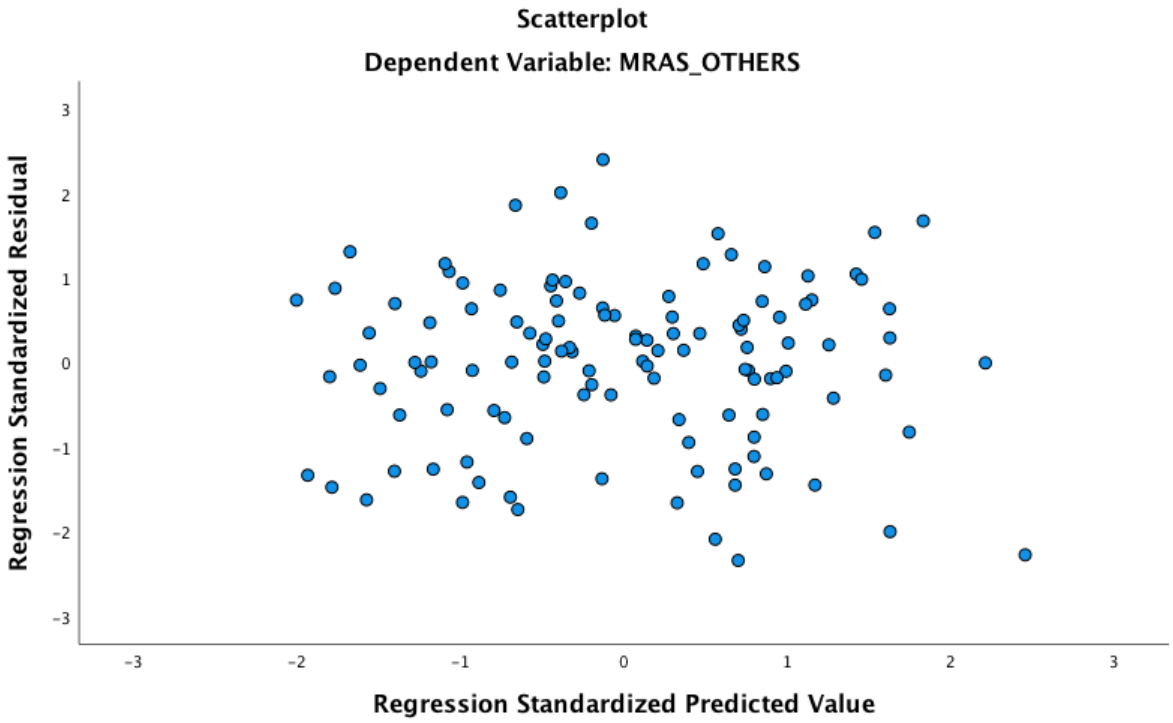
Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Tolerance	VIF
1	(Constant)	111.819	9.852		11.350	<.001		
	CAge	-.654	.207	-.279	-3.153	.002	1.000	1.000
2	(Constant)	63.745	12.277		5.192	<.001		
	CAge	-.327	.201	-.140	-1.633	.105	.826	1.210
	PIRBS_HR	1.299	.640	.166	2.030	.045	.901	1.110
	PIRBS_RR	.826	.599	.125	1.378	.171	.736	1.358
	PIRBS_OP	1.152	.673	.150	1.712	.090	.789	1.267
	PIRBS_ACT_CAUSED	-1.210	.946	-.145	-1.279	.204	.469	2.132
	PIRBS_ACT_INFLUENCE	3.765	1.186	.403	3.175	.002	.375	2.663
3	(Constant)	30.869	14.167		2.179	.031		
	CAge	-.211	.191	-.090	-1.109	.270	.807	1.239
	PIRBS_HR	1.040	.605	.133	1.720	.088	.890	1.123
	PIRBS_RR	.797	.563	.120	1.416	.160	.736	1.358
	PIRBS_OP	.500	.653	.065	.766	.445	.740	1.351
	PIRBS_ACT_CAUSED	-1.405	.891	-.168	-1.578	.117	.468	2.139
	PIRBS_ACT_INFLUENCE	3.091	1.127	.330	2.743	.007	.367	2.724
	c_Group	25.383	6.349	.339	3.998	<.001	.739	1.353

a. Dependent Variable: MRAS_SELF

Regression analyses with MRAS-Others as dependent variable:





Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Tolerance	VIF
1	(Constant)	101.751	8.256		12.325	<.001		
	CAge	-.521	.174	-.266	-2.995	.003	1.000	1.000
2	(Constant)	57.403	10.290		5.578	<.001		
	CAge	-.315	.168	-.161	-1.874	.063	.826	1.210
	PIRBS_HR	1.369	.536	.210	2.553	.012	.901	1.110
	PIRBS_RR	.823	.502	.149	1.639	.104	.736	1.358
	PIRBS_OP	2.219	.564	.346	3.935	<.001	.789	1.267
	PIRBS_ACT_CAUSED	.309	.793	.044	.390	.698	.469	2.132
	PIRBS_ACT_INFLUENCE	.273	.994	.035	.275	.784	.375	2.663
3	(Constant)	40.742	12.400		3.286	.001		
	CAge	-.256	.167	-.131	-1.536	.127	.807	1.239
	PIRBS_HR	1.238	.529	.190	2.339	.021	.890	1.123
	PIRBS_RR	.809	.493	.146	1.641	.104	.736	1.358
	PIRBS_OP	1.888	.571	.294	3.306	.001	.740	1.351
	PIRBS_ACT_CAUSED	.210	.780	.030	.269	.788	.468	2.139
	PIRBS_ACT_INFLUENCE	-.069	.987	-.009	-.069	.945	.367	2.724
	c_Group	12.863	5.557	.206	2.315	.022	.739	1.353

a. Dependent Variable: MRAS_OTHERS

Appendix W: TDRP Instructions to authors for nominated Journal of Obsessive-Compulsive and Related Disorders journal

Aims & Scope

Journal of Obsessive-Compulsive and Related Disorders (JOCRD) is an international journal that publishes high quality research and clinically-oriented articles dealing with all aspects of **obsessive-compulsive disorder** (OCD) and related conditions (**OC spectrum disorders**; e.g., **trichotillomania**, **hoarding**, **body dysmorphic disorder**). The journal invites studies of clinical and non-clinical (i.e., student) samples of all age groups from the fields of psychiatry, psychology, neuroscience, and other medical and health sciences. The journal's broad focus encompasses **classification**, **assessment**, **psychological** and **psychiatric treatment**, **prevention**, **psychopathology**, **neurobiology** and **genetics**. Clinical reports (descriptions of innovative treatment methods) and book reviews on all aspects of OCD-related disorders will be considered, as will theoretical and review articles that make valuable contributions.

Suitable topics for manuscripts include:

- The boundaries of OCD and relationships with OC spectrum disorders
- Validation of assessments of obsessive-compulsive and related phenomena
- OCD symptoms in diverse social and cultural contexts
- Studies of neurobiological and genetic factors in OCD and related conditions
- Experimental and descriptive psychopathology and epidemiological studies
- Studies on relationships among cognitive and behavioral variables in OCD and related disorders
- Interpersonal aspects of OCD and related disorders
- Evaluation of psychological and psychiatric treatment and prevention programs, and predictors of outcome.

SUBMISSION TYPES

Research paper: Clinical and non-clinical research dealing with all aspects of obsessive-compulsive disorder (OCD) and related conditions (OC spectrum disorders; e.g., trichotillomania, hoarding, body dysmorphic disorder)

Review: The journal welcomes systematic reviews and meta-analysis that make valuable contributions on all aspects of OCD-related disorders.

Short communication: A condensed paper with a brief scientific message.

Correspondence: Letters in response to papers published in journal.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
• E-mail address
• Full postal address

All necessary files have been uploaded:
Manuscript:
• Include keywords
• All figures (include relevant captions)
• All tables (including titles, description, footnotes)
• Ensure all figure and table citations in the text match the files provided
• Indicate clearly if color should be used for any figures in print
Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)

Further considerations
• Manuscript has been 'spell checked' and 'grammar checked'
• All references mentioned in the Reference List are cited in the text, and vice versa
• Permission has been obtained for use of copyrighted material from other sources (including the Internet)
• A competing interests statement is provided, even if the authors have no competing interests to declare
• Journal policies detailed in this guide have been reviewed
• Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

References
There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements
There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes. Divide the article into clearly defined sections.

Please ensure the text of your paper is double-spaced—this is an essential peer review requirement.

Figures and tables embedded in text
Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file. The corresponding caption should be placed directly below the figure or table.

Article structure

Introduction
State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results. If the focus of the paper is on a disorder other than OCD (as defined in DSM-IV.TR), provide a rationale for including the disorder as an obsessive-compulsive related disorder (see Editorial Guidance section).

Methods
Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation
A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results
Results should be clear and concise.

Discussion
This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature. Be sure to include limitations of the present study and suggestions for future research.

Conclusions
The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices
If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate

numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Clinical reports and case histories
The Journal will consider clinical reports that articulate the treatment of OCD or related disorders using any theoretical framework (biological, behavioral, cognitive, gestalt, humanistic, psychodynamic, and others). Clinical reports should use the following format (maximum manuscript length is 30 pages in total):

1. Theoretical and Research Basis for the Treatment
2. Case Introduction (presenting complaints, history, etc.)
3. Assessment (what instruments were used [and justification if needed])
4. Case Conceptualization (discuss the clinician's thinking about the case and the treatment selection)
5. Course of Treatment and Assessment of Progress (Describe what happened during treatment and the outcome at post-treatment and follow up. If possible, use single case research design methodology; see Barlow, Nock, &Hersen [2009])

6. Complicating Factors (if any, including medical management)
7. Treatment Implications of the Case
8. Recommendations to Clinicians and Students

Shorter communications/Brief reports
This option is designed to allow publication of research reports that are not suitable for publication as regular articles. Shorter Communications or Brief Reports are appropriate for articles with a specialized focus or of particular didactic value. Manuscripts should be between 3000-5000 words, and must not exceed the upper word limit. This limit includes the abstract, text, and references, but not the title page, tables and figures.

Essential title page information

• ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
• ***Author names and affiliations.*** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
• ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**

• ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Highlights

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.
Authors can make use of Elsevier's Illustration Services to ensure the best presentation of their images and in accordance with all technical requirements.

Keywords

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Appendix X: TDRP Correlation Matrix

		CAge	OCI_TOTAL	OCI_WASHING	OCI_CHECKING	OCI_DOUBTING	OCI_ORDERING	OCI_OBSESSING	OCI_HOARDING	OCI_MENTALNEUTRALISING	WSAS_TOTAL	PIRBS_TOTAL	PIRBS_HR	PIRBS_RR	PIRBS_OP	PIRBS_ACTCAUSE_SC	PIRBS_ACTINFLUE_SC	MRAS_SELF	MRAS_OTHERS
CAge	Pearson Correlation	--																	
	N	120																	
OCI_TOTAL	Pearson Correlation	-.287**	--																
	Sig. (2-tailed)	.002																	
	N	120	120																
OCI_WASHING	Pearson Correlation	-.175	.783**	--															
	Sig. (2-tailed)	.055	<.001																
	N	120	120	120															
OCI_CHECKING	Pearson Correlation	-.259**	.865**	.569**	--														
	Sig. (2-tailed)	.004	<.001	<.001															
	N	120	120	120	120														
OCI_DOUBTING	Pearson Correlation	-.235**	.860**	.585**	.860**	--													
	Sig. (2-tailed)	.010	<.001	<.001	<.001														
	N	120	120	120	120	120													
OCI_ORDERING	Pearson Correlation	-.204*	.810**	.611**	.647**	.700**	--												
	Sig. (2-tailed)	.025	<.001	<.001	<.001	<.001													
	N	120	120	120	120	120	120												
OCI_OBSESSING	Pearson Correlation	-.324**	.751**	.399**	.579**	.591**	.458**	--											
	Sig. (2-tailed)	<.001	<.001	<.001	<.001	<.001	<.001												
	N	120	120	120	120	120	120	120											
OCI_HOARDING	Pearson Correlation	-.083	.536**	.314**	.370**	.378**	.487**	.364**	--										
	Sig. (2-tailed)	.370	<.001	<.001	<.001	<.001	<.001	<.001											
	N	120	120	120	120	120	120	120	120										
OCI_MENTALNEUTRALISING	Pearson Correlation	-.194*	.767**	.489**	.577**	.570**	.601**	.582**	.477**	--									
	Sig. (2-tailed)	.033	<.001	<.001	<.001	<.001	<.001	<.001	<.001										
	N	120	120	120	120	120	120	120	120	120									
WSAS_TOTAL	Pearson Correlation	-.286**	.772**	.607**	.615**	.638**	.591**	.712**	.393**	.532**	--								
	Sig. (2-tailed)	.002	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001									
	N	120	120	120	120	120	120	120	120	120	120								
PIRBS_TOTAL	Pearson Correlation	-.224*	.557**	.369**	.469**	.476**	.353**	.555**	.326**	.450**	.479**	--							
	Sig. (2-tailed)	.014	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001								
	N	120	120	120	120	120	120	120	120	120	120	120							
PIRBS_HR	Pearson Correlation	.015	.158	.112	.111	.124	.051	.232*	-.049	.161	.216*	.457**	--						
	Sig. (2-tailed)	.870	.086	.224	.229	.176	.580	.011	.598	.079	.018	<.001							
	N	120	120	120	120	120	120	120	120	120	120	120	120						
PIRBS_RR	Pearson Correlation	-.007	.284**	.164	.230*	.209*	.183*	.323**	.120	.278**	.187*	.717**	.186*	--					
	Sig. (2-tailed)	.944	.002	.073	.012	.022	.046	<.001	.194	.002	.041	<.001	.041						
	N	120	120	120	120	120	120	120	120	120	120	120	120	120					
PIRBS_OP	Pearson Correlation	-.250**	.456**	.261**	.419**	.457**	.355**	.381**	.275**	.380**	.308**	.564**	-.087	.322**	--				
	Sig. (2-tailed)	.006	<.001	.004	<.001	<.001	<.001	<.001	.002	<.001	<.001	<.001	.342	<.001					
	N	120	120	120	120	120	120	120	120	120	120	120	120	120	120				
PIRBS_ACTCAUSE_SC	Pearson Correlation	-.207*	.414**	.315**	.333**	.348**	.251**	.371**	.372**	.302**	.436**	.714**	.157	.276**	.259**	--			
	Sig. (2-tailed)	.023	<.001	<.001	<.001	<.001	.006	<.001	<.001	<.001	<.001	<.001	.086	.002	.004				
	N	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120			
PIRBS_ACTINFLUE_SC	Pearson Correlation	-.331**	.529**	.379**	.462**	.439**	.322**	.521**	.388**	.340**	.453**	.793**	.224*	.417**	.309**	.725**	--		
	Sig. (2-tailed)	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.014	<.001	<.001	<.001			
	N	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120		
MRAS_SELF	Pearson Correlation	-.279**	.588**	.442**	.523**	.570**	.357**	.588**	.180*	.375**	.464**	.497**	.241**	.333**	.297**	.275**	.479**	--	
	Sig. (2-tailed)	.002	<.001	<.001	<.001	<.001	<.001	<.001	.049	<.001	<.001	<.001	.008	<.001	<.001	.002	<.001		
	N	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	
MRAS_OTHERS	Pearson Correlation	-.266**	.487**	.295**	.474**	.516**	.397**	.401**	.201*	.351**	.451**	.493**	.220*	.327**	.438**	.267**	.336**	.645**	--
	Sig. (2-tailed)	.003	<.001	.001	<.001	<.001	<.001	<.001	.027	<.001	<.001	<.001	.016	<.001	<.001	.003	<.001	<.001	
	N	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120	120

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).