Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych)

23rd May 2025



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Word Count

Systematic review: 6729
Service improvement project: 5310
Theory driven research project: 5358
Executive summary: 606
Connecting narrative: 879

Total word count: 18,882

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Abstracts

Systematic Review of the Literature

Title: Third-Wave Cognitive Behavioural Therapies for Informal Caregivers of People Living with Dementia: A Systematic Review

Background: Informal caregivers of people living with Dementia (PlwD) are at increased risk of psychological distress such as anxiety or depression. Informal caregivers of PlwD are routinely offered group Cognitive Behavioural Therapy (CBT). Appraisals and coping strategies are key components of the caregiver stress model and are targets of third-wave CBT. This systematic review aimed to investigate the acceptability, clinical effectiveness and quality of research exploring third-wave CBT interventions for informal caregivers of PlwD.

Methods: Ovid (PsychInfo, MEDLINE and Embase), Scopus and PubMed databases were searched for peer-reviewed intervention studies investigating a third-wave CBT (ACT, CFT, MBCT or DBT) for informal caregivers of PlwD. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines was used to screen studies and findings were synthesised using the Synthesis Without Meta-Analysis Reporting Guidelines. The Kmet tool was used to assess risk of bias of the included studies.

Results: Twenty studies were included in the review, and 578 participants received a third-wave CBT. Interventions included ACT (k=11), MBCT (k=5), DBT (k=1), CFT (k=1), ACT and CFT fusion (k=1) and ACT and CBT (k =1). Effect sizes ranged from small to very large. Study quality ranged from moderate to high.

Discussion: Results suggest that third-wave CBTs for this population are generally acceptable and effectiveness is observed for ACT interventions. However, a lack of control groups and small sample sizes mean that more high-quality studies are required to fully

understand the effectiveness of these interventions for this population. Interventions should consider unique challenges for informal caregivers to engage in third-wave CBTs.

Service Improvement Project

Title: Improving the experience of adults waiting for an autism diagnostic assessment

Purpose: There has been a rise in referrals to adult autism assessment services. National guidelines suggest that people should be seen for an assessment within 13 weeks. This service improvement project aimed to provide recommendations for improving the experience of waiting for a diagnostic assessment in the Adult ADHD, Autism and Tourette's Team within Northamptonshire Healthcare NHS Foundation Trust. The service is struggling to meet the increased demand and the wait for an assessment from point of referral is now several years. The rates of these referrals are not plateauing and therefore it is crucial that ways to support the population of people waiting are considered.

Methods: Open-ended free text survey responses from service users and focus groups and interviews with staff were analysed with the aim of providing recommendations for the service.

Results: Themes identified from service users included uncertainty, which led them to contact the service more, feeling stuck in limbo during a lonely wait that had implications for their identity and self-diagnosis, impact on day-to-day life and support during the process. Themes generated from staff included challenges at a service level including the role of the screening appointment and an increase in demand with a decrease in resource, feeling powerless, considering ways to support those on the waiting list and systemic challenges.

Conclusion: Recommendations for service improvement focused on increasing certainty and reducing anxiety for service users by increasing communication and support, whilst minimising service demand. The recommendations were shared with the service.

Theory Driven Research Project

Title: "It's a loop that I am stuck in": A Mixed Methods Study Exploring Self-Compassion in Compulsive Exercise in Young People with Eating Disorders

Background: Compulsive exercise is prevalent but poorly understood in eating disorders such as Anorexia and Bulima Nervosa. This study aimed to explore the role of self-compassion in compulsive exercise.

Method: A mixed-methods, cross-sectional online questionnaire study was conducted with 146 young people (aged 16-25) with Anorexia, Bulimia or Atypical Anorexia. Participants were recruited through NHS eating disorder services and social media. Statistical analyses investigated differences in self-compassion between high and low compulsive exercise groups and regression models explored self-compassion as a predictor of compulsive exercise. Qualitative responses from 55 participants were analysed thematically.

Results: Self-compassion was low across the sample. No significant differences were found in self-compassion between those with high and low compulsive exercise, after controlling for eating disorder diagnosis, symptomology, anxiety and mood. Eating disorder diagnosis, symptomology, anxiety, mood and self-compassion were significant in predicting severity of compulsive exercise. Exploratory analyses indicated that self-compassion was a significant predictor of lack of exercise enjoyment. Thematic analysis identified three themes; "Unrelenting standards", "The drive to exercise" and "Secrecy" which all fell under the overarching theme of "It's a loop that I'm stuck in".

Discussion: Findings indicate that anxiety and self-compassion play important roles within compulsive exercise and further research is needed to investigate this relationship. Understanding the function and impact of compulsive exercise may help tailor clinical interventions.

Systematic Review of the Literature

Third-Wave Cognitive Behavioural Therapies for Informal Caregivers of People Living with Dementia: A Systematic Review

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Word count: 6381

Date of submission: 23rd May 2025

Journal: Dementia

Rationale: Dementia is a peer-reviewed journal with an impact score of 2.4 that aims to publish research that adds to the existing literature and lived experience of dementia. It is therefore deemed an appropriate journal for this systematic review. Journal guidelines are in Appendix B.

Abstract

Background: Informal caregivers of people living with Dementia (PlwD) are at increased risk of psychological distress such as anxiety or depression. Informal caregivers of PlwD are routinely offered group Cognitive Behavioural Therapy (CBT). Appraisals and coping strategies are key components of the caregiver stress model and are targets of third-wave CBT. This systematic review aimed to investigate the acceptability, clinical effectiveness and quality of research exploring third-wave CBT interventions for informal caregivers of PlwD.

Methods: Ovid (PsychInfo, MEDLINE and Embase), Scopus and PubMed databases were searched for peer-reviewed intervention studies investigating a third-wave CBT (ACT, CFT, MBCT or DBT) for informal caregivers of PlwD. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were used to screen studies and findings were synthesised using the Synthesis Without Meta-Analysis Reporting Guidelines. The Kmet tool was used to assess risk of bias of the included studies.

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Discussion: Results suggest that third-wave CBTs for this population are generally acceptable and effectiveness is observed for ACT interventions. However, a lack of control groups and small sample sizes mean that more high-quality studies are required to fully understand the effectiveness of these interventions for this population. Interventions should consider unique challenges for informal caregivers to engage in third-wave CBTs.

Keywords: dementia, informal caregivers, third-wave CBT, Acceptance and Commitment Therapy, Mindfulness Based Cognitive Therapy

Introduction

Dementia is a progressive condition comprising several diseases that affect memory, thinking, and the ability to carry out daily activities (Donaldson et al., 1997). Globally, more than 55 million people are currently living with dementia, a figure projected to rise to over 131 million by 2050 due to increasing life expectancy (Gauthier et al., 2021). The majority of people living with dementia (PlwD) reside in the community and receive support from informal caregivers (Chiao et al., 2015; Fam et al., 2019).

Informal caregivers for PlwD span a wide age range and include relatives, partners, friends or neighbours who provide assistance to individuals experiencing cognitive, physical or functional impairments (Schulz & Eden, 2016). Globally it is estimated that informal caregivers contribute around 82 billion hours of unpaid care annually, averaging six hours per day (Wimo et al., 2017). In the UK alone, informal caregivers of PlwD provide approximately 1.34 billion hours of unpaid care, representing 44% of the total cost associated with dementia (Prince et al., 2014). Informal caregivers support with a wide range of tasks such as practical and emotional support, transportation, household chores and companionship and eventually assist with personal care as the disease progresses (McCaffrey et al., 2020). Given the emotional toll of the role which leads to elevated stress, anxiety and depression, informal caregivers of PlwD have been described as ‘invisible second patients’ (Cooper et al., 2007; Schoenmakers et al., 2010).

Informal caregivers of PlwD are at an increased risk for caregiver burden, stress, depression and anxiety compared to informal caregivers of people without dementia (Bertrand et al., 2006; Waite et al., 2004). Within the dementia caregiving literature, the caregiver stress model (Pearlin et al., 1990) based on Lazarus and Folkman’s transactional stress process model is the most widely implemented framework (Gilsenan et al., 2023; Lazarus & Folkman, 1984). The model suggests that caregiver stress occurs within the

sociological context of chronic caregiving whilst recognising that stress develops from immediate caregiving demands (primary stressors) as well as secondary role strains (e.g. change or loss to social identity) and is then moderated by personal and external coping resources (Pearlin et al., 1990). In the context of informal caregivers of PlwD, this model understands the psychological distress associated with primary stressors such as behavioural and cognitive symptoms, memory loss, daily care and secondary stressors such as social isolation, role conflict and navigating emotional grief (Chiao et al., 2015).

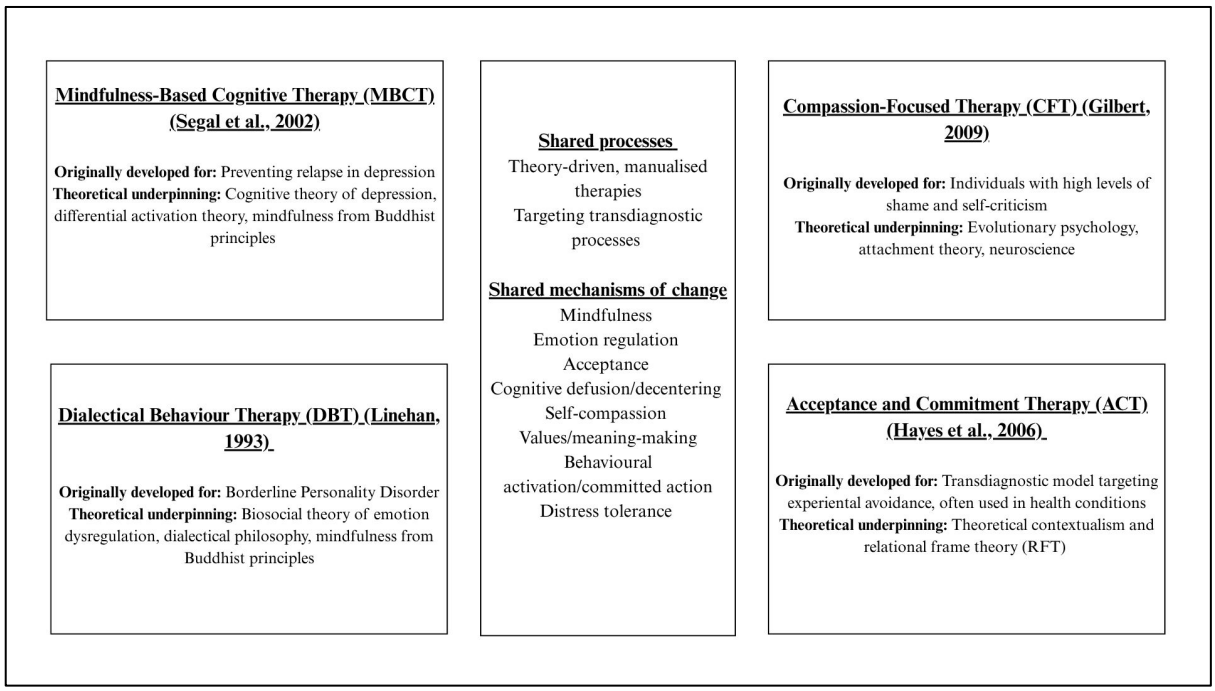
The National Institute of Health and Care Excellence (NICE) highlights that informal caregivers of PlwD are at increased risk of developing depression and recommends interventions such as guided self-help, individual or group cognitive behavioural therapy (CBT), behavioural activation and group mindfulness (NICE, 2018). CBT incorporates principles from both behavioural and cognitive theories (Bandura, 1977; Beck, 1967) and is often used to address maladaptive appraisals such as those in the caregiver stress model (Schulz et al., 2020). Within the National Health Service (NHS) informal caregivers of PlwD are typically offered CBT group for carers, which aims to manage stress and reduce caregiver burden (Fossey et al., 2016). However, research findings on the effectiveness of CBT for this population have been mixed, with some studies only reporting small effect sizes (Hopkinson et al., 2019; McLoughlin, 2022). Furthermore, existing reviews have noted a lack of diversity in study samples, which often do not reflect the broader demographics of caregivers (Gitlin et al., 2019).

In recent decades, third-wave CBTs have emerged with a transdiagnostic focus on therapeutic processes, particularly emotion regulation, mindfulness, compassion and acceptance, rather than on disorder-specific models (Hayes & Hofmann, 2017). Several therapies fall under the ‘third wave’ umbrella, the most recent including acceptance and commitment therapy (ACT) (Hayes et al., 2012), dialectical behaviour therapy (DBT)

(Linehan, 1993), mindfulness-based cognitive therapy (MBCT) (Segal et al., 2002) and compassion focused therapy (CFT) (Gilbert, 2009). These four approaches are grounded in transdiagnostic cognitive behavioural principles, and integrate mindfulness, values-based action and acceptance strategies (see Figure 1).

Figure 1

Visual overview of third-wave cognitive behavioural therapies and shared processes and mechanisms



MBCT, a NICE recommended intervention for depression, combines mindfulness practice with cognitive therapy techniques (Segal et al., 2002). ACT promotes psychological flexibility, defined as the ability to remain present and act in accordance with one's values, even in the presence of distressing thoughts and feelings (Hayes et al., 2006). ACT typically involves three core processes: enhancing nonjudgemental awareness, fostering acceptance, cognitive defusion and identifying personal values to guide behaviour change. CFT aims to support individuals experiencing high levels of shame or self-criticism by promoting the

development of self-compassion (Gilbert, 2009). DBT, initially developed for individuals with borderline personality disorder, targets difficulties in emotion regulation through a combination of acceptance and change-oriented strategies (Linehan, 1993). These approaches share common elements including acceptance, mindfulness, self-compassion and values-focused work (L. A. Brown et al., 2011).

Exploring third-wave CBTs in informal caregivers of PlwD is pertinent, due to the increasing prevalence of dementia, high risk of psychological distress, the wider economic burden of informal caregiving and the limitations of traditional CBT. Additionally, the role of appraisal and coping strategies, as highlighted in the caregiver stress model (Pearlin et al., 1990), are key targets in third-wave CBTs. These approaches have demonstrated effectiveness in improving psychological flexibility, reducing distress and enhancing well-being across a range of populations, including children and adolescent populations (Perkins et al., 2023) and informal caregivers of people living with cancer (Hong et al., 2023).

Third-wave CBTs may be particularly beneficial for informal caregivers of PlwD as they often face prolonged and increasing exposure to stress, grief, role changes and interpersonal challenges. Within the caregiver stress model, these approaches offer strategies to develop awareness of negative appraisals, enhance coping and develop emotional responses. While traditional CBT primarily focuses on identifying and restructuring maladaptive thoughts and responses to reduce symptoms, third-wave approaches place greater emphasis on acceptance of experiences, mindful awareness and personal values. This shift in focus could be particularly beneficial for dementia caregivers as many stressors such as cognitive decline and loss of independence of the care recipient are not amenable to change and thus cognitive restructuring may be less effective. For example, ACT and MBCT involve acceptance of progressive loss and increased uncertainty and promote engagement in valued activities for caregivers (Márquez-González et al., 2010). CFT addresses guilt, shame

and self-criticism which may be present if caregivers perceive themselves as not meeting expectations in the caregiver role, particularly present in the context of increasing demand and stress (Collins et al., 2018). DBT aims to strengthen emotion regulation and distress tolerance in response to challenging behaviours (Drossel et al., 2011).. Overall, with a focus on mindfulness, acceptance and compassion, these third-wave approaches not only aim to reduce distress but to improve quality of life and reduce caregiver burden in the context of increasing demand for informal caregivers of PlwD. Therefore, these approaches have the potential to contribute to the development of the evidence base consisting of traditional CBT interventions that prioritise symptom reduction or comprise a problem specific model, as opposed to a transdiagnostic model (Thoma et al., 2015).

Systematic reviews for informal caregivers of PlwD have focused on informal caregivers of a range of neurodegenerative conditions or included mild cognitive impairment (Atefi et al., 2023; Chan et al., 2020), included meditation or yoga-based practices without a cognitive behavioural component in interventions such as mindfulness-based stress reduction (Murfield et al., 2021), focused solely on a specific intervention and engaging carers in this (Atefi et al., 2023; Chacko et al., 2022; Durepos et al., 2024a) or used scoping methods to explore these third-wave CBTs in informal caregivers of older adults not specific to dementia (Murfield et al., 2021). Therefore, a review and synthesis of third-wave CBTs for this population is important, particularly as clinical psychologists often deliver interventions based on cognitive-behavioural transdiagnostic principles in the NHS. To date, no study has synthesised the effectiveness and quality of third-wave CBTs (ACT, CFT, MBCT and DBT) for this population.

Research questions

The review was developed using the PICO framework to guide eligibility criteria and search terms. The population of interest was informal caregivers of PlwD. Interventions

included third-wave CBTs; ACT, DBT, MBCT and CFT. Outcomes included acceptability and clinical effectiveness on any measure of psychological wellbeing related to the experience of being a caregiver. This systematic review aims to explore the use of third-wave CBTs for family caregivers of PlwD. The research questions are:

1) What is the acceptability (as measured by attrition rates, satisfaction measures, adherence and reasons for drop out) of third-wave cognitive behavioural interventions (ACT, DBT, MBCT and CFT) for informal caregivers of people living with dementia?
2) What is the clinical effectiveness of third-wave cognitive behavioural interventions (ACT, DBT, MBCT and CFT) for informal caregivers of people living with dementia?
3) What is the quality of evidence of third-wave cognitive behavioural interventions (ACT, DBT, MBCT and CFT) being offered and evaluated for informal caregivers of people living with dementia?

Methods

This systematic review followed PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) guidelines (Page et al., 2021) and was pre-registered on Prospero (ID: CRD42024577087).

Eligibility Criteria

Studies were included if they (a) implemented a third-wave CBT individual or group intervention (ACT, MBCT, DBT or CFT) with pre and post measures for informal caregivers, (b) used quantitative measures exploring acceptability and/or effectiveness and (c) were peer reviewed. Studies were excluded if they (a) focused on Mild Cognitive Impairment as opposed to Dementia, (b) included professional caregivers, (c) were case studies, (d) used solely qualitative methods or (e) implemented psychological interventions not deemed as third-wave CBT for the purposes of the current review. Unpublished manuscripts and conference abstracts were excluded from the review. There were no limitations placed on publication date, geographical restrictions or publication language. Informal caregivers were defined as relatives, partners or friends who assist a person living with dementia (Bertrand et al., 2006). Dementia was defined as a syndrome associated with an ongoing decline of brain functioning and included all types of dementia (World Health Organisation, 2023). Third-wave cognitive behavioural approaches were defined as interventions based on ACT, DBT, CFT or MBCT. These four approaches were included in this study as they are four of the most recent third-wave CBTs developed, share common processes, are often delivered by clinical psychologists in the NHS and are included in reviews of third-wave CBTs in older adult populations (Collins & Kishita, 2019) and other populations (Perkins et al., 2023). Studies were included if they used a combination of two of these approaches (for example ACT and CFT (Gallego-Alberto et al., 2021)) or if they included one of these approaches

alongside CBT, but where the third-wave approach guided the intervention (e.g. (Marquez-Gonzalez et al., 2020)).

Search Strategy and Information Sources

Searches were run on 24th July 2024 and updated on 11th May 2025. Databases on Ovid (PsychInfo, MEDLINE and Embase), Scopus and PubMed were searched. The first author also completed forwards and backward citation searching of all included studies to search for additional papers using reference lists and Google Scholar. Search terms corresponding with the PICO framework were applied; informal caregivers (e.g. informal caregiver* or family car*), dementia (e.g. dementia or Alzheimer*) and third-wave cognitive behavioural approaches (e.g. acceptance and commitment therapy or mindfulness based cognitive therapy or compassion focused therapy or dialectical behaviour therapy) were used (see Appendix A for full search strategy).

Selection Process

Studies were imported into EndNote (version 21) where duplicates were removed. Titles and abstracts were screened against the eligibility criteria by the first author (NC). The second author (RB) screened 20% of papers in the title and abstract phase. The first author then screened all studies taken through to full text screening and RB independently screened 25% of these. Any discrepancies were resolved through discussion with the first, second and third author to reach a perfect agreement (k =1) (Cohen, 1960). See Figure 1 for PRISMA diagram of the study selection process.

Data Extraction

The Cochrane tool for extraction for systematic reviews was used to extract data (Li et al., 2023) and Microsoft Excel was used for data extraction. NC extracted data from all the included studies and RB independently extracted 50% of data. Information extracted included study characteristics (author, location, design, aim, third-wave approach, mechanisms of

change, format, delivery, duration, facilitator, comparator), participant characteristics (sample size, age, gender, carer relationship, ethnicity, hours of caring per day, type of dementia, inclusion/exclusion), acceptability (attrition, satisfaction findings, adherence, reported dropout reasons) and clinical effectiveness (assessment timepoints, primary/secondary outcomes, measures, primary/secondary findings, clinically significant change, follow-up data, effect sizes)

Quality assessment

The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004) was used to assess the quality of included studies and elements of risk of bias assessment. The Kmet tool is considered an appropriate tool for quality assessment when there are various designs of studies being compared (Kmet et al., 2004). This tool comprises of 14 questions assessing quality of methods and risk of bias and gives studies a score between 0 and 1, where ≥0.75 is considered high quality, 0.55 to 0.74 is considered moderate quality and <0.55 is considered low quality (Ceretti et al., 2022; Lee et al., 2008). The second author RB independently rated 50% of these and a Cohen's Kappa (Cohen, 1960) indicated a strong level of agreement (k=0.75).

Synthesis Methods

A meta-analysis was not able to be conducted as a minimum of five RCTs in homogeneous interventions is recommended for a meta-analysis (Myung, 2023). The synthesis without meta-analysis (SWiM) approach (Campbell et al., 2020) was implemented in the narrative synthesis. This method is recommended particularly when a meta-analysis is not possible (Campbell et al., 2020). The narrative synthesis grouped studies by the type of third-wave intervention and then by the outcome in the study, e.g. caregiver burden, anxiety, depression. Due to heterogeneity amongst interventions, studies were tabulated and grouped corresponding to each intervention (either ACT, DBT, CFT or MBCT). Investigation of

heterogeneity amongst included studies was examined by delivery format, study quality, and overview of intervention.

Effect Measures

For outcomes, where reported, standardised effect sizes were extracted, including Cohen's d, Standardised Response Mean (SRM), Partial eta squared (ηp^2) and Pearson's r. To interpret the magnitude of the effect sizes, standard interpretative thresholds were applied and reported (e.g. Cohen's d, small = 0.2, medium = 0.5, large 0.8). Given heterogeneity in outcome measures and interventions, all effect sizes on primary outcomes were applied to a qualitative descriptors and patterns of effect and clinical relevance were summarised in the synthesis. Due to a lack of meta-analysis, confidence in certainty of evidence was assessed qualitatively using quality appraisal outcomes, heterogeneity of studies and consistency of findings.

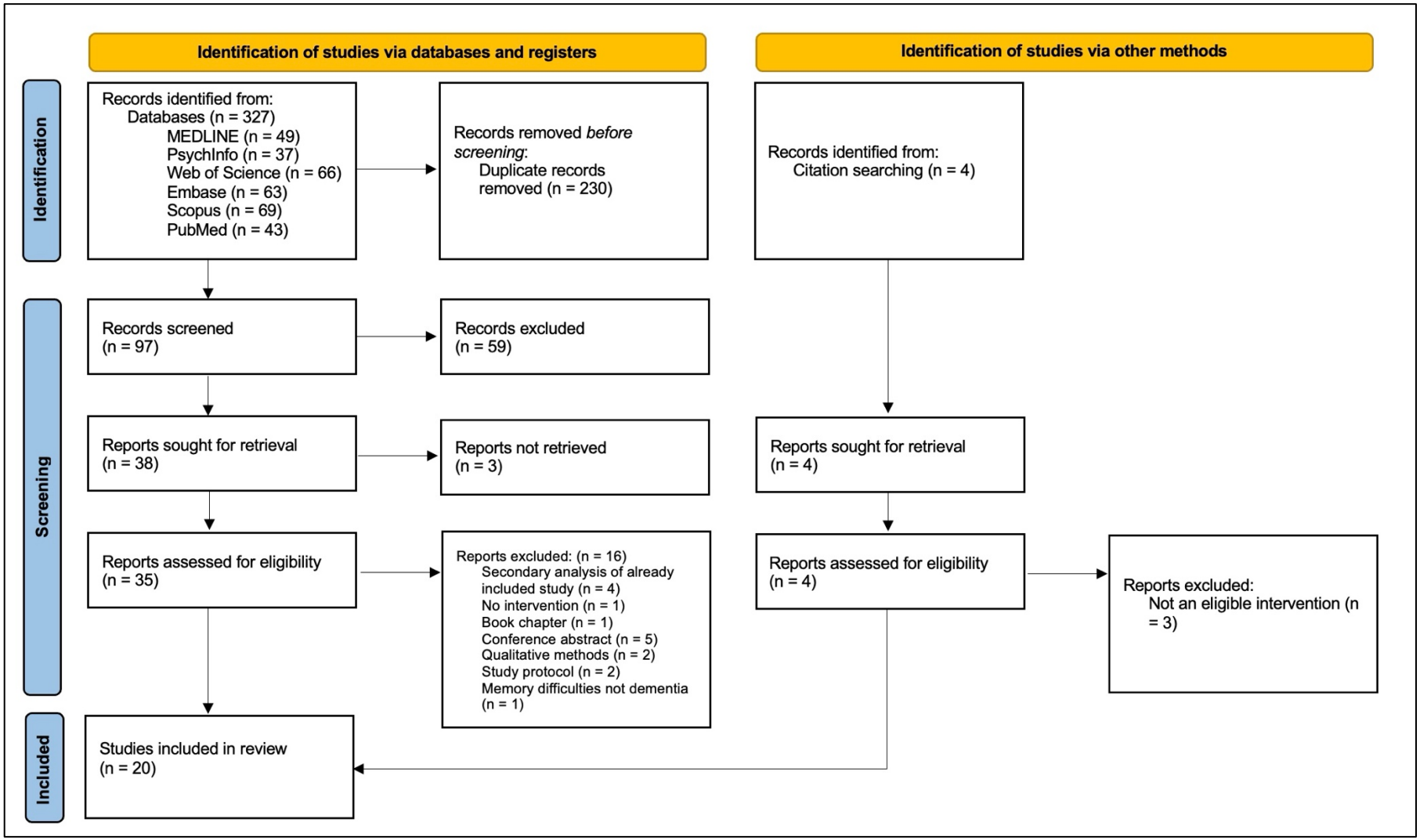
Results

Study selection

Twenty studies met the inclusion criteria and were included in the systematic review. Figure 2 presents the PRISMA flow diagram outlining the study selection process. The search resulted in 327 citations and 97 abstracts were screened after removing duplicates. NC and RB excluded 59 articles based on titles and abstracts. NC then screened 36 full text articles using the inclusion criteria and 16 studies were excluded. There were no disagreements on the included studies. Common reasons for exclusion were non-peer reviewed conference abstracts (for example, Kishita, 2023; Losada et al., 2014). Three papers were not able to be accessed and there was no response after contacting the authors (Gul et al., 2024; Harbi, 2018; Zarei et al., 2020).

Figure 2

Prisma flowchart of selection process (Page et al., 2021)



Study and intervention characteristics

Table 1 shows the characteristics of the included studies and interventions. The 20 studies were published from 2010 to 2025 and conducted in various countries across Netherlands, USA, UK, Republic of Korea, Spain, Germany, Hong Kong, Iran and Canada. The studies employed a range of pre-post designs including randomised controlled trials (RCTs) (k=5), pilot RCT (k= 4), feasibility or pilot studies (k=7), pre-post (k=2) and quasi experimental designs (k=2).

Interventions included ACT (k=11), MBCT (k=5), DBT (k=1), CFT (k=1), ACT and CFT fusion (k=1) and ACT and CBT (k=1). An overview of the interventions and adaptations for informal caregivers of PlwD is presented below.

ACT

Interventions were delivered in individual (k=10) and group (k=1) formats with delivery in-person (k=5), telephone (k=3) and online platforms (k=5). Intervention length ranged from 5 to 12 sessions and session duration ranged from 30 minutes to 2 hours. One study included 6 booster sessions. Interventions were delivered by clinical psychologists (k=4), non-specified therapists with ACT training (k=2), licensed ACT counsellors (k=2), licensed counsellor (k=1), trainee/assistant psychologists (k=1), bachelors level interventionist (k=1), no facilitator as self-guided intervention (k=1), trained research assistant (k=1).

Four of the ACT interventions were based on an adapted ACT protocol for distressed family caregivers of PlwD (Márquez-González et al., 2010). This intervention includes the main components of ACT and focuses on (a) the acceptance of aversive internal and external events (b) choosing meaningful courses of action that are consistent with one's values and (c) value-oriented action (Márquez-González et al., 2010). One other study reported adaptations

that were applied for this population including applying ACT concepts to care-specific vignettes (Fauth et al., 2022). One of the interventions reported a psychoeducation component related to dementia and ACT was implemented to help carers accept one's difficult thoughts about these experiences, with a focus on values work with committed action and experiential exercises (George et al., 2021). One study reported a combination of ACT and CFT (Gallego-Alberto et al., 2021) with the aim of targeting guilt in caregivers. The intervention aimed to explore dysfunctional beliefs in caregivers, and to develop caregivers' ability to tolerate and accept guilt and distressing emotions through ACT and CFT based exercises such as addressing beliefs and guilt, increasing values-based action and self-compassion. Six ACT interventions had a comparator group, which were mostly psychoeducation or treatment as usual groups (k=4) or CBT (k=2). All of the ACT studies reported a focus on the core ACT processes; acceptance, defusion, present-moment awareness, self-as-context, values and committed action.

MBCT

Of the five MBCT interventions, all were delivered in group format and in person. They were mostly 7 weekly sessions of between 1.5-2.5 hours each, and one study had 8 weekly sessions 2.5 hours each. Interventions were delivered by a certified MBCT teacher (2), a clinical psychologist trained in MBCT (1), a certified therapist (1) and one study did not report the facilitator. The MBCT interventions included mindfulness practice (k=5), CBT techniques (k=3), cognitive defusion (k=1) or decentring (k=3), positive reappraisal (k=2) acceptance (k=3) and self-compassion (k=1). Various adaptations were reported for caregivers of PlwD including psychoeducation on caregiving and dementia and adapting for time burden to caregivers by shortening and integrating content.

CFT

One study reported an in-person CFT group dyadic intervention for informal caregivers of PlwD as well as the care recipient (Collins et al., 2018). This was delivered by clinical psychologists, co-facilitated by trainee psychologists. It was based on the model of CFT but was dynamic to the needs of each group. The intervention included CFT psychoeducation, socialisation to the CFT affect regulation model, compassion circles, forms of compassion, fears and blocks to compassion, flows of compassion, multiple selves and soothing rhythm breathing exercise. The CFT model was adapted for this population by understanding Dementia as a threat, which facilitated dementia psychoeducation and conversations about emotions.

DBT

One study explored a DBT skills group for caregivers of PlwD (Drossel et al., 2011). This was an in-person group delivered by student therapists and took place over 9 weekly sessions that were 2.5 hours each. This implemented the DBT skills manual incorporating mindfulness, interpersonal effectiveness, emotion regulation and distress tolerance with homework throughout. Adaptations were made for the caregivers of PlwD including replacing references to be relevant to examples of providing care to PlwD and modifying the interpersonal skills module to be applicable for dementia caregivers.

Table 1

Study Characteristics of third-wave CBTs for informal caregivers of PlwD

Authors	Location	Study Design	Third-Wave	Mechanisms of change	Group or individual	Delivery format	Duration and frequency	Facilitator	Comparator
(Atefi et al., 2025)	Netherlands	Feasibility study	ACT	Six ACT core processes: acceptance, defusion, present-moment awareness, self-as-context, values, committed action	Individual	Online	9-week program and up to 12 weeks allowed, monthly boosters up to 6 months	Motivational coach (trained research assistant)	None
(Fauth et al., 2022)	USA	Pilot study	ACT	Six ACT core processes values, committed action, mindfulness, acceptance, defusion, self-as-context	Individual	Online	10 self-paced sessions (~20–30 min each)	Self-guided	None
(Fowler et al., 2021)	USA	Pilot study	ACT	Six ACT core processes acceptance, defusion, present moment, self-as-context, values, committed action	Individual	Telephone	6 weekly 1-hour sessions	Bachelor's-level trained interventionist (not licensed therapist)	None
(George et al., 2021)	UK	Quasi-experimental feasibility study	ACT	Psychoeducation and ACT processes: mindfulness, acceptance, values, cognitive defusion, committed action	Group	In-person	5 sessions (1.5–2 hours each)	Trainee and assistant psychologists under ACT supervision	None
(Gwak & Park, 2025)	Republic of Korea	Pilot study	ACT	Six ACT core processes acceptance, defusion, being present, self-as-context, values, committed action	Individual	In-person	6 weekly sessions, 1 hour each	Licensed counsellor (Korean Counselling Association)	Psychoeducational control group
(Han et al., 2022)	USA	Feasibility study	ACT	Six ACT core processes and behavioural activation: acceptance, defusion, mindfulness, values,	Individual	Online	10 weekly sessions, 1 hour each	Licensed professional counsellor trained in ACT	None

Authors	Location	Study Design	Third-Wave	Mechanisms of change	Group or individual	Delivery format	Duration and frequency	Facilitator	Comparator
				committed action, present-moment awareness					
(Han et al., 2023)	USA	Pilot RCT	ACT	Six ACT core processes: acceptance, defusion, present moment, self-as-context, values, committed action and behavioural activation	Individual	Online	8 weekly 1-hour sessions	Licensed ACT-trained counsellor	Psychoeducational control group
(Hockemeyer et al., 2025)	USA	Pilot RCT	ACT	ACT core processes: acceptance, cognitive defusion, mindfulness, self-as-context, values clarification, committed action. Telephone sessions included guided mindfulness and home practice.	Individual	Telephone	6 sessions, approx. 1 hour each, weekly (up to 12 weeks)	Non-licensed, bachelor's level interventionists trained in ACT	Minimally Enhanced Usual Care (mEUC) which included signposting
(Kishita et al., 2022)	UK	Feasibility study	ACT	ACT skills: acceptance, defusion, mindfulness, values, committed action, self-as-context	Individual	Internet-delivered guided self-help	8 weekly sessions within 12 weeks	Non-clinical therapists with 2-day ACT training	None
(Losada et al., 2015)	Spain	RCT	ACT	ACT: acceptance, values, committed action, defusion, mindfulness; CBT: cognitive restructuring, behavioural activation	Individual	In-person	8 weekly 90-min sessions	Clinical psychologists trained in CBT and ACT	CBT, psychoeducation control group
(Risch et al., 2024)	Germany	RCT	ACT	Acceptance, value-oriented action, reducing experiential avoidance, mindfulness, self-care	Individual	Telephone-based	8 weekly sessions, 50 min each	Four female clinical psychologists (ACT/CBT trained)	Psychoeducational control group
(Márquez-González	Spain	RCT	ACT Fusion	Behavioural issues, dysfunctional thoughts,	Individual	In-person	8 weekly 1.5-hour sessions and	Clinical psychologists	ACT, CBT, and control

Authors	Location	Study Design	Third-Wave	Mechanisms of change	Group or individual	Delivery format	Duration and frequency	Facilitator	Comparator
et al., 2020)				low rewards, experiential avoidance, low assertiveness, high physiological arousal			3 booster sessions (at 1, 2.5, 5 months)	trained in CBT, ACT, and FAMI	(waiting list)
(Gallego-Alberto et al., 2021)	Spain	Pilot study	ACT, CBT, CFT Fusion	Addressing irrational beliefs, guilt-related experiential avoidance, increasing values-based action and self-compassion	Group	In-person	8 weekly 2-hour sessions	Facilitated by psychologists (unspecified qualifications)	None
(Collins et al., 2018)	UK	Pre-post study	CFT	Soothing rhythm breathing, compassion imagery, psychoeducation, mindfulness, reducing self-criticism and shame	Group (couples)	In-person	6 weekly 2-hour sessions	Clinical psychologist with CFT training and trainee clinical psychologists	None
(Drossel et al., 2011)	USA	Feasibility study	DBT	Mindfulness, interpersonal effectiveness, emotion regulation, distress tolerance adapted for caregivers	Group	In-person	9 weekly sessions (2.5 hours each)	Graduate student therapists trained in DBT and dementia care	None
(Cheung et al., 2020)	Hong Kong	RCT	MBCT	Mindfulness, acceptance, cognitive defusion, CBT techniques (for MBCT), psychoeducation (for MBSR)	Group	In-person	7 sessions over 16 weeks (2.5 hours each) and phone follow-up	Certified therapist with nursing and mindfulness training	MBSR vs. MBCT (head-to-head comparison)
(Kor et al., 2019)	Hong Kong	Pilot RCT	MBCT	Mindfulness training and CBT elements: acceptance, decentering, positive reappraisal	Group	In-person	7 sessions (2h) over 10 weeks and biweekly follow-up	Certified MBCT instructor	Usual family care vs psychoeducation education (control)

Authors	Location	Study Design	Third-Wave	Mechanisms of change	Group or individual	Delivery format	Duration and frequency	Facilitator	Comparator
(Kor et al., 2021)	Hong Kong	RCT	MBCT	Mindfulness practices and CBT techniques: decentring, acceptance, emotional regulation, positive reappraisal	Group	In-person	7 sessions (2h) over 10 weeks and weekly phone follow-ups	Certified MBCT teacher (Oxford Mindfulness Centre)	Usual care and brief education (control)
(Norouzi et al., 2014)	Iran	Quasi-experimental with control group	MBCT	Mindfulness techniques, emotion regulation, awareness, decentering, self-compassion	Group	In-person	8 weekly sessions (2.5 hours each)	?	Waitlist control (delayed intervention)
(Oken et al., 2010)	USA	Pilot RCT	MBCT	Mindfulness practice, awareness of thoughts/emotions, attention regulation, self-efficacy	Group	In-person	7 weeks, 90-min weekly sessions	Clinical psychologist trained in MBCT	Education class and respite-only control

? = not reported.

Participant Characteristics

Table 2 shows the participant characteristics. In total 578 participants received a third-wave CBT. Most informal caregivers were spouses/partners (range from 3.8% to 100%) and children/children-in-law of care-recipient (range from 3.8% to 66.7%). The mean reported participant age was between 56 and 68 and the participants were mostly female (ranging from 50 to 100% female samples). Of the included studies, 64.71% did not report the ethnicity of participants. Of the studies who did report the ethnicity of participants, most participants were 'white' (ranging from 80 to 100% white or 100% 'Caucasian', 'non-Hispanic white' ranged from 3.9% to 71.42%, 'Asian' ranged from 2% to 10%, 'African American' ranged from 10% to 55.6%. Most of the studies (90%) reported that all types of dementia were included and two studies reported the breakdown of this, where Alzheimer's Disease (AD) was the most common. Overall, a range of dementias were included such as AD, Dementia with Lewy Bodies, Vascular Dementia, Frontotemporal Dementia, mixed and Korsakov Dementia.

Only 35.3% of studies reported validation of the diagnosis of dementia. Of these, one study used the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (Losada et al., 2015) and five studies required a confirmed diagnosis of Dementia from a medical practitioner (one study stated that they required neurological examinations, lab tests and neuroimaging as part of this and one study reported that this must be based on ICD-10 criteria within the last 6 months (Collins et al., 2018)).

All studies reported inclusion criteria and 80% of studies reported exclusion criteria. Inclusion criteria included being the primary caregiver (k=4), being an unpaid carer (k=2), being a caregiver for a specific amount of time (k=2) reaching clinical threshold for depression and/or anxiety or caregiver guilt (k=7), internet access (k=1), English-speaking (k=2), no prior or recent therapy (k=4), confirmed diagnosis (k=1), home-based care (k=1),

diagnosis of dementia within the last 6 months (k=1), under a memory assessment service (k=1), elder abuse risk factors (k=1), aged 18 and above (k=4), Cantonese-speaking (k=2), more than 4 hours a day caregiving (k=1), no cognitive impairment in caregiver (k=3) and normal vision (k=1). Exclusion criteria included; not primary caregiver (k=1), cognitive disorder in caregiver (k=1), recent psychotherapy or psychotropic use (k=12), non-family caregivers (k=2), diagnosis of dementia for caregiver (k=1), serious mental illness or psychological disorder in caregiver (k=11), care recipient in long term care (k=2), caregiving for multiple people (k=1), paid caregivers (k=1), physical barriers (k=1), language barriers (k=3), no internet access (k=1), severe physical illness (k=2), non-spouse (k=1), advanced dementia in informal caregiver (k=1), substance use (k=1), suicidal ideation (k=1).

Table 2

Participant characteristics of samples in third-wave CBTs for informal caregivers of PlwD

Authors	Third-Wave	(*N*)	Age in years (mean)	Gender	Carer relationship to PlwD	Ethnicity	Hours of caregiving per week	Type of dementia	Inclusion criteria	Exclusion criteria
(Atefi et al., 2025)	ACT	30	62.5	76% female	61% spouse, 38% daughter	100% non-Hispanic white	≥15 hours/week (most)	AD (52%), Vascular (24%), others	Adult (18+), primary family caregiver, ≥3 hrs per week care for 3+ months, internet access	Cognitive disorder, recent psychotherapy/psychotropic use
(Fauth et al., 2022)	ACT	51	66.0	80% women	53% spouses, others adult children etc.	92% White	Varied (not all co-residing)	Various (AD, Parkinson's, unspecified)	Distress score ≥4, English speaking, caregiver of PLWD, internet access	?
(Fowler et al., 2021)	ACT	15	68.85	80% female	73.3% spouses	100% White, non-Hispanic	≥1 hour/day for ≥3 months	AD, and related dementias (ADRD)	Age ≥21, GAD-7 ≥10, primary family caregiver, English-speaking, 12-month caregiving intent	Non-family caregivers, ADRD diagnosis, serious mental illness, care recipient in long-term care
(George et al., 2021)	ACT	31	66.91	21 female, 2 male	Spouses (17), children (6)	?	?	All types of dementia	Unpaid caregivers, caring for someone not in residential care	?
(Gwak & Park, 2025)	ACT	32	60.69	7 males total (gender imbalance noted)	Spouses, children, daughter-in-law, grandchildren	?	≥40 hours/week caregiving	Moderate to severe dementia (GDS); AD, DLB, FTD	Age 40–80, family caregivers, live with patient ≥40 hrs/week	Psych disorders, caregiving for others, paid caregivers
(Han et al., 2022)	ACT	7	57.3	6 female, 1 male	3 daughters, 2 wives, 1 husband, 1 sister	5 White, 1 Black, 1 Native American	Most >40 hrs/week	A,D vascular; middle and early stage	Primary caregiver ≥3 months, psychological distress (DASS-21), English, internet access	Receiving therapy, ACT experience, cognitive/physical/language barriers
(Han et al., 2023)	ACT	19 randomised (10 ACT,	54.6	100% female	78.9% daughters	47.4% Black, 42.1% White	≥1 hour/day, ≥3 months	Various dementias	Distress (DASS-21 threshold), internet access, adult caregiver	Psych therapy, ACT history, major mental illness, nursing home

Authors	Third-Wave	(*N*)	Age in years (mean)	Gender	Carer relationship to PlwD	Ethnicity	Hours of caregiving per week	Type of dementia	Inclusion criteria	Exclusion criteria
		9 control)								planning, non-English speaker
(Hockemeyer et al., 2025)	ACT	117 randomised participants (58 in TACTICs, 59 in mEUC)	60.7	83.8% female	54.7% adult child/in-law, 40.2% spouse	97.4% non-Hispanic, 73.5% white, 22.2% Black, 4.3% other	Daily caregiving implied.	AD and Related Dementias (ADRD)	Inclusion: >21 years old, primary family caregiver, English-speaking, anticipated caregiving >12 months, clinically elevated anxiety.	Non-family caregivers, diagnosed dementia or serious mental illness in caregiver, care recipient in long-term housing
(Kishita et al., 2022)	ACT	33	62.0	88% female	52% daughters, 33% wives, others	Primarily White British	42% ≥81 hrs/week	AD, vascular, DwLB, mixed, others	Unpaid carer, PHQ-9 or GAD-7 score 6–15, internet access, English-speaking	Current therapy, serious mental illness, no internet access
(Losada et al., 2015)	ACT	135 total (45 ACT, 42 CBT, 48 control)	61.7 years	82–90% female across groups	52% children, 42% spouses	All Spanish caregivers	≥1 hr/day for ≥3 months	AD	Caregiver ≥3 months, CES-D ≥16, no prior therapy	Low depression, not primary caregiver, prior therapy
(Risch et al., 2024)	ACT	81 randomised (41 ACT, 40 control)	61.9	55.7% female	56.1% spouse/partner	100% Caucasian	Mean duration caregiving: 3.7 years	AD n = 21 (51.2%), vascular dementia = 4 (9.8%), frontotemporal dementia = 3 (7.3%), other/unknow	Primary caregiver, confirmed dementia diagnosis in PlwD, home-based care	Ongoing psychotherapy, psychiatric disorder, severe physical illness

Authors	Third-Wave	(*N*)	Age in years (mean)	Gender	Carer relationship to PlwD	Ethnicity	Hours of caregiving per week	Type of dementia	Inclusion criteria	Exclusion criteria
(Márquez-González et al., 2020)	ACT and CBT Fusion	92 total (24 FAMI, 21 ACT, 23 CBT, 24 control)	56	95.2% female	42–58% parent or spouse caregivers	?	Daily house 13.63	n = 13 (31.7%) AD 57.1%	Primary caregiver, CES-D ≥16, no prior psychotherapy	Ongoing therapy, prior interventions, missing cutoffs
(Gallego-Alberto et al., 2021)	ACT, CBT, CFT Fusion	4	Only range reported: 57 to 77	2 male, 2 female	Parent, spouse, sibling	Not specified	1-17 hours per day	AD (3 out of 4) and Korsakoff's dementia (1 out of 4)	Primary caregiver, clinically significant guilt, depression/anxiety	?
(Collins et al., 2018)	CFT	34 caregivers	74.12	62.5% male; 62.5% female	Spouses only	All White, UK	?	AD 47%, Mixed vascular and AD 28%, vascular dementia 12.5%, DwLB (9%), Parkin's with LB dementia 3%.	Diagnosis within 6 months, spousal caregiver, under Memory Assessment Service	Non-spouse, advanced dementia, severe sensory/language issues
(Drossel et al., 2011)	DBT	24	Only rage reported: 38–87	50% female	Spouses and adult children	?	Varied (home or facility care; ≥5 hr per week)	Various dementias (AD, progressive, degenerative)	Caregivers with elder abuse risk factors: prior reports, depression, disability, substance use	?
(Cheung et al., 2020)	MBCT	53 randomised	56	86.8% female	71.7% adult children	100% Chinese	≥3 months caregiving; average 8.7 years	Dementia (not subtype-specified)	18+, primary caregiver, no recent therapy/MBIs	Acute mental/physical illness, recent

Authors	Third-Wave	(*N*)	Age in years (mean)	Gender	Carer relationship to PlwD	Ethnicity	Hours of caregiving per week	Type of dementia	Inclusion criteria	Exclusion criteria
		(27 MBSR, 26 MBCT)					caregiving duration			structured therapy or MBIs
(Kor et al., 2019)	MBCT	36 randomised (18 MBCT, 18 control)	57.1	83.3% female	69.4% adult children, 16.7% spouses	All Chinese (HK)	Average 76.9 hrs/week	Various dementia types	18+, family caregiver ≥3 months, no prior MBI, Cantonese-speaking	Mental illness, physical conditions, prior psychosocial therapy
(Kor et al., 2021)	MBCT	113 randomised (56 MBCT, 57 control)	61.7	61.1% female	53.1% adult children, 34.5% spouses	All Chinese (HK)	≥4 hrs/day caregiving	All types of dementia	18+, primary caregiver, Cantonese-speaking, ≥4hrs/day caregiving	Prior mindfulness practice, acute psych illness, substance use, suicidal ideation
(Norouzi et al., 2014)	MBCT	20 total (10 experimental, 10 control)	?	100% female	All women caregivers; likely mostly daughters and spouses	?	?	AD	Caregivers with depression and high burden, members of Alzheimer's Association	Serious illness, prior therapy
(Oken et al., 2010)	MBCT	31 randomised	63–67)	80% female	Spouse (70%) and children (30%)	80% white	≥12 hours/week caregiving	Progressive dementia	Adult caregiver, PSS >9, cognitively intact, no recent stress-reduction program	Cognitive impairment, unstable conditions, prior MBSR

? = not reported, AD = Alzheimer's Dementia, DwLB = Dementia with Lewy Bodies

Primary research question: acceptability of interventions

Table 3 shows acceptability findings from included studies. Attrition rates ranged from 0% to 68.1% across all interventions, 0% to 68.1% in ACT, 5% to 53% in MBCT, 6% in CFT and 33% in DBT. Six studies reported quantitative satisfaction measures to assess acceptability across session-by-session or overall satisfaction with the intervention. Five of these studies were ACT and one study was CFT and high levels of satisfaction were reported. Regarding adherence to treatment, most studies reported attendance and completion of sessions. This ranged from 32% completion of all sessions to 100% completion of all sessions, generally adherence rates were high. Commonly reported reasons for drop out in ACT studies were; time burden/constraints, death, technical or practical barriers, role change/paid caregiving, health issues and COVID-19. Reasons for drop out of CFT included transport issues or caregiver distress due to progression of dementia. Reasons for drop out of DBT included time constrains, employment or relocation. Reported reasons for drop out of MBCT included practical issues, time constraints, caregiver role conflicts, burden and difficulty using technology. Time constraints, burden and practical barriers were present across all third-wave CBTs.

Table 3

Acceptability findings of third-wave CBTs for informal caregivers of PlwD

Authors	Third-Wave	Attrition rates	Quantitative satisfaction measures	Adherence	Reported reasons for drop out
(Atefi et al., 2025)	ACT	30% attrition from baseline to follow-up	?	?	Burden, time constraints, confronting content, technical issues, death
(Fauth et al., 2022)	ACT	68.1% dropout from initial consent	Sessions rated 3.4–4.0/5 for helpfulness	32% completed all sessions	Not recorded in detail
(Fowler et al., 2021)	ACT	1 dropout before T1, 1 dropout between T2–T3 (13.3%)	All participants rated satisfaction ≥9/10	100% completed all 6 sessions	?
(George et al., 2021)	ACT	11% attrition	?	89% attendance for completers	Practical barriers, illness, inappropriate match
(Gwak & Park, 2025)	ACT	19% attrition	?	≥80% session attendance required; most completed	Withdrawal, role change, paid caregiving
(Han et al., 2022)	ACT	0% attrition	Rated 88.6/100 on SUS	100% completed all sessions	None reported
(Han et al., 2023)	ACT	1 dropout (5.3%)	?	100% of ACT participants completed all 8 sessions	1 dropout (control group, nonresponse)
(Hockemeyer et al., 2025)	ACT	34.5% did not complete all sessions (TACTICs)	Mean satisfaction = 9.35/10	65.5% of participants completed all 6 sessions	Life events (e.g., family death), time constraints
(Kishita et al., 2022)	ACT	27% attrition	?	Average 6.2 sessions out 8 completed; 58% completed all 8	Health issues, COVID-19, death of recipient
(Losada et al., 2015)	ACT	30.3% attrition; 49% follow-up response rate	9.6/10 satisfaction across groups	?	Work conflicts, time demands
(Risch et al., 2024)	ACT	20.9% post-intervention dropout, 28.4% at follow-up	?	Mean sessions completed = 7.82 (range 5–8); adherence monitored and supported	Time constraints, caregiving stress, practical challenges
(Márquez-González et al., 2020)	ACT, CFT Fusion	Post: FAMI 20.8%, ACT 23.8%, CBT 52.2%; Follow-up: FAMI 37.5%, ACT 66.7%, CBT 65.2%	?	FAMI had highest adherence (79.2%)	Caregiver death, nursing home admission, no longer interested
(Gallego-Alberto et al., 2021)	ACT, CFT, CBT Fusion	1 dropout (of 5 eligible)	?	Full adherence among completers	One dropout; others completed fully
(Collins et al., 2018)	CFT	6% (2 couples dropped out)	Sessions rated 7–10/10 by 69–94%; positive feedback	94% completed all sessions	Transport issues, distress from advanced dementia

Authors	Third-Wave	Attrition rates	Quantitative satisfaction measures	Adherence	Reported reasons for drop out
(Drossel et al., 2011)	DBT	33% dropout	?	100% of completers attended all	Time constraints, employment, relocation
(Cheung et al., 2020)	MBCT	3.8% overall dropout	?	63% MBSR and 69.2% MBCT completed ≥80% sessions	Practical issues; no adverse effects reported
(Kor et al., 2019)	MBCT	11.1% dropout	?	Average adherence = 79.4%	Time constraints, caregiver role conflicts
(Kor et al., 2021)	MBCT	8.9% MBCT, 7.0% control	?	84% attended ≥5 sessions; logbooks used to track mindfulness practice	Time constraints, health issues, alternative stress strategies
(Norouzi et al., 2014)	MBCT	1 dropout (5%)	?	83% completed ≥70% of sessions	Time constraints
(Oken et al., 2010)	MBCT	3 dropouts (10%)	?	Attendance ~88%	Time constraints, burden

? = not reported.

Secondary research questions: clinical effectiveness

Table 4 presents the clinical effectiveness of included studies and abbreviations of measures.

ACT

Assessment timepoints ranged from pre and post alone, to pre, post, 3 month follow up and 6 month follow up. Nine out of 11 studies included follow-up data. Primary outcomes commonly assessed anxiety (k=6), depression (k=6), caregiver burden (k=2), grief (k=1), stress (k=1) and guilt (k=1). The ACT studies utilized a wide range of outcome measures, including DASS-21, CES-D (including CES-D 10 and CESD-R), PHQ-8, PHQ-9, BDI-II, BAI, HADS-Anxiety, and GAD-7 to assess psychological distress. Measures of psychological flexibility and values included AAQ-II (as well as AAQ-9 and AAQ-16), CFQ (including CFQ-7), FIT-60, VLQ, Valuing Questionnaire, and ELS. Caregiver burden and related constructs were assessed using ZBI (including ZBI-12, S-ZBI), a one-item burden measure, RMBPC, PAC, DMSS, EACQ, MM-CGI-BF, CGQ, Caregiver Guilt Questionnaire, Caregiver Grief Scale, and SSCQ.

Four studies reported statistically significant improvements in anxiety, four in depression, three in caregiver burden, one in grief, three in stress and one in guilt with effect sizes ranging from small to very large at post-intervention and follow up. Six studies reported large to very large effect sizes of ACT on primary outcome. Secondary outcomes included sense of competence, psychological flexibility, inflexibility, engaged/valued living, burden, stress, quality of life, depression, suffering, coping, positive aspects of caregiving, experiential avoidance, behaviour management, cognitive fusion, meaningful activities, self-compassion, anticipatory grief, avoidance, leisure, physical symptoms, care-related thoughts and acceptance. All ACT studies showed clinically significant change. Six studies included a

comparator group, such as control group, usual care and CBT, in which five studies demonstrated greater effectiveness compared to control groups on primary outcomes.

MCBT

The majority of primary outcomes assessed perceived stress (k=4) and one study had a primary outcome of depression. Four out of five MBCT studies included a follow up timepoint. Psychological distress and stress were assessed using PSS, CES-D, HADS-A and HDS. Caregiver Burden and related constructs were measured using the ZBI, CBI and RMBPC. Mindfulness and related concepts were measured using FFMQ-SF, FFNJ including additional cognitive and attention tasks including the Stroop test. Biological markers included salivary cortisol.

Four studies reported statistically significant improvements in stress, depression (k=3) and anxiety (k=1), with effect sizes ranging from small to medium on primary outcomes. One study reported a large effect of MBCT on depression and another study a large effect on stress. Secondary outcomes included depression, caregiver burden, trait mindfulness, anxiety, resilience, mindfulness, quality of life, self-efficacy, cognition, mood, sleep, cortisol and inflammatory markers. Statistically significant improvements were seen in in caregiver burden in two studies. Clinically significant change was reported in all studies but one. All studies included a comparator group (either control, MBSR or education) and MBCT demonstrated increased effectiveness compared to comparator groups on primary outcomes.

CFT

The CFT study included pre and post measures for primary outcomes (depression, anxiety and respiratory rate). The study used HADS, RR and QoL-AD measures. A significant reduction in respiratory rate was observed for caregivers and there was a clinical

improvement in depression in 80% of caregivers on reliable change indices, with a large effect of CFT on respiratory rate and a small effect of CFT on anxiety.

DBT

The DBT study included measures at pre, post intervention and post booster sessions. The study utilised CES-D, CBI, SF-36, WoC-R and MBI. The primary outcome was depression, and secondary outcomes were caregiver burden, quality of life, coping and emotional exhaustion. Reliable change indices were used to assess change, depression reduced by more than 10% in 40% of the sample. No effect sizes were reported, and no comparator groups were implemented.

Table 4

Clinical effectiveness results of third-wave CBTs for informal caregivers of PlwD

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
(Atefi et al., 2025)	ACT	Pre, post, follow-up (3 months, 6 month)	Stress, anxiety, depression	Sense of competence, psychological flexibility, inflexibility, engaged/valued living	DASS-21, FIT-60, AAQ-II, VLQ, ELS, SSCQ, burden (1-item)	Stress and anxiety reduced significantly (clinically and statistically)	Depression fluctuated but reduced at 6 months; sense of competence increased	Yes, for stress and anxiety (moved from mild/moderate to normal)	N/A	Stress (d=-1.13), Anxiety (d=-1.38), Depression (d=-0.78), Sense of competence (d=0.45), Psychological flexibility (d=0.57), Inflexibility (d=-0.56), Engaged living (d=0.82)	Very large effect of ACT on stress, anxiety, large effect on depression.
(Fauth et al., 2022)	ACT	Pre, post, follow up (4 weeks)	Depression	Burden, stress, BPSD stress appraisals, positive aspects, QoL	CES-D 10, ZBI-12, RMBPC, Valuing Questionnaire, AAQ-II, CFQ, QoL VAS	Significant improvements in depression, burden, BPSD-related stress, positive aspects, QoL ($p<.01$)	Improvements in ACT measures: decreased cognitive fusion and inflexibility; increased values progress	Yes: CES-D fell below clinical threshold post and follow-up	N/A	Depression $\eta p^2=.392$, Burden $\eta p^2=.191$, QoL $\eta p^2=.308$, Fusion $\eta p^2=.335$, Inflexibility $\eta p^2=.209$, Values progress $\eta p^2=.259$	Very large effect of ACT on depression.
(Fowler et al., 2021)	ACT	Pre, post, follow up (3 month, 6 month)	Anxiety	Depression, caregiver burden, psychological flexibility, suffering, coping	GAD-7, PHQ-9, ZBI, AAQ-II, Experience of Suffering, Brief COPE	Large reduction in anxiety sustained through 6 months	Burden and psychological suffering also reduced significantly by T4; other effects small to medium	Yes: significant changes in anxiety and burden over time	N/A	Anxiety: SRM 1.94; Psychological suffering: SRM 0.99; Burden: SRM 0.79; Physical suffering: SRM 0.50	Very large effect of ACT on anxiety.

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
(George et al., 2021)	ACT	Pre, post, follow up (3 month)	Caregiver burden	Positive aspects of caregiving, experiential avoidance, behaviour management	ZBI, PAC, DMSS, EACQ	Only one variable (intolerance of negative thoughts and emotions) significantly improved post-intervention	Increased awareness, empathy, valued living; peer support and mindfulness rated highly	Yes, for EACQ-INT (intolerance of negative thoughts)	N/A	?	Small effect of ACT on caregiver burden.
(Gwak & Park, 2025)	ACT	Pre, post	Caregiver burden	Depression, Anxiety, Psychological flexibility	S-ZBI, BDI-II, BAI, AAQ-16	Significant improvements in burden, depression, and anxiety post-intervention ($p<.05$)	Improved psychological acceptance (AAQ-16), correlated with BDI-II change ($r = -0.44$)	Yes, significant correlation between increased acceptance and reduced depression	ACT group outperformed control group across all outcomes ($p < .05$)	BAI: $d = 0.99$, BDI-II: $d = 1.15$, ZBI: $d = 0.81$, AAQ-16: $d = 1.45$	Large effect of ACT on caregiver burden.
(Han et al., 2022)	ACT	Pre, post	Depression, anxiety, stress, burden	Psychological flexibility, experiential avoidance, cognitive fusion, meaningful activity	DASS-21, ZBI-12, EACQ, AAQ-II, CFQ-7, EMAS	Significant reductions in depression ($p=.043$), anxiety ($p=.018$), stress ($p=.027$), burden ($p=.018$)	Positive change in ACT process scores, though not statistically significant; high usability and engagement	Yes, all significant changes showed medium effect sizes (0.54–0.63)	N/A	Depression: $d=0.54$, Anxiety: $d=0.63$, Stress: $d=0.59$, Burden: $d=0.63$	Medium effect of ACT on depression, anxiety, stress and burden.
(Han et al., 2023)	ACT	Pre, post, follow up (1 month)	Grief	Anxiety, depression, stress, burden, psychological QoL, psychological flexibility,	DASS-21, ZBI, MM-CGI-BF, CGQ, WHOQOL-BREF, AAQ-II,	ACT significantly reduced grief post-intervention; other outcomes	Small effects in anxiety, QoL, meaningful activity, psychological flexibility;	Yes: Significant within-group improvement in stress, grief, guilt, flexibility, QoL, self-compassion	ACT > control for grief; small to medium effects in other domains	Grief: $r = 0.49$ (post), Psychological flexibility: $r = 0.44$ (F/U), QoL: $r = 0.32$ (post),	Medium to large effect of ACT on grief.

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
				guilt, cognitive fusion, self-compassion, meaningful activity	CFQ-7, EMAS, SCS-SF	improved non-significantly	ACT improved several within-group outcomes			Engagement: r = 0.33	
(Hockemeyer et al., 2025)	ACT	Pre, post, follow up (3 month, 6 month)	Anxiety	Depression, caregiver burden, suffering (physical/psychological/existential), anticipatory grief	GAD-7, PHQ-8, ZBI, Experience of Suffering, AGS	Moderate reductions in anxiety, not statistically significant vs mEUC	Significant psychological suffering reduction at T2 (p = .0118) other changes not significant	Yes: Anxiety decreased from 'moderate' to 'mild'; depression, grief SRM gains	TACTICs > mEUC only for psychological suffering at T2	Anxiety (SRM 4.1 T4), Depression (SRM 3.1), Burden (SRM 6.3), Suffering-psych (SRM 3.4), Anticipatory grief (SRM 6.1); d = 0.55 for psych suffering at T2	
(Kishita et al., 2022)	ACT	Pre, post	Anxiety	Depression, inflexibility, cognitive fusion, avoidance	GAD-7, PHQ-9, CESD-R, AAQ-II, CFQ, EACQ	GAD-7 scores improved, reliable improvement in anxiety	26% improved in depression; positive trends in ACT process outcomes	Reliable improvement: 40% anxiety, 26% depression (RCI > 1.96)	N/A	Anxiety (d=0.70), Depression (d=0.15) Avoidance (d=0.63), Cognitive Fusion (d=0.32)	Medium effect of ACT on anxiety.
(Losada et al., 2015)	ACT	Pre, post	Depression	Anxiety, dysfunctional thoughts, experiential avoidance, leisure	CES-D, POMS, EACQ, DTAC, leisure, demographics	Both ACT and CBT reduced depression CBT maintained at follow-up	ACT better for anxiety post; experiential avoidance improved only in ACT	26.7% CBT and 24.2% ACT met RCI; 0% in control	ACT and CBT more significant control; ACT better for anxiety post, CBT longer-term for depression	Depression: CBT d=0.98, ACT d=1.17; Anxiety ACT d=0.79; Follow-up: CBT d=0.74, ACT d=0.39	Very large effect of ACT on depression at post intervention, small effect at follow up.

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
(Risch et al., 2024)	ACT	Pre, post, follow up (6 month)	Depression, anxiety	Physical symptoms, pre-death grief, care-related thoughts, acceptance, QoL, coping, well-being	CES-D, HADS-Anxiety, GBB-24, Caregiver Grief Scale, CTS, AAQ-9, WHOQoL-BREF, FFMQ-SF	Significant reduction in depression at T1 not sustained at T2, no effect on anxiety	Improvements in rheumatic pain, pre-death grief, emotional well-being, QoL (physical), coping, resource use	Yes for depression (T1); small proportion showed RCI > 1.96	ACT better than control in multiple domains post-intervention; some effects persisted at 6 months	Depression (d = -0.50), Anxiety (d = -0.11), Physical symptoms (d = -.30), Coping with pre-death grief (d = -0.69)	Medium effect of ACT on depression, very small effect of ACT on anxiety.
(Márquez-González et al., 2020)	ACT, CFT Fusion	Pre, post, follow up (6 month)	Depression	Anxiety, comorbid distress	CES-D, POMS	FAMI reduced depression significantly with large effect sustained at follow-up	Anxiety only sustained in FAMI; ACT and CBT lost gains by follow-up	Yes: CES-D and POMS changes met RCI; FAMI had highest % recovered at follow-up	FAMI > ACT & CBT in sustaining anxiety and comorbid improvements	Depression: d = 1.48 (FAMI), Anxiety: d = 0.84 (FAMI), RCI gains in 60% (FAMI)	Large effect of ACT/CFT fusion on depression.
(Gallego-Alberto et al., 2021)	ACT, CFT, CBT Fusion	Pre, post	Guilt	Depression, anxiety	Caregiver Guilt Questionnaire, CES-D, POMS-Tension/Anxiety	Clinically significant reduction in guilt	2 of 4 improved in anxiety; 3 of 4 in depression; one worsened due to external stressor	Yes: RCI for guilt (3.62), depression (7.72), anxiety (3.97)	N/A	Not reported.	Not reported.
(Collins et al., 2018)	CFT	Pre, post	Depression, anxiety, respiratory rate	Quality of life	HADS, RR count, QoL-AD	Significant reduction RR	Trends of anxiety reduction; clinical improvement in 80% (depression)	Yes: RCI for HADS used; 57% PwD and 80% spouses improved in depression	N/A	RR (d = 0.70), Anxiety (d = 0.37)	Large effect of CFT on respiratory rate, small effect of CFT on anxiety.

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
(Drossel et al., 2011)	DBT	Pre, post, post booster	Depression	Caregiver burden, QoL, coping, emotional exhaustion	CES-D, CBI, SF-36, WoC-R, MBI	CES-D dropped in 40% by ≥10%; problem-focused coping, emotional well-being, fatigue improved	6 completed booster groups	Yes: CES-D and SF-36 improvements; RCI reported for CES-D (1 participant met threshold)	N/A		
(Cheung et al., 2020)	MBCT	Pre, post, follow up (3 month)	Perceived stress	Depression, caregiver burden, trait mindfulness	PSS, CES-D, ZBI, FFMQ-SF	MBCT significantly reduced stress over time (p = .019); both groups showed improvement in stress, depression, burden	Trait mindfulness improved in both groups; MBCT had greater effect on stress	Yes; stress (Cohen's d = 0.54), depression (d = 0.77), burden (d = 1.12)	MBCT > MBSR in reducing stress; others similar	Stress (d = 0.54), Depression (d = 0.77), Burden (d = 1.12), MBCT > MBSR in stress reduction (d = 0.63)	Medium effect of MBCT on perceived stress.
(Kor et al., 2019)	MBCT	Pre, post, follow up (3 month)	Perceived stress	Depression, anxiety, burden, QoL, resilience, mindfulness	PSS, CES-D, HADS-A, ZBI, SF-12, BRS, FFMQ-SF	Significant reductions in stress and depression (T1 and T2)	Significant burden reduction (T2), QoL improved (physical domain)	Yes: Stress (d = 0.9), Depression (d = 0.7–0.8), Burden (d = 1.0)	MBCT > control in all psychological outcomes	Stress: d = 0.9; Depression: d = 0.7–0.8; Burden: d = 1.0; QoL (physical): d = 0.6; Mindfulness: d = 0.6	Large effect of MBCT on perceived stress.
(Kor et al., 2021)	MBCT	Pre, post, follow up (6 month)	Perceived stress	Depression, anxiety, burden, QoL, resilience, BPSD in care recipients	PSS, CES-D, HADS-A, ZBI, SF-12, BRS, FFMQ-SF, NPI-Q	Significant reduction in stress, depression, and anxiety at T1 and T2	Improved mental QoL, reduced BPSD-related caregiver distress; no	Yes: clinically significant changes in stress, depression, anxiety	MBCT > control at all timepoints for main outcomes	Stress: d=0.7; Depression: d=1.4; Anxiety: d=1.0; BPSD distress: d=0.8; Mental QoL: d=0.6	Medium effect of MBCT on perceived stress.

Authors	Third-Wave	Assessment timepoints	Primary outcomes	Secondary outcomes	Measures used	Primary findings	Secondary findings	Clinically significant change	Comparative effectiveness	Effect size (Cohen's d unless otherwise indicated)	Qualitative effect size on primary outcome
(Norouzi et al., 2014)	MBCT	Pre, post, follow up (2 month)	Depression	Caregiver burden, quality of life	Hamilton Depression Scale, Caregiver Burden Inventory (CBI), SF-36	Significant reductions in depression at post-test and follow-up	change in resilience Significant burden reduction. QoL improved post but not sustained at follow-up	Yes: significant changes in depression and burden at follow-up	MBCT > control in all outcomes	Depression: d = 0.8; Burden: d = 1.0; QoL: d = 0.7 post, non-sig at follow-up	Large effect of MBCT on depression.
(Oken et al., 2010)	MBCT	Pre, post	Caregiver stress (RMBPC Reaction)	Self-efficacy, cognition, mood, sleep, cortisol, mindfulness, inflammatory markers	RMBPC, CES-D, PSS, GPSE, MAAS, ANT, Stroop, salivary cortisol, cytokines	Both meditation and education reduced RMBPC stress vs. respite; no difference between meditation and education	Meditation improved self-efficacy, some cognitive outcomes; mindfulness unchanged	RCI not reported, but statistical significance achieved on RMBPC and Stroop/ANT alerting	Meditation = Education > Respite in stress and self-efficacy	RMBPC d = 0.3–0.5; Stroop interference, ANT alerting and cognitive RT showed group differences ($p < .05$)	Small to medium effect of MBCT on caregiver stress.

Abbreviations: AAQ-11, AAQ-9, AAQ-16 = Acceptance and Action Questionnaire (Bond et al., 2011), ANT = Attention Network Test (Fan et al., 2002), BAI = Beck Anxiety Inventory (A. T. Beck et al., 1988), BDI-11 = Beck Depression Inventory (A. T. Beck et al., 1961), COPE = Brief COPE Inventory (Carver, 1997), BRS = Brief Resilience Scale (Smith et al., 2008), CBI = Caregiver Burden Inventory (Novak & Guest, 1989)*, CGI = Caregiver Guilt Questionnaire (Losada et al., 2010), CGS = Caregiver Grief Scale (Meichsner et al., 2016), CFQ, CFQ=7 = Cognitive Fusion Questionnaire (McCracken et al., 2014), CES-D = Centre for Epidemiologic Studies Depression Scale (short forms CES-D-10, CESD-R (Radloff, 1977)), CGQ = Caregiver Quality of Life Questionnaire (Oliver et al., 2019) DASS-21 = Depression Anxiety Stress Scales* (Lovibond & Lovibond, 1995)*, DMSS = Dementia Management Strategies Scale* (Hinrichsen & Niederehe, 1994)*, DTAC = Dysfunctional Thoughts about Caregiving Questionnaire (Losada et al., 2006), EACQ = Emotion Approach Coping Questionnaire (Stanton et al., 2011), ELS = Engaged Living Scale,(Trompetter et al., 2013), ESS = Experience of Suffering Scale (Schulz et al., 2010), EMAS = Engagment in Meaningful Activities Scale(Eakman, 2012), FIT-60 = Flexibility Index Test* (Batink & Delespaul, 2015)*, FFMQ-SF = Five Facet Mindfulness Questionnaire – Short Form (Baer et al., 2006), GAD-7 = Generalised Anxiety Disorder Scale (Spitzer et al., 2006), GPSE = Generalised Perceived Self-Efficacy Scale* (Schwarzer & Jerusalem, 1995)*, GBB-24 = Giessen Complaints Questionnaire -24 items (Petrowski et al., 2022), HDRS = Hamilton Depression Rating Scale (Hamilton, 1960), HADS = Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983)*, MAAS = Mindful Attention Awareness Scale* (K. W. Brown & Ryan, 2003)*, MM-CGI-BF = Modified Mini-Cog Global Impression.- Brief Form (Borson et al., 2000), NPI -Q = Neuropsychiatric Inventory Questionnaire (Kaufer et al., 2000), PHQ-8 and PHQ-9 = Patient Health Questionnaire* (Kroenke & Spitzer, 2002)*, PSS = Perceived Stress Scale (S. Cohen et al., 1983), PAC = Preparedness for Caregiving Scale (Archbold et al., 1990), POMS = Profile of Mood States including Tension/Anxiety subscale* (Heuchert & McNair, 2012)*, QoL-AD = Quality of Life in Alzheimer's Disease Scale (Logsdon et al., 2011), RMBPC = Revised Memory and Behaviour Problems Checklist (Teri et al., 1992), RR = Respiratory Rate, SSCQ = Single-Item Subjective Caregiver Strain Questionnaire, SF-12 = Short Form Health Survey and 36 item version (SF-36) (Ware et al., 1996), Stroop Colour and*

Word Test (Scarpina & Tagini, 2017)*, VLQ = Valued Living Questionnaire (Wilson et al., 2010), WoC-R = Ways of Coping Questionnaire – Revised (Folkman et al., 1986), WHOQOL-BREF = WHO Quality of Life (THE WHOQOL GROUP, 1998), ZBI = Zarit Burden Interview (including ZBI-12 = 12 item version and S-ZBI = Spanish version) (Bédard et al., 2001; Martín-Carrasco et al., 2010; Zarit et al., 1980 ? = Not reported*

Quality Appraisal

Table 5 shows information regarding quality of included studies using the Kmet tool. Over half the studies (60%) were of high quality, with a range from 0.75 to 0.93. The remaining studies were of moderate quality and had a score of 0.71. Across the studies, areas of weakness included lack of appropriate sample size, lack of sample size justification, lack of control group, lack of reported randomisation, lack of control for confounding variables and lack of follow up-data. Strengths of included studies comprised of clear research questions, transparent reporting of randomisation in RCTs, validated outcome measures and statistical analysis appropriateness.

Table 5

Study quality using Kmet Criteria (Kmet et al., 2004)

Authors	Quality index	Quality	Strengths	Limitations
(Atefi et al., 2025)	0.86	High	Clear research questions, and appropriate design, transparent reporting of results	Partial control for confounding.
(Fauth et al., 2022)	0.71	Moderate	Clear research questions, validated outcomes	No control group, small sample size, high attrition
(Fowler et al., 2021)	0.75	High	Clear research questions, high adherence, validated outcome measures	No control, small sample
(George et al., 2021)	0.71	Moderate	Clear research questions and appropriate design, thorough outcomes and analysis	No randomisation, Limited control for confounding. No control group comparison and reliance on self-report. Small sample size.
(Gwak & Park, 2025)	0.86	High	Clear research questions, design and participant characteristics, robust outcome measures, results presenting in detail	
(Han et al., 2022)	0.71	Moderate	Clear research questions, detailed RCT procedures, appropriate analytic methods, strong adherence	No control group or randomisation, small sample
(Han et al., 2023)	0.82	High	Clear research questions, RCT design, appropriate analytic methods	Partial control for confounding variables.
(Hockemeyer et al., 2025)	0.86	High	Clear research questions, appropriate methods, sufficient detail in results	Partial control for confounding variables.
(Kishita et al., 2022)	0.71	Moderate	Clear research questions, detailed intervention, transparent reporting of clinical and feasibility outcomes	No control group, no blinding, modest sample size and no follow up
(Losada et al., 2015)	0.93	High	Randomisation, blinding of assessors, clear outcomes, strong sample size and long term follow up	
(Risch et al., 2024)	0.82	High	Clear research questions, RCT design, good adherence tracking	Lack control for confounding
(Márquez-González et al., 2020)	0.86	High	Randomised control trial design, clear methods, detailed statistical analysis and reporting of effects	Small sample size
(Gallego-Alberto et al., 2021)	0.71	Moderate	Clear research questions, clear outcome measures, transparent procedure and intervention details	Small sample size, no control group, no long term follow up.
(Collins et al., 2018)	0.71	Moderate	Clear research questions, well defined outcomes, clinically significant indices, detailed reporting of participant characteristics and session data.	No control group, small sample and partial outcome completion.
(Drossel et al., 2011)	0.71	Moderate	Clear research questions, defined outcome measures, pre-post testing with appropriate analysis	No control group, small sample with high drop out
(Cheung et al., 2020)	0.82	High	Clear research questions and intervention description, randomisation procedures	Lack of blinding. Partial control for confounding.

Authors	Quality index	Quality	Strengths	Limitations
(Kor et al., 2019)	0.82	High	Clear research questions validating outcome measures, effect size reporting	Small sample, short follow up period.
(Kor et al., 2021)	0.93	High	randomisation, clear reporting, strong intervention monitoring	reliance on self-reported adherence data
(Norouzi et al., 2014)	0.71	Moderate	Clear research questions pre-post design with follow up, detailed analysis, reported effect sizes	No randomisation, small sample, limited detail on sampling strategy and participant characteristics.
(Oken et al., 2010)	0.93	High	Three arm randomised design with comparator, clear description of randomisation, analysis and adherence, comprehensive outcome measures including both self-report and physiological measures	

Discussion

This novel systematic review aimed to explore the literature of third-wave cognitive behavioural interventions for informal caregivers of people living with dementia. The review explored the acceptability and effectiveness of these interventions and the quality of the studies. The current review included ACT, MBCT, DBT and CFT interventions. Most of the interventions were either ACT or MBCT.

Regarding the primary research question, the findings of the current review suggest that though levels of acceptability vary across intervention types, third-wave CBTs are generally acceptable for informal caregivers of PlwD. The highest attrition rates were observed in ACT, and the lowest in CFT, however there was only one CFT study. Primarily ACT studies assessed satisfaction, which indicated positive satisfaction amongst participants. Reasons for attrition were often context dependent or logistical barriers, such as time constraints in the context of caregiving demands and technical barriers, rather than dissatisfaction with the third-wave CBT. The findings suggest that it is important that third-wave CBTs must account for the unique challenges faced by informal caregivers of PlwD such as increasing caregiving responsibilities over time, death and access to technology.

Regarding the secondary research question, the findings of the current review suggest preliminary support for the clinical effectiveness of third-wave CBTs for informal caregivers of PlwD, particularly for psychological distress and caregiver-related outcomes. ACT was the most studied third-wave CBT and most studies included follow-up data assessing the effect of ACT on anxiety, depression, caregiver burden and stress. Statistically and clinically significant improvements were observed across these outcomes, with large effect sizes observed. In most of the studies, ACT showed greater effectiveness over and above a control group. MBCT also showed promising results for informal caregivers, particularly in reducing stress and depression, with large effect sizes observed also and greater effectiveness than

control conditions, but generally these were smaller effects and less consistent than ACT interventions. CFT and DBT only included one intervention respectively and so conclusions are limited, however both suggest tentatively promising results as improvements were seen in both. Overall, ACT and MBCT are the most extensively investigated third-wave CBT and may offer clinically meaningful outcomes for caregivers of PlwD.

These findings are consistent with previous reviews that have observed positive effects of acceptance (Atefi et al., 2023; Durepos et al., 2024b) and mindfulness-based interventions (Chacko et al., 2022; Murfield et al., 2021) for informal caregivers of PlwD. The effectiveness of third-wave CBTs for informal caregivers of PlwD can be understood through the caregiver stress model whereby caregiver stress results from a combination of primary and secondary stressors as well as personal and external coping resources (Pearlin et al., 1990). The mechanisms of change within third-wave CBTs, particularly ACT, on psychological flexibility, values-based action and acceptance may target these stressors and develop caregivers' skills to respond adaptively, as seen in improvements in stress, anxiety, burden and guilt.

The third research question investigated the quality of evidence of third-wave cognitive behavioural interventions for informal caregivers of PlwD. Most of the studies (71%) were published within the last five years, which reflects the growing evidence base for third-wave CBTs for informal caregivers of PlwD. Thus, many of the studies were small-scale pilot or feasibility studies and although they scored between moderate to high in quality appraisal, there was a lack of blinding and a lack of control groups. Some studies did not report if or how they validated the diagnosis of dementia. Most of the sample included white female caregivers which limits the generalisability of the findings to other cultures. This is particularly crucial to consider as research highlights that caregivers from the global majority may face unique challenges that may not be considered or adapted for in the included studies

(Samson et al., 2016). Future research should endeavour to explore the applicability of these interventions in diverse samples to ensure generalisability and further exploration of cultural adaptations. More high-quality randomised controlled trials are required to strengthen and develop the evidence base for this population.

There are limitations of the current review to consider. Firstly, there was significant heterogeneity across studies regarding intervention, format, delivery, duration and outcome measures. Therefore, statistical comparisons and meta-analyses were not feasible. A wide variety of outcome measures were used as well as inconsistent reporting of effect sizes, which further introduces bias in comparing the interventions. Secondly, there are some limitations to the use of Kmet's tool for quality appraisal as it applies equal weight to all quality domains and it has been argued that it does not fully assess bias (Kmet et al., 2004). While alternative tools, such as Cochrane Risk of Bias tool may provide a more thorough appraisal of bias (Sterne et al., 2019), the Kmet tool was utilised in the current review due to its flexibility across diverse study designs such as feasibility studies, pilot trials and quasi-experimental interventions. Thirdly, whilst the term 'third-wave CBTs' is widely used to refer to ACT, MBCT, DBT and CFT due to their shared conceptual underpinnings and mechanisms of change, there exists a debate about crucial distinctions in the development of these approaches (Dozois & Beck, 2011) and caution should be applied when considering their acceptability and effectiveness as a whole for informal caregivers of PlwD. However, considering the application of these approaches together is pragmatic and used in other reviews (Hendriks et al., 2024; Hong et al., 2023; Kishita et al., 2017) and is clinically meaningful, particularly for clinical psychologists who draw on processes from CBT, ACT, MBCT, CFT and DBT in NHS mental health services (Hayes & Hofmann, 2021).

The current systematic review suggests that third-wave CBTs for informal caregivers of PlwD have promising potential across a variety of structures and formats. These

interventions share mechanisms of change such as acceptance, mindfulness, self-compassion, psychological flexibility and an emphasis on values-based living. These mechanisms appear to be particularly promising for informal caregivers of PlwD who experience chronic, complex and emotional issues associated with dementia caregiving. These findings build upon existing CBT literature that comprises core cognitive-behavioural principles such as cognitive restructuring, behavioural activation and skills training, extending them to target prevalent experiences for this population including experiential avoidance, unhelpful coping and self-criticism. In particular, ACT appears to be effective for informal caregivers of PlwD and clinicians should consider ACT processes in interventions such as psychological flexibility and values-based living in the context of providing informal care for a PlwD.

Future research should continue to build upon this review by determining which third-wave approaches offer additional benefits for informal caregivers of PlwD over traditional CBT approaches, identifying the most active therapeutic components and establishing the comparative effectiveness of ACT, MCBT and CBT for this population in particular. Adequately powered randomised controlled trials are required as well as thorough reporting of demographics to assess inclusivity and accessibility of interventions. Longitudinal designs and mediation analyses may allow for further exploration of effects of acceptance, mindfulness and self-compassion for informal caregivers of PlwD.

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Service Improvement Project

Improving the experience of adults waiting for an autism diagnostic assessment

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Northamptonshire Healthcare NHS Foundation Trust

Word count: 4930

Date of submission: 23rd May 2025

Journal: Journal of Autism and Developmental Disorders (JADD)

Rationale: JADD is a peer reviewed journal on all aspects of autism and related developmental conditions with an impact score of 4.6. The journal's scope includes advancing theory and research for autism and aims to explore clinical diagnoses and treatments for autistic people. See Appendix H for journal guidelines and Appendix I for lay summary required for the submission.

Abstract

Purpose: There has been a rise in referrals to adult autism assessment services. National guidelines suggest that people should be seen for an assessment within 13 weeks. This service improvement project aimed to provide recommendations for improving the experience of waiting for a diagnostic assessment in the Adult ADHD, Autism and Tourette's Team within Northamptonshire Healthcare NHS Foundation Trust. The service is struggling to meet the increased demand and the wait for an assessment from point of referral is now several years. The rates of these referrals are not plateauing and therefore it is crucial that ways to support the population of people waiting are considered.

Methods: Open-ended free text survey responses from service users and focus groups and interviews with staff were analysed with the aim of providing recommendations for the service.

Results: Themes identified from service users included uncertainty, which led them to contact the service more, feeling stuck in limbo during a lonely wait that had implications for their identity and self-diagnosis, impact on day-to-day life and support during the process. Themes generated from staff included challenges at a service level including the role of the screening appointment and an increase in demand with a decrease in resource, feeling powerless, considering ways to support those on the waiting list and systemic challenges.

Conclusion: Recommendations for service improvement focused on increasing certainty and reducing anxiety for service users by increasing communication and support, whilst minimising service demand. The recommendations were shared with the service.

Key words: *autism spectrum disorder, neurodiversity, waiting times, service improvement project*

Introduction

Autism spectrum condition (ASC), also known as autism spectrum disorder (ASD) is a neurodevelopmental condition involving difficulties with social communication and interaction, and restricted or repetitive behaviours or interests (American Psychiatric Association, 2013). The current paper adopts identity-first language as this is endorsed by autistic people (Kenny et al., 2016). The prevalence of diagnosed autism in the UK is about 1.1% (Huang et al., 2020). The rate of diagnosis of autism is increasing exponentially in the UK, particularly in adults and females (Russell et al., 2022). Between 0.77% and 2.12% of the population may be autistic and undiagnosed (O'Nions et al., 2023). Higher levels of underdiagnosis are estimated in adult and older adult age groups compared to children and young people, indicating an urgent need to improve adult autism services (O'Nions et al., 2023).

National context

The National Health Service (NHS) Long Term Plan recognises autism as a national priority and commits to reducing waiting times and improving access to timely diagnostic assessments (NHS, 2019). The national strategy for children, young people and adults 2021 to 2026 also commits to reducing waiting times and improving assessment pathways for autism (UK Government, 2021). The National Institute for Health and Care Excellence (NICE) and NHS Constitution recommend an assessment starts within three months of referral to ensure initiation of appropriate support (Department of Health, 2023; National Institute for Health and Care Excellence, 2021). However, as of December 2023, there were 172,022 people in the UK waiting for an autism assessment with 86% of people waiting longer than the recommended 13 weeks (NHS Digital, 2023).

It is thought that various factors contribute to the rise in adults referred for an autism assessment. These include an increase in public awareness and destigmatisation of

neurodiversity, changes in identification and awareness of autism in females as well as cuts to child services in the NHS (Gellini & Marczak, 2024; Russell et al., 2022). As the co-morbidity of emotional, behavioural and/or social difficulties is high in autistic people, timely detection of autism is crucial to identify needs, provide support and access to services. Adults without a diagnosis may be treated for these co-morbidities without the core difficulty being recognised within their formulation (Gellini & Marczak, 2024). Within the literature it is still unclear if the rise in diagnosis reflects a true increase in prevalence, a rise in overdiagnosis, a combination of factors, or a previous unmet need that people are now coming forward for support with (Russell et al., 2022).

Waiting for a neurodevelopmental diagnostic assessment in adulthood introduces challenges for an individual (Rutherford et al., 2018). Attribution theory suggests that to understand and increase one's perceived sense of control over their environment and experience, individuals attribute external cause and meaning to their experiences (Heider, 1958; Kelley, 1973). In the context of this theory, it is possible that a diagnosis of autism in adulthood supports an individual to make sense of their experiences as an external attribution. However, when individuals are on long waiting lists without a diagnosis, they may struggle to make sense of their difficulties, leading to internal negative appraisals and attributions and thus increasing self-criticism and psychological distress (Attoe & Climie, 2023). Indeed, increased hopelessness and low self-esteem are associated with a later life diagnosis of neurodevelopmental conditions (Attoe & Climie, 2023). Moreover, intolerance of uncertainty (IoU) is experienced when an individual has negative beliefs about uncertainty and its implications (Dugas & Robichaud, 2007) and is more common amongst autistic individuals (Jenkinson et al., 2020) who have a strong preference for routine and predictability (Ashburner et al., 2013; Trembath et al., 2012). Long waiting times for an autism assessment in adulthood can therefore increase already significant psychological distress, particularly due

to ongoing uncertainty about diagnosis and support. Receiving a neurodevelopmental diagnosis in adulthood has been highlighted as facilitating several positives for individuals, including access to relevant support and increased sense-making of oneself and one's experiences (Young et al., 2019) as well as a positive change in beliefs about self (Punshon et al., 2009). Receiving a diagnosis has been found to elicit an immediate sense of relief and acceptance for an individual, particularly after a long wait for assessment (Young et al., 2019). A diagnosis of autism also allows individuals to disclose this to their employer, leading to reasonable adjustments (Equality Act, 2010) which are associated with positive psychological outcomes (Romualdez et al., 2021).

Service context

The current project is based in the Adult ADHD, Autism and Tourette's Team (AAATT) in Northamptonshire NHS Foundation Trust (NHFT). The service has an assessment pathway and post-diagnostic treatment pathway and is open to all genders aged 18 and above. The service has experienced an increase in referral rates; referral records revealed a 165.92% increase in referrals between 2019 (1,250 per year) and 2022 (3,324 per year). Associated with this, there has been an increase in waiting times; in 2019 service users were typically seen within 1-2 years from referrals, whereas service users are now expected to wait 3 or more years for an assessment. Some work within the service has been facilitated aiming to reduce the wait times, however there is little research exploring how to better meet the needs of people waiting, given the years that people may now spend on these waiting lists.

The project aims to understand the needs of adults waiting for a diagnostic assessment for autism on the waiting list and develop recommendations for the service to meet the needs of this population. The service improvement project aims to address the following questions:

1. What is the experience of adults waiting for an assessment for Autism in the Adult Autism Assessment service in NHFT?
2. What changes can be made to improve the experience of adults waiting for an assessment?

Methods

The HRA decision tool indicated that the project was not classified as research therefore ethical approval was not required. This project was approved by NHFT's audit committee (Appendix C). Stakeholders within the service, including experts-by-experience were consulted as part of the design of the project (Appendix D)

The study comprised of an anonymous online survey with free text responses for service users on the waiting list and a focus group for staff members. Due to logistical implications related to staff recruitment, a post-hoc decision was made for staff in the treatment pathway to take part in individual interviews, with the same questions as the focus group. See Appendix E-G for information sheets, online surveys and focus group/interview schedule.

Participants

Service users

Two hundred service users on the waiting list were contacted via email with a flyer detailing the project. Half of the people contacted were people who had waited the longest and were at the top of the waiting list, and half were those who had most recently been referred to the service.

Staff members

All staff were provided with an information sheet and gave written informed consent to take part in the focus groups. Staff were then contacted by the first author (NC).

Procedure

Recruitment for service users was continued until a combination of data saturation (repetition in responses was identified) occurred and to ensure limited burden on administration staff. Initially, 100 service users were contacted on the waiting list in May 2024. There were low numbers recruited, and a further 100 service users were contacted in July 2024. The survey was then closed on 29th August 2024. All anonymous data was exported and sent to the first author and analysed in Microsoft Word.

The interview/focus group schedule for staff was developed using a combination of identified aims from management within the service and stakeholder perspectives. The questions were reviewed iteratively by the first author, using a combination of research supervision from second and third authors (one of which was external to the service and one internal to the service), consultation from a lived experience panel (see Appendix D for examples of amendments made following consultation to this panel) and further iterations following initial service-user responses. All interviews/focus group were between 45-60 minutes on Microsoft Teams, recorded using an encrypted audio device and transcribed verbatim. The first author was external to the service and had no relationship with participants.

Analysis

Qualitative data was analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2019), adopting an experiential approach within a critical realist epistemological framework. This allowed for analysis of large datasets and identification of themes across service users and staff. The service user and staff data were analysed separately and integrated at the point of identifying recommendations for the service. Initially, the first author familiarised themselves with the data, by transcribing, reading and re-reading and making a note of initial thoughts and impressions of the data. Initial stages of Braun and Clarke's thematic analysis of service-user responses revealed common experiences of lack of

communication and awareness about service processes. These recurring patterns then informed the development of the staff interview/focus group schedule aimed at exploring their experiences of communication processes, information sharing and service pathways. Questions remained open-ended and neutral, to allow staff to identify additional issues beyond those identified in the service-user data and ensure a rich understanding of staff perspectives.

All service-user and staff data was semantically coded by the first author who adopted an inductive approach to capture participants' meanings and ensure the codes were grounded in the data. Following this, the codes were sorted into potential themes, which were iteratively reviewed and refined to ensure they captured meaningful patterns across the data.

In order to maintain reflexivity throughout, feedback from second and third authors and supervision discussions supported the refinement of themes. This prompted the first author to revise and reorganise the structure of the analysis to better reflect the research aims. The final themes were then defined and written into a narrative capturing the complexity of both staff and service users experiences as well as the influence of contextual factors. Throughout, the analytic process was iterative and non-linear, consistent with reflexive thematic analysis (Braun & Clarke, 2019).

Findings

Sample Characteristics

Staff

In total, seven members of staff took part in the project, out of a possible 21 (an overall response rate of 33.3%, and a response rate of 63% and 20% in the assessment and post-diagnostic pathway respectively). See Table 1 for details of participants. Only representatives from Psychology and Occupational Therapy participated. The mean length of

employment in the assessment pathway (n=5) was 1.5 years (SD = 2.5) and 8 years (SD = 0) in the post-diagnostic pathway (n=2).

Service users

In total, 200 people on the waiting list were sent the details of the service improvement project and 39 individuals took part (a response rate of 19.5%). The mean age of participants was 40.36 years (*SD* = 14.33). See Table 2 for sample characteristics.

Table 2
Sample Characteristics of Service Users

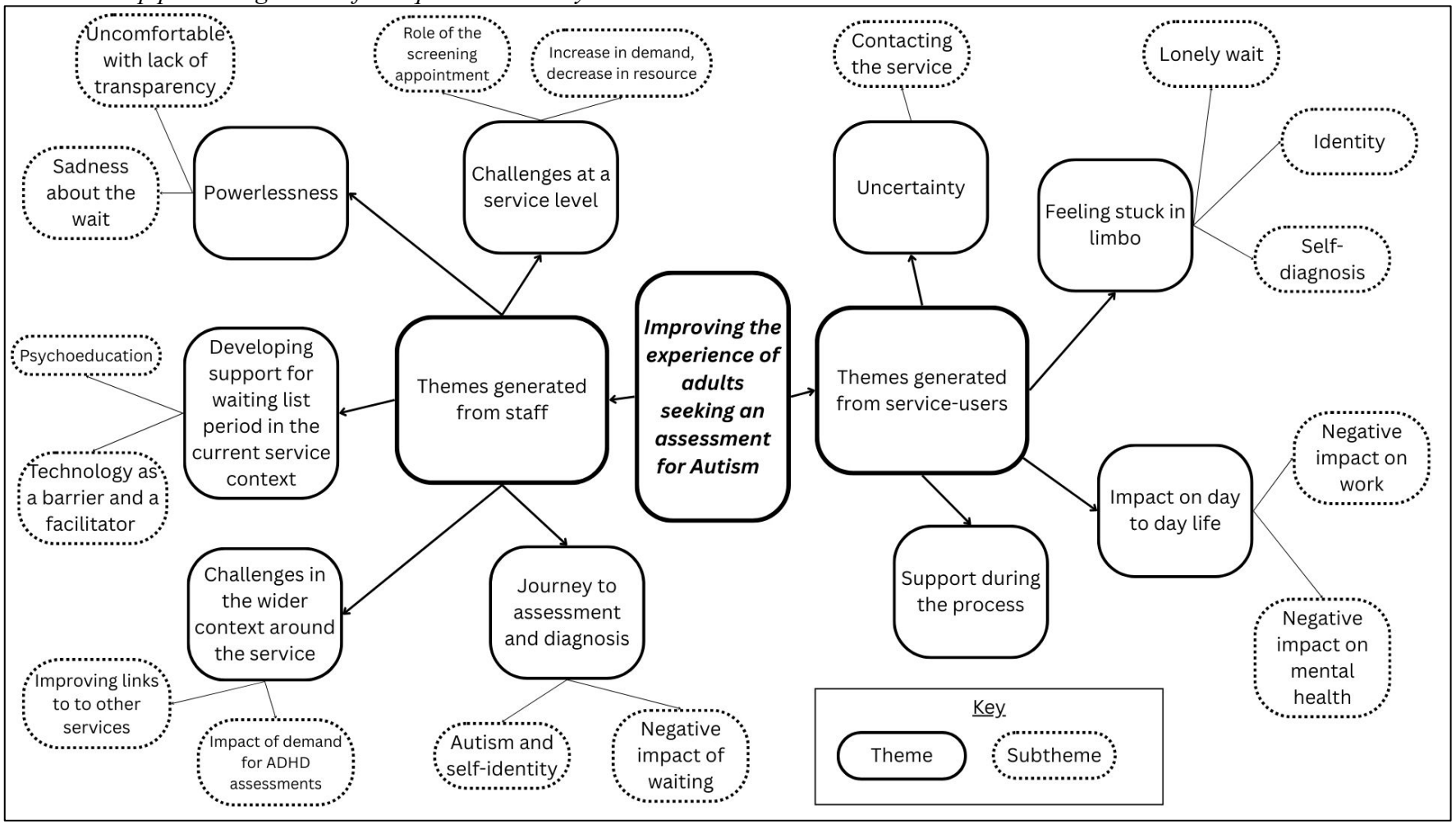
	Service users sample	
	N	%
Gender		
Female	24	61.5
Male	9	23.1
Non-binary	5	12.8
Prefer not to say	1	2.6
Current Assessment Point		
Had initial screening appointment	37	94.9
No appointment	2	5.1
Waiting Time Since Referral		
<1 year	4	10.3
>1 year	22	56.4
>2 years	4	10.3
>3 years	9	23.1

Qualitative Analysis

Quotations are labelled with abbreviations; SU indicates a service user, and SM indicates a staff member. A thematic map is presented in Figure 1 and supporting quotes are presented in Table 3 and 4 for service users and staff respectively. A narrative of thematic analysis findings is presented below.

Figure 1

Thematic map presenting themes from qualitative analysis



Thematic analysis of service user surveys

Uncertainty. More than half of the participants reported feeling uncertain whilst waiting for their assessment. This uncertainty stemmed from the wait being *"much longer than originally stated"* (SU10) and a lack of communication and reassurance that left them *"wondering if I am still on the list, which adds to my anxiety"* (SU25). Most participants reported that routine contact to reassure them they are on the list would help to manage this uncertainty. Three participants also reported that psychoeducation and support around managing this uncertainty would be helpful.

Subtheme: Contacting the service. Some participants reported that they were reaching out to the service or their GP because of this uncertainty and anxiety. However, some participants reported that the anxiety of reaching out was a barrier for them to asking for reassurance. This led to a vicious cycle of service users feeling anxious and not reaching out thus increasing anxiety, or service users feeling anxious and reaching out, thus adding demand on the service.

Feeling stuck in limbo. Service users reported a sense of feeling stuck *"in limbo" (SU25)* whilst waiting for their assessment.

Subtheme: Lonely wait. Service users reported feeling lonely, isolated and forgotten during the process. One participant reported feeling *"left in the dark" (SU17)* and another reported that *"it can be a lonely place when you don't quite fit in like other people" (SU12).*

Subtheme: self-diagnosis. Due to the long wait and lack of support, several participants reported "*coming to terms with my personal 'self-diagnosis'*" (SU10). However, some participants felt that without a diagnosis they are not taken seriously and continued to feel stuck without an official diagnosis.

Subtheme: Identity. Participants identified that a long wait for an assessment and diagnosis was difficult when understanding and developing their identity.

Impact on day-to-day life. Participants highlighted a significant impact of the long waiting period on their daily life, sharing its impacts on their work and mental health.

Subtheme: Negative impact on work. There was an impact for service users on being able to access support at work and on their wider life.

Subtheme: Negative impact on mental health. Some people felt their mental health and experience of possible autism became increasingly difficult to manage during the wait due to the lack of support and length of time spent waiting and others reported that they are also on waiting lists for other mental health services which exacerbated the impact of waiting.

Support during the process. Service users reported that several things had helped them during the wait. These included some participants having positive experiences with the team, such as feeling *"supported"* and *"positive" (SU19)* in the screening appointment or any contact with the team.

Table 3

Supporting quotes from service users

Theme	Sub-theme	Quote
Uncertainty		*"some form of update, even just automated emails once/twice a year to confirm I am still on the waiting list, would have been dearly welcome" (SU19)*
		"some kind of contact every six months or so to say I have not been forgotten would be good" (SU33).
		"Resources specifically dealing with uncertainty, anxiety, and some form of continued support would be really helpful (though probably beyond the available budget/capacity)." (SU19)
	Contacting the service	*"I had to ask my GP surgery to confirm if I was still on the waiting list because I was anxious that I'd been lost in the system" (SU8).*
		"It has been horrendous there is no update ever, nobody replies to emails or phone calls, I have no idea how long I will be waiting I've already gone over the 3 year mark when I was told it should be within 18 months, there has been a massive decline in my mental well-being, overall the whole thing has been detrimental to me" (SU38)
		"When I have reached out via phone call and email, I have not received any further information."(SU10)
Feeling stuck in limbo		*"although I've had my first appointment, it feels like I'm stuck in limbo, waiting endlessly for the next steps without any clear timeline." (SU25).*
		"Of course services are stretched so I understand that side of things but there are certain struggles that might come with not knowing if you are a certain way or not and confusion and waiting can continue these feelings."(SU29)
		"Leaving people who typically need structure and definitives completely in the dark is really unfair" (SU10)
	Lonely wait	*"complete isolation and silence. I don't even know if I am on the list" (SU15).*
		"I have been completely on my own in terms of trying to find resources to help"(SU38)
		"Keep in touch more regularly, or set up a website or Facebook page where we can get information or reach out to other people like ourselves. It can be a lonely place when you don't quite fit in like other people." (SU12)
	Self-diagnosis	*"I have felt a lot of stress coming to terms with my personal 'self-diagnosis' and how to move on or deal with that while I'm in limbo of not having an official diagnosis" (SU10)*
	Identity	*"of course services are stretched so I understand that side of things but there are certain struggles that might come with not knowing if you are a certain way or not and confusion and waiting can continue these feelings" (SU29).*
		"four years is a very long time to be kept waiting especially considering my age" (SU21).
Impact on day-to-day life		

Theme	Sub-theme	Quote
	Negative impact on work	*"I feel my physical health has deteriorated partly due to overwhelm and exhaustion of being in a busy workplace and seen as 'normal'/able to cope the same as everyone else" (SU31)* *"As someone who's needs affect my capacity for work, it would be useful to have an official document confirming that I am awaiting assessment so that I could provide my workplace and Universal Credit with proof. Similarly, some services will only accept people with an official diagnosis, and having a preliminary "awaiting assessment" letter may help provide access to services for those who need it." (SU8)*
	Negative impact on mental health	*"Being on the waiting list has exasperated my condition and been frustrating"(SU13)*
Support during the process		*"My experience with the initial screenings was quite positive, I felt like I was given opportunities to explain my answers, everything was explained clearly, and I felt supported throughout the process"(SU19)* *"I'm not aware of any official services I can seek. Instead I have turned to online groups for people with ASD for support." (SU8)* *"En-Fold have been a lifeline at times, although unable to provide medical advice or support their group activities have made me understand a little about my own ""neurodivergence "" and my the similarities between me and other attendees who have shared their life stories."(SU20)*

Thematic analysis of staff interviews and focus group data

Challenges at a service level. Staff reflected on the challenges felt at a service level that were impacting the experience of adults waiting for an autism assessment.

Subtheme: Increase in demand, decrease in resource. Challenges included an increase in the demand for the service *"without an increase in resources to match those referrals"(SM1)* which left service users frustrated with the service.

Subtheme: Role of the screening appointment. Two members of staff in the assessment pathway reported that the screening appointment potentially presented a challenge to the service as it added to workload for staff, but did not tend to screen people out. Despite this, staff reported that they have considered the potential for rescreening people on the waiting list over time. Some staff felt that the screening appointment was a helpful, therapeutic point of contact.

Powerlessness. Most participants (85%) reported feeling powerless or helpless about the wait that service users have for an autism diagnostic assessment.

Subtheme: Uncomfortable with the lack of transparency. Participants reported difficult situations where they *"really don't know how long the waiting will be" (SM4)* and one member of staff felt that this was *"embarrassing"* and that *"it's all very vague" (SM6)*. Moreover, staff felt uncomfortable about not being able to communicate the length of wait to service users and lack of transparency and felt the pressure of this on an individual level.

Subtheme: Sadness about the wait. Three members of staff felt that *"shock"* when hearing how long the current waits are *("my heart broke")* and that they're *"surprised"* if service users take this well *(SM7).*

Developing support for the waiting period in the current service context. Participants reported several ways in which they creatively develop methods of support for

service users in the context of the rising demand and lack of resource, as well as ideas for how to do this.

Subtheme: Psychoeducation. In particular, there were some ways of delivering psychoeducation that the ADHD diagnostic pathway are currently developing that could be implemented in the autism diagnostic pathway that would be *"great to be able to signpost people to" (SM2).* Moreover, one participant felt that recorded workshops aimed at general coping strategies for those on the waiting list and *"available on the website for anybody to access"* would be a good source of support. Other participants identified areas that would be helpful to cover in these workshops and psychoeducation material including *"sensory approaches"*, *"emotional understanding"* and *"social communication"* that are more general and strategy based as opposed to *"understanding autism"* psychoeducation which is aimed at those who have received a diagnosis (*SM6).*

Subtheme: Technology as a barrier and a facilitator

One participant identified that there is lots of *"website content"* with materials and psychoeducation but keeping this updated is a *"whole job on its own really" (SM7).* One participant reported that the limited use of technology impacts on communication for the service. Three participants mentioned signposting as a method of supporting service users. One participant felt that it is important to consider how a person with ADHD or autism might read the letter with signposting information on and that they *"might just just skim the letter ... its not clear whether the client reads it or not" (SM3).*

Challenges in the wider context around the service. Staff shared that other services did not always have a good understanding of what the service is able to offer.

Subtheme: Improving links to other services. All participants highlighted the importance of improving the links to other services, one participant reported that the community mental health teams had a poor understanding of the support offered to service

users waiting for an assessment and *"discharged them because they are now with us"* and so a *"better understanding of how we work and not do that so they still have support" (SM3).* Two participants reported that GPs seem to refer people to the service with *"no vetting"* and *"seems to put anyone through because they have asked" (SM3).* One staff member also highlighted the importance of local charities such as one *"set up by autistic adults for autistic adults"* and a *"recovery college who do some sessions there as well around sensory and anxiety and autism" (SM7).*

Subtheme: Impact of demand for ADHD assessments. Four participants also acknowledged the impact of the increased demand for ADHD assessments as impacting the wait for autism assessments.

The journey to assessment and diagnosis. Staff shared their experience of supporting service users in their journey to assessment and diagnosis. One participant acknowledged that the service does not see them until the assessment following screening, which lasts several years.

Subtheme: Autism and self-identity. All participants shared that service users felt the diagnosis was important to their identity; *"it does seem to feature more heavily in the autism pathway than the ADHD like [SM1] said that being a massive part of your identity and working through that" (SM2).* One participant felt that this could mean being discharged by the service or experiencing a long wait could be difficult. One participant also reflected on how an autism diagnosis being tied up in one's identity means that it's important to protect the post-diagnostic autism support group for those who have a diagnosis.

Subtheme: Negative impact of waiting. Participants identified the negative impact of waiting, including a lack of support and not being able to access reasonable adjustments.

Table 4

Supporting quotes from staff

Theme	Sub-theme	Quote
Challenges at service level		
	Increase in demand, decrease in resource	*"without an increase in resources to match those referrals"(SM1)* *"really experienced people in our team leaving because of a lack of resources" (SM6)* *"they say oh I understand I have seen that on the news the other day" (SM4)* *"we don't have the work force is the reality of it" (SM7).*
	Role of the screening appointment	*"I don't think many people are screened out, I don't know about you guys, but for me its maybe like 1 in 10 […] we've always sort of been told, if there's a bit of question mark about whether there is traits that's what an assessment is for, we're not assessing at that point so you've kinda gotta air on the side of caution" (SM2).* *"helpful stage as an introduction, especially if our clients are waiting for x amount of years" (SM2)* *"one of the few times we can signpost or actually refer people to other services" (SM5).*
Powerlessness		*"it is soul destroying seeing people and they have waited a year just to get the first contact and knowing it will be quite a few more years before they're assessed again … and when you see the impairment on their day-to-day life… and you know you're sort of in a bit of a helpless position" (SM2).* *"being like the first point of contact and also having the like least amount of […] impact so we have to kind of deal with the aftermath of seeing somebody that questions around waiting time … it's also difficult for us because we know they're struggling and there's not much we can do really around that" (SM4).*
	Uncomfortable with the lack of transparency	*"what's been tricky is sort of transparency about waiting lists […] there's been a lot of miscommunication around it and I feel like from a from a higher level you know the unseen people that are making some decisions that aren't that you not actually having any contact with you don't really understand what the rationale for certain decisions are" (SM6).* *"a sense of sort of not being supported by people with much higher up in the organisation as a team … sort of has been … and caused setbacks" (SM6).*
	Sadness about the wait	*"my heart broke" (SM7).*
Developing support for the waiting period in the current service context		*"wonderful if we had like a lot more resources" (SM4)*
	Psychoeducation	*"I think the teams currently putting together like a presentation type thing … which sort of gives people an idea of what is ADHD, what does ADHD look like, so its not like personalised treatment, but I think its quite a nice step in the right direction in terms of showing that we are there for people" (SM2).*
	Technology as a barrier and a faciliator	*"you can't even do group texts which makes it really hard to communicate with a large group of clients" (SM7).*

Theme	Sub-theme	Quote
		"there is some information on our website […] I don't know how much that is being done (signposted) *now" (SM7).*
Challenges in the wider context around the service		*"stricter or tighter referral to come through would help" (SM5).*
	Improving links to other services	*"sometimes feels like there's not really been a full conversation about why our service might be relevant its more but you're the autism service and they are autistic so they come to you"* (SM6) *"there's a lack of understanding of what the service is" (SM6)* *"GP referrals didn't have as much details as maybe if there was an external service referring them to us" (SM4).*
	Impact of demand for ADHD assessments	*"just because of the rate of how many ADHD there are versus autism there is less autism available, so its making that wait a bit longer because of how ADHD is impacting" (SM5)*
Journey to assessment and diagnosis		*"we don't kind of go back and look or check up on people" (SM5).*
	Autism and self-identity	*"they've held this within their self-identity for the past year"* and *"if they do get discharged they take it really quite personally like negatively because they've just really identified with autism" (SM5).* *"being with people in that group setting and knowing everybody in there is autistic is really really important as well" (SM6).*
	Negative impact of waiting	*"as a service we don't really provide support unless they have a diagnosis" (SM2)*

Discussion

This service improvement project was developed with the Adult ADHD, Autism and Tourette's Team in NHFT. It aimed to explore the experience of adults waiting for an autism diagnostic assessment and develop recommendations to improve this process in the context of increasing demand on the service. To the authors' knowledge, this is the first study that has explored this experience and developed recommendations for services to navigate the increased demand. The current service reported a rise in referrals for adult autism assessments in line with national statistics (NHS Digital, 2023).

With regards to the primary research question, adults waiting for an autism assessment felt stuck with a lack of certainty leading to challenging implications on their day-to-day life and on the development of their identity. Service-users reported feeling lonely and forgotten during the process. Given there is a high prevalence of trauma in autistic populations, there is a risk of re-enacting mistrust and feelings of neglect towards services, thus ensuring these cycles are not perpetuated is crucial (Andrzejewski et al., 2024). Staff within the service felt powerless in the context of long waiting times with a lack of resource to support individuals. A long wait with minimal communication introduces anxiety for the individual and difficulties with development of one's identity, whilst also increasing feelings of powerlessness from staff and hopelessness from service users.

There were parallels in the themes from service-users and staff, who both felt frustrated with the limited resource and waiting times but also valued the connection at various points in the diagnostic journey. This is in line with previous research that reports the process of waiting for an autism assessment to introduce uncertainty and distress (de Broize et al., 2022; Gellini & Marczak, 2024; Jones et al., 2014; Leedham et al., 2020) and findings that report staff working in specialist autism teams feel powerless due to long waiting times and limited resources (Beresford et al., 2020).

In line with attribution theory (Heider, 1958; Kelley, 1973) and models of intolerance of uncertainty (Dugas & Robichaud, 2007), lack of communication or certainty about assessment appeared to amplify psychological distress. Therefore, to reduce this distress, and potentially subsequently reduce demand on the service, participants suggested improvements in communication, including regular confirmations that they remain on the waiting list. Increasing communication, support and clarity for this population during the waiting period could help reduce psychological distress and in turn reduce demand on the service. Service users felt that automated confirmation they remained on the waiting list over the years would help to contain uncertainty about whether they had been missed. Many service users reported no communication for several years, leaving them unsure where they could access support during the wait. Although staff described recent efforts to improve the team's website, including updated information, signposting and resources, no service users reported using this, possibly because they were unaware or had forgotten about it over time. As a result of this, information about the assessment process and sources of support were inaccessible. Moreover, the long gap between their initial screening appointment and subsequent assessment left many unsure about what to expect from the assessment itself.

Staff also reported feeling uncomfortable when explaining the assessment process, particularly as they could not provide a clear timeframe for the assessment and were unaware themselves. Staff reported an implementation of pre-recorded psychoeducational webinars on the ADHD pathway, which enabled them to deliver support on a large scale without increasing demand. Service users requested support specifically focused on managing the anxiety associated with waiting times.

Finally, systemic challenges were also highlighted from staff, including inappropriate referrals to the service or a lack of understanding about the team's capacity and remit. Thus

further straining resources and extending waiting times, emphasising the need for improved communication between services and clear referral criteria.

Regarding the secondary research question, several changes were identified in the data that could be made to improve the experience of adults waiting for an assessment. Recommendations (see Table 3) were developed following the findings from the service improvement project in the context of reducing demand on the service to support both service users and staff. These recommendations were based on providing regular updates and reminders of support to those waiting for an assessment, creating support specific to waiting without increasing demand on service, providing clear information on the assessment process, developing information for referrers, supporting staff to manage anxiety of the waiting list and keeping accurate referral data and further audits.

Table 3

Recommendations developed from the service improvement project

Recommendation	Findings that support this recommendation	How to implement
(1) Increase communication to reduce anxiety and uncertainty	• Service users find that the lack of communication whilst they are on the waiting list increases uncertainty and anxiety. Research shows that autistic people find uncertainty difficult. • In turn this may lead to more demand placed on the service as service users may contact the team to check they are still on the waiting list. • Other services use waiting list updates.	• Provide automated regular updates (e.g. every 6 months) waiting list update letters. ○ Includes signposting to already available resources (e.g. service website) and third-sector organisations that participants found helpful (e.g. En-Fold) • Admin can bulk send letters out to people on the waiting list for up to 100 people at a time. • Automated response on voicemail/email for enquiries, detailing why the service are unable to give a timeframe for assessment. • Reconsider the role of the screening appointment, perhaps using this as a means of structured support rather than solely triaging.
(2) Provide regular reminders of where people can get support whilst waiting.	• Service users feel that no signposting for support or psychoeducation whilst they are waiting is provided, despite there being lots of information and resources on the website for the team. This information appears not to be accessible, or people have been waiting so long the initial letters with this information have been misplaced/forgotten. • Service users found support from local charities that have been set up by autistic people and able to support individuals before they have a diagnosis to be very helpful.	• On 6 monthly waiting list update letters, provide a reminder of signposting information for mental health support and provide a link or barcode to psychoeducation information on website and local charities.

Recommendation	Findings that support this recommendation	How to implement
(3) Develop accessible psychoeducation for those on the waiting list	• Services users report that they continue to struggle with experiences possibly related to autism whilst they are waiting for the assessment. • Staff members observe significant impact on day-to-day life for people at the point of screening appointment.	• Develop pre-recorded psychoeducation materials specifically aimed at those on the waiting list, topics could include; managing uncertainty and anxiety, strategies for sensory sensitivities and social communication, support at work and accessing reasonable adjustments. • This could be available on the website and reminders of these could be sent in regular automated waiting list updates. • Ensure the materials are developed with autistic adults and are accessible.
(4) Provide visual overview of the assessment process, from referral to diagnostic assessment and options beyond this	• Service users find the screening appointment a helpful introduction to the service and are able to discuss their difficulties and/or be signposted to other services. However, they are then not contacted for several years and may forget what the process looks like. Service users commented that a visual overview to help them understand the process would be helpful.	• Visual diagram of assessment and diagnostic process included in the following documents: o Information leaflets about the service for service users or referrers o On the website o On automated waiting list update letters to service users
(5) Provide information for other teams and professionals within the Trust about what the service is able to offer and the limits of this.	• Staff found that there was sometimes a misunderstanding from other teams within the Trust about what the service is able to offer. • Service users reported that they felt there was limited link in between the service and other services they might be accessing, such as the CMHT or IAPT.	• Development of service information leaflet with referral criteria and visual overview of the assessment process. • Attend and present information on the service at the quarterly Trust Clinical Governance Meetings, offering staff the space to ask questions. • Link in with the GP training programme to offer information and/or a session on the service and referral process. • Consider regular newsletters or webinars about the service's remit and limits of the service.
(6) Provide support specific to managing the waiting period.	• Many service users report feeling stuck and 'in limbo' whilst waiting for the diagnostic assessment. • Many service users felt that hearing the experience of others who have been in a similar position has been helpful.	• Involve experts by experience in the development of pre-recorded webinars that are tailored to specific support on the waiting period, such as managing the uncertainty and include stories of people who have a shared experience. • Signpost service users to online forums or communities to allow them to build a sense of community and/or support.

Recommendation	Findings that support this recommendation	How to implement
	• Other services such as North East London Foundation Trust, Sheffield Health and Social Care NHS Foundation Trust, and Leeds and York Partnership NHS Foundation Trust have resources specifically tailored to waiting (e.g. 'while you wait") on their websites and in communication to service users.	• Consider peer-support model to support the experience of waiting for so long, in the context of the reported isolation and feeling stuck.
(7) Develop a clear message to support anxiety around the wait and a rationale for not giving a timeframe for staff when communicating with service users.	• Staff reported it can be uncomfortable and difficult to know what to say to service users who desire a timeframe and certainty for their diagnostic assessment. • Service users have reported it is difficult when they are waiting longer than they are told they would be as this increases their anxiety about being forgotten.	• Continue to provide service users with validation for how difficult it can be to wait for a long period of time for something so important. • Provide a clear rationale for why it is not helpful to specify a timeframe, as this can increase anxiety if it has to change due to an increased demand on the service or a reduced capacity of the service. • Consider reflective spaces for staff to share the impact of powerlessness for them personally and professionally.
(8) Develop data collection and audit processes for assessment and referral data.	• Data was not available within the service about separate autism and ADHD referrals and combined assessments.	• Collect data to accurately separate autism and ADHD referrals and combined assessments. • Collect demographic data to explore access to the service and waiting times for those from the global majority. • This would allow for a more detailed audit of referral forms to be conducted and highlight further and/or specific areas to target for improvement within the service.

Methodological Strengths and Limitations

One strength of the current project is its triangulation of methods and recruitment of both staff and service users through online surveys, interviews and focus groups thus increasing validity. Moreover, experts by experience were involved in the development of the project and in ensuring the study materials were accessible for autistic people which is crucial in autism research (Pellicano et al., 2022).

However, consideration of the differential impact of power and positioning as a result of using both focus groups and individual interviews is a crucial implication for the current project. Within the focus groups, organisational hierarchy, workplace culture and peer influence may have led staff to align with dominant narratives and more powerful voices. Whilst the position of the first author as an external researcher may have led to deeper insight into staff perspectives in individual interviews, fear of challenging dominant narratives within focus groups may have influenced discussion and thus the richness of the data. Consideration of GRACES and intersectionality is also crucial given visibility of difference within focus groups and that of the researcher. This may have impacted who felt comfortable sharing their perspective and people with multiple marginalised identities may have felt less safe to speak about their experiences. Whilst individual interviews may have offered a more private setting that could have elicited different perspectives, this data is also shaped by the identities and position of both the participant and the researcher. In both methods, at different levels, what is shared is influenced by power, positionality and relational dynamics and reflexive practice is crucial to acknowledge these effects on the data.

One limitation of the current project is the low response rate of both staff and service users. The low staff response rates may reflect the high demands currently on staff. However, the study did not capture why staff or service users chose not to take part. The service was unable to provide the total number of people on the waiting list for an autism assessment, so

it is not possible to report what proportion of service users participated. Further sample demographic data of service users was not collected, such as ethnicity and socioeconomic status to protect confidentiality and limit participant burden. This is important due to health inequalities within these demographics, particularly those from the global majority (Bishop-Fitzpatrick & Kind, 2017). Moreover, a report by the National Autistic Society identified increased difficulty for Black, Asian and minority ethnic groups to receive a diagnosis of autism (Slade, 2014). This, combined with the low staff response rate and lack of representation of the staff team, mean that it is vital to interpret these findings cautiously as they may not be representative of all perspectives within the service. It is also possible that there was a response bias from service users, in that those who are less happy with the service completed the questionnaire.

This project did not implement changes within the service that were evaluated. Future research could implement the recommendations and evaluate these against the current practice. One way to measure this could be in frequency of contacts to the service or number of complaints to the service.

Conclusion

This paper presents a service improvement project with the aim of improving the process of waiting for an autism assessment in adulthood. Service users and staff were recruited through online surveys, focus groups and interviews and qualitative methods were implemented to identify recommendations. The project observed significant challenges at both a service user and staff level in the context of increasing demand and lack of resource. Recommendations were developed for the service to increase communication, support and clarity throughout the waiting period and increase wider knowledge of the team amongst professionals.

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Theory Driven Research Paper

"It's a loop that I am stuck in": A Mixed Methods Study Exploring Self-Compassion in Compulsive Exercise in Young People with Eating Disorders

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Oxford Health NHS Foundation Trust

Word count: 5000

Date of submission: 23rd May 2025

Journal: Journal of Eating Disorders

Rationale: Journal of Eating Disorders is a peer reviewed journal on eating disorders with an impact score of 3.5 in 2023 and a 5-year impact factor of 4. Journal of Eating Disorders aims to advance the understanding of eating disorders and is therefore considered an appropriate journal for the current paper. Journal guidelines can be found in Appendix P.

Abstract

Background: Compulsive exercise is prevalent but poorly understood in eating disorders such as Anorexia and Bulima Nervosa. This study aimed to explore the role of self-compassion in compulsive exercise.

Method: A mixed-methods, cross-sectional online questionnaire study was conducted with 146 young people (aged 16-25) with Anorexia, Bulimia or Atypical Anorexia. Participants were recruited through NHS eating disorder services and social media. Statistical analyses investigated differences in self-compassion between high and low compulsive exercise groups and regression models explored self-compassion as a predictor of compulsive exercise. Qualitative responses from 55 participants were analysed thematically.

Results: Self-compassion was low across the sample. No significant differences were found in self-compassion between those with high and low compulsive exercise, after controlling for eating disorder diagnosis, symptomology, anxiety and mood. Eating disorder diagnosis, symptomology, anxiety, mood and self-compassion were significant in predicting severity of compulsive exercise. Exploratory analyses indicated that self-compassion was a significant predictor of lack of exercise enjoyment. Thematic analysis identified three themes; “Unrelenting standards”, “The drive to exercise” and “Secrecy” which all fell under the overarching theme of “It’s a loop that I’m stuck in”.

Discussion: Self-compassion was not significantly different in young people who did and did not meet clinical levels of compulsive exercise, or predict compulsive exercise severity. Qualitative findings highlighted experiences of feeling stuck, high standards, self-punishment and secrecy suggest there is a complex relationship between self-compassion and compulsive exercise. Future research is needed to understand self-compassion as a meaningful therapeutic target within compulsive exercise.

Key words: eating disorders, anorexia nervosa, bulimia nervosa, self-compassion, compulsive exercise, young people

Introduction

Eating disorders

Eating disorders (EDs), including Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Atypical AN or Atypical BN are serious mental illnesses. Atypical AN and BN fall under the Otherwise Specified Feeding and Eating Disorders (OSFED) category in the *Diagnostic and Statistical Manual* (1), accounting for 44% of ED cases (2). In the UK, ED prevalence is 12.5% in 17- to 19-year-olds and 5.9% in 20- to 25-year-olds (3). These EDs involve weight and shape concerns, disordered eating and compensatory behaviours, such as compulsive exercise (4).

Eating disorders and compulsive exercise

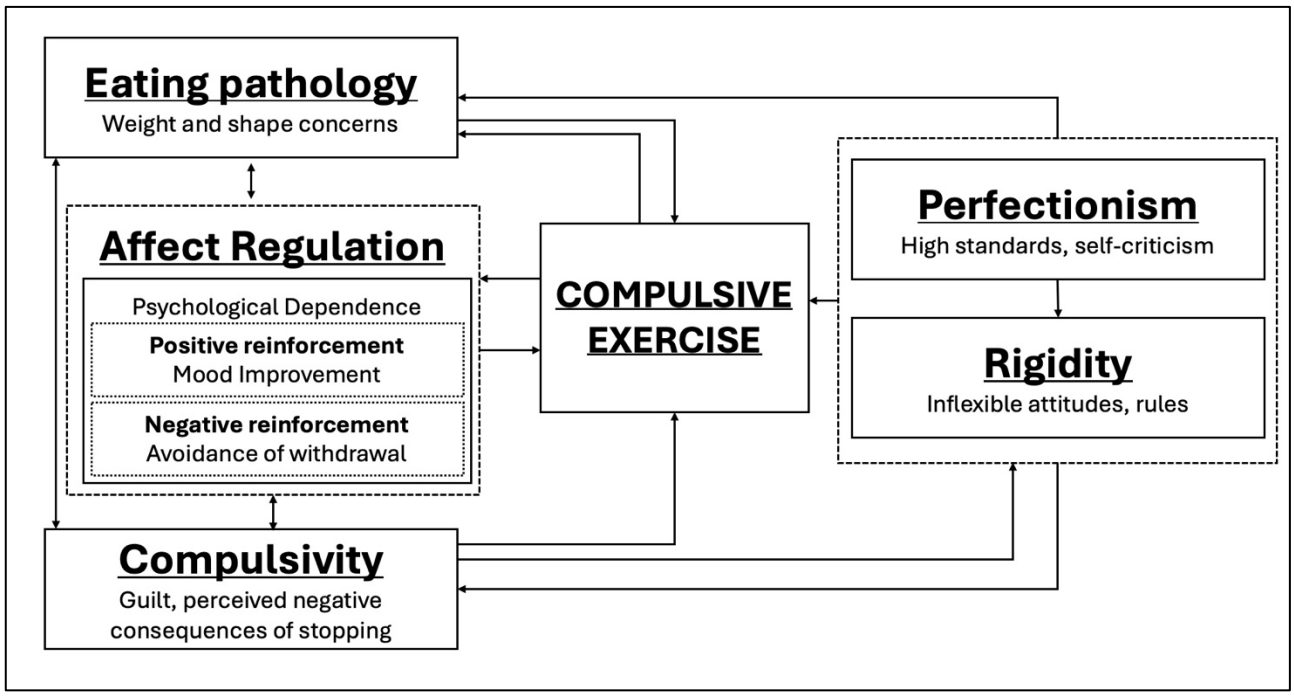
Compulsive exercise (CE) refers to highly rigid exercise that negatively impacts mental and physical health (5,6). Terms like 'excessive', 'driven', or 'obligatory' exercise have been used (7). However, a Delphi study suggested that CE is the preferred term by clinicians (7) and people with lived experience of EDs (8). CE is a common compensatory behaviour in AN (9), BN and atypical AN/BN (10,11), but is not typically associated with Binge Eating Disorder (BED), Avoidant/Restrictive Food Intake Disorder (ARFID), Pica and Rumination Disorder which lack compensatory behaviours and differ in mechanism (1,9,12,13). CE prevalence ranges from 31% to 81% in AN (14–16) and 20% to 66% in BN (14,15,17).

CE is associated with negative outcomes, greater pathology and increased relapse risk (11,18), yet remains under-researched compared to other ED features (7). CE is mostly conceptualised by a cognitive behavioural therapy (CBT) model (6) (Figure 1), which highlights weight and shape concerns, affect regulation, compulsivity, perfectionism, and

rigidity. In line with Skinner's reinforcement theory (19), short-term positive or negative reinforcement is considered key in the maintenance of CE (20).

Figure 1

Cognitive Behavioural Framework for Compulsive Exercise



Note: Adapted from Meyer et al. *(6)*

Despite consensus on the complexity of CE, there is a lack of clear guidelines and interventions for CE (7). CBT interventions such as the Loughborough Exercise Activity Programme (LEAP) have been developed to address the key maintenance factors (21). However, studies have found no increased positive outcomes for LEAP over general interventions for EDs such as CBT (21). While LEAP has been adapted for children and

adolescents, it has not been compared to a control group (22) and interventions for EDs such as CBT-E do not specifically address CE (9).

There is a lack of understanding, guidelines, and recommended interventions for young people with EDs experiencing CE (7). Due to physical health concerns, exercise abstinence is often recommended during treatment, which has been linked to poor outcomes (8,18). A significant gap persists between the views of individuals with lived experience, research evidence and clinical practice (8). Qualitative studies suggest individuals feel a part of their ED remains untreated and that CE will continue or delay recovery due to missed opportunities to learn alternative coping strategies (8,23).

Self-compassion

Self-compassion, the ability to respond to personal suffering with mindfulness and self-kindness (24), is a crucial protective factor across mental health conditions (25). Neff's theory of self-compassion comprises three core components: self-kindness versus self-judgement, common humanity versus isolation and mindfulness versus over-identification (26,27). Gilbert extended this conceptualisation and developed Compassion Focused Therapy (CFT) (28). Grounded in an evolutionary neurobiological model of affect regulation, CFT comprises three systems, the threat system, linked to anxiety and survival, the drive system, linked to motivation and reward and the soothe system, linked to safety and self-compassion. CFT aims to regulate threat and drive, and develop the soothe system, which is often underdeveloped in people with high self-criticism (25).

Self-compassion and eating disorders

Research increasingly highlights a link between self-compassion and EDs (29). Individuals with EDs have lower levels and an increased fear of self-compassion (30,31). According to Neff's framework (26), individuals with EDs often exhibit self-judgement related

to weight and shape concerns, along with heightened feelings of isolation and over-identification with body dissatisfaction (32). Gilbert's model further supports this, positing that individuals with EDs have an overactive threat system, driven by shame, guilt and self-criticism and an underdeveloped soothe system, associated with lack of self-compassion (33). The drive system regulates distress through compensatory behaviours like CE, reinforcing cycles of psychological distress. A recent meta-analysis highlights CFT effectiveness in reducing ED symptomology, suggesting support for this model (34).

To date, only two studies have explored the link between self-compassion and CE (35,36). In nonclinical participants, self-compassion was a significant predictor of CE, even after controlling for variables such as eating disorder symptomology, anxiety and depression (35). In female athletes, higher levels of self-compassion were a protective factor for CE (36). As higher levels of anxiety and depression are associated with lower self-compassion (37), controlling for these variables allows for a more isolated analysis of the relationship between self-compassion and compulsive exercise. Emerging adulthood, defined as 16-25, is often neglected in ED literature (38). CE is thought to be the most common compensatory strategy for young people with AN and BN (39) and treatment pathways have recently been developed to specifically target EDs that develop in this period (40).

Aims

No studies to date have explored the relationship between self-compassion and CE in a clinical sample of young people with EDs. The current study aimed to explore the current understanding of CE and to consider the role of self-compassion for young people aged 16-25 with AN, BN or Atypical AN/BN. Due to limited guidelines for CE, a mixed methods approach is proposed to assess the relationship between self-compassion and CE and explore lived experiences, allowing for triangulation of findings.

Research questions and hypotheses

1. After controlling for ED diagnosis, symptomology, mood and anxiety, are there differences in levels of self-compassion in young people aged 16-25 with EDs (either AN, BN or Atypical AN/BN) who experience high levels of CE compared to young people aged 16-25 with EDs who experience low levels of CE?
    a) Hypothesis: There will be a significant difference in self-compassion between young people with eating disorders who report high levels of CE compared to those who report low levels of CE.
2. Whilst controlling for ED diagnosis, symptomology, mood and anxiety, what effect does self-compassion have on the severity of CE in young people aged 16-25 with EDs (either AN, BN or Atypical AN/BN) and what elements of self-compassion (self-kindness, self-judgement, common humanity, isolation, mindfulness, over-identification) are the strongest predictors of CE?
    a) Hypothesis: Self-compassion will be significantly associated with the severity of CE in young people with EDs, after controlling for ED diagnosis, symptomology, mood and anxiety.
    b) Hypothesis: Components of self-compassion will significantly predict the severity of CE In young people with EDs.
3. What is the experience of CE and self-compassion in young people aged 16-25 with AN, BN, or atypical AN/BN who report high levels of CE?

Method

Design

The study utilised a mixed-methods, cross-sectional, between-groups design to investigate whether self-compassion differs between young people with EDs who experience clinically significant CE versus those that do not and to explore the lived experience of young

people who experience CE. Integration of quantitative and qualitative methods occurred through a convergent design whereby data was collected and analysed in parallel and integrated through a narrative, continuous approach in the discussion. The study was sponsored by Oxford Health NHS Foundation Trust (OHFT) and given a REC favourable opinion by Chelsea Research Ethics Committee and Health Research Authority approval (IRAS project ID: 338717, REC reference 24/LO/0833, see Appendix J). Experts by experience were involved in the study design (Appendix K).

Participants

Participants were recruited via convenience sampling through (a) child and adult ED services (flyers and posters in waiting rooms) (b) advertisements on social media (e.g. Instagram posts) and ED charity websites. Recruitment occurred between November 2024 and March 2025. Participant inclusion criteria included being aged between 16 and 25, diagnosed with AN, BN or atypical AN/BN, UK-based and fluent in English. Exclusion criteria included a diagnosis of BED/ARFID or receiving inpatient care.

Procedure

Advertisements invited young people to access an information sheet, provide consent and complete an anonymous Qualtrics survey. Participants were screened out of the study if they did not meet the inclusion criteria and shown a brief explanation and debrief information. Participants scoring above the clinical threshold for CE were invited to answer qualitative questions. Participation was voluntary, anonymous and uncompensated. A debrief sheet was available throughout and after the survey.

Measures

Demographic information. Participants self-reported age, gender identity, ethnicity and any neurodevelopmental or mental health diagnoses.

The Eating Disorder Diagnostic Scale (EDDS) (41). The EDDS is a 22-item self-report measure used to validate diagnosis of AN, Atypical AN/BN, BN and BED as in the DSM-5 (1). The EDDS is validated for use in clinical populations of people with EDs and non-clinical populations for research purposes (42). It has been validated for use in ages 16-25 (41,43). The EDDS was used to indicate if participants were eligible to take part in the study by validating self-reported clinical diagnoses.

The Self Compassion Scale (SCS) (26). The SCS is a 26-item measure of self-compassion, across three components of self-compassion (self-kindness versus self-judgement, common humanity versus isolation, mindfulness versus over-identification). The total and subscale scores were used. It consists of a five-point Likert scale from 'not like me at all' (1) to 'like me very much' (5). The SCS has been used in clinical ED samples (29,44,45) and non-clinical samples of young people and adolescents and has shown good internal consistency in both (44,46) and good reliability in samples exploring CE in EDs in young people (35). Scores between 1 and 2.5 indicate low self-compassion, between 2.5 and 3.5 indicate moderate self-compassion and between 3.5 and 5 indicate high self-compassion (26). ED research has used this interpretation to identify levels of self-compassion (47,48). The Cronbach alpha for the SCS-Global score was 0.87, indicating good internal consistency. Subscales ranged from 0.65 (Isolation) to 0.83 (Self-kindness). Some alphas were slightly lower where subscales comprised of only a few items, which is to be expected (49).

Compulsive Exercise Test (CET) (5). The CET is a 24-item self-report questionnaire on a Likert scale, comprising subscales; avoidance and rule-driven behaviour, weight control exercise, mood improvement, lack of exercise enjoyment and exercise rigidity. It has been validated and widely used in young people with EDs and ages relevant to the current study (50,51). A cut-off score of greater than or equal to 15 on the measure is considered an appropriate indicator of CE (52) and has been used to identify clinical levels of CE in ED

populations in young people aged 16 and above (52–54). In the current study, the Cronbach alpha of the CET total score was 0.89 and the subscales ranged from 0.75 (exercise rigidity) to 0.89 (lack of exercise enjoyment). The total and subscale scores were used in the current study.

Eating Disorder Examination Questionnaire (EDE-Q) (55). The EDE-Q was used to examine overall ED symptoms and severity. It explores attitudes and beliefs across four subscales (dietary restraint, eating, shape and weight concerns). It consists of 22 items rated on a Likert scale. The EDE-Q has been validated in young people with EDs from the age of 14 and has good reliability across clinical and community samples (Carter et al., 2001). In the current study, the Cronbach alpha for the EDE-Q total score was 0.87. The EDE-Q total score was used in the current study.

Generalised Anxiety Disorder Assessment (GAD-7) (56). The GAD-7 is a 7-item measure to assess the severity of generalised anxiety disorder. Participants are asked to rate the severity of anxiety symptoms over the past two weeks on a four-point scale from 'not at all' to 'nearly every day'. The GAD-7 has been validated for use with the general population and young people with GAD, demonstrating good reliability and validity (56). The GAD-7 has been used in nonclinical disordered eating youth populations and clinical samples of young people with EDs (57,58). In the current study, the Cronbach Alpha for the GAD-7 was 0.85.

Patient Health Questionnaire eight-item depression scale (PHQ-8) (59)**.** The PHQ-8 assessed for depression. The PHQ-8 was utilised in the current study due to omitting a ninth item, as in the PHQ-9, related to suicidal or self-injurious thoughts, as the current study was not able to follow up on risk as it was an anonymous survey. Research shows that the PHQ-8 is as valid as the PHQ-9 (59) and has acceptable reliability and validity in nonclinical

(60,61) and clinical samples of young people with EDs (61). In the current study, the Cronbach Alpha for the PHQ-8 was 0.87.

Open ended free text questions (Appendix L). Nine questions were co-developed with young people with lived experience of EDs and derived from gaps in the literature.

Analysis

Quantitative Analysis

SPSS version 29.0.2.0 was used to conduct the statistical analysis. A priori power analysis for ANCOVA conducted using G*Power version 3.1 (62) indicated that a required sample of 128 to detect a medium effect ($\alpha = 0.05$, power = 0.80). Due to the lack of previous research, a medium effect size was utilised.

For the primary research question, an analysis of covariance (ANCOVA) was conducted, which controlled for ED diagnosis, symptomology, mood and anxiety, whilst exploring the difference in self-compassion between high and low CE. For the secondary question, a hierarchical regression model investigated whether self-compassion total and subscale scores predicted CE severity, controlling for the same covariates. Exploratory analyses investigated the impact of self-compassion on CE subscales.

Qualitative Analysis

Free-test survey responses were analysed using Braun and Clarke's thematic analysis (63). The author first familiarised themselves with the data and adopted an experiential, interpretivist orientation to explore how young people with EDs make sense of their relationship with CE and self-compassion. A deductive approach guided coding, informed by existing CE theory. Both semantic and latent coding was implemented to represent participants' voices. Codes were grouped into initial themes and reviewed iteratively.

The first author was a trainee clinical psychologist with a research interest in the current area which shaped the decision to explore this phenomenon through an experiential

lens. Reflexivity was held in mind through regular supervision and reflexive journalling (Appendix N).

Results

Sample Characteristics

In total, 146 young people participated with the majority (98%) being recruited through social media. Sample characteristics can be found in Table 1 (further characteristics in Appendix O). Of the total sample, 93% (n=136) identified as female, were aged between 16 and 25 (M=20.4, SD=2.6), and 89.7% were White British. Based on CET scores, 80.8% (n=118) scored above 15, indicating clinical levels of CE. Of the sample, 47.3% (n=69) were currently under a specialist ED team and of the remaining participants who were not, 79.4% had been under an ED team previously. As shown in Table 1, there were no significant differences between those who scored high in CE and those who scored low in CE across age, gender, ethnicity and whether they were under an ED service. The most common diagnosis was AN (52.7%), followed by BN (24%) and Atypical AN (23.3%). Of the total sample, 14.3% self-reported a diagnosis of autism, 8.8% self-reported a diagnosis of ADHD, whilst 15% were on the waiting list for neurodevelopmental assessment. Across the overall sample and the high and low CE groups, self-compassion was in the low range.

Table 1
Demographic and Sample characteristics, Across Total Sample, High and Low Compulsive Exercise groups.

	Total sample (*N* = 146)		Low CET scores (*n* = 28)		High CET scores (*n* = 118)		Chi-Square	
Variable	*M*	SD	*M*	SD	*M*	SD	t	*p*
Age	*20.4*	2.6	*19.7*	2.1	*20.6*	2.7	1.529	*.128*
	n	%	*n*	%	*n*	%	X^2	*p*
Gender							1.551	.671
Female	136	93.2	27	96.4	109	92.4		
Male	4	2.7	1	3.6	3	2.5		

Variable	Total sample (*N* = 146)		Low CET scores (*n* = 28)		High CET scores (*n* = 118)		Chi-Square	
	M	SD	*M*	SD	*M*	SD	t	*p*
Non-Binary	4	2.7	0	0	4	3.4		
Gender queer	1	.7	0	0	1	.85		
Trans Male	1	.7	0	0	1	.85		
Ethnicity								.07†
Asian/Asian British	5	3.4	0	0	5	4.2		
Black/African/Caribbean/Black British	1	.7	0	0	1	0.8		
Mixed/Multiple Ethnic Groups	7	4.8	0	0	7	5.9		
Other ethnic group	2	1.4	0	0	2	1.7		
White	131	89.7	28	100	103	87.3		
Diagnosis (EDDS)							2.175	.337
Anorexia Nervosa	77	52.7	18	64.3	59	50		
Bulimia Nervosa	35	24	6	21.4	29	24.6		
Atypical Anorexia Nervosa	34	23.3	4	14.3	30	25.4		
Under the care of ED team							.884	.347
Yes	69	47.3	11	39.3	58	49.2		
No	77	52.7	17	60.7	60	50.8		
Neurodevelopmental condition								
Neurodevelopmental query/waiting list	22	15	5	17.9	17	14.3		
Neurodevelopmental diagnosis								
Autism	21	14.3	3	10.7	18	15.1		
ADHD	13	8.8	4	14.3	9	7.6		
Parent or sibling with neurodevelopmental diagnosis	35	24	10	35.7	2	20.2		
	M	*SD*	*M*	*SD*	*M*	*SD*		
CET Total Score	16.9	3.4	11.4	2.9	18.3	1.8		
EDE-Q Total Scores	4.8	.8	4.7	.8	4.8	.8		
GAD7 Score	15.2	4.6	14.4	5	15.4	4.5		
PHQ8 Score	16.4	5.6	17.6	5	16.1	5.8		
SCS Global Score	2	.5	2.1	.5	2	.4		

Note. Where Chi-Square statistics are missing, sample size is too small to compute.
† Fisher's Exact Test was used as Chi Square assumptions being violated.

Quantitative Findings

Primary research question.

An ANCOVA was run to determine if there was a difference in self-compassion between those experiencing clinical levels of CE and those not, whilst controlling for eating disorder symptomology, eating disorder diagnosis, anxiety and depression. After adjusting for eating disorder symptomology (and its interaction effects), eating disorder diagnosis, anxiety

(and its interaction effects) and depression, there was not a statistically significant difference in self-compassion between those who experience a clinical level of CE and those who do not, F(1, 138) = 4.616, p = .369, partial η^2=0.006.

Secondary research question.

A hierarchical linear regression was run to determine whether self-compassion predicts additional variance in CE severity when controlling for eating disorder symptomology (symptoms and diagnosis) in step one and comorbidity (anxiety and depression) in step two. The full model of eating disorder symptoms, diagnosis, anxiety, depression and self-compassion was statistically significant, R^2 = .081, F(5,140) = 2.460, p = .036; adjusted R^2 = .048, explaining 8.1% of the variance in compulsive exercise, a small-to-medium effect size (64).

The addition of anxiety and depression to the model over and above eating disorder symptomology and diagnosis led to a statistically significant increase in R^2 of .059, F(2, 141) = 4.490, p = 0.013. The addition of self-compassion to the prediction of CE severity led to a statistically non-significant increase, R^2 of .004, F(1, 140) = .670, p =.415, explaining 0.4% of the variance in compulsive exercise, a small effect size (64).

Table 2

Hierarchical Linear Regression Predicting Severity of CE from Predictor Variables; Eating Disorder Diagnosis, Symptomology, Anxiety, Depression and Self-compassion.

Variable		B	95% CI for B		β	R^2	ΔR^2
			LL	UL			
Step 1						.018	.018
	Constant	14.292	10.804	17.780			
	Eating disorder symptomology	.492	-.216	1.201	.114		
	Eating disorder diagnosis	.171	-.288	.630	.061		
Step 2						.76	.59*
	Constant	12.222	8.535	15.908			
	Eating disorder symptomology	1.054	.167	1.941	.244*		
	Eating disorder diagnosis	.127	-.327	.582	.046		
	Anxiety	.190	.040	.340	.260*		
	Depression	-.208	-.357	-.060	-.347*		
Step 3						.81	.004*

	Constant	14.134	8.220	20.049	
	Eating disorder symptomology	.929	-.010	1.867	.215
	Eating disorder diagnosis	.141	-.315	.597	.050
	Anxiety	.174	.019	.329	.238*
	Depression	-.206	-.355	-.057	-.343*
	Self-compassion global score	-.565	-1.930	.800	.077

Note. CI = confidence interval; LL = lower limit, UL = upper limit; R2 = variance in CE severity explained by independent variables; ΔR^2 = the change in R^2 between models, β = standardised beta.
* $p < .05$

A hierarchical regression investigated which components of self-compassion were predictive of CE severity after controlling for eating disorder symptomology, diagnosis, anxiety and depression. None of the subscales were significant predictors of CE (see Table 3).

Table 3
Hierarchical Linear Regression Predicting Severity of CE from Predictor Variables; Eating Disorder Diagnosis, Symptomology, Anxiety, Depression and Self-compassion Subscales.

Variable		B	95% CI for B		β	R^2	ΔR^2
			LL	UL			
Step 1						.18	.18
	Constant	14.292	10.804	17.780			
	Eating disorder symptomology	.493	-.216	1.201	.061		
	Eating disorder diagnosis	.171	-.288	.630	.114		
Step 2						.76	.059*
	Constant	12.222	8.535	15.908			
	Eating disorder symptomology	1.054	.167	1.941	.244*		
	Eating disorder diagnosis	.127	-.327	.582	.046		
	Anxiety	.190	.040	.340	.260*		
	Depression	-.208	-.357	-.060	-.347*		
Step 3						.121	.044
	Constant	15.624	9.024	22.223			
	Eating disorder symptomology	.668	-.330	1.665	.155		
	Eating disorder diagnosis	.097	-.360	.555	.035		
	Anxiety	.167	-.003	.336	.228		
	Depression	-.187	-.339	-.035	-.311		
	Self-compassion subscales						
	Self-kindness	-.126	-1.519	1.267	-.024		
	Self-judgement	-1.420	-2.975	.136	-.216		
	Common humanity	-.763	-1.855	.329	-.155		
	Isolation	.270	-.836	1.376	.055		
	Mindfulness	.530	-.616	1.676	.109		
	Over-identification	.487	-.693	1.667	.097		

Note. CI = confidence interval; LL = lower limit, UL = upper limit; R2 = variance in CE severity explained by independent variables; ΔR^2 = the change in R^2 between models, β =

standardised beta.
* p <.05

Exploratory analyses

Exploratory analyses explored whether self-compassion predicted specific subcomponents of CE (Table 4). Lack of exercise enjoyment was significantly negatively predicted by self-compassion after controlling for eating disorder symptomology, diagnosis, anxiety and depression.

Table 4
Exploratory Analyses of Hierarchical Regressions for Self-Compassion Predicting CET Subscales Compassion after Controlling for Eating Disorder Symptoms, Diagnosis, Anxiety and Depression

CET subscale (DV)	ΔR^2	F for ΔR^2	B	β	t	*p*
Avoidance and rule-driven behaviour	.001	.163	-.103	-.038	-.404	.687
Weight control exercise	.008	1.272	-.202	.179	-1.128	.261
Mood improvement	.032	4.820	.529	.208	2.195	.105
Lack of exercise enjoyment	**.037**	**5.568**	**-.614**	**-.222**	**-2.360**	**.020**
Exercise rigidity	.003	.464	-.175	-.064	-.681	.497

Note. ΔR^2 = change in R2 from step 1 (ED symptoms, ED diagnosis, anxiety, depression) to step 2 (addition of total self-compassion). B = unstandardised regression coefficient, β = standardised regression coefficient. SC = self-compassion total score. Analyses were exploratory and uncorrected for multiple comparisons. Significant predictors are shown in bold, p <0.05.

Qualitative Findings

Fifty-five participants who scored above the clinical threshold for compulsive exercise provided qualitative responses. Table 5 shows a frequency analysis of exercise types reported. Table 6 shows quotes supporting the themes below and Figure 2 shows a thematic map.

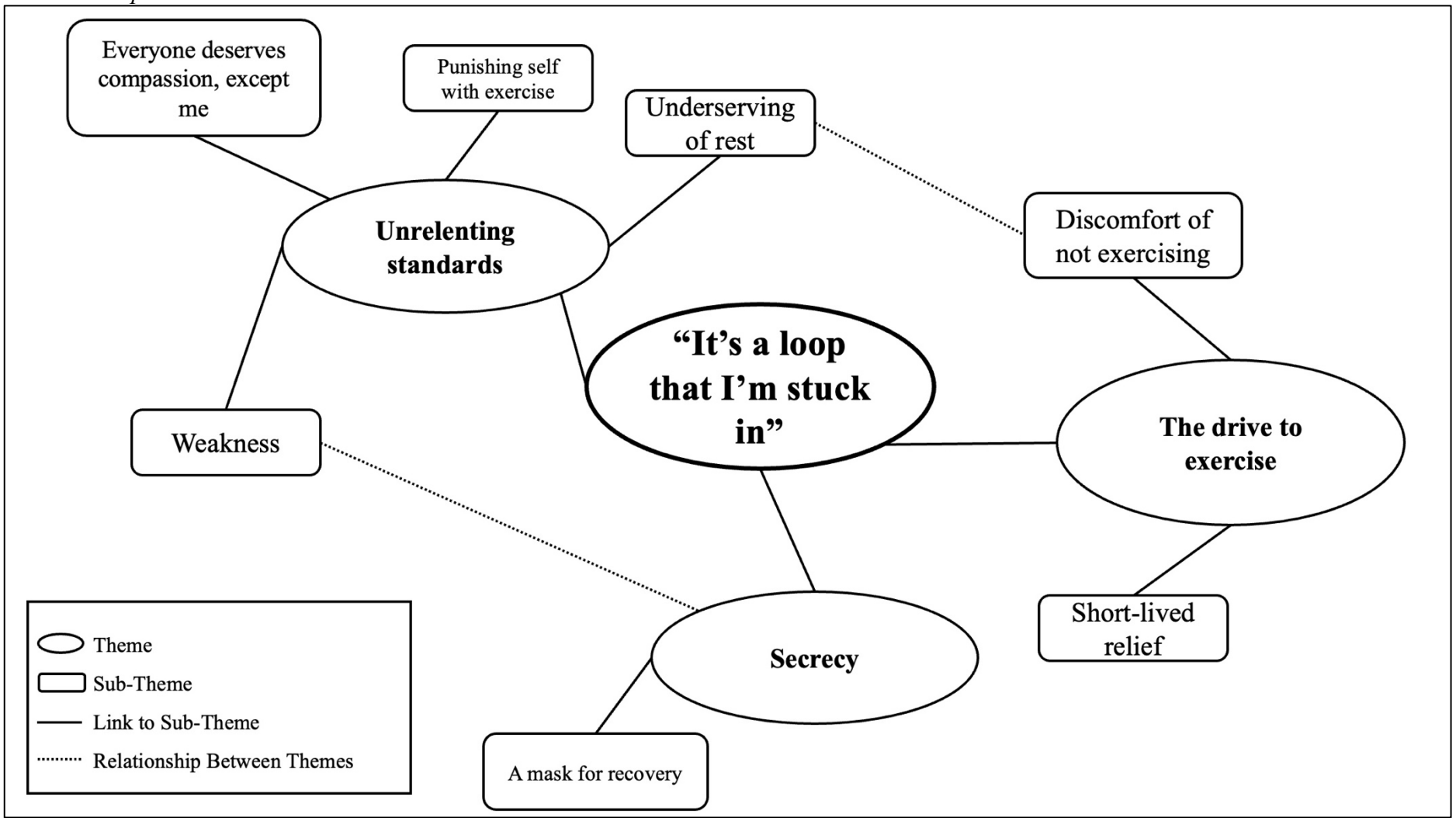
Table 5
Frequency analysis of a typical day's exercise

	Percentage reported
Pacing	7.27%
Walking	72.72%
Running	23.64%
Moving whilst working/doing other things	5.45%
Swimming	9.09%
Gym	12.73%
Gym cardio	29.09%

Gym weights	27.27%
Pilates/structured abdominal workout	12.73%
Online exercise videos	9.09%
Horse riding	3.64%
Competitive sport	7.27%
Group sport	12.73%

Figure 2

Thematic map



Overarching Theme: "It's a loop that I'm stuck in"

Participants shared their experiences feeling trapped in their CE and ED and that they felt unable to break the cycle. One participant shared that *"It's a loop that I am stuck in. It's thinking that its the only thing that can make you happy with yourself - an addiction." (P13)*

1. Theme: The drive to exercise

Different drivers to exercise were reported, summarised in the subthemes below.

1a. Subtheme: Discomfort of not exercising

Participants shared an intense discomfort when faced with the idea of not exercising, which increased negative thoughts about self and contributed to the maintenance of CE. Participants reported that the discomfort was experienced as an increase in weight and shape concerns and fear of food, for example one participant reported *"when I can't exercise, I feel like my thoughts around food get a lot worse and the thoughts about my self appearance get a lot worse, I feel more fat."* (P133), and another that *"whenever I think I can't go out I become literally terrified. my head loses it, and I start walking around in circles in my house. I become stressed and panicked and I feel that I'm being weak"* (P4).

1b. Subtheme: Short-lived relief

Participants reported that exercise brings *"relief from my mind"* (P178) and that the *"after feeling is the only sense of joy and satisfaction I get as now I have earned the right to eat a healthy amount of food"* (P125). However, this relief was often short-lived as they reported feeling *"never fully satisfied" and "like I could've always done more"* leading to *"stress sometimes and guilt for finishing the exercise"* (P133).

2. Theme: Unrelenting standards

Participants shared unrelenting standards that they felt compelled to live by, often expressed as something they have to do. For example, one participant shared that "*if it means pacing for hours that's what will have to happen"* (P123). Moreover, another participant

shared that they had to *"earn the right to eat"* (P125) through exercise. Participants also shared strong beliefs around failure; *"Any failure that I do, I beat myself up over it and think that it means the end of the world for me."* (P34).

2a. Subtheme: Weakness

When exploring self-compassion, many participants shared that this felt inaccessible and intolerable. For example, one participant described self-compassion as "*being weak. And not self-disciplined." It feels like letting myself get away with being lazy and weak and sad. And it feels pointless"* (P14).

2b. Subtheme: Undeserving of rest

Participants commonly reported feeling underserving or unworthy of things such as rest or compassion. For example, one participant shared *"I don't deserve to rest"* (P46).

2c. Subtheme: Punishing oneself

Participants reported that their exercise is "*painful tiring and punishing"* and that they had to exercise *"no matter what"* (P14).

2d. Subtheme: Everyone deserves compassion, except me

Participants shared that it was much easier to be compassionate towards others as opposed to themselves, for example one participant shared that *"I wish I held the compassion for me that I do for other people however all I tend to feel towards myself is negativity"* (P176).

3. Theme: Secrecy

Participants shared that they often exercised alone, secretively and that professionals weren't aware of their CE. For example, one participant shared that *"I've been with my care team for like 3 and a half years, since I was 13 and I've never been helped with my exercise so far, I also don't bring it up as I feel embarrassed for some reason.*" (P113). Participants often expressed that they exercised alone and in secret to avoid concern from others; *"I can't*

exercise when there's other people home because they'd be concerned about my ED getting worse so if they're at home I just feel trapped." (P133).

3a. Subtheme: Mask for recovery

Several participants reported the illusion created by CE, as it often leads to *"quieter ED thoughts".* Participants also reported that this seems to happen due to the social acceptability of exercise, particularly on social media as a "*socially acceptable way to be disordered and people seeing it don't realise and copy as it's marketed as recovery." (P*59).

Table 6

Example quotes thematic analysis

Theme	Sub-theme	Quotes
"It's a loop that I am stuck in"		*"I feel trapped in my ED and exercise addiction" (P301)* *"I feel a bit trapped" (P133)* *"When I can't exercise, it normally disrupts my day and I become fixated on how to burn calories and get rid of food if I have eaten" (P153)*
The drive to exercise	Discomfort of not exercising	*"When I cant exercise I feel like my thoughts around food get a lot worse and the thoughts about my self appearance get a lot worse, I feel more fat." (P133)* *"If I don't exercise I feel dirty and unworthy" (P282)* *"whenever I think I can't go out I become literally terrified. my head loses it, and I start walking around in circles in my house. I become stressed and panicked and I feel that I'm being weak because I just need to go out and do it. I climb my stairs over and over again (30-40 times) just to feel like I'm not wasted" (P4)* *"I feel like a slob, like I should be doing something or moving my body in some way." (P31)* *"I think if I was more compassionate towards myself then I wouldn't feel completely dependent on exercising. I think I would allow myself to be sick, to stay at home when it's raining and storming." (P4)* *"If unable to exercise then causes great levels of anxiety and negative self talk like not worthy or good enough so exercise to avoid these thoughts." (P239)* *"I feel overwhelmed with extreme guilt when I can't exercise, as it makes me feel like the calories are "sticking" to me" (P282)* *"I was previously in inpatient (I was discharged in Nov 2023) I wasn't allowed to exercise at all and it felt like torture, I still feel like that when I cant exercise at home" (P133)* *"I feel I can't have food until it's done." (P4)* *"I feel insanely guilty when I can't exercise, especially when it's out of my hands in situations like illness or bad weather." (P75)*
	Short-lived relief	"*I get relief from my mind" P178* *"I like how it makes me feel after, the after feeling is the only sense of joy and satisfaction I get as now I have earned the right to eat a healthy amount of food" P125* *"Even though it can make me better I feel like no matter how much exercise I do I'm never fully satisfied, I usually feel like I could've always done more and could've always burned more even if the exercise I had just done was a long one, I never feel satisfied which causes me stress sometimes and guilt for finishing the exercise." (P133)* *"Even when I exercise, it can feel like it's not enough." (P78)*

Theme	Sub-theme	Quotes
Unrelenting standards		"*now I have earned the right to eat a healthy amount of food" (P125)* "*I need control and if it means pacing for hours that's what will have to happen" (P123).* *"Any failure that I do, I beat myself up over it and think that it means the end of the world for me." (P34)* *"I am hard on myself and my mistakes" (P95)* *"By the time school ends I must have done 10000- 12000 steps or I will have to make it up later, even if I make it up later. I still feel the looming anxiety of not reaching my goal when I should have" (P125)* *"need to do this…the more steps I get the better I am… I am superior to others who don't exercise… if I don't exercise I will get skinny fat… exercise makes me gain muscles not fat" (P46)* *"for me, especially when it's bad, exercise is the key to everything. If I want a drink I have to do 40 star jumps while the kettle boils, if I don't fall asleep fast enough I have to do x amount before I can try again, if I get the bus and someone else walked I have to do twice the walk later." (P59)*
	Weakness	[Self-compassion means] "*being weak. And not self-disciplined." It feels like letting myself get away with being lazy and weak and sad. And it feels pointless" (P14)* *"I don't feel much self-compassion, it feels a bit like a waste of time when I could be improving myself instead" (P231)* *"I have no right to self pity. I should just get over it" (P73)* *"[self-compassion] Makes me feel lazy and uncomfortable" (P71)*
	Undeserving of rest	*"I don't deserve to rest I don't deserve to do anything I enjoy I don't deserve to eat" (P46)*
	Punishing oneself	*"I had to hit the numbers no matter what; it was painful tiring and punishing." (P14)* *"my compulsive exercise is like a form of self harm" (P24)* *"I feel I use exercise as punishment sometimes so maybe if I was more self-compassionate I would be less inclined to want to punish myself?" (P37)*
	Everyone deserves compassion, except me	*"If someone is self-compassionate about feeling too tired to exercise, maybe they won't feel guilty or anxious about not exercising. […] Also maybe people who are self compassionate are more accepting of their bodies, meaning they're less likely to exercise in order to change it." (P78)* *"I cant seem to apply compassion to myself but if someone were to tell me about a similar situation happening to them, I would be able to rationalise their thinking to them and tell them the compulsive exercise is completely ridiculous and unhealthy and they need to stop" (P127)* *"'I've always told people around me if they're having a hard time to be kind to themselves but I cant do it myself."(P133)*

Theme	Sub-theme	Quotes
		"I wish I held the compassion for me that I do for other people however all I tend to feel towards myself is negativity" (P176) *"I am trying to be better at self compassion and to treat myself like someone I love. But most days it's much easier said than done. I would never tell anyone else the things I tell myself, but I also can't not tell myself those things" (P72)*
Secrecy	Mask for recovery	*"I've been with my care team for like 3 and a half years, since I was 13 and I've never been helped with my exercise so far, I also don't bring it up as I feel embarrassed for some reason.*" (P113) *"I cant exercise when there's other people home because they'd be concerned about my ED getting worse so if they're at home I just feel trapped." (P133)* *"The influx of people starting out recovery by getting into the gym has been really difficult to watch as someone who's had an ED for 12yrs in and out of treatment because 90% of the time it's just a more socially acceptable way to be disordered and people seeing it don't realise and copy as it's marketed as recovery." (P59)* *"You may physically recover but you will still want to overexercise and then you back in the same boat as before" (P123)*

Discussion

Regarding the primary research question, no significant difference in self-compassion was found between young people with EDs who did and did not meet clinical levels of CE, after controlling for ED symptomology, diagnosis, anxiety and depression. This suggests that self-compassion alone may not differentiate between these groups. Self-compassion was low across the overall sample which is consistent with previous research and suggests it is a valuable target in ED interventions (29,44,65–67). Assumption testing revealed significant interactions between CE and covariates (anxiety and ED symptoms), suggesting these covariates play a greater role in those with higher CE.

For the secondary research question, the full model explained 8.1% of variance of CE severity. Self-compassion contributed minimally (0.4%) and non-significantly, suggesting it is not a strong predictor of CE severity. This contradicts previous findings that indicate a role of self-compassion in compulsive exercise in a non-clinical sample, where compulsive exercise significantly explained 1% of the variance in compulsive exercise (35). None of the subscales of self-compassion predicted compulsive exercise. Exploratory analyses showed that lower self-compassion significantly predicted less enjoyment in exercise (3.7%), indicating a possible role for self-compassion in specific aspects of CE. This supports existing research that also found lower self-compassion predicted less enjoyment in exercise in a nonclinical sample (35).

Regarding the third research question, thematic analysis revealed the overarching theme of “It’s a loop that I’m stuck in”, capturing the sense of entrapment participants felt in their CE. Participants described discomfort when they were not able to exercise and experienced short-lived relief after exercising. These findings align with the CBT model, where CE is used to manage negative emotions, in line with reinforcement theory (19). The theme of “Unrelenting standards” connects with Gilbert’s model, supporting the role of CE in

the threat system as a function of self-punishment or control in response to perceived failure. Themes of “Weakness” and “Everyone deserves compassion, except me” are consistent with previous research that shows individuals with ED fear self-compassion (67). The theme of “Secrecy” aligns with previous literature that shows CE is often overlooked by professionals, thus underscoring the importance for clinicians to assess the function of CE directly (8).

Overall, when integrating qualitative and quantitative findings, self-compassion did not predict CE severity, however participants with EDs and clinical levels of CE described several constructs related to self-compassion including “Unrelenting standards”, “Weakness”, “Underserving of rest”, “Punishing oneself” and “Everyone deserves compassion, except me”. These findings also support quantitative analyses that showed lower levels of self-compassion predict less exercise enjoyment, suggesting the relationship towards exercise and use of exercise as a punishment is important to consider. Therefore, self-compassion may be a meaningful therapeutic target when exploring relationships with exercise and understanding the interlinked overactive role of the threat and drive system in the context of an underdeveloped soothe system.

Several limitations must be acknowledged. Treatment history was not collected, so it is unclear whether participants had previously received interventions targeting CE or self-compassion which could have introduced bias into the data. The study did not control for common comorbidities such as OCD and relied on self-report for neurodevelopmental diagnoses, which may have led to confounding effects (68). Although ANCOVA assumptions violated the homogeneity of regression slopes, interaction terms were used to address this, however future studies could explore the moderation effects more directly. Despite these limitations, the mixed-methods design allowed for triangulation of data and rich exploration of the phenomenon. The findings of the primary research question were limited by the group size differences. Whilst the low CE group reported a mean score of 11.4 on the compulsive

exercise test compared to 18.3 within the high CE group, the low CE group was considerably smaller than the high CE group (28 compared to 118) and this may have limited the ability to detect meaningful difference of self-compassion between the two groups. Therefore, the absence of differences in self-compassion between the high and low CE group should be interpreted with caution. Future research would benefit from recruiting a larger and more balanced sample to enable more reliable group comparisons.

Given the discomfort associated with abstaining from exercise and secrecy of CE, clinicians should ensure direct assessment of CE and consider the role of high-standards, secrecy and motivations to exercise when formulating an individual's relationship to exercise. Meaningful therapeutic targets could include integration of CFT based activities around the importance of physical rest. Future research should adopt longitudinal or experimental designs to explore self-compassion and related constructs further in CE.

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Executive Summary

Background

Eating disorders such as Anorexia (AN), Bulimia Nervosa (BN) and atypical AN/BN are serious mental illnesses and involve weight and shape concerns, disordered eating and compensatory behaviours such as compulsive exercise. Compulsive exercise is rigid exercise that has a negative impact on mental and physical health. Compulsive exercise is associated with an increased risk of relapse but often treatments for eating disorders do not include components specific for compulsive exercise. Compulsive exercise is mostly understood through a cognitive behavioural framework that comprises weight and shape concerns, affect regulation, compulsivity, perfectionism and rigidity. Existing interventions for compulsive exercise show limited benefits.

Self-compassion is the ability to respond to personal suffering with kindness and mindfulness. Compassion focused therapy (CFT) was developed in line with an evolutionary neurobiological model of affect regulation and self-compassion.

Research has shown that people with eating disorders often have a lack of self-compassion and CFT interventions have been shown to be effective for this population. Some research has found that self-compassion may be protective against compulsive exercise, but this has not been explored in clinical eating disorder populations. Young people aged 16-25 are particularly vulnerable to eating disorders and compulsive exercise, yet are often neglected in the literature.

The present study aimed to explore the experience of, and understand the link between, self-compassion and compulsive exercise in young people with eating disorders.

Method

A mixed methods study was conducted using online questionnaires. Participants were 146 young people aged 16-25 with a diagnosis of either AN, BN or Atypical AN.

Questionnaires validated eating disorder diagnosis and captured eating disorder symptoms, compulsive exercise, self-compassion, anxiety and mood. Participants who scored above the clinical threshold for compulsive exercise were compared to those who scored below. Statistical analyses compared these two groups to see if they had a significant difference in self-compassion, after controlling for eating disorder diagnosis, eating disorder symptoms, anxiety and mood. Further analyses also explored if self-compassion predicted the severity of compulsive exercise across the whole sample. Young people who scored above the clinical threshold for compulsive exercise were invited to take part in qualitative questions that explored their experience of compulsive exercise and self-compassion further. Thematic analysis was implemented.

Main findings

Levels of self-compassion were low across the total sample and there were no significant differences in self-compassion between those who experience clinical levels of compulsive exercise and those who do not. Self-compassion was not a significant predictor of compulsive exercise severity after controlling for eating disorder symptoms, diagnosis, anxiety and mood. However, eating disorder diagnosis, symptoms, anxiety, mood and self-compassion overall were significant in predicting compulsive exercise severity. Anxiety was the strongest predictor of compulsive exercise severity.

Fifty-five participants took part in qualitative questions. Participants reported that their compulsive exercise felt like a loop they were stuck in, driven by high standards, punitive drivers to exercise and secrecy. Participants felt unable to allow themselves to rest and were not able to tolerate the discomfort of not exercising.

Conclusion

These findings suggest that self-compassion is not statistically significantly associated with compulsive exercise after controlling for eating disorder constructs. The findings highlight the role of anxiety in predicting severity of compulsive exercise. Qualitative findings align with aspects of the CBT in that cognitions interact with emotion regulation to maintain compulsive exercise. Aspects of self-compassion were present in qualitative findings such as not allowing oneself to rest, punishing oneself with exercise and having high standards. It is important that future research continues to explore the relationship between these constructs. Clinicians should directly assess and formulate compulsive exercise in eating disorder treatment to understand how self-compassion and anxiety may play a role for individuals.

Connecting Narrative

At first glance, my projects felt very distinct from each other. However, on reflection, they mirror the breadth of my journey on training. I have been privileged to work with people across the lifespan, considering attachment theory when working with mothers and babies in the perinatal period, to considering life review work with older adults on end-of-life care. In parallel, my research has reflected this, spanning development stages across the lifespan. My theory driven research project is focused on adolescents and young people, my service improvement project on adults, and my systematic review on caregivers for an older adult population.

My personal interest in compassion, mindfulness and acceptance guided my professional curiosity towards the exploration of the application of third wave cognitive behavioural therapies (CBT). Particularly their role in improving outcomes for people accessing mental health services in the NHS. My TDRP explored the novel consideration of self-compassion in compulsive exercise, a prevalent compensatory behaviour in eating disorders. My SRL explored the acceptability and feasibility of third-wave CBT such as acceptance and commitment therapy, compassion focused therapy and mindfulness based cognitive therapy. My SIP developed recommendations to improve the process of waiting for an autism assessment.

Systematic Review of the Literature

Before training, I had not anticipated carrying out research in older adults. However, my first placement in an older adult community mental health team led to me feeling struck by the psychological complexity and impact of later life depression, anxiety and caregiver burden, possessing me with a newfound desire to consider a project in this population. Identifying a research question for the SRL was challenging, especially when navigating the delicate balance between investigating a novel topic with enough papers to review. As I became immersed in the literature, I found I was able to integrate my interests of third-wave

CBTs and improving outcomes whilst contributing to a novel area. A colleague and I were involved in inter rater reliability of each other's projects (theirs also on acceptance and commitment therapy for a paediatric population).

Throughout the project I was struck by the lasting impact of being a caregiver for a person living with dementia and I will continue to hold in mind this impact when working systemically in my career.

Service Improvement Project

My service improvement project was developed with Northamptonshire Healthcare NHS Foundation Trust in an adult autism assessment service. In most of my professional work in my career thus far, I have been exposed to the challenge of waiting times and seen the impact of this for individuals, in particular those associated with neurodevelopmental assessment services. Even though the project was in adult services, it is a common dilemma I have faced in child and family services also.

I found aspects of this project challenging, as many service users were unhappy and impacted by how long they had to wait. The reality of NICE guidelines for timely assessments felt distant. The scale of the national problem felt overwhelming at times and I noticed a sense of imposter syndrome when carrying out the project; who was I to tell the service how to improve in the context of what has been described as a national epidemic? However, my commitment to representing the voices of service users and staff, helped to navigate this feeling and develop recommendations for meaningful change.

Theory Driven Research Project

My interest in my TDRP topic grew out of my pre-training experience as an assistant psychologist in inpatient child and adolescent eating disorder services. I was involved in the development of a randomised controlled trial investigating the effectiveness of CBT for

compulsive exercise. Delivering the intervention and seeing the importance of a specialist programme for young people struggling with their relationship with exercise stayed with me.

I enjoyed the process of integrating quantitative and qualitative methods during the design and analysis stages, allowing me to explore lived experience alongside the statistical analysis. Initially the project was much more ambitious, recruiting only through specialist CAMHS and recruiting young people under 16. Over time the scope of the project was made more feasible, a pragmatic decision to support recruitment and time constraints. Gaining sponsorship and ethics proved challenging and lengthy. I am glad we included recruitment from social media as it appeared there were lots of people experiencing compulsive exercise keen to take part in research. Whilst conducting the project, professionals from services across the United Kingdom reached out to me with interest in the project and were keen to see a published report. This further confirmed the importance of research in this area, as exercise is not commonly integrated within eating disorder treatments.

Summary

Overall, the participants in all projects inspired me throughout training and helped me to remember why I decided to pursue a career in clinical psychology in the first place. I have always wanted to give back to the NHS by contributing to psychological knowledge and I am grateful to all the participants and service-users that I have been lucky enough to meet in my training. Post-qualification I hope to continue to develop as a scientist-practitioner, embedding evidence-based practice into my role as an active researcher and clinical psychologist. I am also keen to continue to utilise qualitative methods to ensure the lived experience of individuals is captured in research.

Acknowledgments

I would like to thank everybody who participated in my research and to the experts by experience for consulting and assisting with the design of the projects. It was a privilege to work alongside you and represent your voice.

I would like to thank my research supervisors for their advice and encouragement. Thank you to my course tutor, Libby, for supporting me across the whole three years and for being so compassionate and kind to me.

To Abi, Amber, Fran and Rachel, I am so proud of us for getting through this and I could not have done this journey without you. Thank you especially to Rach for your assistance with the SRL, I loved our cosy study days with Poppy and Lola. To Medha, thank you for being an unwavering constant. Your compassion and the way you've always shown up for me, whether I needed to rant, cry or yap has meant so much to me. To my family who have supported me throughout my career. Thank you for all the facetimes that kept me going!

To Pete, I am so grateful for you. Thank you for all the cups of tea, for always making me smile and all the encouragement over my career so far. You've been by my side through it all. And of course, thank you to Lola who joined us halfway through but who I could not have completed the course without. Lastly, thank you Grandad who I know is smiling down on us, with the knowledge that your car got me through the lengthy commutes and that I've completed a doctorate.

Appendices

Appendix A SRL Search Terms

Medline (Ovid MEDLINE® Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE®) 1946 to present

1	Dementia/	67763
2	dementia.ab,kf,ti.	162060
3	Alzheimer Disease/	133701
4	"Alzheimer*".ab,kf,ti.	218304
5	1 or 2 or 3 or	4337298
6	Caregivers/	57660
7	("informal caregiver*" or caregiver* or "family car").ab,kf,ti.	110625
8	(acceptance and commitment therapy).ab,kf,ti.	2311
9	compassion focused therapy.ab,kf,ti.	204
10	Dialectical Behavior Therapy/	381
11	dialectical behavio?r therapy.ab,kf,ti.	1226
12	mindfulness-based cognitive therapy.ab,kf,ti.	981
13	6 or 7	127152
14	8 or 9 or 10 or 11 or 12	4615
15	5 and 13 and 14	49

Appendix B SRL Journal Guidelines

Your article must be within the scope of the journal and be of sufficient quality. If not, it will not be reviewed. Please read the journal's Aims and Scope to see if your article is appropriate.

The manuscript must be your original work, you must have the rights to the work, and you must have obtained and be able to supply all necessary permissions for the reproduction of any copyright works not owned by you, including figures, illustrations, tables, lengthy quotations, or other material previously published elsewhere.

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Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Clinical trial registration

The journal conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first participant enrollment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

Reporting guidelines

Your manuscript **must** follow the relevant EQUATOR Network reporting guidelines, depending on the type of study. The EQUATOR wizard can help identify the appropriate guideline. You will need to upload the appropriate checklist with your submission.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

If your research involves animals, you will be asked to confirm that you have carefully read and adhered to the ARRIVE guidelines.

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Abstract

Please include an unstructured abstract of 300 words between the title and main body of your manuscript that concisely states the purpose of the research, major findings, and conclusions. If your research includes clinical trials, the trial registry name and URL, and registration number must be included at the end of the abstract. Submissions that do not meet this requirement will not be considered.

For clinical trials, the trial registry name and URL, and registration number must be included at the end of the abstract.

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- Acknowledgments section
- Declaration of conflicting interest
- Funding statement
- Ethical approval and informed consent statements
- Data availability statement
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Acknowledgments

If you are including an Acknowledgements section, this will be published at the end of your article. The Acknowledgments section should include all contributors who do not meet the criteria for authorship. Per ICMJE recommendations, it is best practice to obtain consent from non-author contributors who you are acknowledging in your manuscript.

Writing assistance and third party submissions: if you have received any writing or editing assistance from a third-party, for example a specialist communications company, this must be clearly stated in the Acknowledgements section and in the covering letter. Please see the Sage Author Gateway for what information to include in your Acknowledgements section. If your submission is being made on your behalf by someone who is not listed as an author, for example the third-party who provided writing/editing assistance, you must state this in the Acknowledgements and also in your covering letter. **Please note that the journal editor reserves the right to not consider submissions made by a third party rather than by the author/s themselves.**

Statements and declarations

To ensure proper anonymization, please include a section with the heading 'Statements and Declarations' on your title page, after the Acknowledgements section [and Author

Contributions section if applicable] including each of the sub-headings listed below. If a declaration is not applicable to your submission, you must still include the heading and state 'Not applicable' underneath. Please note that you may be asked to justify why a declaration was not applicable to your submission by the Editorial Office. This information will be added to the end of your published paper.

Ethical considerations

Please include your ethics approval statements under this heading, even if you have already included ethics approval information in your methods section. If ethical approval was not required, you need to explicitly state this. You can find information on what to say in your ethical statements as well as example statements on our Publication ethics and research integrity policies page.

All papers reporting studies involving human participants, human data or human tissue must state that the relevant Ethics Committee or Institutional Review Board approved the study, or waived the requirement for approval, providing the full name and institution of the review committee in addition to the approval number. If applicable, please also include this information in the Methods section of your manuscript.

Consent to participate

Please include any participant consent information under this heading and state whether informed consent to participate was written or verbal. If the requirement for informed consent to participate has been waived by the relevant Ethics Committee or Institutional Review Board (i.e. where it has been deemed that consent would be impossible or impracticable to obtain), please state this. If this is not applicable to your manuscript, please state 'Not applicable' in this section. More information and example statements can be found on our Publication ethics and research integrity policies page.

Consent for publication

Submissions containing any data from an individual person (including individual details, images or videos) must include a statement confirming that informed consent for publication was provided by the participant(s) or a legally authorized representative. Non-essential identifying details should be omitted. Please do not submit the participant's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent to publish but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file in addition to the statement confirming that consent to publish was obtained within the manuscript text. If this is not applicable to your manuscript, please state 'Not applicable' in this section.

Declaration of conflicting interest

The journal requires a declaration of conflicting interests from all authors so that a statement can be included in your article. For guidance on conflict of interest statements, see our policy on conflicting interest declarations and the ICMJE recommendations.

If no conflict exists, your statement should read: 'The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article'.

Funding statement

All articles need to include a funding statement, under a separate heading, **even if you did not receive funding**. You'll find guidance and examples on our Funding page.

Data availability

The Journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the Sage Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- Share your research data in a relevant public data repository
- Include a data availability statement linking to your data. If it is not possible to share your data, use the statement to confirm why it cannot be shared.
- Cite this data in your research

Reference style and citations

The journal follows the APA reference style. View the APA guidelines to ensure your manuscript conforms.

Every in-text citation must have a corresponding citation in the reference list and vice versa. Corresponding citations must have identical spelling and year.

Authors should update any references to preprints when a peer reviewed version is made available, to cite the published research. Citations to preprints are otherwise discouraged.

Supplemental material

This Journal can host additional materials online (e.g. datasets, podcasts, videos, images etc.) alongside the full text of the article. Your supplemental material must be one of our accepted file types. For that list and more information please refer to our guidelines on submitting supplemental files.

English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using Sage Author Services. Visit Sage Author Services for further information.

Appendix C SIP Trust approval

Specific Concerns METHODOLOGY & ETHICS If in your judgement you have specific issues that you wish to draw to the attention of the investigators please detail these below or attach details.	Do these issues/concerns indicate that the investigation should not proceed? YES ☐	NO ☒
The questions as they are phrased in the draft are very broad. We appreciate they will be worked on in phrase 1. Consider adding prompt questions, such as explaining what 'signposting' is and wording the questions specifically, for example: what has your experience of being on the ASD waiting list been like? Suggest ensuring a certain percentage of women in the sample of participants? (control for if women are more forthcoming with taking part in research compared to men and also women being recognised for ASD screening compared to men). Cut off of 100 participants – less than 100 is acceptable for thematic analysis. Ethical considerations; have the participants given consent to be contacted for research purposes? And how are you gaining consent from the participants to take part in the research?		

	Yes	No	Un-clear	N/A
B) RELEVANCE, IMPACT & IMPORTANCE				
Relevance				
• Does the investigation address issues of relevance to local/national NHS needs and priorities?	☒	☐	☐	☐
Impact and importance				
• Are the expected values and benefits of the investigation made clear?	☒	☐	☐	☐
• Will the investigation add to current knowledge or have training value?	☒	☐	☐	☐
• Can the investigation be generalised? i.e. has potential application beyond NHfT?	☒	☐	☐	☐
Dissemination				
• Does the applicant intend to disseminate the findings?	☒	☐	☐	☐
• Will the results of the investigation be made available to the participants?	☐	☐	☒	☐

Specific Concerns IMPACT If in your judgement you have specific issues that you wish to draw to the attention of the investigators and/or the Research Office, please detail these below	Do these issues/concerns indicate that the investigation should not proceed? YES ☐	NO ☒

	Yes	No	Un-clear	N/A
C) FEASIBILITY & RESOURCE UTILISATION				
Feasibility				
• Is the investigation feasible within the local context i.e. the service?	☒	☐	☐	☐
• Is the investigation feasible within the timeframe and resources proposed?	☒	☐	☐	☐
Resource utilisation				
• Does the Trust/Directorate have the capacity to support the investigation at this time?	☒	☐	☐	☐
• Are the resource implications to the Directorate reasonable and acceptable?	☒	☐	☐	☐
• Have appropriate support departments been notified/ agreed to support this investigation?	☐	☐	☒	☐

Specific Concerns FEASIBILITY & RESOURCES If in your judgement you have specific issues that you wish to draw to the attention of the investigators and/or the Research Office, please detail these below	Do these issues/concerns indicate that the investigation should not proceed?	
	YES ☐	NO ☒
How are the questionnaires being administered (post or online)? If by post, consider cost implications (eg including stamped addressed envelopes)		

	Yes	No	Un-clear	N/A
D) APPLICANT & SUPERVISOR				
• Does the applicant have (or have access to supervision) the necessary experience and expertise to undertake the investigation?	☒	☐	☐	☐
• Does the applicant have the necessary time and resources to undertake the investigation?	☒	☐	☐	☐
• Where relevant, has a multidisciplinary and multi-professional approach to addressing the investigation's question been adopted?	☒	☐	☐	☐

Specific Concerns APPLICANT & SUPERVISOR If in your judgement you have specific issues that you wish to draw to the attention of the investigators and/or the Research Office, please detail these below	Do these issues/concerns indicate that the investigation should not proceed?	
	YES ☐	NO ☒

Comments
Please provide comments you may wish to make on the proposal, particularly any suggestions as to detailed amendments that should be included in any resubmission. Your comments will be used to provide feedback to the principle investigator.

Reviewer Recommendation:

Approve: ☒ Approve with amendments described above: ☐ Resubmit after amendment as described above: ☐ Reject: ☐

Signature: **Anna Rickard and Alice Leeson**

Date: **10th January 2024**

Appendix D SIP Community involvement statement

Table 5 presents changes recommended by PPI as well as the actions done in response to this. The experts by experience were a part of the service's LEAP (Lived Experience Advisory Panel) and were autistic adults.

Table 5

Changes implemented following PPI involvement

Feedback from PPI	Actions done
Question 7 What happens when someone duplicates another person's non-identifiable code?	If there are duplicates of any ID codes, then the researcher will match these based on the time completed (as both information sheet and survey have to be completed together at the same time).
Question 8 As the diagnostic pathway is for all cultures, should 'name and surname' be rephrased as 'first name and last name / surname / family name'?	Yes, these have been changed to reflect that the diagnostic pathway is for all cultures.
Question 3 Is the last option (currently blank) supposed to state 'Other – please state'? I would identify as female or trans-female. I think trans-female and trans-male should also be options in order to collect data and assess any correlation between transgender and autism.	Yes this has been changed to reflect this.
Question 4 'Up to one year': Do all initial diagnostic screening appointments take place within 1 year since referral? 'Main assessment appointment': Just a query. How much notice is provided for the appointment – several weeks or months?	Nothing needs to be changed here as only people who fall within these groups will be contacted. Several weeks are provided as notice.
Question 5 Perhaps offer a few examples? My answer as an autistic person might simply be "it was a very long wait, so I became very anxious".	The question has been changed from: "What has your experience of being on the Autism waiting list been like?" to: "What has your experience of being on the Autism waiting list been like? Examples of this could include talking about how being

	on the waiting list has made you feel or things that you disliked or liked about this process. “ I have not given specific examples like the one suggested to avoid leading examples. This is interesting to note – I’m not sure who the question is directed at but potentially highlights that people are not sure of where to get support whilst waiting?
Question 7 For my own knowledge. While a person is waiting for an appointment, where could they go to seek more support?	
Question 8 For my own knowledge. While a person is waiting for an appointment: • for what type of reasons could the person want to be signposted? Are some examples for increased anxiety or wanting reasonable adjustments in work or education? • what organisations could the person be signposted to?	As above.
Question 9 ‘Resources’ is a general term, so some autistic persons might not be able to think what type of resources may be, or may have been, useful to them. Perhaps offer some examples?	Agree, question has been changed to support understanding. Question changed from: “Would you have liked to be offered any resources in the waiting period? If so, what?” To “Resources are things that provide further information about something. These could be leaflets, books, videos, apps etc. Would you have liked to be offered any resources in the waiting period? If so, what?”
Question 10 Is a preferred method of communication offered? Some young autistic people do not like using a telephone. Email is often not a method used by the NHS due to security and GDPR reasons.	Question changed from “How did you find the communication from the team from the point of being referred to now?” To “Communication is any contact you had with the team from being referred to being discharged. For different services this could be in the form of things like letters, phone calls or emails. Different services have different ways of communicating due to security reasons. How did you find the communication from the team from the point of being referred to now?”

Poster The attachment to your email was named 'SIP Poster'. What does the 'I' stand for, as the poster heading is 'Service Evaluation Project'?	The I stands for improvement, as this is a service improvement project as it hopes to provide recommendations for the service to improve following the service evaluation. However, for the purposes of recruitment the project has been entitled 'service evaluation project' on the flyer currently.
4th paragraph "… assessment which hope to …". This does not sound grammatically correct to me.	Changed from: "The survey asks you some questions about your experience of waiting for an ASD assessment which hope to help improve the experience of waiting for an assessment." To: "The survey asks you some questions about your experience of waiting for an ASD assessment. We hope to use the findings of this project to help improve the experience of waiting for an assessment."

Appendix E SIP Information sheets

Information sheet for service users

How long do I have to complete this survey?

This survey link is open until Monday 26th August. Please complete this survey, if you would like to do so, before then. You do not have to take part, it is entirely up to you and deciding not to take part will have no impact on your care received.

What is this project about?

You have been invited to take part in a service evaluation project that is aiming to improve the experience of adults waiting for an autism assessment.

We are mindful you may still be waiting or have been waiting for a period of time, if this applies to you, you are still on the waiting list and you will be contacted as soon as you reach the top of the list.

The is a service evaluation project that aims to explore the experiences of individuals on the waiting list for an autism spectrum disorder (ASD) diagnostic assessment and their needs.

What are we aiming to achieve?

We hope that asking service users about their experiences will help us to understand these service users better and to direct future research and service provision.

Our waiting list times have increased, like many similar services nationwide. We would like to understand more about the needs of those people on the waiting list and how we can better meet these.

What do I have to do to take part in this survey and is it anonymous?

We would like you to fill in a questionnaire for us. This survey is anonymous, but there is a unique identifier that will be attached to your responses. This means that if you wish to withdraw your responses, or if we are concerned about yours or somebody else's safety then we can use this to identify you.

You will be asked to create your own anonymous unique identifier, please keep a record of this so that when you fill in our questionnaire you can enter this.

Once the data has been analysed, we will not be able to identify you so that the results remain anonymous and you can no longer withdraw at this point. The results will be used to consider the best steps forward as a service. The results could also be used in a published report. No identifiable data will be included.

What do I do if I have questions or need more support?

If you have any further questions specifically about the project please contact the researchers robyn.price@nhft.nhs.uk. Please note the researchers will not be able to answer any questions about your clinical care, please do not direct questions about your care to the researchers.

This questionnaire is about understanding the experience of being on the waiting list and what the service could do to support people in this time. We are not asking directly about any specific difficulties you have or other mental health conditions. Please contact your GP or the mental health crisis number for Northamptonshire if you require support for your mental health, as we are not able to support you with this following the survey.

The Mental Health Number: https://www.nhft.nhs.uk/mentalhealth-number/
For local support and services give one of our mental health navigators a call, anytime of the day or night.
0800 448 0828 - Lines available 24 hours a day, seven days a week

Information sheet for staff

You have been invited to take part in a service evaluation project that is aiming to improve the experience of adults waiting for an autism assessment.

Information about the study

The project aims to explore the experiences of individuals on the waiting list for an autism spectrum disorder diagnostic assessment and their needs.

We have asked service users to complete questionnaires. We hope that by asking clients about their experiences will help us to understand these clients better and to direct future research and service provision.

We are also planning to conduct focus groups with staff members who work on the ASD pathway. We would like to hear about your thoughts on the pathway and how to continue to meet the needs of the people waiting for an assessment in the context of growing demands and pressures.

These focus groups will be completed with a Trainee Clinical Psychologist who is external to the service. The focus groups will be recorded and transcribed in order to allow us to capture the richness of themes from the discussion. The recordings will be deleted as soon as the transcription is complete.

The transcription will not be saved along with any identifiable data. Any quotes shared in the write up will be anonymised.

The findings of the evaluation will then be written up as a service improvement project, with the potential for publication, so that they can be shared with a wider audience.

The focus groups will be conducted on Microsoft Teams. There are two slots for the focus groups:

You will be asked to indicate which one you can attend below. If you are unable to make these slots but would like to take part, please indicate this in the form below and the research will arrange another time to meet with you.

If you have any questions about the project, please contact the researcher:

Appendix F SIP Online questionnaires

1. Please indicate your age below in years.
2. Please indicate your gender identity

    Male
    Female
    Non-binary
    Trans-female
    Trans-male
    Prefer not to say
3. We are asking people at different points on their diagnosis journey. Please indicate which group you fall into below.

    I have had my initial screening appointment, and I have been waiting under a year since referral.
    I have had my initial screening appointment, and I have been waiting over a year since referral.
    I have recently received my main assessment appointment.
    It has been less than three months since I had my main assessment appointment.
4. What has your experience of being on the Autism waiting list been like? Examples of this could include talking about how being on the waiting list has made you feel or things that you disliked or liked about this process.
5. While you were waiting have you been offered any support from the team or from another third party service. If so, please describe this and whether you found this helpful.
6. While you were/have been waiting are/were you aware of where you could go to seek more support related to your assessment for Autism?

We would like to understand more about what is helpful currently, and what could be helpful as part of waiting for an autism assessment.

7. Signposting is where the team may have told you about places you can get support whilst you have been waiting for an assessment. Please indicate below if you think you would have benefited from any signposting? If so, what for/where to? If not, can you tell us why not.

8. Resources are things that provided further information about something. These could be leaflets, books, videos, apps etc. Would you have liked to be offered any resources in the waiting period? If so, what?
9. Communication is any contact ou had with the team from being referred to being discharged. For different services this could be in the form of things like letters, phone calls or emails. Different services have different ways of communicating due to security reasons. How did you find the communication from the team from the point of being referred to now?
10. Do you think there is anything else that would be helpful for people on the waiting list for an autism assessment?
11. Do you have any additional comments or suggestions for the team?

End of survey.

Appendix G SIP Interview/focus group schedules

Introductions

Thank you for making the time to join today.

This project is exploring the experiences of those on the waiting list, from both staff and service users and developing some recommendations based on the findings from the project.

There's no right or wrong, if you're not sure how to answer a question or don't want to, that's fine.

I'm an external member of the team and the space is confidential and anonymous, I'm recording it so that I can type up what we have spoken about and I might use quotes in the right up of the project, but these will be anonymous and won't be linked to any identifiable information.

Initial Questions

1. What is your role?
2. How are you involved in the pathway, which aspects do you support with?
3. How long have you worked in the service?

Key questions:

1. Based on your experiences what do you think are the challenges that present to the service currently?
2. What is your experience communicating with other professionals and how effective this communication is?
    a. *Follow up prompt:* For example, GPs, community mental health teams etc
3. What is your experience of supporting people on the autism waiting list?
4. Based on your experience (whether that's supporting people in the assessment or post-diagnostic pathway), what sense do you make of the experience of adults seeking a diagnosis of Autism whilst on the waiting list?
    a. *Follow up prompt:* has this changed over time? Have referrals changed?
5. Do you get a sense of what support people currently find helpful whilst they are waiting for an autism assessment?
    a. *Follow up prompt:* what things do the team do well in your opinion in supporting these people?
    b. *Follow up prompt:* What support do you think that people find helpful post-diagnosis?

6. Do you get a sense of what support people might need, that they currently do not have, whilst waiting for an autism assessment?
7. Based on your experiences, what might be useful to consider going forward when supporting adults waiting for an autism assessment, how do you think the system work in a different way to meet the needs of this group?
    a. *Follow up prompt:* Do you have a sense of resources that could be helpful for people waiting for an autism assessment?
    b. *Follow up prompt:* Do you think there is anything else that would be helpful for people on the waiting list for an autism assessment?

Closing:

1. Any issues we haven't covered which you think is important?
2. Any questions?

Appendix H SIP Journal Guidelines

Journal of Autism and Developmental Disorders

Submission guidelines

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.

APA Style

APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth).

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

*JADD is no longer accepting manuscripts with only one participant or group studies without an appropriate comparison group.

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report: A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. Must meet the demands of scientific rigor required of a JADD article but can be preliminary findings.
- A Letter to the Editor/Commentary is 6 or less double spaced pages with shorter references, tables and figures.

Style sheet for Letter to the Editor:

- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth):-

- 6 or less double spaced pages with shorter references, tables and figures
- Line 1: "Letter to the Editor"
- Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages:
    - Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.
    - Anonymized Abstract, manuscripts and References without contact information
    - Appendix
    - Figure Caption Sheet
    - Figures
    - Tables
2. JADD submissions should include:
    - A structured abstract with the Purpose, Methods, Results, and Conclusion.

- COI and other author statements placed on the title page.
- No more than 40 double-spaced pages, including double-spaced references (with hanging indents), tables, and figures.
- Tables and Figures placed at the end of the manuscript with callouts in the text.

3. JADD Checklist

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink "Submit manuscript" and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Suggestions for Inclusive Language in JADD Submissions

JADD Inclusive Language Guide (Download pdf, 134 kB)

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.
For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.
Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript. The use of an LLM (or other AI-tool) for "AI assisted copy editing" purposes does not need to be declared. In this context, we define the term "AI assisted copy editing" as AI-assisted improvements to human-generated texts for readability and style, and to ensure that the texts are free of errors in grammar, spelling, punctuation and tone. These AI-assisted improvements may include wording and formatting changes to the texts, but do not include generative editorial work and autonomous content creation. In all cases, there must be human accountability for the final version of the text and agreement from the authors that the edits reflect their original work.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials

- Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never

include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.:Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185

- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435

- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.

- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.

- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

Tables

- All tables are to be numbered using Arabic numerals.

- Tables should always be cited in text in consecutive numerical order.

- For each table, please supply a table caption (title) explaining the components of the table.

- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Appendix I SIP Lay summary

Autism is a neurodevelopmental condition. Services that assess adults to see if they have a diagnosis of autism are facing increased pressure because more adults are being referred. This project aimed to explore what recommendations could be made to improve the experience of waiting for an assessment with a service that assesses adults in Northampton. This service has seen a big rise in referrals. The project used surveys with people waiting for an assessment and interviews with staff members to identify recommendations. The results of the study showed that waiting for an assessment is associated with uncertainty and loneliness, and that staff want to help but feel powerless to do so. Therefore, recommendations were made to support people waiting for an assessment and staff working in the service.

Appendix J TDRP Ethics and sponsorship

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Natasha Cogings
Oxford Institute of Clinical Psychology Training & Research
ISIS Education Centre, Warneford Hospital
Headington, Oxfordshire
OX3 7JX

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

18 November 2024

Dear Miss Cogings

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

Study title:	**Exploring Self-Compassion in Compulsive Exercise in Young People with Eating Disorders**
IRAS project ID:	**338717**
Protocol number:	**18470**
REC reference:	**24/LO/0833**
Sponsor	**Oxford Health NHS Foundation Trust**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

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

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **338717**. Please quote this on all correspondence.

Yours sincerely,



Danielle Bromage
Approvals Specialist
Email: approvals@hra.nhs.uk

Copy to: *Ms Natalia JastrzÄ™bska, Research and Development department, Oxford Health NHS Foundation Trust*

Oxford Health
NHS Foundation Trust

Professor Vanessa Raymont
Research & Development Director
Warneford Hospital
Warneford Lane
Oxford
OX3 7JX
Email: research@oxfordhealth.nhs.uk

13/12/2024

Confirmation of Capacity and Capability

Re: Exploring Self-Compassion in Compulsive Exercise in Young People with Eating Disorders
Research and Development Reference: 18470
IRAS Reference: 338717
Research Ethics Committee Reference: 24/LO/0833
Sponsor: Oxford Health NHS Foundation Trust

Dear Dr Joanna Adams,

On behalf of Oxford Health NHS Foundation Trust, I am pleased to confirm Trust Capacity and Capability for the above research as outlined in the application received.

The study is not supported by a Research Delivery Team.

The study team members are as follows: Sonia Bues.

Approved Documents

Protocol Version 2 dated 26/09/2024 is recognised as the most current to date.

The documents approved for use at this Trust are as listed in the following approval documents:
Health Research Authority Letter dated: 18/11/2024
Research Ethics Full Approval Letter dated: 18/11/2024

Any subsequent, relevant amendments are additionally included to date.

Metrics and Recruitment

First participant target date: 21/12/2024
Recruitment target figure: 128
Recruitment target date: 01/05/2025
Anticipated study end date: 01/05/2025

To comply with national research performance requirements the Trust will monitor and publish recruitment for your study:
1. Performance of the recruitment of the first participant.
2. Recruiting planned participants to time and target.

NHS
Oxford Health
NHS Foundation Trust

Reporting recruitment via Siteline

As confirmed during the study set-up study accruals will be recorded via Siteline. It was agreed that **Natasha Cogings** will update the records at least once a month and no later than 7th of each month (e.g. by 7th August upload accruals for July etc.)

Should you feel at any time that you will be unable to realistically achieve your contracted recruitment target, please get in touch with the Research Team on research@oxfordhealth.nhs.uk as soon as possible.

Conditions of Approval

The following conditions apply to this approval:

a) The study is conducted in compliance with all the relevant legislation and the relevant OHFT policies.
b) All staff working on the study have the appropriate training and experience and have responsibilities formally delegated to them.
c) Should you plan to leave your position in OHFT, you will notify RD immediately of your plans, to enable discussions around the future of study conduct.
d) The Trust expects the named Principal Investigator to allocate regular support time to the study; this must be agreed with the research team prior to the study commencing. This may be reviewed by RD at any time.
e) All relevant documents will be maintained and will be sent to research@oxfordhealth.nhs.uk, to facilitate compliance checks, formal audits and regulatory inspections.
f) You will notify RD via the email above of any amendments.
g) You will promptly inform RD via the email above of progress and safety reports as well as the end of the study. For more detail, please refer to: Managing your approval - Health Research Authority (hra.nhs.uk).
h) You will respond in timely manner to RD periodic checks email.

I wish you every success with the study.

Yours sincerely,



Professor Vanessa Raymont
Director of Research Development

Appendix K TDRP PPI involvement

Experts by Experience who were young people with lived experience of mental health and/or eating disorders from Article 12 and the McPin Foundation were consulted as part of the design of the study. Article 12 is a youth forum where young people have the right to express their views, feelings and wishes in all matters affecting them. The McPin Foundation exists to transform mental health research by putting the lived experience of people affected by mental health issues at its heart, the Young People's Network as part of the McPin Foundation is made up of young people who are interested in being involved in mental health research.

The young people consulted on design of the project, including materials relating to the study (information sheet, consent form, online format and measures used in the study comprising questionnaires and interview schedule). Four young people reviewed the study materials and gave feedback. Some aspects of the materials were adapted, such as language used in the qualitative questions to make this more accessible. Language used to describe compulsive exercise on Participant Information Sheets was also adapted slightly to ensure it was understandable for young people and clear that not all young people with eating disorders experience compulsive exercise. Generally young people felt that the study materials made sense and the questions were not upsetting. Service users were reimbursed for their time.

Appendix L TDRP Open ended free text questions

Individuals who scored above the clinical cut off score for compulsive exercise were invited to complete these further optional qualitative questions about compulsive exercise and self-compassion. The questions were developed and created with young people with lived experience of eating disorders and derived from gaps in the literature. These were free text questions where participants could write up to 1000 characters for each question. See Appendix for the questions.

1. What kind of exercise do you do on a typical day?
2. What thoughts or feelings do you have about exercise?
3. What thoughts or feelings do you have when you are not able to exercise?
4. *Compulsive exercise happens when a person feels like they need to exercise too much, which can have a negative impact on their psychological or physical health. People who experience compulsive exercise might find it difficult if they are not able to do exercise.* What do you think compulsive exercise means to you?
5. What do you see as the positive things that you get from exercise?
6. What are some of the negative things about your exercise?
7. *Self-compassion means being warm, gentle and understanding to ourselves if we are struggling, rather than being mean to ourselves*. When you read this definition, what does this mean to you? Is this something you relate to?
8. Do you think self-compassion could be related to somebody's relationship with exercise?
9. What do you think would be, or has been, helpful to think about or consider in somebody's recovery from an eating disorder with regard to their relationship with exercise? Is there anything you have found helpful from other people?

Appendix M TDRP Statistical test assumptions

ANCOVA assumption testing:

Standardised residuals for the two groups were normally distributed, as assessed by Shapiro-Wilk's test (p >.05). There was homoscedasticity, as assessed by visual inspection of the standardised residuals plotted against the predicted values. There was homogeneity of variances, assessed by Levene's test of homogeneity of variance (p =.173). There were no outliers in the data, as assessed by no cases with standardised residuals greater than ± 3 standard deviations. Tests for homogeneity regression slows revealed that that there were significant interaction terms between the IV (CET group) and the covariates; anxiety and eating disorder symptomology, suggesting that the relationship between the covariates and the dependent variable differed across groups. To account for this, the interaction terms were included in the model to ensure that the model allowed for differing slopes between the covariates and the DV across the levels of the IV. All assumptions for ANCOVA were met, however the covariates of anxiety and eating disorder symptomology were interacting significantly with the independent variable suggesting that there was a violation of homogeneity of regression slopes (see Figure 3 and 4). Therefore, the interaction terms for these covariates were included in the model as the relationship between the covariate and the DV (self-compassion) was different across the two groups of high and low compulsive exercise. These interaction terms were both significant in the model, for anxiety and group, $F(2,138) = 72.335$, $p = 0.002$, partial $\eta^2=0.084$ and eating disorder symptoms and group, $F(2,138) = 74.740$, $p = 0.002$, partial $\eta^2=0.087$, suggesting the model is accounting for these differences.

Figure 3

Scatterplot showing homogeneity of regression slopes and interaction terms between anxiety (covariate) and dependent variable (self-compassion).

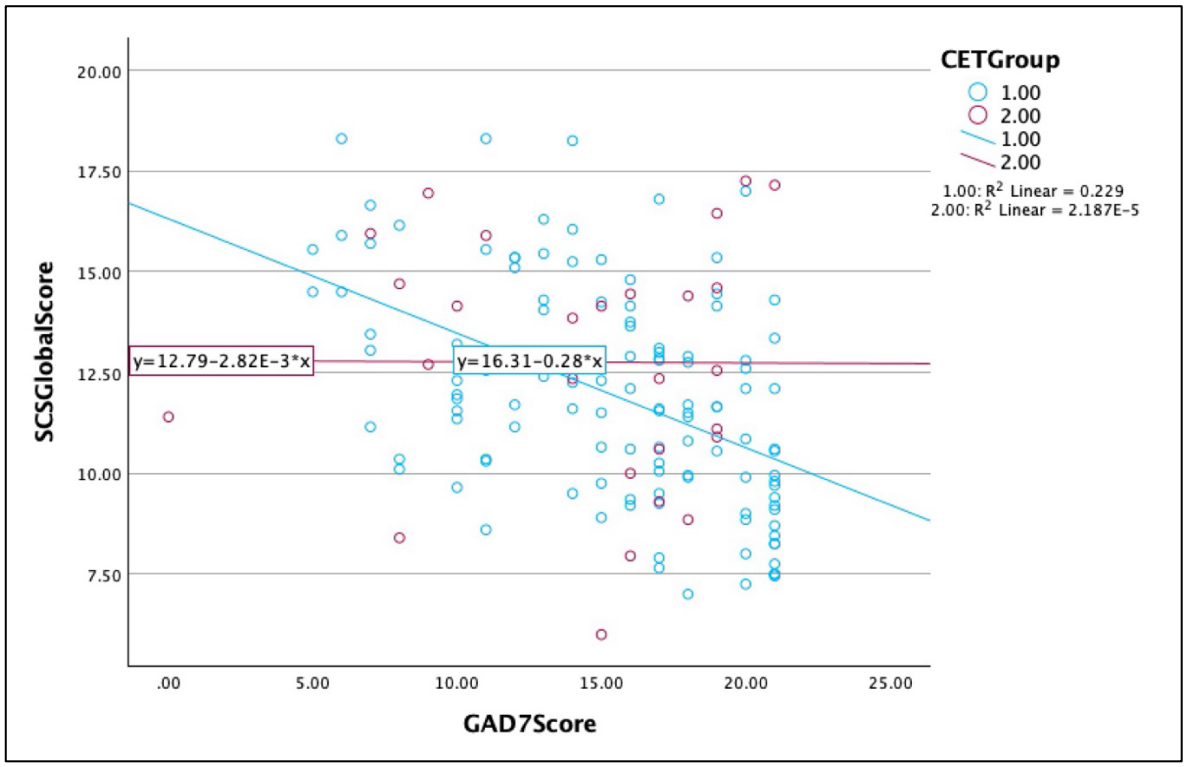
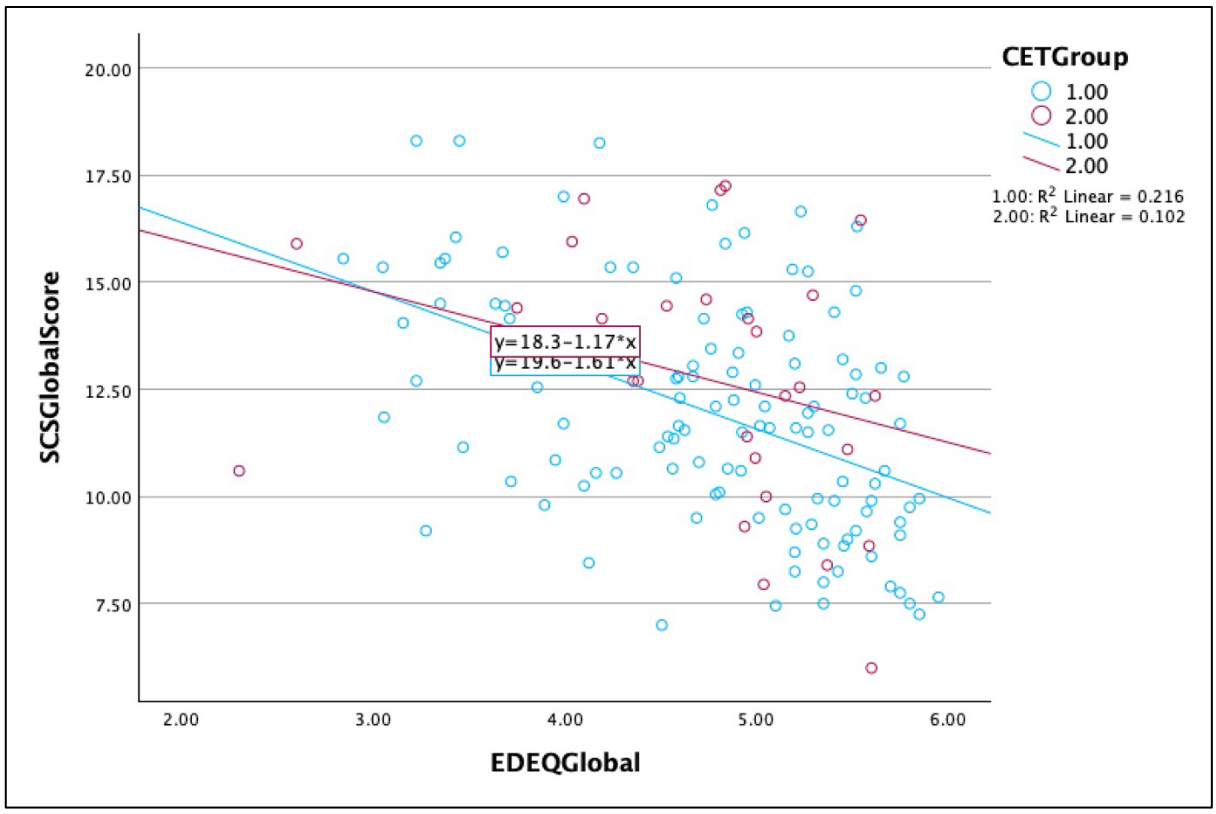


Figure 4

Scatterplot showing homogeneity of regression slopes and interaction terms between eating disorder symptoms (covariate) and dependent variable (self-compassion).



Regression assumption testing:

There was linearity as assessed by visual inspection of partial regression plots and studentized residuals against predicted values. The Durbin-Watson statistic was .8, would potentially indicate that independence of residuals was violated. However, due to the cross-sectional and independent sampling method implemented, as well as visual inspection of residual plots which showed no positive autocorrelation, the data was assumed to meet the independence of residuals statistics. The Durbin-Watson statistic is thought to be less relevant in cross-sectional studies (70). There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardised predicted values. As tolerance values were greater than 0.1, there was no evidence of multicollinearity. There were no leverage

values greater than 0.2 and no values for Cook's distance above 1. The data was normally distributed as assessed via Q-Q plot.

Appendix N TDRP Reflexivity details

To increase transparency of the iterative process, the first author completed a bracketing interview and kept an audit trail of the process and in line with reflexivity. A research journal of personal biases and reflections was maintained throughout the project. See example extracts below:

"I am mindful of my experience as an assistant psychologist in an inpatient eating disorders unit for children and adolescents where I worked with lots of young people who struggled with compulsive exercise. I ran a CBT group for compulsive exercise and so feel passionate about developing treatments in this area as I witnessed how self-compassion or related themes such as shame are not included in these treatments. I want to be mindful of this bias when familiarising myself with the data and when conducting my thematic analysis. I have witnessed lots of incidental exercise occurring in an inpatient ward and so I am mindful of what I have seen to be 'obsessive' or 'compulsive' exercise and want to remain open to other forms that I may not be as used to. I also observed the impact for young people when they are not being able to exercise and how difficult this was for young people, as well as how uncomfortable it felt as a staff member to be noting/reporting exercise in the ward. Particularly as my relationship with exercise is what I would consider healthy, I am thinking back on how uncomfortable this felt for me - to be tarnishing exercise as a bad thing. Potentially because of my experience I feel more empathetic to those who struggle with compulsive exercise."

"I am mindful of not looking for themes around self-compassion in the data and acknowledging where quotes and themes are in support of existing models of compulsive exercise."

"I am reflecting back on the early stages of analysis and I noticed my tendency to over-code, possibly from feeling overwhelmed by all of the datasets (55 completed

questionnaires). Since discussions with my supervisor, I am making a conscious effort to re-code and re-define themes with a more open mindset and allowing myself to trust the iterative process. I think this has allowed me to develop more meaningful themes that reflect the data."

"I am starting to see how perfectionism themes from the CBT model may overlap with what I consider to be self-criticism and align with self-compassion models. I am also feeling the emotional impact of the high standards that participants set themselves to, and the guilt and shame that they feel when they are not able to reach this. I found this to have a heavy impact for myself and I am trying to be mindful of not projecting my emotional response into the dataset by distancing myself from the data and giving myself regular self-care breaks when immersing myself."

Appendix O TDRP Sample characteristics (continued)

Variable	Total sample (n=146)		Low CET score (N=28)		High CET scores (N=118)	
	M	SD	M	SD	M	SD
CET Total Score	16.9	3.4	11.4	2.9	18.3	1.8
CET Avoidance Subscale	3.6	1.2	1.7	1.1	4.1	.7
CET Weight Control Exercise Subscale	4.1	.9	2.9	1	4.4	.6
CET Mood Improvement Subscale	3.4	1.2	2.6	1.5	3.6	1
CET Lack of Exercise Enjoyment Subscale	2.3	1.3	2.5	1.5	2.3	1.2
CET Exercise Rigidity	3.5	1.3	1.8	1.1	4	.8
EDE-Q Total Scores	4.8	.8	4.7	.8	4.8	.8
EDE-Q Restraint	4.8	1	4.8	.9	4.8	1
EDE-Q Eating Concern	4.2	1.1	4.4	1	4.2	1.1
EDE-Q Shape Concern	5.2	.9	4.9	1.1	5.2	.8
EDE-Q Weight Concern	4.8	.9	4.8	1.1	4.9	.9
GAD7 Score	15.2	4.6	14.4	5	15.4	4.5
PHQ8 Score	16.4	5.6	17.6	5	16.1	5.8
SCS Global Score	2	.5	2.1	.5	2	.4
SCS Self-Kindness	1.8	.6	1.9	.6	1.8	.6
SCS Self-Judgement	1.6	.5	1.8	.6	1.6	.5
SCS Common Humanity	2.3	.7	2.4	.8	2.3	.7
SCS Isolation	2	.7	2	.7	2	.7
SCS Mindfulness	2.5	.7	2.5	.7	2.4	.7
SCS Over Identification	1.9	.7	2	.7	1.9	.7

Appendix P TDRP Journal guidelines

Criteria

Journal of Eating Disorders strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible. Please see Springer Nature's information on recommended repositories.

Plain English summary

All articles in *Journal of Eating Disorders* require a **Plain English summary** of between 100 and 200 words, in addition to the Abstract. This should be a summary of the article written in language suitable for people with lived experience of illness and the wider public to easily understand. It should not contain technical terminology or complicated statistics. It should convey the key messages of your paper.
Please include this within the main body of your manuscript file. Please do not include the plain English summary as part of the official scientific abstract that is requested separately by the journal submission system. The plain English summary should be inserted immediately after the official scientific abstract within the manuscript file under the heading "Plain English summary".
By adding a plain English summary, we hope to broaden the reach of the article and bring it to the attention of a more general audience. Researchers are trained to be highly focused, specific, and conservative with extrapolation and speculation. These attributes are useful for scientific publications, but not for wider public understanding. Many non-scientists have difficulty understanding technical terms and jargon, and the public requires more context-setting by way of introduction and more help drawing a conclusion.

The following resources provide further information: INVOLVE Plain English summaries resource; The Plain English Campaign guide on medical writing; Cochrane Library.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"

    - or for non-clinical or non-research studies a description of what the article reports
- list the full names and institutional addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
    - Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.
- indicate the corresponding author

Abstract
The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords
Three to ten keywords representing the main content of the article.

Background
The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods
The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials

- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results
This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion
This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions
This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations
If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations
All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate
Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

See our editorial policies for more information.
If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication
If your manuscript contains any individual person's data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).
See our editorial policies for more information on consent for publication.
If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials
All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv https://searchrxiv.org/, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.
Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]

- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.
BioMed Central strongly encourages the citation of any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare.
2014. http://dx.doi.org/10.6084/m9.figshare.853801
With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]
If you wish to co-submit a data note describing your data to be published in *BMC Research Notes*, you can do so by visiting our submission portal. Data notes support open data and help authors to comply with funder policies on data sharing. Co-published data notes will be linked to the research article the data support (example).
Competing interests

All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.
Please use the authors initials to refer to each authors' competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding
All sources of funding for the research reported should be declared. If the funder has a specific role in the conceptualization, design, data collection, analysis, decision to publish, or preparation of the manuscript, this should be declared.

Authors' contributions
The individual contributions of authors to the manuscript should be specified in this section. Guidance and criteria for authorship can be found in our editorial policies.
Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements
Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

See our editorial policies for a full explanation of acknowledgements and authorship criteria.
If you do not have anyone to acknowledge, please write "Not applicable" in this section.

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Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

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hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

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Smith JJ. The world of science. Am J Sci. 1999;36:234-5.

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Rohrmann S, Overvad K, Bueno-de-Mesquita HB, Jakobsen MU, Egeberg R, Tjønneland A, et al. Meat consumption and mortality - results from the European Prospective Investigation into Cancer and Nutrition. BMC Medicine. 2013;11:63.

Article within a journal by DOI
Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. Dig J Mol Med. 2000; doi:10.1007/s801090000086.

Article within a journal supplement
Frumin AM, Nussbaum J, Esposito M. Functional asplenia: demonstration of splenic activity by bone marrow scan. Blood 1979;59 Suppl 1:26-32.

Book chapter, or an article within a book

Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. International review of cytology. London: Academic; 1980. p. 251-306.

OnlineFirst chapter in a series (without a volume designation but with a DOI)
Saito Y, Hyuga H. Rate equation approaches to amplification of enantiomeric excess and chiral symmetry breaking. Top Curr Chem. 2007. doi:10.1007/128_2006_108.

Complete book, authored
Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

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Dataset with persistent identifier
Zheng L-Y, Guo X-S, He B, Sun L-J, Peng Y, Dong S-S, et al. Genome data from sweet and grain sorghum (Sorghum bicolor). GigaScience Database.
2011. http://dx.doi.org/10.5524/100012.

Figures, tables and additional files

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