Thesis Submitted in Partial Fulfilment of the Requirements of the Degree of Doctor of Clinical Psychology (DClinPsych)

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Abstracts

Systematic Review of the Literature: Multiple Concussions and Later-Life Cognitive Functioning: A Systematic Review

Aims: This study aimed to review the evidence relating to the possible association of multiple concussions with later-life cognitive decline. *Method:* A systematic search was performed across five databases: Medline, Embase, Web of Science, PsycINFO, and SportDISCUS. Studies were included if they were original research investigating later-life cognitive function in individuals with multiple concussion histories, in any setting, using at least one neuropsychological measure. Data on study design, participant characteristics, exposure and outcome assessment, and key findings were extracted from included studies. Risk of bias was assessed using the Newcastle-Ottawa scale. Findings were qualitatively synthesised, due to the heterogeneity of included studies, for the domains of complex attention, learning and memory, executive function, language, and perceptual-motor function. *Results:* Twenty-three cross-sectional studies were identified (conducted with former football, rugby, and ice hockey players, and military veterans). The strongest evidence was for a subtle effect of multiple concussions on verbal learning and memory, and language. Evidence with regards to executive function was mixed, and the evidence did not support effects in the domains of complex attention or perceptual-motor function. *Discussion:* This review found no conclusive evidence of a relationship between multiple concussions and later-life cognitive decline; however, the findings should be interpreted with consideration of significant methodologic limitations in the literature. Further high-quality, powered, longitudinal research is needed, which includes a wider range of populations known to sustain multiple concussions, in order to draw firm conclusions about any associations between multiple concussions and later-life cognitive decline. Clinical implications of the findings are discussed.

Service Improvement Project: "When You're on a Machine, You Want Some Kind of Humanity Around You": An Exploration of the Psychological Needs and Experiences of Patients with End-Stage Renal Disease Treated with Haemodialysis within a Regional Renal Service

Aims: This study aimed to provide a descriptive exploration of the psychosocial needs and experiences of patients receiving hospital-based haemodialysis treatment in a regional renal service, in order to inform meaningful developments in the provision of emotional and psychological support within the service. *Design:* A qualitative study using semi-structured interviews and questionnaires was conducted between September and December 2020. *Method:* A sample of 34 patients receiving hospital-based haemodialysis treatment participated in the study. Interviews were conducted with seven participants about their experiences of living with haemodialysis and receiving support from the service. To maximise the proportion of unique patient perspectives that could be included, interview data were supplemented with open-ended written feedback from a further 27 participants. Both datasets were combined and analysed using thematic analysis. *Results:* Four themes were developed from the qualitative data: *'a restricted life', 'the psychological impact', 'coping',* and '*meeting patient needs.' Discussion:* The findings demonstrated a considerable impact on quality of life for patients living with haemodialysis and highlighted the need for an integrated approach to providing renal care. Identified needs are discussed and recommendations are made to the service to guide future developments in the emotional and psychological support offered to patients receiving haemodialysis treatment.

Theoretically Driven Research Project: Thought-Action Fusion as a Mediator of the Relationship Between Mental Imagery and Obsessive-Compulsive Symptoms

Aims: The purpose of this study was to extend research about the cognitive-behavioural model of obsessive-compulsive disorder (OCD), as it relates to intrusive mental images. It aimed to do this by investigating one mechanism potentially theorised to mediate the relationship between mental imagery and OCD symptoms, namely thought-action fusion (TAF), a cognitive bias relating to exaggerated beliefs about the *morality* of having certain thoughts or the *likelihood* that they will come true. *Method:* Participants (n=131) completed online measures relating to mental imagery use, TAF, and OCD symptoms. Mediation analyses were conducted using a percentile bootstrapping method. Participants were also asked questions about their lived experience of intrusive obsessional imagery. Secondary analyses (using a mix of quantitative and qualitative methods) compared the responses of participants who scored high for OCD, to those who scored low for OCD. *Results:* The proposed model of TAF mediating the relationship between mental imagery use and OCD symptom severity was supported in this sample. When likelihood- and moral-TAF were included in the model separately, only likelihood-TAF was a significant mediator. Also, participants scoring high for OCD reported more frequent, vivid, uncontrollable, and distressing intrusive images, and stronger likelihood- and moral-TAF appraisals of idiosyncratic intrusive images, than low scorers. *Discussion:* Overall, these results are in line with the key assumptions of cognitive-behavioural models of OCD. Findings are discussed, and the strengths and limitations of the study are considered.

Systematic Review of the Literature

Multiple Concussions and Later-Life Cognitive Functioning: A Systematic Review

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Thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology

Trinity Term 2021

Internal Supervisor: Dr Nigel King

Proposed Journal: This report is intended for submission to Brain Injury. This journal has been chosen due to its focus on articles relevant to clinical practice in the area of neurorehabilitation (see Appendix A for author guidelines).

Abstract

Aims: This study aimed to review the evidence relating to the possible association of multiple concussions with later-life cognitive decline. *Method:* A systematic search was performed across five databases: Medline, Embase, Web of Science, PsycINFO, and SportDISCUS. Studies were included if they were original research investigating later-life cognitive function in individuals with multiple concussion histories, in any setting, using at least one neuropsychological measure. Data on study design, participant characteristics, exposure and outcome assessment, and key findings were extracted from included studies. Risk of bias was assessed using the Newcastle-Ottawa scale. Findings were qualitatively synthesised, due to the heterogeneity of included studies, for the domains of complex attention, learning and memory, executive function, language, and perceptual-motor function. *Results:* Twenty-three cross-sectional studies were identified (conducted with former football, rugby, and ice hockey players, and military veterans). The strongest evidence was for a subtle effect of multiple concussions on verbal learning and memory, and language. Evidence with regards to executive function was mixed, and the evidence did not support effects in the domains of complex attention or perceptual-motor function. *Discussion:* This review found no conclusive evidence of a relationship between multiple concussions and later-life cognitive decline; however, the findings should be interpreted with consideration of significant methodologic limitations in the literature. Further high-quality, powered, longitudinal research is needed, which includes a wider range of populations known to sustain multiple concussions, in order to draw firm conclusions about any associations between multiple concussions and later-life cognitive decline. Clinical implications of the findings are discussed.

Multiple Concussions and Later-Life Cognitive Functioning: A Systematic Review

Concussion is a type of mild traumatic brain injury (mTBI), characterised by symptoms experienced after a blow to the head, including loss of consciousness, headaches, nausea, difficulties with sleep, concentration or balance, and changes in thinking and mood (1). Research shows concussion is also associated with a range of acute neuropsychological effects, notably in delayed memory, memory acquisition, and global cognitive functioning (2). In the short term, full recovery within a period of days to weeks is generally expected for most who experience concussion (3), and so historically it has been seen as a transient, minor injury. However, in recent years, there has been increasing concern about whether sustaining multiple concussions over one's lifetime may represent an important risk factor for a range of later-life health outcomes, including cognitive decline and neurodegenerative conditions (4,5).

Multiple Concussion Literature and the Media

In their seminal 1975 study, Gronwall and Wrightson (6) were some of the first researchers to suggest a possible cumulative effect of repeated concussion exposure on cognition. Since then, there has been a proliferation of research attempting to identify the effects of sustaining multiple concussions over both the short- and longer-term. Over the last decade, such research has encouraged increased recognition of concussive injuries (3,7), however the evidence relating to the long-term effects of concussion on cognitive health remains unclear (4,8). Two possible mechanisms for cognitive decline following multiple concussions have been proposed: (i) that accumulation of several concussive injuries may erode cognitive reserve, accelerating the expression of cognitive decline resulting from normal aging, or (ii) that repeated concussion may initiate a specific neurodegenerative process (i.e., 'Chronic Traumatic Encephalopathy'; 9-11). However, not all findings have agreed that an increased risk of cognitive impairment after multiple concussions exists, and it

has been argued that any conclusions drawn about the later-life effects of concussion are premature (5,12-15). Despite this, in recent years substantial attention in the media has been given to cases of high-profile athletes who sustained multiple concussions during their careers, who later developed significant degenerative neurological symptoms (e.g., 16,17). Coverage ranges from articles in major news sources (e.g., 18,19) to the production of a film, '*Concussion'* (20), all of which have gathered significant public attention and have arguably overshadowed the emergence of empirical findings on the topic (17).

Clinical Implications

A model which may be relevant in understanding the potential implications of this is Leventhal's (21) Common-Sense Model of Self-Regulation (CSM). This model proposes that an individual's beliefs about an illness - including how severe or controllable they perceive it to be, its cause, likely consequences, and time-line – are associated with how they respond and adjust to an illness. These beliefs are thought to develop based not only on an individual's own experience of the symptoms of an illness, but importantly also based on a range of external messages from others, including those in their social network, healthcare professionals, and the media (21). It has therefore been proposed that there may be important clinical implications for members of the public who have sustained concussions, who are exposed to messages about these injuries and their consequences in the media and may develop fears that concussive injures inevitably lead to later-life cognitive decline (22). This fits within a wider debate in the literature about the extent to which persisting post-concussion symptoms, which is when concussion symptoms continue beyond the expected recovery time, may have organic versus psychological aetiology (23); in line with the CSM, anxiety resulting from such beliefs could exacerbate post-concussion symptoms and adversely impact recovery from concussive injuries. Two previous studies guided by the CSM lend support to this hypothesis, linking subjective beliefs about what it means to acquire a concussion to outcomes in populations with mTBIs (24,25). Anecdotal evidence

further suggests that anxiety relating to beliefs about neurodegenerative sequelae following concussive injury are increasingly commonly seen in clinical practice (22,26). Moreover, a recent single-case study (22) was the first to describe a case in which beliefs about the long-term consequences of multiple concussions proved key to the formulation and treatment of persisting post-concussion symptoms.

Purpose of the Present Review and Aims

The purpose of this review is to clarify the current understanding with regards to whether there may exist a relationship between multiple concussions and later-life cognitive impairment, given inconsistent findings reported in the literature. This is timely given the considerable media attention this topic has received in recent years, which may have contributed to changing perceptions within the general population about what it means to have a concussion. Previous reviews have been published looking at the long-term impact of *sports-related* concussions specifically (e.g., 13-15, 89-92). Yet, the incidence of multiple concussions is not limited to sporting populations, with military veterans (e.g., 27,28), survivors of domestic abuse (29,30), and individuals who engage in head banging (31) increasingly recognised as populations for whom multiple concussions are also an important clinical concern. To our knowledge, there are no existing reviews which synthesise the evidence across sports and non-sports populations, despite the growing implication that it may be exposure to multiple concussions in general that is associated with a greater risk of health outcomes later in life, not risk factors from sport-related types of injury specifically (32-34). Therefore, research into multiple concussions resulting from any activity will be considered in this review, and the search strategy aims to encompass this. Notably, previous reviews in the area include samples in early-to-mid-adulthood, which it has been argued may be too young to show later-life cognitive effects in line with the proposed mechanisms of cognitive decline outlined above (93). They also include studies in which concussion exposure was not actually quantified, or was assumed based on proxy measures (e.g.,

presence of a contact-sports career history alone), which may more closely reflect exposure to 'repetitive sub-concussive head injury', purported to be a separate variable by many researchers (5,35). This limits the extent to which findings can be directly compared and prevents robust conclusions about the effects of multiple concussions on later-life cognition being drawn from this evidence. Therefore, there is also a gap in the literature for a review with more stringent inclusion criteria with relation to age and concussion exposure.

In summary, in the present review, studies exploring the association between multiple concussions and later-life cognitive functioning are systematically identified and critically appraised. Key findings are summarised and used to consider the clinical implications for practice - namely, to inform accurate psychoeducation for clients presenting to clinics following concussion. The research question being asked of the literature is: *'to what extent are multiple concussions associated with later-life cognitive decline?'*

Method

A systematic review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; 36). Review aims and methodology were agreed before the search was performed.

Identification and Selection of Studies

A search strategy was developed using keywords and subject headings relating to three key components: (i) the population (i.e., those shown by previous research to be susceptible to multiple concussions); (ii) the exposure (i.e., history of multiple concussions); and (iii) the outcomes of interest (i.e., measures of cognitive functioning). Potential search terms were tested for suitability and piloted to ensure known relevant studies were retrieved (see Table 1.1 for an overview of key search terms). The draft search strategy was peer-reviewed by two librarians with expertise in systematic review.

Table 1.1

Key search terms used in the search strategy, organised by PEO component.

Population	Populations research suggest are more likely to acquire multiple concussions *Key search terms: sport-related, contact sports, athlete, boxing, football, soccer, American football, Australian rules football, rugby, basketball, hockey, lacrosse, cricket, baseball, racquet sports, tennis, squash, volleyball, softball, martial arts, judo, Tae kwon do, wrestling, cycling, BMX, snow sports, skiing, snowboarding, extreme sports, racing driving, climbing, mountaineering, horse racing, military-related, army, navy, air force, marines, veterans, combat, blast, explosion, domestic violence, head banging, self-injurious behaviour, whiplash, falls*
Exposure	Multiple concussions (i.e., 'periods of temporary impairment of brain functioning following a blow to the head') *Key search terms: multiple mild traumatic brain injury, concussions*
Outcome	Measures of cognitive functioning *Key search terms: neurodegeneration, neuropsychological testing, learning, memory, attention, language, verbal fluency, executive function, visuo-spatial, psychomotor, intelligence, mild cognitive impairment, dementia, chronic traumatic encephalopathy*

Note. See Appendix B for a full example search strategy, including thesaurus terms and database-specific syntax.

Five databases were searched: Medline, Embase, Web of Science, PsycINFO, and SportDISCUS. These were chosen based on their health, social science, and sport focus. The search was conducted 18-19th April 2020 and updated on 1st May 2021 following the steps recommended by Bramer and Bain (37). No date restrictions were applied, but the search was limited to articles in the English Language. Relevant journals, reference lists of previous reviews, and the abstracts of the 'International Conference on Concussion in Sports'

consensus meetings (2001–2018) were hand-searched, and keywords were used to search Google Scholar and the Drake Foundation database. Results from all searching methods were combined, and duplicate results removed, using referencing programme Mendeley (Version 1.19.4).

Screening was conducted by two reviewers: A Trainee Clinical Psychologist and a Cognitive Neuroscience MSc graduate. Initial screening of article titles and abstracts was performed by the first reviewer to identify studies that potentially met inclusion criteria. If eligibility was not clear from the title and abstract, the article was included for assessment in the next screening stage. Full texts of potentially relevant studies were reviewed for eligibility by the first and second reviewers independently. Inter-rater reliability calculations indicated that there was 97% agreement between reviewers at this stage of screening (Cohen's K=0.82, indicating 'almost perfect' agreement; 38). Instances of disagreement (n=9) were resolved through discussion.

Inclusion Criteria. Detailed *Population, Exposure, and Outcome* criteria (PEO; 39) were developed to assess studies for eligibility (see Table 1.2). Articles were included if they were original research comparing later-life cognitive function in individuals with and without a history of multiple concussions. An assessment of cognitive function must have been used as an outcome measure. Criteria were piloted on a small number of full-text papers and refined before screening began.

Table 1.2.
Summary of eligibility criteria for including studies

Dimension	Inclusion Criteria	Exclusion Criteria
Population	Sample or subsample of human participants with average sample age over 50 years [a].	Animal studies. Neuropathological studies.
Exposure	Studies with samples or subsamples with a history of multiple concussions (sample mean ≥ 2), acquired in any setting. There are no universally accepted criteria for concussion diagnosis, thus all definitions of concussion were considered for this review.	Studies with samples with a history of single (sample mean <2) concussion, or reporting *assumed* multiple concussions history based on a proxy measure such as contact sport history. Studies that did not separate their findings by TBI severity level and included participants with a history of moderate or severe TBI, or with only repeated sub-concussive head impacts.
Outcomes	Studies that assess cognitive function using objective neuropsychological testing; or that measure subjective cognitive concerns using validated self- or informant-report measures.	Studies that do not relate to the presence (or not) of cognitive sequelae. Studies assessing acute rather than long-term cognitive outcomes.

[a] An age of 50 years was used as a cut off to operationalise *later-life* for the purpose of this review.

Exclusion Criteria. Articles were excluded if they were qualitative or single-case design studies, book chapters, review articles, or non-empirical articles. Conference abstracts were excluded where no corresponding full paper could be found, as it was felt that to include these would preclude full risk of bias assessment; efforts to identify full papers were made in these cases, including contacting authors. It was decided post-screening to additionally exclude fifteen studies which compared cognition in participants reporting positive cognitive symptomatology to a healthy control group for the purpose of defining groups before neuroimaging investigations, as to include these would have artificially inflated the presence of cognitive difficulties among multiply concussed participants, introducing an unacceptable bias.

Where eligible articles reported overlapping samples, all were included in an attempt to exclude the minimum number of relevant studies, to ensure breadth of the review. Authors were contacted to confirm suspected overlapping samples across articles, and any information received about the proportion of shared participants has been detailed in the below sections.

Data Extraction

A template for data extraction was developed (see Appendix C). Data including study design, geographical location, study aims, recruitment methods, inclusion and exclusion criteria, participant characteristics, method of concussion history assessment (including how concussion was defined), potential confounders, cognitive outcome ascertainment, statistical methods, and key findings were extracted by the first reviewer. Findings pertaining to outcomes beyond the scope of the research question of this review (e.g., neuroimaging techniques, genotyping) were not extracted. Completed data extraction forms were reviewed by the second reviewer for accuracy and completeness, and any disagreements were resolved through discussion. Due to the heterogeneity of methodologies used and cognitive outcomes

assessed by the included studies, a meta-analysis was not conducted, and a narrative synthesis approach was used to summarise results.

Risk of Bias Assessment

The Newcastle-Ottawa Scale (NOS; 40) was used to guide appraisal of the included studies. The NOS assesses sources of bias common in the design of non-randomised studies across three domains: selection, comparability, and outcomes. Points are awarded where aspects of high-quality methodology are demonstrated, thus higher scores indicate lower risk of bias. An unofficial version of the NOS was used for this review, which has been adapted for use specifically with cross-sectional research designs by Alshabanat and colleagues (41; see Appendix D). Presently, no single tool is recognised as a 'gold-standard' for assessing methodological quality in cross-sectional research (42), however the cross-sectional NOS has been used in several previous systematic reviews (41,43,44) and a preliminary attempt to assess its psychometric properties demonstrated it to have moderate-good reliability (intraclass correlation coefficient=0.73; 42). The NOS was further modified for this review by replacing terminology used in Alshabanat and colleagues' (41) version, to be relevant to the research area of this review. An item was added for the purpose of this review to assess how studies defined *concussion* for participants. Thus, studies were assessed for: (i) representativeness of their sample; (ii) sample size justification; (iii) selection of the control group; (iv) ascertainment of concussion history and (v) concussion definition; (vi) control of confounding factors; (vii) assessment of cognitive outcomes; and (viii) appropriateness of the analysis. Studies could be given a maximum of 12 points, although eligible studies were included irrespective of score. Quality assessment was conducted at the outcome level, concerning comparison of cognitive outcomes. The second reviewer independently rated 30% of studies (n=8) to check agreement and reliability in the use of the scale. Inter-rater

reliability was found to be satisfactory (K=0.83), so the first reviewer assessed the remaining studies alone.

Results

Search Results and Study Selection

A flowchart summarising the steps used for the selection of studies, developed in line with the PRISMA guidelines (36), is presented in Figure 1.1. The initial searches identified 10296 records. Following the removal of duplicate and non-eligible studies, 22 articles met the eligibility criteria (45-65). The search update returned a further 758 records, from which one additional eligible article was found (67).

The 23 included articles comprised research from 14 research groups. Overlapping samples were identified across Hart et al. (64), Strain et al. (65,66) and Fields et al. (67), all of which were publications from the same longitudinal study at different time points of data collection (C. Munro & J. Strain, personal communication, September 28, 2020). The sample described by Goswami et al. (50) was a subset of participants of an ongoing longitudinal study reported by Tarazi et al. (49), Misquitta et al. (48) and Terpstra et al. (47), published at a preliminary stage of data collection. Due to differences in eligibility criteria, the latter three studies' samples overlapped closely but not entirely (R. Green, personal communication, September 9, 2020). Terry et al. (51,52) reported cognitive findings of a fully shared sample - and this was a subset of the sample reported by Terry et al. (53). Two papers by Tremblay et al. (60,61) similarly reported cognitive findings for a fully shared sample. Data was extracted from all studies, but in cases where two or more articles reported on closely overlapping samples, these were grouped as above during data extraction so that findings from the same participants were not considered in the results more than once. Thus, 14 individual studies are discussed in the synthesis of results.

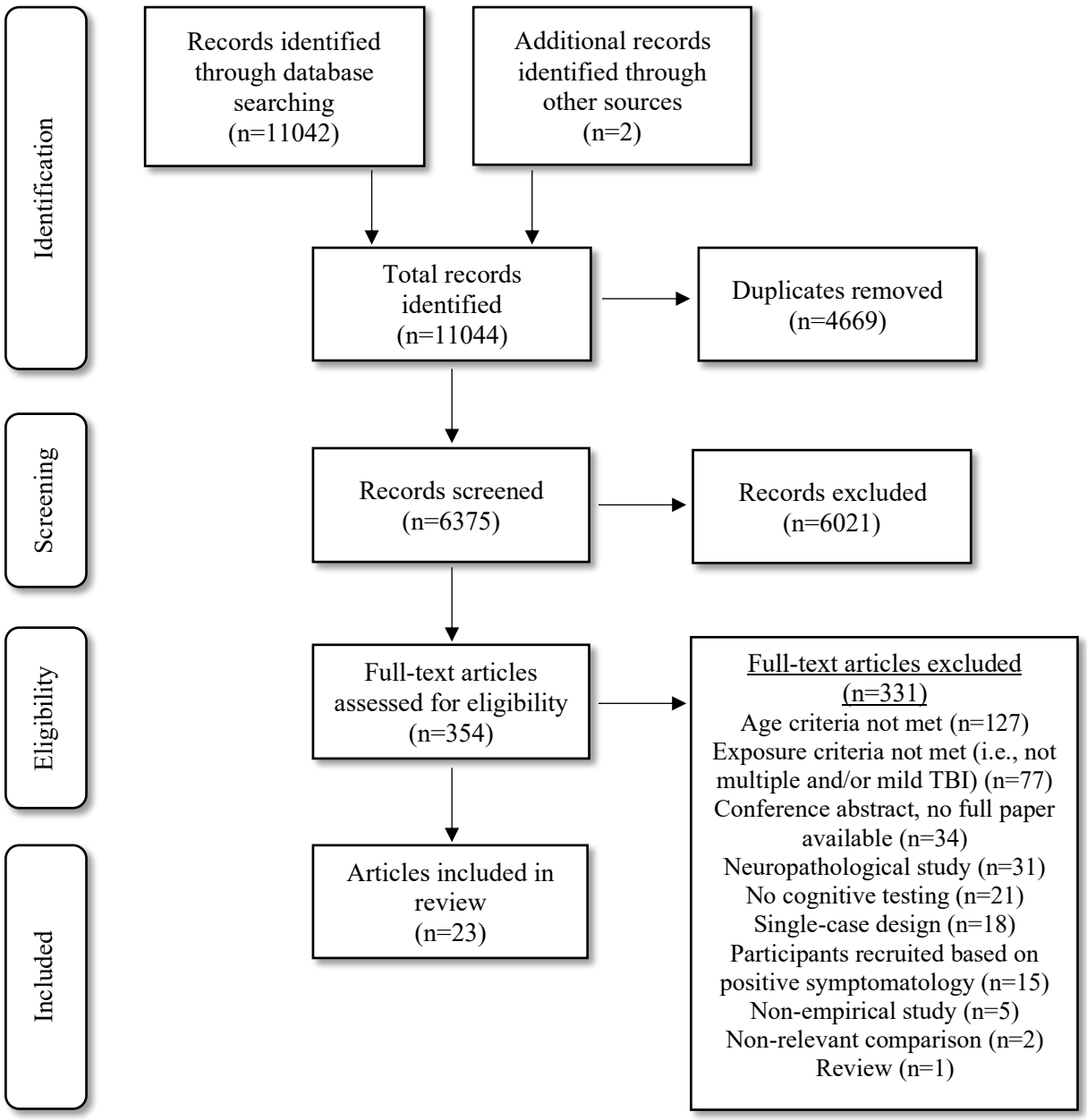


Figure 1.1

Flowchart of search process based on the PRISMA guidelines.

Characteristics of Included Studies

A summary of data extracted from the included studies is presented in Table 1.3.

Study Design

All articles reported observational research, and either used an analytical cross-sectional design or were preliminary publications from longitudinal studies analysed cross-sectionally.

Study Setting

The articles were published between 2005 and 2020. The majority of studies were conducted in the US (n=8; 45, 51-54, 56, 59, 62-67), with four in Canada (46-50, 55, 60, 61), and one each in France (58) and Scotland (57). All, but one, were conducted within a sports setting, with former American or Canadian football (45-54, 59, 62-67), rugby (57,58), or ice hockey (55) players, or mixed university-level contact-sport athletes (60,61). Participants in the remaining study were military veterans (56). No eligible studies were identified with participants from any other non-sports population.

Nine studies were funded via non-commercial sources (46-57, 60, 61, 64-67), whereas two studies received partial (59) or full (58) funding from commercial sources. Three did not disclose the source of their funding (45,62,63)

Participants

Sample sizes ranged widely from 9 to 3474 participants (median=41). All but one study (56; 89% male) used entirely male samples. Although the sample mean age was over 50 years in all studies, only six recruited samples in which all participants were over the age of 50 years (54, 56, 59-61, 63, 67); the majority included some younger participants in their 20s, 30s and 40s within their samples. Only eight articles (35%) reported participant ethnicity. Most participants in these studies identified as Caucasian, with the percentage of non-White participants ranging from 8-42%.

Table 1.3.

Summary of studies included in the review

First Author (date)	**Sample Characteristics** (Mean age (years; SD))	**Concussion Exposure**	**Measurement of Cognitive Outcomes** ▪ domains assessed	**Summary of Relevant Findings**
Fields (2020)[67]	*2020:* 35 former NFL players (64.5; 7.6)	*2020:* Sample mean concussions = 5.83 (SD = 3.86, range 1-17)	Neuropsychological tests ▪ Episodic memory ▪ Attention/processing speed ▪ Visuospatial skills ▪ Executive function ▪ Psychomotor speed ▪ Language/confrontation naming	▪ Verbal episodic memory scores were significantly lower (albeit in the healthy range) in former players than controls (p=0.002). ▪ No significant differences were found in verbal episodic memory scores between former players with MCI and control participants with MCI. ▪ No group differences were found in non-verbal episodic memory scores. (65) ▪ Former players scored significantly worse on a test of visual confrontation naming compared to controls (p=0.005) (66). ▪ No significant correlations were found between total number of concussions and scores on any cognitive domain (range of p-values: 0.5 to 0.9; 67, 64). ▪ No significant group-differences were found in number of concussions between cognitively normal and cognitively impaired participants. (67)
Strain (2017)[66] *Overlapping sample*	*2017:* 25 former NFL players (61.1; 12.2); 22 cognitively normal controls (59.4; 11.8)	*2017:* Former players' mean concussions = 4.0 (SD = 3.4, range 1-12)		
Strain (2015)[65] *Overlapping sample*	*2015:* 28 former NFL players (58.1; 13.0); 21 healthy controls with no history of concussion (59.0; 12.0); 6 control participants with MCI (68.0, 8.3).	*2015:* Former players' mean concussions = 3.9 (range 1-10)		
Hart (2013)[64] *Overlapping sample* (US)	*2013:* 34 former NFL players (61.8; 8.9); 26 healthy controls (60.1; 11.1)	*2013:* Former players' mean concussions = 4.0 (range 1-13) ▪ *Ascertainment:* self-reported at interview ▪ *Definition:* American Academy of Neurology guidelines (68).		

Roberts (2019)[45] (US)	3474 former NFL players (58.2; 14.2)	Sample mean concussions = 3.2 (SD 2.8) ▪ *Ascertainment:* self-report questionnaire ▪ *Definition*: stated but source not given "a blow to the head, neck, or upper body followed by: headaches, nausea, dizziness, loss of consciousness, memory problems, disorientation, confusion, seizure, visual problems, and feeling unsteady on your feet?"	Validated self-report measure ▪ Subjective cognition related QOL	▪ Frequency of previous concussion symptoms was strongly associated with subjectively poor cognition related QOL. ▪ The highest quartile for frequency of previous concussion symptoms was associated with a 22.3-fold greater risk of poor cognition-related QOL compared with the lowest quartile (p<.001).
Ruiter (2019)[46] (Canada)	19 former CFL players (57.6; 6.7); 20 controls (53.7; SD not reported)	Former players' mean concussions = 4 (SD = 3.1, range 1-11) ▪ *Ascertainment:* self-report questionnaire ▪ *Definition:* no description	Neuropsychological tests ▪ Verbal and visual memory ▪ Motor speed ▪ Reaction time ▪ Impulse control/attentional processing	▪ No significant group-differences were found between former players and controls for any cognitive domain.
Terpstra (2019)[47]	*2019*: 61 former CFL players (55.0; 12.8) ▪ 26 'low' (0-3) concussion exposure ▪ 35 'high' (4+) concussion exposure 31 healthy controls (49.7; 12.1).	*2019:* Former players' mean concussions = 4.4 (SD = 2.8) ▪ 'High' concussion exposure mean = 6.1 (SD = 2.4, range 4-13) ▪ 'Low' concussion exposure mean = 2 (SD = 0.9, range 0-3)	Neuropsychological tests Validated self-report measure (2018b only) ▪ Attention, processing speed ▪ Verbal and visual learning and memory	▪ Former players made more errors on a test of inhibitory control (medium effect size) than controls. ▪ Participants with 'high' concussion exposure scored significantly worse than control participants. 'Low' exposed participants did not score significantly differently than 'high' exposed participants or controls (47)

Misquitta (2018a)[48] *Overlapping sample*	*2018a:* 53 former CFL players (55.6; 12.9); 25 healthy controls (50.8; 10.0).	*2018a:* Former players' median concussions = 4.0 (IQR = 3-8.5)	▪ Executive functioning/impulsivity ▪ Motor function ▪ Intellectual functioning	▪ In the pilot study, former players had faster reaction times and made more errors compared to controls, indicative of lower response inhibition (p<0.05) (50)
Tarazi (2018b)[49] *Overlapping sample*	*2018b:* 45 former CFL players (53.4; 10.3), and 25 healthy controls (50.0; 10.9).	*2018b:* Former players' mean concussions = 5.1 (SD = 4.2)		▪ Former players scored significantly higher (and in the high average range) on a test of processing speed (p=0.023). However, no significant differences were found in the 2019 follow up (49)
Goswami (2016)[50] *Pilot study* (Canada)	*2016:* 22 former CFL players (50.0; 12.0); 17 healthy controls (46.0; 10)	*2016:* mean concussions not reported; all reported two or more (range 2-15) ▪ *Ascertainment:* self-reported, unclear ▪ *Definition*: Zurich Consensus statement (69)		▪ No significant differences were found between groups on any other cognitive domains ▪ Former players self-reported significantly more subjective memory (78:16%, p<0.001), executive functioning (53:8%, p<0.001) and behavioural change concerns (67:20%, p<0.001) than controls (49)
Terry (2019)[51] *Terry et al. (2018)*[52] *Shared sample* *Terry (2015)*[53] *Overlapping sample* (US)	*2018/9:* 40 former high school football players ▪ 20 with multiple concussions (53.1; 7.3) ▪ 20 no concussion history (50.0; 7.8). *2015:* 41 former high school football players ▪ 25 with a history of multiple concussions (52.0; 8.1) ▪ 16 with no history of concussion (49.1; 8.3).	Concussed groups' mean concussions = 4.3 (SD = 3.7, range 2-15) ▪ *Ascertainment:* self-report questionnaire followed by Acute Concussion Evaluation (70) ▪ *Definition:* American Congress of Rehabilitation Medicine (71)	Neuropsychological tests ▪ Visuospatial skills ▪ Attention ▪ Language ▪ Memory	▪ No significant between-group differences were found between concussion and control groups on any cognitive domains.

Clark (2018)[54] (US)	61 (cognitively unimpaired) former football players 31 former collegiate-level players: ▪ 16 with multiple (3+) concussions (58.2; 3.4) ▪ 15 with 0-1 concussion (58.9; 4.1). 30 former NFL players: ▪ 15 with multiple concussions (57.9; 3.7) ▪ 15 with 0-1 concussion (59.2; 3.6)	Former collegiate-level players: ▪ 3+ concussions group mean concussions = 7.2 (SD = 6.9) ▪ 0-1 concussions group mean concussions = 0.6 (SD = 0.5) Former NFL players: ▪ 3+ concussions group mean concussions = 7 (SD = 7.0) ▪ 0-1 concussions group mean concussions = 0.5 (SD = 0.5) ▪ *Ascertainment:* self-report questionnaire ▪ *Definition:* Zurich Consensus statement (69)	Neuropsychological tests ▪ Attention ▪ Memory ▪ Visuospatial skills ▪ Processing speed ▪ Global cognition	▪ No between-group differences were found for any neuropsychological test scores across the four concussion-history-career-duration stratifications (all $p>0.05$).
Esopenko (2017)[55] (Canada)	33 former professional ice hockey players (54.3; 10.4); 18 healthy controls (53.5; 10.2).	Former players' mean concussions = 4.8 (SD = 2.7) Controls' mean concussions = 0.6 (SD = 0.8) ▪ *Ascertainment:* self-reported, unclear ▪ *Definition:* Zurich Consensus statement (69)	Neuropsychological tests Validated self-report measure ▪ Attention ▪ Memory ▪ Visuospatial skills ▪ Executive/intellectual functioning	▪ Former players had worse scores on a composite measure of executive/intellectual functioning compared to controls. ▪ Number of concussions was significantly associated with executive/intellectual functioning. ▪ No association was found between number of concussions and performance for any other cognitive domains. ▪ Former players self-reported significantly more subjective cognitive difficulties than controls.

Kaup (2017)[56] (US)	169 military veterans ▪ 88 with lifetime TBI (mean age = 77.9, SD = 10.3) ▪ 81 without lifetime TBI (mean age = 80.3, SD = 8.6 years).	Sample split into groups reporting 0, 1, and multiple concussions, and additionally those reporting moderate/severe TBI. 41 (19.6%) reported multiple concussions. ▪ *Ascertainment:* Ohio State TBI Identification Method structured interview (72), corroborated by medical records ▪ *Definition:* Department of Veterans Affairs & Department of Defence (73)	Neuropsychological tests ▪ Attention, processing speed ▪ Memory/learning ▪ Language ▪ Executive functioning/working memory	▪ Veterans with multiple concussions had worse scores on tests of processing speed and executive function compared to those with no TBI history or single concussion history. ▪ There was a significant linear trend effect across increasing levels of TBI (i.e., no TBI, single concussion, multiple concussions and moderate-to-severe TBI) for processing speed and executive functioning (both p=0.03). There were no linear trends found for the remaining cognitive domains (all p>0.05).
McMillan (2017)[57] (Scotland)	52 former international rugby union players (53.5; 13.0); 29 healthy controls (55.1; 9.0). *Subgroups of former players were formed based on concussion history (0-1, 2-9, and 10+).*	Former players' mean concussions = 13.9 (SD = 18.9, range 0-100). ▪ *Ascertainment*: self-reported on a structured assessment form administered at interview ▪ *Definition*: Stated but source not given "a blow or injury to your head where you may or may not have lost consciousness and then had symptoms such as dizziness, blurred vision, nausea, vomiting, headache, poor concentration. It might be that symptoms were not noticeable straight away, but	Neuropsychological tests ▪ General cognitive function ▪ Sustained attention, processing speed ▪ Executive function ▪ Memory, learning ▪ Visual perception	▪ Former players performed within the 'normal' range on all cognitive tests, although performed worse than controls on a test of verbal learning (p=0.02). No significant differences were found in any other cognitive domains (p>0.05). ▪ No significant between-group difference was found on a screening measure for cognitive decline; 9 former players (17%) were diagnosed with a cognitive impairment, compared with one (3%) control participant (p=0.09). ▪ No significant differences were found on cognitive tests between concussion frequency subgroups. There were also no correlations of scores with overall frequency of concussions.

		you may have noticed them later or have had 'gaps' in your memory for the game that were unusual, or you might have remembered little at all about the game"		
Decq (2016)[58] (France)	239 former national- or international-level rugby union players (median age = 52, IQR = 49-55.8); 138 other retired sportsmen (median age = 52, IQR = 49-55)	Former rugby players' mean concussions = 3.1 (SD = 5.0). Other sportsmen mean concussions = 0.7 (SD = 1.8). ▪ *Ascertainment*: self-report questionnaire ▪ *Definition*: Unclear	Neuropsychological tests ▪ Verbal Fluency	▪ No significant difference was found in verbal fluency between former players and other sportsmen ▪ No association was found between number of concussions and verbal fluency score.
Coughlin (2015)[59] (US)	9 former NFL players (64.8; 5.3).	Sample mean concussions = 7.2 (range 1-40) ▪ *Ascertainment*: self-reported at interview ▪ *Definition*: American Academy of Neurology guidelines (68)	Neuropsychological tests ▪ Verbal learning and memory	▪ Former players had varied performance on a test of verbal learning and memory, although mean percentile scores were in the *Average* range compared with age-adjusted population norms.

Tremblay (2013)[60] *Tremblay (2014)*[61] *Shared sample* (Canada)	30 former university-level athletes (70% ice hockey, 30% American football) ▪ 15 with a history of concussion (60.9; 7.5) ▪ 15 with no prior history of concussion (58.1; 5.3)	Concussed group's mean concussions = 2.1 (SD = 1.3, range 1-5) ▪ *Ascertainment*: self-reported at interview using Standard Concussion history questionnaire (74). ▪ *Definition*: Zurich Consensus Statement on Concussion in Sports (88)	Neuropsychological tests ▪ General cognitive function ▪ Verbal fluency ▪ Verbal and visual episodic memory ▪ Visual attention	▪ Former athletes with multiple concussions had lower scores on tests of semantic verbal fluency (p=0.04) and episodic memory (both delayed recall (p=0.03) and recognition (p=0.02)). They also had lower figural memory scores (p=0.04). ▪ No significant differences were found between the groups on the remaining cognitive domains.
Amen (2011)[62] (US)	100 active and retired NFL players (57.3; 12.4), compared with a standardised MicroCog sample (n=810).	Players' mean concussions (with LOC) = 2.7 ▪ *Ascertainment*: self-reported at interview ▪ *Definition*: Centre for Disease Control and Prevention (75)	Neuropsychological tests ▪ Attention ▪ Memory ▪ Reasoning ▪ Spatial processing ▪ Reaction time	▪ Players scored in the bottom half of percentile placements compared to population norms in all domains except spatial processing and reaction time (both in the top half).
Guskiewicz (2005)[63] (US)	2552 former NFL players (53.8; 13.4) *(Cognitive findings were based on a subset of 758 participants all over the age of 50 years).*	Sample split into groups reporting 0, 1, 2 and 3+ concussions. 597 (24%) reported 3 or more concussions. ▪ *Ascertainment*: self-report questionnaire ▪ *Definition*: Stated but source not given; aligned with American Academy of Neurology (68) "an injury resulting from a blow to the head that caused an alteration in mental status and one or more of the following	Validated self-report measure ▪ Memory	▪ A significant positive association was found between history of multiple concussions and self- (p=0.001) and spouse- (p=0.04) reported memory impairment ▪ Former players reporting 3 or more concussions were three times as likely to report significant memory impairment compared with players with no history of concussion. ▪ A positive association was also found overall between number of concussions and memory impairment.

	symptoms: headache, nausea, vomiting, dizziness/balance problems, fatigue, trouble sleeping, drowsiness, sensitivity to light or noise, blurred vision, difficulty remembering, and difficulty concentrating."	

CFL = Canadian Football League, MCI = mild cognitive impairment, NFL = National Football League, TBI = traumatic brain injury, QOL = quality of life

Note. Unless otherwise stated, control groups had no concussion history.

[a] Standard deviation calculated from confidence intervals. Athletes 95% CI 57.8-65.7; healthy controls 95% CI 55.6-64.6.

Classification of Concussion Exposure

The reported mean number of concussions in concussed groups ranged from 2.1 (60,61) to 13.9 (57). Concussion history was self-reported by participants retrospectively in all included studies using interviews or questionnaires, with participant self-report only supported by medical records in one study (56). Across the studies, there was variability in the way '*concussion'* was defined. The authors of two studies did not clearly report how they defined concussion for participants (46,58), which may reduce the validity of participants' self-reported concussion histories in these studies. Nine used standard definitions, as outlined by the American Congress of Rehabilitation Medicine (n=1; 71), American Academy of Neurology (n=2; 68), Centres for Disease Control and Prevention (n=1; 75), 2009 (n=1; 88) and 2013 (n=3; 69) Consensus Statements of Concussion in Sport, and Department of Veterans Affairs & Department of Defence (n=1; 73), and three studies detailed an uncited definition that represented a variation of these (45,57,63). A comparison of the components of concussion these definitions comprised is presented in Appendix E. Notably, definitions were generally seen to be broad and, in many cases, represented a potentially lower threshold for diagnosis than is typically seen in the wider mTBI literature.

Measurement of Cognitive Outcomes

Across the studies, a total of 36 neuropsychological measures were used to assess aspects of cognitive function; these are detailed in Appendix G. The majority of studies reported results on more than one cognitive domain. Mostly, studies used objective neuropsychological testing only to assess cognitive function. One study (55), however, used a mixture of objective neuropsychological testing and subjective self-report measures, and two (45,63) used only subjective self-report measures.

Risk of Bias Assessment

Results of the risk of bias assessment are presented in full in Appendix F, and a comparison of scores across the studies for each of the three NOS subdomains is illustrated in Figure 1.2. The mean overall score among the studies was seven out of 12 (SD=1.3), though it should be noted that the quality of the studies was seen to be variable (range=five to ten out of 12), and this has been considered throughout the synthesis of results.

The following sections outline themes relating to methodological quality across the included studies in relation to selection, comparability, and outcomes.

Selection

No studies received the maximum score of seven for selection using the modified NOS scale. In this domain, scores ranged from one to six. The most common methodological weaknesses were the use of retrospective self-report to ascertain concussion history (introducing potential recall bias in the measurement of concussion exposure), and the use of nonprobability (i.e., convenience, volunteer, and snowball) sampling methods. Even in studies that identified a sampling frame, response rates were generally low, therefore the included samples may not be wholly representative of their wider populations, limiting generalisability. Only Clark et al. (54) provided a power calculation to justify their sample size, so it is also unclear the extent to which some studies could potentially be underpowered. Selection of the comparison group varied across the included studies, with some designs in this respect better placed to assess the effect of multiple concussions than others. Seven studies assessed individuals with varying levels of concussion exposure from within the same population (45, 51-54, 56, 60, 61, 63, 67), thus their participants were the most likely to be similar in terms of lifestyle and other psychosocial factors, minimising potential unmeasured

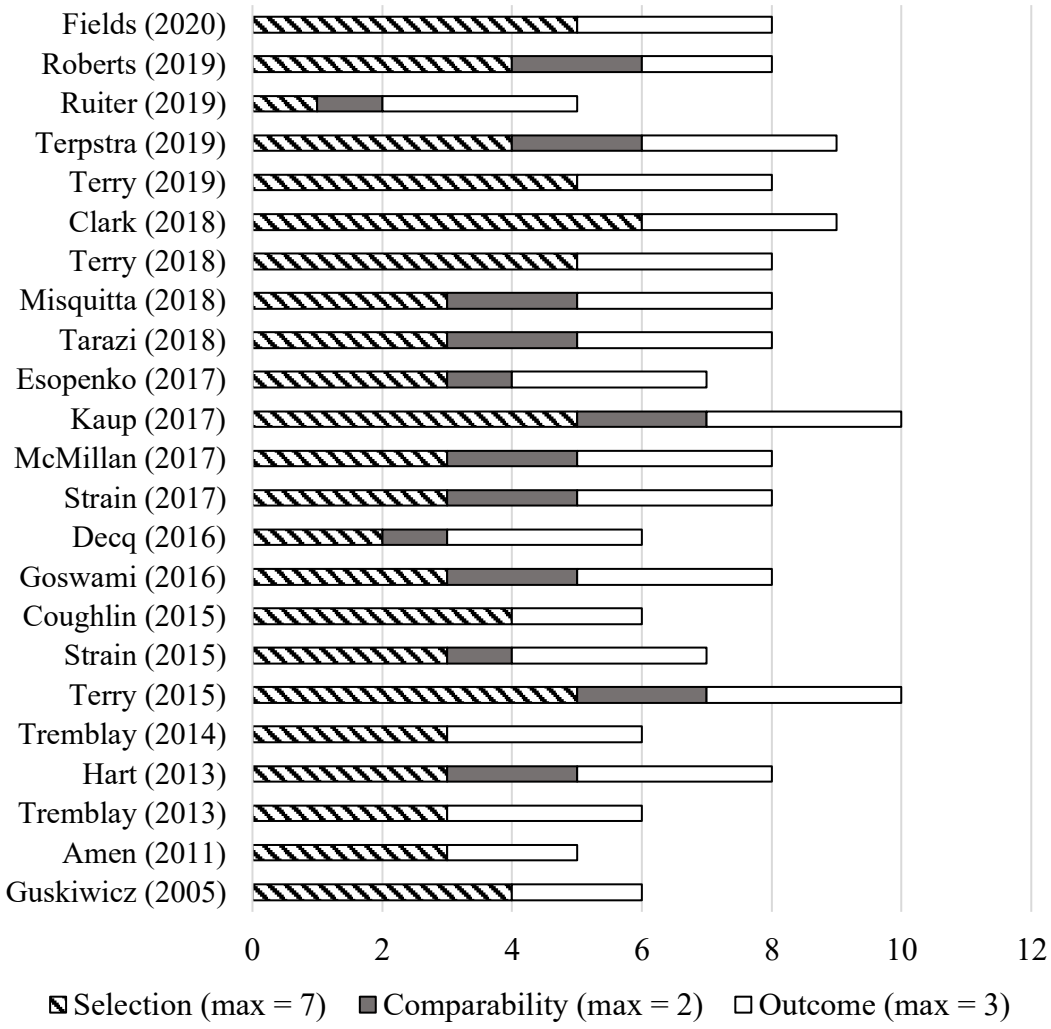


Figure 1.2

Summary of risk of bias assessment of included studies using the modified Newcastle-Ottawa Scale.

confounding variables. One identified a different (sports) population the authors considered comparable in terms of their competitive level and general health (58). Five used an external comparison group of non-concussed controls from the general population (46, 48-50, 55, 57, 64-66), therefore these findings may have been more affected by differences between concussed and control groups (e.g., potential healthy cohort effects). Two studies did not use a control group and only standardised participants' cognitive scores based on general

population normative data (59,62), limiting the conclusions that can be drawn from these studies' findings.

Comparability

Scores in this domain ranged from zero to two (out of two). Most studies matched or statistically adjusted for some potential confounders, with age (45-50, 53, 55-57, 64, 66), education (48-50, 53, 56, 57, 64-66), and estimated pre-morbid IQ (51-53, 64-66) the potential confounders most frequently controlled for. Seven studies did not adequately report how potential confounding variables were controlled in analyses of cognitive outcomes (51, 52, 54, 59-63, 67) and thus it was not possible to understand the impact of bias introduced by possible third variables in these findings.

Outcomes

The majority of included studies scored the maximum of three on this domain. Where points were lost, this related to the use of self-report measures of subjective cognitive function instead of objective neuropsychological testing (45,63), or to a lack of appropriate statistical methods (59,62). Fewer than half of the studies reported details of the training of individuals responsible for administering neuropsychological testing, and only three reported any attempt to blind these individuals (54, 60, 61, 64); thus, it is not clear to what extent interviewer bias may have affected some findings. All studies reported *P*-values within their results, but several did not report effect sizes, which is a reporting weakness in these studies and impacts the comparability of findings across studies.

Summary of Key Findings, by Cognitive Domain

For the purposes of reporting, cognitive findings have been classified according to the following domains: complex attention, learning and memory, executive function, language,

and perceptual-motor function (76). Table 1.4 presents an overview of the key findings across all these domains. A list of abbreviations is included in Appendix G.

Complex Attention

Thirteen publications reporting findings from nine studies (46, 47, 49, 51, 52, 55-57, 60-62, 64, 67) assessed aspects of complex attention using a variety of measures (see Appendix G). Only two reported any evidence of reduced performance in this domain for participants with multiple concussion histories. Incidentally, one of these was the only study which verified self-reported concussion history using medical records; in this study, Kaup et al. (56) reported that a subgroup of veterans reporting a history of multiple concussions performed significantly worse compared to those reporting one or zero concussions, on a composite measure of processing speed comprising scores across two tests (TMT-A/WAIS-R Digit Symbol); nevertheless, this was in the range of a 'small' effect (f^2=0.08; 77). Notably, the definition of concussion used in this study required participants to have needed 'medical care', so may have represented more severe injures than the other studies. No other studies using measures of processing speed or other aspects of attention found any evidence of reduced scores in this domain for participants with multiple concussions compared to internal comparisons of non-concussed former athletes (51,52, 60, 61, 67) nor non-concussed controls from the general population (46, 47, 49, 55, 57, 64). Moreover, Tarazi et al. (49) found that multiply concussed former football players actually scored significantly higher (and in the high average range) on the TMT-A than non-concussed controls (a 'medium' effect, *d*=0.55). Amen et al. (62) tested former American football players on subtests of attention from a computerised battery (MicroCog) and found participants scored in the bottom half of percentile placements compared to general population norms; however, this study included no comparison group. Overall, the balance of evidence did not support an effect of multiple concussions on later-life complex attention.

Table 1.4

Summary of findings across all studies by cognitive domain, in order of methodological quality score

Is there a relationship between sustaining multiple concussions and later-life cognitive decline?											
Study	**Complex attention**		**Learning and memory**		**Executive functions**		**Language**		**Perceptual-motor function**		**Risk of Bias Score (/12)**
First author (year)	***Y***	***N***	***Y***	***N***	***Y***	***N***	***Y***	***N***	***Y***	***N***	
Kaup (2017)[56]	Yes			No	Yes			No		-	10
Terry (2015)[53]		-		No		-		-		-	10
Clark (2018)[54]		-		-		-		-		-	9
Terpstra (2019)[47]		No		No	Yes*			-		-	9
Tarazi (2018)[49]		No		No*		No*		-		No	8
Misquitta (2018)[48]		-		No		-		-		-	8
Goswami (2016)[50]		-		-	Yes			-		-	8
Terry (2018, 2019)[52,51]		No		No		-		No		No	8
Roberts (2019)[45]		-		-		-		-		-	8
McMillan (2017)[57]		No	Yes			No		-	Yes*	-	8
Fields (2020)[67]		No		No		-		No		-	8
Hart (2013)[64]		No	Yes			No	Yes			No	8
Strain (2017)[66]		-		-		-	Yes			-	8
Strain (2015)[65]		-	Yes			-		-		-	7
Esopenko (2017)[55]		No		No	Yes			-		No	7
Decq (2016)[58]		-		-		-		No		-	6
Coughlin (2015)[59]		-		No*		-		-		-	6
Tremblay (2013, 2014)[60,61]		No	Yes			-	Yes			-	6
Guskiewicz (2005)[63]		-	Yes			-		-		-	6
Ruiter (2019)[46]		No		No		-		-		No	5
Amen (2011)[62]	Yes		Yes			-		-		No	5

- = Domain not examined/reported on

* In Coughlin et al. (59) 'variable' performance was reported in verbal learning and memory, but this finding could not be placed in the context of population normative data and no statistical analysis was completed on the data. Tarazi et al. (49) found no evidence of objective memory or executive function decline but reported more *subjective* cognitive concerns in concussed participants in these domains. Terpstra et al. (47) found evidence of lower performance in inhibitory control but no other aspects of executive function. McMillan et al. (57) found evidence of decline in motor function only, not visuospatial function.

Note. Shading indicates partially overlapping samples. Studies reporting re-analyses of fully shared samples with no unique cognitive data have been grouped together in the table.

Learning and Memory

Eighteen publications across eleven studies used measures of learning and memory (46-49, 55-57, 59-62, 64, 65, 67). Two publications, containing preliminary data from a longitudinal study, found former American football players with multiple concussion histories performed worse on a test of verbal episodic memory (CVLT-II) than non-concussed controls (64,65). McMillan et al. (57) similarly found that concussed rugby players performed significantly worse on a subtest of verbal learning (RAVLT immediate, though not delayed, recall) than non-concussed controls. Participants in the latter study reported on average a higher frequency of concussions than others in this domain, although reporting of procedures around ascertainment of concussion exposure in this study was unclear. The authors also reported a low response rate (22%) during recruitment, so selection bias may limit generalisability of this finding. Notably, across both studies, concussed participants' scores fell within the 'Normal' range compared to general population norms. Tremblay et al. (60,61) reported evidence of subclinical alterations on a task of figural memory in a small sample of former university-level athletes, with concussed participants performing significantly worse than participants with no concussion history (a 'large' effect, d=0.80). Two studies reported lower than expected (62) and 'variable' (59) age-standardised scores on tests of memory (MicroCog/CVLT-II) compared to general population norms, but lacked any comparison to specific population normative data, greatly limiting the conclusions that can be drawn from these studies. Seven studies reported no evidence of an effect of multiple concussions across objective measures of verbal (46-49, 51-53, 55, 56, 60, 61, 67) and visual (46-48, 51, 52, 55, 64, 67) memory and learning. Two further studies included self-report measures of *subjective* memory concerns (49,63). Guskiewicz et al. (63) found former American Football players with three or more concussions were three times as likely to self-report memory impairments compared to those with no concussion history and, despite finding no evidence of memory impairment on objective measures of memory, Tarazi et al.

(49) also found former Canadian football players with multiple concussions self-reported significantly more subjective memory concerns than controls. Overall, results in this domain were mixed, although there was some evidence of a detectable, but potentially non-clinical, effect of multiple concussions, particularly with regards to verbal learning and memory – and evidence of increased subjective memory concerns.

Executive Function

Seven publications reporting findings from five studies assessed executive functions (47, 49, 50, 55-57, 64). Three studies, comparing samples of multiply concussed former athletes with healthy controls, found no evidence of an effect of multiple concussions in this domain (47, 49, 57, 64); though, despite finding no evidence of objective difficulties, concussed former athletes in Tarazi and colleagues' study self-reported significantly more subjective executive function concerns than controls (49). Using a bigger, potentially more severely concussed, sample than the other studies in this domain, Kaup et al. (56) found veterans with multiple concussions performed worse on a composite measure of executive function compared to those with one or zero concussions, in the range of a small effect (f^2=0.06; 56). Esopenko et al. (55) also found that former ice hockey players reporting multiple concussions performed significantly worse than controls reporting one or fewer concussions on the WCST (but not measures of inhibition). This small study did not report effect sizes or group scores on cognitive measures, so it is difficult to discern how clinically meaningful this finding was. A further study used the SART with former Canadian Football players reporting multiple concussions and non-concussed controls (47,50). The authors concluded their results were indicative of lower response inhibition. However, it was acknowledged this test may be influenced by factors other than inhibitory control given this is not the cognitive domain it was primarily designed to assess. One study alone assessed working memory, using Digit Span and Spatial Span tasks (47). The authors found no

significant differences between multiply concussed former Canadian football players and controls. Overall, evidence for an effect of multiple concussions on executive functioning in later-life was mixed.

Language

Nine publications across five studies used measures of language (51, 52, 56, 58, 60, 61, 64, 66, 67). Only two, comparing former athletes with healthy controls, found evidence of an effect of multiple concussions in this domain (60, 61, 64, 66). One presented evidence of mild difficulties in confrontation naming and word finding (using the BNT/SORT Naming) in multiply concussed former American football players compared to non-concussed controls (66). An effect size calculation based on reported group mean and standard deviations indicated this was in the range of a large effect (d=0.87). Yet, no significant association was found between frequency of concussions and scores for confrontation naming nor word finding (64,67). No effect of multiple concussions was found in verbal fluency (Animal Fluency/COWAT) (64,67). Two studies, in sports (58) and veteran (56) populations, found no linear trends in scores on measures of confrontation naming and verbal fluency across participants with multiple, versus one or fewer concussions. The former study did not give a clear description of how, or if, they defined concussion to participants, which may call to question the validity of these participants' self-reported concussion histories. Conversely, Tremblay et al (60,61) found former university-level athletes with multiple concussions reported significantly lower semantic (though not phonemic) fluency scores than those with no concussion history on a verbal fluency task (a medium-large effect, d=0.79). It is unclear how this sample was recruited, and therefore selection bias may limit interpretation of this finding. On the other hand, concussion classification criteria in this study were applied stringently, and it is possible the inconsistency in findings may reflect the differences in methodologies and measures used across these studies. Overall, there was some evidence of

potential effects of sustaining multiple concussions on semantic verbal fluency, word finding, and confrontation naming.

Perceptual-Motor Function

Seven publications reported findings on perceptual-motor function from six studies (46, 47, 49, 51, 52, 55-57, 60-62, 64, 67). Only one reported evidence of reduced performance in this domain for participants with multiple concussion histories (57) - in motor function. Macmillan et al. measured fine motor coordination in the hands using a Grooved Pegboard task, reporting poorer performance in the dominant hand for concussed former rugby players compared to healthy controls. However, note that former players' scores on this test still fell within the 'Normal' range, and a similar investigation comparing multiply concussed former Canadian football players to non-concussed controls found no significant differences in scores using this measure (49). Ruiter et al. (46) found no significant group-differences between former Canadian football players with multiple concussions and non-concussed controls on a measure of motor speed (ImPACT), although it is not clear to what extent this was an appropriate measure to have used with their sample, as it was designed to support return-to-play decisions in the immediate aftermath of concussive injuries, and has no normative data available for the age range of many of the participants in the sample (46). Measures of visuospatial function (most commonly the JLO/ROCFT) were used in five studies to compare retired athletes with multiple concussions to healthy controls (51, 52, 55, 57, 62, 64). Across these studies, no evidence of deficits in visuospatial function following multiple concussions were found. Overall, the evidence reviewed suggests that individuals who have experienced multiple concussions do not demonstrate later-life deficits in perceptual-motor function.

General Cognition/Intelligence

Two studies used measures of *general* cognition with former American football players. Clark et al. (54) reported no significant differences in global scores of two neuropsychological batteries (WAIS-IV/RBANS) between participants with three or more concussions compared to those with one or fewer concussions. Using self-report measures, Roberts et al. (45) found that subjectively poor cognition-related quality of life was found to be significantly associated with frequency of previous concussions. It should be noted that this study implied required loss of consciousness in their classification of concussion; given previous research suggests only approximately 10% of concussions are associated with loss of consciousness (78), it is possible that the injuries reported by participants in this study were comparably more severe than in other studies. Several included studies additionally used brief screening measures of intellectual or general cognitive decline with former athlete populations (47, 57, 58, 60-62). Due to differences in the measures used and criteria used to operationally define general cognition, no meaningful comparison of these additional findings is possible.

Discussion

Summary of Findings

This study aimed to systematically review the evidence relating to whether a relationship exists between multiple concussions and later-life cognitive decline. It aimed to advance the results of previous reviews by using more specific criteria in relation to participant age and concussion exposure, as well as seeking to include evidence on a broader range of populations known to be susceptible to experiencing multiple concussions. Using a systematic search strategy and predefined eligibility criteria, 23 articles were identified which compared cognitive functioning in individuals with a history of multiple concussions and controls, using a variety of neuropsychological measures. Results were synthesised for the

domains of complex attention, learning and memory, executive function, language, and perceptual-motor function. Overall, fewer than half of the reviewed studies presented any evidence of an effect of multiple concussions on cognitive function, and no studies reported that concussed participants demonstrated clinically significant cognitive impairment. Across the domains, the strongest evidence was for subtle effects of multiple concussions on (verbal) learning and memory, and language; evidence on executive function was mixed; and the evidence did not support effects in the domains of complex attention or perceptual-motor function. These findings are largely consistent with those of previous reviews (13-15, 89-92), which suggest that some 'detectable', but likely non-clinical, differences in cognition (in particular, memory) between concussed and non-concussed participants may be attributable to repeated concussion exposure.

Interestingly, all studies that included self-report measures of cognitive function consistently found significantly increased *subjective* cognitive concerns in participants with multiple concussion histories compared to non-concussed controls (45, 49, 55, 63), even in the absence of objective difficulties, which is in keeping with the findings of a previous review (13). It has previously been suggested that subjective cognitive difficulties may be an early detectable sign of some neurodegenerative conditions (e.g., Alzheimer's disease; 79,80). On the other hand, this finding could be indicative of a psychological component to subjective cognitive concerns experienced by those who have sustained multiple concussions, in line with the assumptions of the CSM (21).

Limitations of the Literature

The findings of this review should be interpreted cautiously given several limitations of the literature. In general, ascertaining concussion exposure by retrospective self-report may be problematic, with evidence in the wider literature suggesting the reliability of self-

reported concussion history, when compared with accurately recorded concussion incidence, 'may be low' (81). The literature has been criticised for a 'lack of precision' in the term *concussion* (82), and the results of this review similarly highlight that a standard definition is urgently needed to increase the validity of findings in this area. All included articles used cross-sectional designs, therefore causal inferences cannot be made about the relationship between multiple concussions and later-life cognitive function. Moreover, the included studies mostly used small samples and did not report power calculations, thus it is unclear the extent to which many of the studies could be underpowered. This is important, considering the high proportion of null findings discussed above. The homogeneity of populations of focus in the included studies is a further limitation of the literature (i.e., only one study was identified which did not use a former athlete population). Moreover, the studies reviewed almost exclusively used male participants, which represents an important gap in the literature - especially given research suggesting that, within comparable settings, female athletes may sustain a greater number of concussive injuries compared to males (83, 84, 85).

Limitations of this Review

A strength of this study was the systematic review method used and comprehensive search for evidence. Nevertheless, as can be seen in Figure 1.1, a large number of articles were excluded at the full-text screening stage for not ascertaining multiple concussion exposure, or due to using samples with lower average ages than the *a priori* cut-off set for this review. Since we aimed to provide a more rigorous evaluation of the literature than has previously been conducted and given the intended inclusion of different populations across the concussion literature, the use of stringent and consistent eligibility criteria in this review, in relation to both of these variables, felt essential. However, it is acknowledged that this may have led to some studies being excluded which may have correctly assumed multiple

concussion history using proxy measures and therefore may have been relevant to the research question.

The NOS, used to appraise the methodological quality of the included studies, has previously been recommended by the Cochrane Collaboration as a tool for assessing risk of bias in observational research (86). However, the cross-sectional version is not fully validated and was further adapted for this review, which weakens its psychometric properties. This was addressed by reporting the results of the risk of bias assessment descriptively, rather than giving the studies interpretive quality ratings. Due to limited resources, only English language studies were included. Also, the second reviewer screened only at the stage of full-text screening and independently conducted NOS assessments of only 30% of the included studies. Whilst reliability measures taken at each stage were considered satisfactory enough for the first reviewer to complete these tasks alone, these measures would not have completely reduced the bias inherent in this review being conducted mostly by one reviewer.

Clinical Implications

Returning to the CSM (21), the model assumes illness-related beliefs can be updated over time. Therefore, it is hoped that the current findings will be useful to clinicians in developing psychoeducation that more accurately reflects the state of the evidence, to counter promotion bias in the media. Importantly, there are notable differences in the sports literature and wider mTBI literature in how concussions are defined and treated (87). Witnessing the types of head injuries that are treated in professional sports settings (i.e., potentially at the lower end of what could be classed as a ‘concussion’ due to a cautious approach to head injury management in elite sports settings; 7) may, over time, lower the public’s threshold for what they perceive to be a concussion, and mean more individuals are exposed to mixed messages about the severity, cause, likely time-line, and later-life consequences of

concussive injuries. It will be important for psychoeducation to emphasise that the current evidence relating to multiple concussions provides no strong indication that there exists any significant risk of later-life cognitive impairment.

Conclusions and Future Directions for Research

This review found no conclusive evidence of a relationship between multiple concussions and later-life cognitive decline. However, there were large differences in the methodologies and quality of the included studies. There is a need for additional research which addresses current limitations of the literature, by employing longitudinal designs, using larger samples, addressing selection and recall bias, and improving control of potential confounding variables. To assess the generalisability of current findings outside contact-sports populations, future research should also aim to fill gaps in the literature by including under-studied non-sporting populations susceptible to sustaining multiple concussions.

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Service Improvement Project

"When You're on a Machine, You Want Some Kind of Humanity Around You": An Exploration of the Psychosocial Needs and Experiences of Patients with End-Stage Renal Disease Treated with Haemodialysis in a Regional Renal Service

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External Supervisor: Dr Louise Hankinson

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Abstract

Aims: This study aimed to provide a descriptive exploration of the psychosocial needs and experiences of patients receiving hospital-based haemodialysis treatment in a regional renal service, in order to inform meaningful developments in the provision of emotional and psychological support within the service. *Design:* A qualitative study using semi-structured interviews and questionnaires was conducted between September and December 2020. *Method:* A sample of 34 patients receiving hospital-based haemodialysis treatment participated in the study. Interviews were conducted with seven participants about their experiences of living with haemodialysis and receiving support from the service. To maximise the proportion of unique patient perspectives that could be included, interview data were supplemented with open-ended written feedback from a further 27 participants. Both datasets were combined and analysed using thematic analysis. *Results:* Four themes were developed from the qualitative data: *'a restricted life', 'the psychological impact', 'coping',* and '*meeting patient needs.' Discussion:* The findings demonstrated a considerable impact on quality of life for patients living with haemodialysis and highlighted the need for an integrated approach to providing renal care. Identified needs are discussed and recommendations are made to the service to guide future developments in the emotional and psychological support offered to patients receiving haemodialysis treatment.

"When You're on a Machine, You Want Some Kind of Humanity Around You": An Exploration of the Psychosocial Needs and Experiences of Patients with End-Stage Renal Disease Treated with Haemodialysis in a Regional Renal Service

Chronic kidney disease (CKD) is a long-term condition characterised by a progressive decline in kidney function. CKD is divided into five stages of increasing severity, the last of which is reached when the kidneys are functioning below 15% of their expected capability (Kidney Research UK, 2017). At this stage, patients are described to be experiencing end-stage renal disease (ESRD) and require medical intervention using dialysis or kidney transplantation to survive (NICE, 2014). Haemodialysis, which involves the use of an external machine to perform the role of the kidneys, is the most common treatment for patients with ESRD. Haemodialysis takes up to five hours and must be repeated several times per week (NICE, 2018). The most recent prevalence data estimated that over 25,000 people with ESRD in the UK receive hospital-based haemodialysis treatment (MacNeill et al., 2018).

As well as the physical impact of ESRD, patients receiving haemodialysis experience psychosocial challenges linked to their illness and treatment, including fluid and dietary restrictions, repeated hospitalisations, and potential losses relating to employment, family role, leisure activities and sexual function (Gerogianni & Babatsikou, 2013). It is recognised that the process of adjusting to these changes can be difficult and negatively impact patients' quality of life and psychological wellbeing (e.g., Chan et al., 2011; Cukor et al., 2007). The most common psychological difficulties reported in patients receiving haemodialysis are depression and anxiety, although prevalence estimates for both vary across the literature, from 7-50% and 12-52%, respectively (Palmer et al., 2013; Murtagh et al., 2007). Several studies have described important clinical implications of untreated psychological distress for this population, including non-adherence to treatment (Seng et al., 2020; Reyes et al., 2021)

and increased rates of hospitalisation, morbidity, and mortality (Hedayati et al., 2010; Loosman et al., 2016; Schouten et al., 2019).

Provision of emotional and psychosocial support is an integral part of the National Health Service's (NHS) approach to the management of all long-term conditions (Department of Health, 2014) and is increasingly emphasised across national renal guidelines and quality standards (Department of Health, 2004; 2005; NICE, 2014). Nevertheless, recommendations about what shape this support should take remain vague, with the current NHS England service specification for hospital-based haemodialysis (2017) stating patients should be offered access to psychological support 'as required'. Thus, whilst the importance of renal services being able to effectively identify and address psychological distress as part of delivering comprehensive care is clear, it can be difficult to contextualise current recommendations in terms of developing this support within individual services. Following from this, the current project was commissioned by a regional NHS renal service, with an aim of developing a greater understanding of the psychosocial needs and experiences of patients receiving haemodialysis, to inform meaningful improvements in the service's provision of emotional and psychological support for this group of patients.

Several methodologies exist to guide the structure of service improvement projects in healthcare settings. One widely used method involves Plan, Do, Study, Act cycles (Taylor et al., 2014), through which service improvement is guided by the following steps: ***Plan***. Agreeing objectives to be met and developing a plan to address them; ***Do***. Carrying out the planned activities/intervention and collecting data; ***Study***. Conducting analysis of the data and reflecting on what was learnt; and ***Act***. Preparing actions to inform subsequent PDSA cycles. In this way, improvement is seen as an iterative process, with multiple cycles needed to build knowledge, test changes, and achieve quality improvement. The PDSA method will be used

as a framework to structure this report, following an initial, exploratory iteration of a Plan, Do, Study, Act (PDSA)-based cycle.

Plan

The planning phase involved the trainee consulting with the clinical psychologist and Renal Clinical Lead of the commissioning service, to understand the service setting and define the objectives that the project would set out to accomplish.

Service setting. The service is run by a multidisciplinary team of consultant physicians, renal specialist nurses, patient advisors, dieticians, and a psychologist, who provide a range of inpatient and outpatient treatments for individuals with renal diseases, from diagnosis and early-stage disease management to provision of dialysis and kidney transplants. The supervising Clinical Psychologist reported that the service provides hospital-based haemodialysis treatment for approximately 120 patients at any one time in its primary unit, with additional patients seen in satellite units in neighbouring counties. Patients receiving haemodialysis attend the service in-person for treatment up to three times a week and the length of time patients remain users of the service ranges from days to many years.

Psychological support has been embedded within the service since 2016; all patients can ask to be referred to the Clinical Psychologist at any time or can be referred by a nurse or their consultant physician. Yet, it was observed that patients receiving haemodialysis frequently encountered the psychology service at the point of experiencing significant distress and reporting feeling unable to cope with treatment. Furthermore, it was noted that in 2019-20, a significant proportion (up to 37%) of psychology referrals were for patients receiving haemodialysis. The service therefore wanted to explore whether there may be

psychological needs in patients receiving Haemodialysis treatment going unrecognised, or that could be better supported earlier on.

The main aims for the project were agreed as follows[1]:

(1) To explore the emotional and psychological needs of patients undergoing haemodialysis, from a patient perspective

(2) To explore patient experiences of receiving emotional and psychological support from the service; and

(3) To use the findings to inform recommendations on potential areas for service improvement.

The trainee facilitated further consultations with four members of the nursing team and two patient representatives, to shape how the proposed project could be most relevant and beneficial to the service and prioritise areas to explore with participants.

1. As a further aim, the service were interested in investigating the prevalence of depression and anxiety symptoms in patients undergoing hospital-based haemodialysis treatment. Results pertaining to this aim are included as a supplementary analysis in Appendix M.

Do

Overview

A qualitative semi-structured interview and questionnaire design was used to explore patients' psychosocial needs and their experiences of receiving support as patients of the service. Data collection took place between September and December 2020. The method and reporting followed the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) guidelines (Tong et al., 2007).

Participants

Participants were 34 patients of the renal service. All patients were invited to take part if they were aged 18-years or older and receiving hospital-based haemodialysis - and deemed by the nursing team to have capacity to give informed consent. Purposive sampling was used due to the specific aims and small-scale nature of this project, in order to take a focussed look at one group of patients (i.e., patients receiving hospital-based haemodialysis treatment). Of this sample, a consecutive self-selecting sample of seven participants took part in one-to-one interviews; 27 gave written feedback via a questionnaire.

Measures

Brief demographic and medical details were collected by self-report including gender, age, time on dialysis and primary cause of kidney failure.

Interviews

A semi-structured interview schedule was developed (see Appendix I). Areas explored included psychosocial experiences related to living with dialysis, experiences of receiving emotional and psychological support from the service, facilitators and barriers to accessing support, and suggested improvements to the support offered by the service.

Written Feedback

In line with the broad areas explored in the interview schedule, participants who chose to give written feedback were offered free-text space with no word limit to respond to the following questions:

1. *Dialysis doesn't just impact your physical health; it can also affect you emotionally and mentally. In your words, what are some of the ways it can impact you emotionally and mentally?*
2. *Do you feel that these needs are being recognised and supported? What has helped (or not helped) with this?*
3. *What else might be helpful to support dialysis patients emotionally and mentally, and how might this be provided?*

Data Collection

Recruitment was conducted in collaboration with unit staff. Eligible patients were given written information about the project upon arrival to their routine dialysis appointment during one week in September 2020. Given the prevalence of cognitive and visual difficulties within this population, a psychology student on placement with the service offered support to those completing written feedback in-clinic. As a hospital-based service, the Trust did not routinely gather consent for contacting patients for the purpose of research and audit, thus recruitment was mostly limited to patients with appointments on days data was being collected in-clinic. Furthermore, data collection took place during a time of restrictions in place in response to the Coronavirus-19 pandemic, which limited the time staff had available to support recruitment. Therefore, the planned number of participants to be included in the study was chosen based on practical considerations and it should be considered that the sample may not be representative of all patients who use the service. No information was available about patients who chose not to take part.

Participants who gave consent to be contacted for an interview (n=12) were emailed an invitation to arrange this. A reminder was sent two weeks later to participants who did not respond. Seven participants were successfully contacted for interview, which took place individually via Microsoft Teams video call (n=5) or, where this was not possible, telephone (n=2). Interview questions were delivered flexibly, allowing topics raised by participants to be explored. The first interview served as a pilot; following this, it was not felt any changes to the interview schedule were needed, and the data from this interview was included in the analysis. Interviews lasted 36-54 minutes and were audio-recorded to allow verbatim transcription. Transcripts were checked for accuracy and anonymised before recordings were deleted.

Ethical Considerations

Approval as a service evaluation was granted by the local service provider's clinical audit team (Reference 5948; see Appendix K); full NHS ethics was not required. All participants were provided an information sheet and gave written informed consent before taking part (see Appendix L). Given the personal nature of the topics discussed, time was taken at the end of each interview to debrief participants and ensure they were not experiencing distress following their participation.

Study

Analysis

Descriptive statistics were used to summarise the demographic characteristics of the sample. Data from the interview transcripts and questionnaire responses were combined into one dataset for analysis, as both addressed the same project aims. Thematic analysis was performed, using the six-phase methodology outlined by Braun and Clarke (2006). First, interview transcripts and free-text questionnaire responses were read and re-read, in order for

the trainee to be familiarised with their content. Preliminary codes were generated inductively for all potentially relevant quotations across the entire dataset, using NVivo (Version 12). Codes were then examined and collapsed into potential themes, based on patterns of similarity and dissimilarity at the semantic level. Themes were reviewed and refined, with codes and extracts re-visited to ensure themes made sense in terms of the data set and addressing project aims. Finally, descriptions determining the scope and focus of the themes were developed, with an overarching name decided for each. Thematic analysis was chosen as an approach that was suitable for being applied flexibly in order to integrate data collected using multiple methods (Braun & Clarke, 2006). The analysis was completed from a realist stance (i.e., assuming a unidirectional relationship between meaning, experience, and language), as the project aimed to provide recommendations for service improvement, rather than theorise participants' meaning making around their experiences. One of the patient representatives remained involved to undertake lay member validation, discussing with the trainee his thoughts on a preliminary written draft with regards to whether emerging findings seemed useful, meaningful, and to reflect the data accurately from his perspective. Overall, he reported that the descriptions of themes and subthemes resonated with his experiences. His feedback on one of the subthemes (i.e., impact on social relationships) led the trainee to return to the analysis of the whole dataset and resulted in a more complete subtheme description.

Results

Demographic Characteristics of the Sample

Table 2.1 presents demographic characteristics. The most commonly reported age group was 65-74, followed by 45-54, and the majority of participants (71%) were male. Complications of diabetes was the most frequent known cause of ESRD (21%), followed by

Table 2.1.

Summary of demographic and medical characteristics of participants.

	Interviews	***Written Feedback***	***Totals***
	N	*N*	*N (%)*
Gender			
Male	5	19	24 (71%)
Female	2	7	9 (26%)
Age Range			
35-44	0	1	1 (3%)
45-54	1	9	10 (29%)
55-64	2	2	4 (12%)
65-74	2	8	10 (29%)
75+	2	6	8 (24%)
Aetiology			
Diabetes	0	7	7 (21%)
Unknown cause	1	4	5 (15%)
Kidney diseases	1	3	4 (12%)
Medication	2	1	3 (9%)
Autoimmune disorders	1	2	3 (9%)
Congenital cause	0	3	3 (9%)
Cancer	0	2	2 (6%)
Transplant failure or kidney injury	0	2	2 (6%)
Infections	1	0	1 (3%)
Urinary tract blockages	1	0	1 (3%)
Hypertensive disease	0	1	1 (3%)
Drugs and alcohol	0	1	1 (3%)

[a] Data were missing for gender (n=1) and age (n=1), thus percentages for these variables do not all add up to 100.

specific kidney diseases (12%) and medication (9%). The time participants had been on dialysis ranged widely from three months to 11 years.

Thematic analysis

Four themes and 13 sub-themes were developed from the coded data (see Figure 2.1 for an overview). Themes and subthemes are described below, alongside illustrative quotes chosen for each from across all interview transcripts and questionnaire responses.

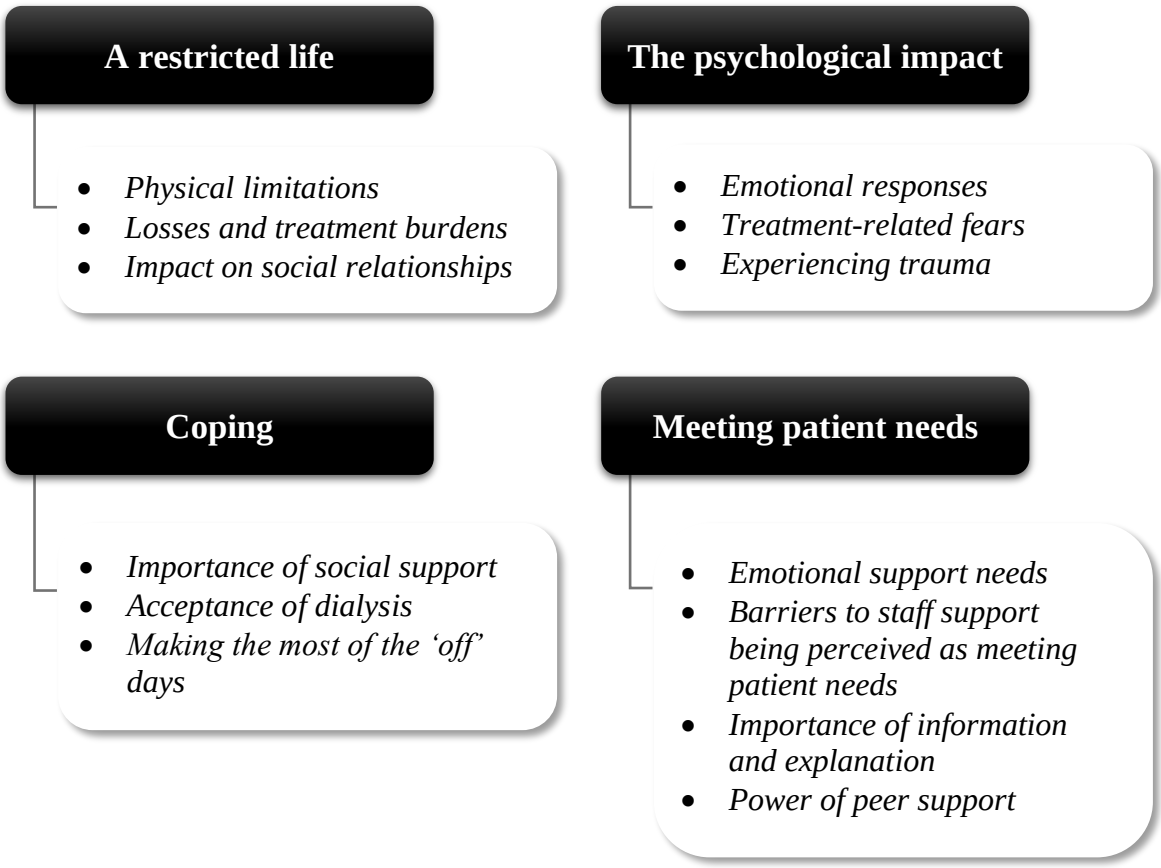


Figure 2.1

Overview of themes and sub-themes

Theme 1: A restricted life

This theme reflected participants' stories about the impact dialysis had on their ability to participate fully in life and perform meaningful life roles.

Physical limitations

The impact of dialysis was frequently described in terms of physical problems participants experienced, and things they perceived they could no longer do as a result. Pain, weakness, and lack of energy were highlighted as having a significant impact on participants' daily lives and functioning, in turn negatively impacting their emotional wellbeing.

> "…even ironing, the iron just feels so heavy, you feel weak all the time...Things like that, when you know you should be able to do them... I've got no energy. It's depressing" (P4, female, 55-64).

> "It leaves me fatigued and in pain which severely demotivates me and stops me processing things the way I normally do. The pain can be a major depressant when it is severe and debilitating, and I often dread dialysis" (Q, male, 45-54).

Losses and treatment burdens

Across all interviews, participants described a range of losses they associated with dialysis, notably including loss of work, independence, and personal freedom. One participant described how losing his working role affected his sense of identity and purpose:

> "I had a lot of pride in what I did… That's a huge sense of loss for me that I still haven't got over… I'm left trying to find a new purpose, is the personal problem I'm going through" (P6, male, 45-54).

Practical treatment burdens including diet and fluid restrictions, and especially the time involved with attending dialysis appointments, were further raised as limiting participants' lifestyles ("quite seriously", P2, male, 65-74).

> "Dialysis is about hanging around. You seem to be forever waiting." (P5, female, 55-64)

Impact on social relationships

Participants also described how living with dialysis impacted their relationships, wider family, and interactions with others. Participants described an increased '*reliance on others*' since their illness. As a result, many experienced changes in roles held within family relationships, as loved ones took on caregiving responsibilities. Several participants reflected on challenges this brought into their relationships.

> "It did put a strain on our relationship, in that it's such a big thing. Such a big responsibility for her and something out of the blue" (P2, male, 65-74).

Participants also described changes in the perceptions and attitudes of others towards them; descriptions ranged from friends and loved ones treating them differently since their illness, to experiencing social stigma and discrimination. For two participants, concerns around what others would think led them to attempt to hide their illness.

> "…now they say, 'oh now you've got to be careful'". (P7, male, 65-74)

> "It doesn't help when you're being told you're not really ill because, walk a mile in my shoes and you'll know what it's like.... It's not, it's not something you can see. You can't see a broken leg or a broken arm, it's all inside" (P4, female, 55-64).

Theme 2: The psychological impact

This theme encompassed participants descriptions of their emotional and psychological experiences in relation to receiving dialysis.

Emotional responses

Participants described experiencing a range of emotional responses to their illness and treatment. For some, this included feeling '*low'* and '*upset'*, '*anxious'*, '*stressed'*, '*anger'* and '*frustration'*, which were often described as consequences of the physical and social limitations participants faced living on dialysis.

> "It's depressing because you want to go out and do things, you have really down days…You get upset at the slightest thing" (P4, female, 55-64).

> "Some of us are on three days a week, which is a hell of a drain on your mental health… I do feel low sometimes" (P3, male, 75-84).

A few participants further expressed a sense of hopelessness, with one describing feeling '*trapped in an endless repeating cycle' (Q, male, 45-54).*

Notably, however, several participants did not report negative feelings and considered themselves to be coping well with dialysis.

> "I don't think it does have a mental impact on me at all really. It doesn't bother me at all". (P7, male, 65-74)

Treatment-related fears

Some participants reported feeling *'confused and disturbed*' (Q, male, 65-74) by dialysis initially. One participant recalled an example of an early session in which he experienced a strong reaction to having dialysis:

> "The really weird thing was the first time I held on to the lines and they were warm… that was a real almost freak out moment for me… at that point, I realised that actually, this was my life essence coming out of my body". (P6, male, 45-54)

Other participants reported ongoing fear and uncertainty about the future. In this regard, several participants reported fears about future physical deterioration, including of their heart and veins, as well as further decline in kidney function. Across the interviews, participants also reported experiencing fears about death and their mortality.

> "…there's so many people dying and although they do die in life, for other people it's not in front of front of you all the time". (P4, female, 55-64)

Experiencing trauma

Some stages of the dialysis journey were described as more difficult than others; in particular, participants who experienced commencing dialysis as traumatic suggested that they would have appreciated additional support and information around this.

> "I collapsed at work and ended up at [A&E]… by Thursday I was having an operation to start me up on dialysis. So, all of that was just a blur. In all, I was thinking that I'm gunna die because I didn't know anything..." (P4, female, 55-64).

Memories of difficult and upsetting experiences in previous dialysis sessions were also seen to prompt worries for some participants about future sessions.

> "I've had a few traumas where things have gone wrong…the very first time I had a real trauma with the needles, there was blood everywhere. So that's, that's a bit of a tension forming…" (P3, male, 75-84).

Theme 3: Coping

This theme included things participants expressed were important in enabling them to cope with the impact of dialysis.

Importance of social support

Participants emphasised the role of support from their family and friends as a means of coping and adapting to living with dialysis.

> "It is my family who provide the greatest recognition of my needs and give tremendous support" (Q, male, 65-74).

One participant also described how their faith linked them into a religious community, providing them a further source of social support. In contrast, participants without a strong support network expressed they would appreciate some additional form of support.

> "I think it would be nice if there was more, if you felt you were struggling, particularly if you're living alone". (P2, male, 65-74)

Acceptance of dialysis

Many participants identified the importance of acceptance of dialysis in helping them to cope. For some, acceptance reflected a perceived value of dialysis in keeping them alive, regardless of its challenges.

> "…however tedious and cross it makes me feel, at least it gives me the option to continue life" (P2, male, 65-74).

For others, acceptance was described in more resigned terms - of recognising they had no alternative. These participants found that a pragmatic attitude of *'getting on with it'* enabled them to cope.

> "I just think I've got to have it done and that's the end of it. I'm quite black and white…I can't not do it". (P5, female, 55-64)

Making the most of the 'off days'

Several participants reported that concentrating on making the most of the days they do not have dialysis helped them to feel that life and dialysis were worthwhile.

> "…the next free day, I really try to put it out of my mind and make the most of life...makes life sort of, of value, worthwhile really, because if it was dialysis every day I'm not sure I'd want to continue for a great length of time". (P2, male, 65-74)

Connected to this, participants expressed a desire to retain a sense of '*normality'* outside of treatment, and to continue previously meaningful activities.

> "I am very determined to do as much as I can do...As I see it, the point for me is to try and go on doing the things that I was doing before this wretched thing" (P1, male, 85-94).

Theme 4: Meeting patient needs

This theme reflected how well current service provision was described to be meeting patient support needs.

Emotional support needs

The importance of emotional support being offered alongside support for physical renal health was raised by almost all participants, with one describing a need for patients to be seen as '*whole people, rather than kidney patients*' (P5, female, 55-64). Most participants described positive experiences of emotional support from professionals in the service, emphasising the '*patience*', '*kindness'* and '*caring attitudes'* of the nursing team in making them feel supported and safe during dialysis sessions.

> "…they are so gentle. They're so caring, I feel very comfortable there...I don't know how they have the patience sometimes to go on being so kind, but I find that very supportive". (P3, male, 75-84)

> "A couple of them are just brilliant, absolutely brilliant. They make you feel really safe". (P5, female, 55-64)

Participants reported finding informal emotional support from staff particularly helpful, in which they simply had someone to talk to and felt heard.

> "Really, it's a case of needing someone to talk to, isn't it? That's what it boils down to.... when you're on a machine, you want some kind of humanity around you". (P1, male, 85-94)

However, for this to be seen as meeting patient support needs, participants felt it important for professionals to create a space for patients to raise emotional issues; having to start this conversation themselves was mentioned as a barrier to accessing emotional support.

> "When someone comes and asks you, it's different from you having to be the one to open up first. Sometimes you need that conversation, that space to be there first". (P4, female, 55-64)

The two participants who had experience of accessing formal psychological input from the service were positive about the support they had received and reported this input had been helpful. Of those who had not accessed formal psychological support, a number

identified that they would have liked some form of additional emotional support at certain points of their dialysis journey – primarily around diagnosis and commencing dialysis.

Barriers to staff support being perceived as meeting patient needs

Although most participants described positive experiences of care and support that they had received from the service, some voiced complaints about staff-patient interactions and organisational culture. In this regard, some participants commented on their perception of constraints on the nursing team, especially of them being '*too busy'*, which they felt had been a barrier to them receiving emotional support.

> "The nurses often seem to think of patients as numbers to be got through as quickly as possible. There is a need for nurses to realise that patients are people who have lives of their own". (Q, male, 75+)

> "They are so busy. They don't have the time to be the caring aspect of the nurse as opposed to the clinical aspects of the nurse". (P6, male, 45-54)

Importance of information and explanation

Across the interviews, participants reported variability in the information they had received about what to expect from treatment. In particular, participants who had started dialysis unexpectedly, or under emergency circumstances, felt they were given very little information or explanation at the outset of treatment. Others felt that they had been given enough medical information but were not well enough prepared for the psychological impact of dialysis.

> "I was very, very frightened. I didn't know what was going on. Nobody really spoke to me and took me step by step as to what was happening". (P1, male, 85-94)

> "While I was aware of what was clinically going to happen for me, perhaps I wasn't quite as aware of how it was going to affect me, psychologically". (P6, male, 45-54)

One participant felt that this information was available, but that the responsibility was on the patient to ask for it.

> "I basically had to find things out by asking questions... things which I think I should have been told about...I think there should be more of an induction for patients". (P3, male, 75-84)

Nevertheless, provision of information proved to be the most common area participants in this study suggested could be improved by the service. Across the interviews, participants saw having sufficient and tailored information early on in dialysis care as being essential to managing initial fears about treatment as well as helping patients feel a greater sense of control.

> "One thing I would suggest to you is that there needs to be much clearer explanation to new patients coming in… They need to understand what the situation is, why they're going to be wired up to a machine for so many hours. And then it's all right, it isn't some kind of, some kind of torture". (P1, male, 85-94)

Notably, most participants reported being unaware of what psychological support was available to them as dialysis patients.

Power of peer support

Finally, participants spoke about valuing opportunities the service had provided in the past for patients on dialysis to meet other patients and share their experiences. Ideas for increasing peer-led support were proposed by participants, including peer support groups and online networks.

> "… there are these really useful patients who, you know, people who just can openly talk about it, what it's been like for them long term… it's almost the 'we are not alone' moment… I am not the only person. The general journey is the same for all of us and that's comforting to know". (P6, male, 45-54)

Act

The above findings were discussed with the clinical psychologist and shared with the Clinical Renal Lead. Several recommendations for service development were made, as outlined in Table 2.2. Feedback from the Clinical Psychologist and Clinical Renal Lead indicated that the project aims were met. Plans have been made for the trainee and supervising clinical psychologist to present the findings to the wider team as part of an existing improvement initiative within the service, “Education Express”, and as part of this to facilitate a reflective discussion with team attendees about how the findings and recommendations could be used within the service and taken forwards on a day-to-day basis within their roles. The supervising Psychologist also discussed plans to incorporate the findings of the project into teaching sessions run for staff members at the unit. Other initial ideas raised during discussions with the trainee included the possibility of reinstating a patient’s conference which previously was held in the service, which was an event aimed at providing information about haemodialysis to new patients and acted as a platform for patients to share their experiences with each other; and exploring the feasibility of running a group intervention, possibly aimed at supporting patients with adjusting to and coping with life on dialysis. It will be important for future work to evaluate any such changes that are implemented in response to the findings of this project, thus the next PDSA cycles should focus on implementing and evaluating the actions identified by the service.

Table 2.2

Recommendations for areas of service development arising from the project

Area	Recommendations
1. Awareness of psychosocial issues	To support care planning, conduct ongoing assessments of psychosocial stressors, coping methods and social support in line with the themes raised as important by participants in this study. This would support early psychosocial intervention, and flag opportunities to strengthen support and increase patient coping strategies.
2. Information provision	Include guidance about what to expect of the emotional and psychosocial impact of dialysis in the information provided to patients at the start of dialysis treatment. Particular consideration should be given to the information available for patients when their start to dialysis is unplanned, as this seemed to be a potential gap relative to patients who had a planned start to dialysis. Information about the psychological support available in the service and how to access it should be available to all patients. Based on the expressed value participants placed on receiving information from a peer voice, consider expanding on the findings of this project by developing a resource with patients about their experiences of the psychosocial impact of dialysis, with a view to normalising common emotional responses to treatment for patients commencing dialysis.
3. Creating a space for informal emotional support	The role of patient-staff communication was emphasised in promoting coping and emotional wellbeing. In particular, participants valued staff offering informal chats, where they listened and showed empathy. This was a particular strength of current service provision that the service should continue to build on.
4. Peer support	Consider ways to increase opportunities within the service for peer-led support and sharing of experiences.

5.	Clinical psychology provision	Signpost to clinical psychology patients who experience the beginning of dialysis treatment or events in subsequent sessions as traumatic, as this was identified as a factor in increased anxiety around dialysis procedures and perceptions of not coping with treatment. Consider introducing an evidence-based group intervention around coping with dialysis and feeding this into an open peer support group. This approach may be more appropriate than individual therapy given limited resources and potentially high need for support - and would also provide a context for patients to support each other.
6.	Future research	Whilst qualitative interviews with patients were an effective method of exploring the support offered by the service, staff perspectives were not captured. Given participants identified the vital role the nursing team play in making them feel supported and listened to, and conversely the impact of perceived service pressures on this support, interviews with staff would provide additional valuable information.

Discussion

This study aimed to explore patient perspectives of the main psychosocial issues facing patients on haemodialysis and their experiences of receiving support from a regional renal service, in order to inform meaningful developments in the provision of emotional and psychological support within the service. In addressing the aims of the study, four themes were identified from qualitative data: '*a restricted life'*, '*psychological impact'*, '*coping*' and '*meeting patient needs.*' Consistent with previous literature, the findings demonstrated a considerable impact on quality of life for patients living with haemodialysis. In this regard, participants described experiencing decreased physical health, loss of meaningful life roles and activities, restrictions in time and freedom, changes in social relationships, and changes in emotional and psychological wellbeing, highlighting the importance of taking an integrated approach to providing renal support. These findings largely replicate those of qualitative studies with other groups of patients with ESRD cross-culturally (Gerogianni & Babatsikou, 2013; Tong et al., 2009; Frontini et al., 2020; Jones et al, 2017; Ng et al., 2020). Notably, themes common in the literature that did not arise in the current study include the impact of dialysis on body image and sexuality (Álvarez-Villarreal et al., 2019; Theofilou, et al., 2013), and cognitive functioning (Jones et al, 2017).

In general, the findings demonstrated that the service is providing good quality care that largely meets patient support needs. Participants identified the important role that informal and day-to-day staff-patient communication plays in helping to meet the emotional support needs of patients, and preferred an approach from staff in which they felt the focus was on themselves, rather than on their kidney disease. In terms of areas for development, the main gap identified in current service provision was around informational support. In line with this finding, a previous exploration of informational needs in patients with CKD urged

clinicians to consider information about coping and adjusting to the psychosocial impact of CKD and its treatment, as well as details of who can provide patients with additional support when needed, as core information needs of all patients (Ormandy et al., 2008). Participants also highlighted a preference for peer-led support. There is a lack of research considering peer-led support and education programmes for ESRD, although in the broader CKD literature it has been suggested that peer support may offer aspects of emotional support such as feeling accepted and understood (Taylor and Gutteridge, 2013; Wood, 2014). Group-based approaches in general may be appropriate for these patients, given potentially prevalent psychosocial needs in a service with limited psychological resources – and there is some evidence in the literature that groups can lead to improvements in quality of life, mood, and anxiety for patients on haemodialysis (Duarte et al., 2009; Sohn et al., 2018). This also fits with clinical guidance from NICE (2009), in which group-based programmes with peer-support are one of the recommended interventions for adults with chronic physical health problems experiencing mild to moderate depression. Finally, participants described certain points in their dialysis journey as eliciting a stronger need for emotional support than others. In this regard, the time around diagnosis and commencing dialysis was identified by participants as a period that they felt patients would most benefit from additional support. Given this finding, future studies could focus on gaining further understanding of the needs of patients in the pre-dialysis clinics to explore what forms of targeted support may be useful at the early stages of, and preparation for, dialysis treatment.

Strengths and Limitations

An advantage of supplementing the interview data with open-ended written feedback was that a larger proportion of unique patient perspectives could be included. Recruitment for the study was guided by pragmatic constraints rather than principles of data saturation,

however no new themes were identified when analysing the final data, implying adequate content validity. Due to time and resource constraints, double rating was not completed – to enhance the trustworthiness of the analysis, lay member checking was carried out with a person with experience of dialysis. Nevertheless, the analysis presented is the trainee's interpretation of the data and other interpretations are possible.

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Please refer to Appendix O for a lay summary

of the service improvement project

Theoretically Driven Research Project

Thought-Action Fusion as a Mediator of the Relationship Between Mental Imagery and Obsessive-Compulsive Symptoms

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Thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology

Trinity Term 2021

Internal Supervisor: Dr Craig Steel
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Proposed Journal: Behaviour Research and Therapy. This journal publishes peer-reviewed research papers relevant to cognitive-behavioural models and methods - and 'encourages submissions investigating mechanisms that contribute to psychopathology and that offer new treatment targets' (see Appendix P for author guidelines).

Abstract

Aims: The purpose of this study was to extend research about the cognitive-behavioural model of obsessive-compulsive disorder (OCD), as it relates to intrusive mental images. It aimed to do this by investigating one mechanism potentially theorised to mediate the relationship between mental imagery and OCD symptoms, namely thought-action fusion (TAF), a cognitive bias relating to exaggerated beliefs about the *morality* of having certain thoughts or the *likelihood* that they will come true. *Method:* Participants (n=131) completed online measures relating to mental imagery use, TAF, and OCD symptoms. Mediation analyses were conducted using a percentile bootstrapping method. Participants were also asked questions about their lived experience of intrusive obsessional imagery. Secondary analyses (using a mix of quantitative and qualitative methods) compared the responses of participants who scored high for OCD, to those who scored low for OCD. *Results:* The proposed model of TAF mediating the relationship between mental imagery use and OCD symptom severity was supported in this sample. When likelihood- and moral-TAF were included in the model separately, only likelihood-TAF was a significant mediator. Also, participants scoring high for OCD reported more frequent, vivid, uncontrollable, and distressing intrusive images, and stronger likelihood- and moral-TAF appraisals of idiosyncratic intrusive images, than low scorers. *Discussion:* Overall, these results are in line with the key assumptions of cognitive-behavioural models of OCD. Findings are discussed, and the strengths and limitations of the study are considered.

Thought-Action Fusion as a Mediator of the Relationship Between Mental Imagery and Obsessive-Compulsive Symptoms

Obsessive-compulsive disorder (OCD) is characterised by the experience of obsessions and compulsions, where 'obsessions' are defined as recurrent and unwanted cognitions that can variably take the form of thoughts, urges, or mental images, and 'compulsions' are defined as repeated behaviours performed in response to these cognitions (American Psychiatric Association, 2013). Mental imagery is distinct from other forms of cognitions included in this definition, being conceptualised as mental representations "that possess sensory qualities, as opposed to those that are purely verbal or abstract" (Hackmann, 1998, p.301). In this way, mental images have been characterised as "'seeing with the mind's eye', 'hearing with the mind's ear', and so on" (Kosslyn et al., 2001). Previous research suggests that obsessions in the form of intrusive mental imagery are commonly reported by individuals with OCD, with prevalence estimates ranging from 81-95% (Lipton et al., 2010; Speckens et al., 2007). Yet, to date there has been comparatively limited research investigating the role of mental imagery within OCD. Interview-based phenomenological investigations suggest intrusive images in OCD tend to be recurrent and experienced as vivid and distressing (Lipton et al., 2010; Speckens et al., 2007) – and, like other types of intrusions in OCD, mental images are typically ego-dystonic in nature, featuring themes such as unacceptable harm, contamination, or blasphemy (de Silva, 1986; Lipton et al., 2010).

Psychological intervention, including cognitive therapy with exposure and response prevention, is recommended as a first-line treatment for OCD (NICE, 2005). Whilst this is known to be effective, previous meta-analyses show it is also associated with high drop-out and relapse rates, with up to 50% of individuals potentially requiring further treatment (Newman et al., 2008; Öst et al., 2015; Taylor et al., 2015). It has been suggested that

intrusive imagery may be particularly challenging to address using existing OCD treatments (McKay et al., 2015; Rachman, 2007), which has led to suggestions that augmenting existing treatments with imagery-specific therapeutic techniques may be beneficial for some individuals (Gapinski, 2000; Rachman, 2007). However, preliminary investigations targeting OCD-related imagery directly have yielded mixed outcomes (Maloney et al., 2019; Mpavaenda, 2016; Veale et al., 2015). Thus, whilst it makes intuitive sense that intrusive imagery would represent an important treatment target, further investigation of the role of mental imagery in OCD is warranted.

Cognitive-behavioural models of OCD (e.g., Rachman, 1997; Salkovskis, 1985) are based on an observation that unwanted intrusive cognitions are commonly experienced in some form (i.e., thoughts, images, or urges) by most people (e.g., Rachman & de Silva, 1978; Radomsky et al., 2014). According to these models, it is not the cognitions themselves, but rather an individual's appraisals of these cognitions and their responses to them, that lead to a cycle of increased distress and the development of obsessive-compulsive (OC) symptoms. This notion was further elaborated by the Obsessive-Compulsive Cognitions Working Group (OCCWG, 1997), who outlined several types of appraisals of intrusions thought crucial in understanding how obsessions and compulsions develop and are maintained. One of these, which may be relevant in understanding the mechanism underpinning the maintenance of intrusive imagery in OCD, is *thought-action fusion* (TAF; Shafran et al., 1996; Shafran & Rachman, 2004), a cognitive bias comprising two specific beliefs. The first is a belief that simply having a thought is morally equivalent to acting on the thought (i.e., 'moral-TAF'); second is the belief that having a thought makes it more likely that the content of the thought will happen (i.e., 'likelihood-TAF'; Shafran et al., 1996). As such, TAF represents underlying beliefs about the meaning of intrusive cognitions. Previous research has consistently supported an association between TAF and OCD, albeit with stronger evidence in relation to

likelihood-, than moral-TAF (Berle & Starcevic, 2005; Rassin et al., 2001; Shafran & Rachman, 2004).

Research has begun to highlight potential links between mental imagery and TAF. Recently, two fMRI studies aimed to explore the neurobiological basis for cognitive-behavioural models of OCD by using TAF induction paradigms with healthy participants (Lee, 2019; 2021). Both studies demonstrated brain regions responsible for visual imagery were activated during TAF induction, providing intriguing evidence that visual imagery may play an important role in the development of TAF. Furthermore, in a questionnaire study conducted with participants with contamination fears, Coughtrey and colleagues (2013) observed that intrusive contamination-related imagery was associated with increased levels of reported TAF. Therefore, whilst mental imagery has been shown to be uniquely able to directly influence the emotional systems in the brain (Holmes & Matthews, 2008; 2010; Lang, 1979; Rachman, 2007), it is also possible that intrusive images may contribute towards OC symptomatology through an indirect pathway. Considering this within a cognitive-behavioural framework and in light of recent research, it is possible that the experience of mental imagery contributes towards the formation of TAF biases, which in turn drive the development and maintenance of OC symptoms. Yet, the literature does not currently contain any studies which directly investigate the relationship between mental imagery, TAF and OC symptoms.

Study Aims

The aim of the current study was to contribute to the literature on the role of mental imagery in OCD. A cross-sectional design was used with participants who self-identified with OC experiences, to investigate the potential role of TAF in the relationship between

mental imagery and OC symptomatology. Based on preliminary research and the assumptions of cognitive-behavioural models of OCD, it is proposed that TAF may act as a mediator.

A secondary aim was to contribute to the literature on how mental imagery is experienced within OCD, by comparing self-reported intrusive imagery in individuals with different levels of OC symptoms. Previous empirical investigations are comprehensive but have tended to use small samples or participants recruited from specialist inpatient settings (e.g., Speckens et al., 2007; Lipton et al., 2010). Hence, it is unclear how representative their findings may be of the experiences of individuals with OCD. In this respect, this study sought to replicate and extend previous findings in a larger sample than has previously been studied.

Hypotheses

(1) Greater use of mental imagery will be associated with higher levels of TAF and OC symptoms.

(2) The relationship between mental imagery use and OC symptoms will be mediated by TAF.

    - Given previous research suggests that likelihood-TAF may be more specific to OCD than moral-TAF (Berle & Starcevic, 2005; Shafran & Rachman, 2004), further exploratory analysis of this relationship will be conducted by considering subscales relating to likelihood- and morality-TAF separately.

(3) Individuals who report higher levels of OC symptoms will report more frequent, uncontrollable, vivid, and distressing intrusive images than those who report lower levels of OC symptoms.

Methods

Design

A mixed-methods cross-sectional questionnaire design was used. Data collection took place in March-April 2021. Ethical approval was obtained from the University of Oxford Central University Research Ethics Committee (R70783/RE001; Appendix Q).

Participants

Participants were recruited from the general population using a web-based approach. Study advertisements were posted to social media platforms Twitter, Facebook, and Reddit, and charitable mental health organisations (e.g., OCD Action, OCD UK) promoted the study through their websites and email networks. In addition, a snowballing approach was used, whereby participants were encouraged to share the study with others.

A total of 131 participants (76 female, 52 male, 3 non-binary) were recruited. To be eligible, participants had to be at least 18 years old, with no upper age limit. The recruitment strategy was intentionally inclusive, thus there were no other exclusion criteria. For secondary analyses, scores on the Obsessive-Compulsive Inventory-Revised (Foa et al., 2002), a diagnostic tool widely used to screen OCD, were used to classify participants into one of two subgroups: high (n=84; scores above the clinical cut-off of 21) and low (n=47; scores 20 or lower) OC symptoms. The Low-OC group was included as a quasi-experimental-control group.

Measures

Standardised study measures are outlined in Table 3.1. Sociodemographic characteristics were also collected by self-report, including participants' age, gender, ethnicity, employment status, and level of education.

Intrusive Imagery

A questionnaire was additionally developed to investigate the presence and characteristics of idiosyncratic, intrusive obsessional imagery (see Appendix R), based on items from interviews used in previous research (Coughtrey et al., 2014; Hackman et al., 2011; Lipton et al., 2010; Speckens et al., 2007). Participants were provided with a definition of mental imagery (adapted from Coughtrey et al., 2014 and Hales et al., 2014) and examples of obsessional themes (Goodman et al., 1989) – and asked whether they identified with experiencing intrusive obsessional imagery. Participants who reported they did were asked to describe in detail the most distressing or recurrent intrusive image they had experienced in the past month. They were asked to rate its frequency and report the main form they experienced it in (i.e., visual image, sensation, or impression), as well as the sensory modalities it involved. Using Likert-type items, participants were asked to rate imagery characteristics highlighted by previous research (Holmes and Matthews, 2010; Speckens et al., 2007), including vividness, controllability, and the distress associated with the image. They were additionally asked to rate appraisals of the image in relation to TAF-relevant beliefs (i.e., likelihood- and moral-TAF).

Table 3.1

Overview of standardised measures used in the study

Domain	Measure
Obsessive-Compulsive Symptoms	*Obsessive-Compulsive Inventory-Revised (OCI-R; Foa et al., 2002)* The OCI-R was used to screen and measure severity of OCD symptoms. This has been found to demonstrate good internal consistency, test-retest reliability, and discriminant validity (Foa et al., 2002; Hubbert et al., 2007). Using a cut-off score of 21 or more, the OCI-R has been shown to have good diagnostic ability for OCD (Abramowitz & Deacon, 2006). It is suggested that online administration of the OCI-R is equivalent to paper administration (Coles et al., 2007). The full scale of the OCI-R was found to have high internal consistency in the current sample (Cronbach's α=0.93)
Thought-Action Fusion	*Thought-Action Fusion scale (TAF; Shafran et al., 1996)* The TAF was used to assess participants' tendency towards TAF biases. It yields a total score as well as two subscale scores for moral-TAF and likelihood-TAF. Higher scores indicate a stronger tendency towards TAF biases. The TAF scale has demonstrated good internal consistency and acceptable reliability (Shafran et al., 1996; Rassin et al., 2001). The full scale of the TAF had high internal consistency in this sample (α=0.96). The Likelihood-TAF (α=0.98) and morality-TAF (α=0.96) subscales both had high internal consistency.
Trait Use of Mental Imagery	*Spontaneous Use of Imagery scale (SUIS; Kosslyn et al., 1998; Reisberg et al., 2003)* The SUIS was used as trait measure of participants' mental imagery use. A higher summed score indicates greater tendency towards using mental imagery in everyday life. The SUIS has shown acceptable reliability and convergent validity (Nelis et al., 2014). It has been used in previous research investigating

	how mental imagery relates to psychopathology in other conditions (e.g., de Simplicio et al., 2016; Holmes et al., 2008; Tallon et al., 2020). The SUIS showed good internal consistency in this sample (α=0.86).
Vividness of Visual Imagery	*Vividness of Visual Imagery Questionnaire (VVIQ; Marks, 1973)* The VVIQ was included as a measure of trait ability to generate vivid mental imagery. Respondents are asked to generate mental images in relation to four described situations and, across 16 items, rate the vividness of their self-generated images. It should be noted that on this measure a *lower* summed score represents *greater* self-rated vividness. The VVIQ has demonstrated reliability and good internal consistency and construct validity (Campos & Pérez-Fabello, 2009; Cui et al., 2007), including when administered online (e.g., Nelis et al., 2014). Marks (1973) recommended the scale be administered twice (once with eyes open and once with eyes closed), however a meta-analysis conducted by McKelvie (1995) found no effect of completing the measure with eyes open or closed. Thus, to minimise participant' burden the VVIQ was administered once only and, following Ashen's (1987) recommendation, participants followed their own preference for keeping their eyes open or closed. The VVIQ was found to have high internal consistency in this sample (α=0.94).
Depression and Anxiety Symptoms	*Depression, Anxiety and Stress scale (DASS-21; Lovibond & Lovibond, 1995)* The DASS measures symptoms of depression, anxiety, and stress. The DASS is a dimensional measure, with higher scores indicating a more negative emotional state across the subscales. The DASS-21 has demonstrated strong internal consistency and concurrent validity (Henry & Crawford, 2005; Osman et al., 2012). The DASS showed high internal consistency in this sample (α=0.96). The depression subscale (α=0.94), anxiety subscale (α=0.90) and stress subscale (α=0.91) all showed high internal consistency.

Procedure

Data were collected through an anonymous online survey hosted by *JISC Online Surveys*. Participants navigated to the survey via weblinks included on study advertisements. In the opening pages of the survey, participants were presented with an information sheet and consent form (Appendix S). Upon agreeing consent and checking boxes to confirm they met eligibility criteria, participants were invited to complete the battery of study measures (including the OCI-R, TAF, SUIS, VVIQ, DASS-21, and intrusive imagery questionnaire) followed by demographic questions. Most participants completed the survey in 20-30 minutes. After submitting their response, participants were debriefed.

Patient and Public Involvement

The online survey was piloted with two people with experience of OCD from a local public involvement group before recruitment commenced, with particular focus on whether the survey was suitable for online completion. Overall, feedback indicated participant burden was minimal and the survey was clear, functional, and accessible. Changes made following piloting included the addition of a progress bar, and inclusion of examples of obsessional themes to make the explanation of intrusive imagery clearer.

Sample Size

Previous simulation-based methodological work has determined required minimum samples needed to detect mediation effects (Fritz & MacKinnon, 2007). Using a percentile bootstrap method of mediation (80% power, α=0.05), a total sample of 78 participants are needed to detect medium-sized effects in both α- and β-paths. No previous studies were found which provided direct comparison for effect size estimation, so these parameters were theoretically derived.

Data Analysis

Statistical analysis was performed using IBM SPSS (Version 27), interpreted with reference to 0.05 significance levels with Bonferroni correction for multiple comparisons. Data were screened for deviations from normality and univariate outliers using visual methods and interpretation of skewness and kurtosis. Descriptive statistics were used to summarise sociodemographic and clinical characteristics across the whole sample and between subgroups.

Differences in variables of interest between subgroups were explored. Chi-Squared tests were used for categorical variables, or Fisher's Exact Tests where expected frequencies were less than five (Field, 2009). Independent-samples *t*-tests were used for continuous variables, using correction for unequal variances where indicated. Pearson's correlation coefficient was used to explore associations between variables of interest where scatterplots showed no evidence of non-linearity. Effect sizes were calculated for all comparisons, except sociodemographic data.

Data relating to the main hypothesis concerning the relationship between mental imagery use, TAF, and OC symptoms were analysed using mediation analyses, with bootstrapping, using the *PROCESS* macro for SPSS (Version 3; Hayes, 2017). A bootstrapping method has been recommended for testing mediation effects because it is a procedure which controls for type I error yet retains high levels of power (Preacher & Hayes, 2008). Assumptions were checked using linear regression methods (see Appendix T); none were found to be violated, so no adjustments to the data were made. Covariates included age, gender, and DASS total score (to control for depression and anxiety symptoms). Indirect effects were considered significant if zero was not within the 95% bootstrap confidence interval.

As a secondary analysis, individual Likert-type items relating to participants lived-experience of intrusive imagery (i.e., frequency, vividness, controllability, distress, TAF-like appraisals) were treated as ordinal data and analysed between-groups using Mann-Whitney U-tests. The Mann-Whitney U-test was chosen as it has been shown to be robust to type I error when comparing two independent groups on five-point Likert-type items (Rasch et al., 2007; De Winter and Dodou, 2010).

Qualitative data relating to imagery content were analysed using content analysis, following the methodology described by Erlingsson & Brysiewicz (2017). Individual written descriptions of participants' idiosyncratic images were used as meaning units. First, these were condensed into shorter units, then the condensed data were given *codes* describing the condensed meaning. Codes were grouped into *categories*, which were chosen as the highest level of abstraction for this analysis. Coding was conducted both inductively (i.e., developed heuristically from the data), and deductively (i.e., with consideration of the extant OCD literature; Lipton et al., 2010, Ferrier & Brewin, 2005; Rachman, 2007; Speckens et al., 2007; OCCWG, 1997). Qualitative data was separated from quantitative data for analysis, thus the rater was blind to group assignment when completing content analysis. A draft structure of categories was reviewed by a supervisor.

Results

Supplementary information of data analyses, including data screening, assumption checking and additional details of statistical analyses, are included in Appendix T.

Sample characteristics

Table 3.2 presents sociodemographic and clinical characteristics for the High- and Low-OC groups and the whole sample. Overall, participants were aged between 18 and 76 years, with a mean of 34.2 years (SD=13.68). Participants were mostly female (58%, 40% male), with 2% defining themselves as non-binary (n=2) or genderfluid (n=1). With respect to ethnicity, 89% identified as White, 4% as Asian, 2% as Hispanic and 5% identified as being from mixed or 'other' ethnic groups.

Sixty-four percent of participants scored in the clinical range for OCD based on a score ≥21 on the OCI-R and were assigned to the High-OC group. There were no significant associations between group and gender (FET=1.71, p=0.453) or ethnicity (FET=1.48, p=0.599). However, participants in the High-OC group had a significantly lower mean age than the Low-OC group (t(77.7)=3.08, p=0.003). Symptoms of depression (t(121.72)=-9.53, p<0.001) and anxiety (t(125.25)=-12.731, p=0.001) were significantly higher in the High-OC than Low-OC group. The High-OC group additionally demonstrated a significantly greater trait ability to generate vivid mental imagery than the Low-OC group (as measured by the VVIQ; t(129)=2.91, p=0.004, d=0.53, a medium-sized effect; Cohen, 1988). Additional sample characteristics are included within Appendix T.

Table 3.2

Sociodemographic characteristics and scores on main clinical measures for the whole sample and across High- and Low-OC subgroups

	Whole Sample (n = 131)	**High-OC** (n = 84)	**Low-OC** (n = 47)
Demographics			
Gender *(n, %)*			
Male	52 (40%)	52 (62%)	24 (51%)
Female	76 (58%)	30 (36%)	22 (47%)
Non-Binary	3 (2%)	2 (2%)	1 (2%)
Age *(mean, SD)*	34.2 (13.68)	31.4 (11.89)	39.3 (15.24)
Ethnicity *(n, %)*			
White	117 (89%)	73 (87%)	44 (94%)
Asian	5 (4%)	3 (4%)	2 (4%)
Hispanic	2 (2%)	2 (2%)	0 (0%)
Mixed	6 (5%)	5 (6%)	1 (2%)
Other ethnic group	1 (1%)	1 (1%)	0 (0%)
Employment status *(n, %)*			
Employed	63 (48%)	28 (33%)	35 (74%)
Unemployed	23 (18%)	21 (25%)	2 (4%)
Retired	7 (5%)	4 (5%)	3 (6%)
Student	32 (24%)	26 (31%)	6 (13%)
Homemaker	6 (5%)	5 (6%)	1 (2%)
Education *(n, %)*			
No formal schooling	1 (1%)	1 (1%)	0 (0%)
Some secondary school	6 (5%)	5 (6%)	1 (2%)
GCSE or equivalent	12 (9%)	7 (8%)	5 (11%)
A-level or equivalent	24 (18%)	18 (21%)	6 (13%)
Bachelor’s degree or equivalent	50 (38%)	31 (37%)	19 (40%)
Master’s degree or equivalent	23 (18%)	12 (14%)	11 (23%)
Doctoral degree or equivalent	6 (5%)	3 (4%)	3 (6%)
Not reported	9 (7%)	7 (8%)	2 (4%)

Table 3.2 continued

	Whole Sample (n = 131)	**High-OC** (n = 84)	**Low-OC** (n = 47)
Clinical Variables	***(Mean, SD)***	***(Mean, SD)***	***(Mean, SD)***
OCI-R	28.46 (17.32)	38.82 (12.20)	9.94 (5.66)
TAF total	28.95 (21.30)	37.95 (19.94)	12.87 (12.35)
Likelihood	*10.02 (9.88)*	*14.31 (9.31)*	*2.34 (5.07)*
Morality	*18.94 (13.85)*	*23.64 (13.47)*	*10.53 (10.12)*
SUIS	38.37 (10.44)	42.26 (8.89)	31.43 (9.42)
VVIQ [a]	39.62 (13.63)	37.10 (12.84) [a]	44.13 (13.97)
DASS Total	53.86 (35.00)	72.64 (26.89)	20.30 (19.04)
Depression	*9.16 (6.83)*	*12.25 (6.01)*	*3.64 (4.27)*
Anxiety	*7.32 (6.24)*	*10.49 (5.42)*	*1.66 (2.49)*

OCI-R = Obsessive-Compulsive Inventory-Revised, TAF = Thought-Action Fusion scale, SUIS = Spontaneous Use of Imagery scale, VVIQ = Vividness of Visual Imagery scale, DASS = Depression, Anxiety, and Stress scale

[a] Note that the VVIQ is inversely scored (i.e., lower scores indicate greater imagery vividness), hence this difference indicated that the High-OC group reported more vivid self-generated mental imagery than the Low-OC group.

Hypothesis 1: Greater Use of Mental Imagery will be Associated with Higher Levels of TAF and OC Symptoms

Pearson's correlation coefficients with Bonferroni correction were calculated to explore the relationship between participants' scores on the SUIS, OCI-R, and TAF across the whole sample (see Table 3.3). A large (Cohen, 1988) significant positive relationship was found between SUIS and TAF scores ($r(129)=0.51$, $n=131$, $p<0.001$), indicating greater imagery use was associated with greater endorsement of TAF. There was also a large

significant positive relationship between SUIS and OCI-R scores (r(129)=0.57, n=131, p<0.001), indicating greater use of imagery was associated with a higher level of OC symptoms.

Table 3.3

Correlation matrix of main study variables

Variable	OCI-R	TAF total	*Likelihood*	*Moral*
OCI-R	-			
TAF total	0.62**	-		
Likelihood	0.68**	0.86**	-	
Moral	0.47**	0.93**	0.60**	-
SUIS	0.57**	0.51**	0.51**	0.42**

* p<0.05, ** p<0.01 (two-tailed). These results remain significant at Bonferroni corrected confidence level of p<0.002 (i.e., correcting for 21 comparisons).

Hypothesis 2: The Relationship Between Mental Imagery Use and OC Symptoms will be Mediated by TAF

Mediation analyses (Hayes, 2017) were conducted to investigate whether TAF mediated the relationship between use of mental imagery and OC symptoms. The direct effect of imagery use on OC symptoms is illustrated in Figure 3.1. Imagery use was found to have a significant effect on OC symptoms (c=0.472, p<0.001). A mediation effect can be said to exist when accounting for a significant relationship involving an indirect path through a third variable, or mediator, M, reduces the size of the direct relationship between variables X and Y, either partially or completely. The overall mediation model was found to be significant (see Appendix T for statistical outputs). Unstandardised parameter estimates for the model are presented in Figure 3.2. These show greater use of mental imagery was associated with stronger TAF beliefs (a=0.614, p<0.001) and, in turn, stronger TAF beliefs

were associated with greater OC symptoms (*b*=0.119, *p*=0.03). The 95% confidence interval for the size of the indirect effect (*ab*=0.073, *p*<0.05) of mental imagery use on OC symptoms through TAF beliefs, based on 5000 bootstrap samples, was entirely above zero (95% CI=0.001-0.175). Furthermore, there was evidence that the direct effect of mental imagery use on OC symptoms was reduced when considered independent of its effect on TAF beliefs (c=0.472, p<0.001*; c'*=0.398, p<0.001), indicating a *partial* mediation effect.

A second, exploratory mediation model was constructed to investigate whether the mediation effect was being driven by likelihood-TAF, moral-TAF, or both. A single parallel mediation model was used rather than multiple single mediation models, as recommended by Hayes (2017), with scores on Likelihood-TAF and moral-TAF entered simultaneously into the model (Figure 3.2). This model indicated that likelihood-TAF was a significant *partial* mediator (95% CI=0.062-0.263), but moral-TAF was not (shown by bootstrap confidence intervals which contained zero, 95% CI=-0.091-0.023). Preacher and Kelly (2011) advise against the use of classic effect size indices in mediation. Therefore, in addition to using informal descriptors to interpret the mediation effects as *complete* or *partial*, the ratio of the indirect effects to the total effect were calculated. Taken together (Figure 3.2), TAF accounted for approximately 15.5% of the total effect. When considered separately (Figure 3.3), Likelihood-TAF accounted for 29.3% of the total effect and Moral-TAF -5.4%.

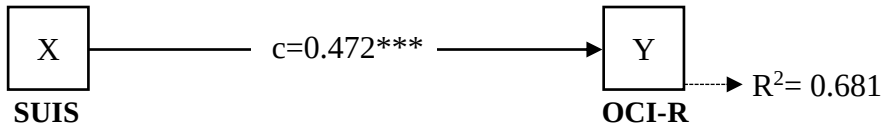


Figure 3.1

Statistical diagram illustrating the direct effect of imagery use on OC symptoms

*p<0.05, **p<0.01, ***p<0.001

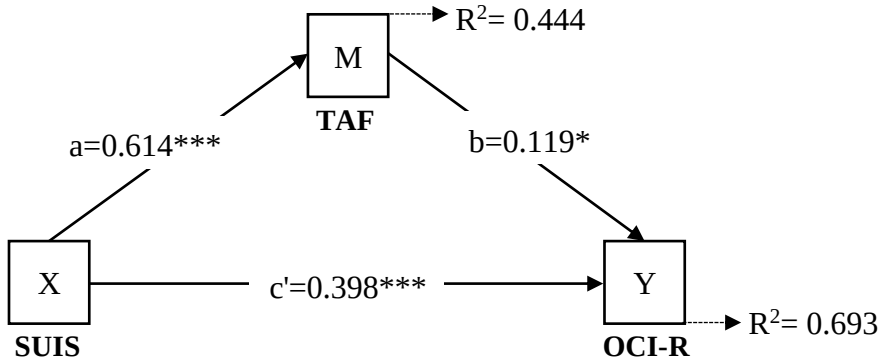


Figure 3.2

Statistical diagram illustrating the relationship between imagery use and OC symptoms as mediated by overall TAF [3]

*p<0.05, **p<0.01, ***p<0.001

3. Data from the whole sample were analysed together to increase power for the analysis, with OCI-R score included as a continuous measure. The pattern of results presented herein were unchanged when participants scoring in the clinical range for OCD were analysed separately.

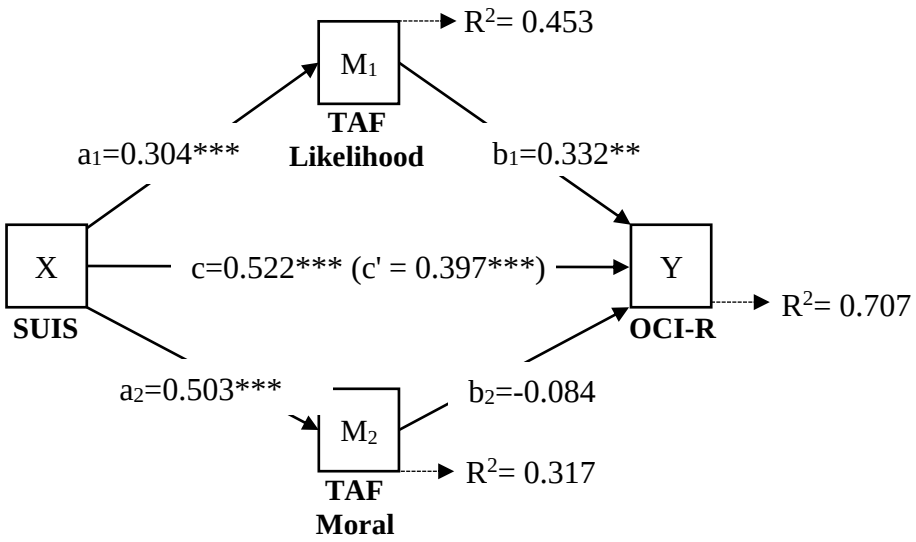


Figure 3.3

Statistical diagram illustrating the relationship between imagery use and OC symptoms as mediated by Likelihood- and Moral-TAF [3]

*$p<0.05$, **$p<0.01$, ***$p<0.001$

Secondary Analyses of Idiosyncratic Intrusive Imagery Data

Eighty-two percent of participants in the High-OC group reported experiencing intrusive obsessional imagery, compared to 45% in the Low-OC group. Table 3.4 presents data for both groups across all imagery characteristic variables. Most participants across both groups reported experiencing their most recurrent image mainly as a visual picture (High-OC=80%, Low-OC=57%). There was no significant difference in the mean number of sensory modalities involved in participants' images ($t(88)=-1.880$, $p=0.063$; $d=0.86$, a large effect); both groups generally reported images experienced over one or two senses. Vision was the most frequently involved sense across both groups, followed by sound and touch.

Content of Intrusive Images

Table 3.5 presents seven content categories that were identified from descriptions of intrusive images reported by participants, in decreasing order of frequency, with examples which broadly illustrate each category. Clinical images were most frequently categorised as relating to ideas of *harm* (either intentional, accidental or by omission) or *contamination and illness*. Other categories identified related to *sexual* images, *relationships*, and *losing control*.

Hypothesis 3: Individuals Who Report Higher Levels of OC Symptoms will Report More Frequent, Uncontrollable, Vivid, and Distressing Intrusive Images Than Those Who Report Lower Levels of OC Symptoms

As predicted, the High-OC group rated their idiosyncratic images as stochastically more frequent (U=1042.50, $p=0.001$; r=0.33, a medium effect), uncontrollable (U=418.00, $p=0.001$; r=0.32, a medium effect), vivid (U=389.00, $p=0.001$; r=0.36, a medium effect), and distressing (U=1177.50, p=0.000; r=0.49, a medium effect) than the Low-OC group.

Table 3.4

Comparison of idiosyncratic intrusive imagery data between High- and Low-OC subgroups

	High-OC (n = 69)	**Low-OC** (n = 21)	**Test Statistic**
Imagery experienced as *(n, %)*			
Visual picture	55 (80%)	12 (57%)	
Impression	8 (12%)	7 (33%)	
Sensation	6 (8%)	2 (10%)	
Sensory modalities involved *(mean, SD)*	1.78 (0.94)	1.38 (0.50)	$t(88) = -1.880$, $p = 0.063$ (two-tailed)
Vision *(n, %)*	69 (100%)	21 (100%)	
Sound *(n, %)*	29 (42%)	4 (19%)	
Touch *(n, %)*	17 (25%)	4 (19%)	
Smell *(n, %)*	6 (9%)	1 (5%)	
Taste *(n, %)*	2 (3%)	0 (0%)	
Frequency in last week *(n, %)*			$U = 1042.50$, $p = 0.001$*
Not at all	0 (0%)	0 (0%)	
Once	7 (10%)	1 (5%)	
2-5 times	11 (16%)	11 (52%)	
5-10 times	14 (20%)	6 (29%)	
10-20 times	13 (19%)	3 (14%)	
>20 times	24 (35%)	0 (0%)	
Vividness *(n, %)*			$U = 389.00$, $p = 0.001$*
Perfectly realistic, as vivid as normal senses	18 (26%)	0 (0%)	
Realistic and reasonably vivid	29 (42%)	9 (43%)	
Moderately realistic and vivid	17 (25%)	3 (14%)	
Dim and vague	5 (7%)	8 (38%)	
No image at all, only ‘know’ am thinking of it	0 (0%)	1 (5%)	
Distress *(n, %)*			$U = 1177.50$, $p = 0.000$*
Not at all	0 (0%)	0 (0%)	
Slightly	0 (0%)	3 (14%)	
Moderately	8 (12%)	10 (48%)	
Very	19 (28%)	5 (24%)	
Extremely	42 (61%)	3 (14%)	
Controllability *(n, %)*			$U = 418.00$, $p = 0.001$*
Not at all	26 (38%)	3 (14%)	
Slightly	26 (38%)	4 (19%)	
Moderately	13 (19%)	12 (57%)	
Very	2 (3%)	1 (5%)	
Completely	2 (3%)	1 (5%)	

TAF-like beliefs relating to the image *(n, %)*			
Likelihood-TAF			$U = 1007.50$, $p = 0.003$*
Disagree strongly	9 (13%)	4 (19%)	
Disagree	9 (13%)	7 (33%)	
Neutral	19 (28%)	7 (33%)	
Agree	17 (25%)	3 (14%)	
Agree strongly	15 (22%)	0 (0%)	
Moral-TAF			$U = 1019.50$, $p = 0.002$*
Disagree strongly	12 (17%)	7 (33%)	
Disagree	14 (20%)	7 (33%)	
Neutral	13 (19%)	5 (24%)	
Agree	14 (20%)	2 (10%)	
Agree strongly	16 (23%)	0 (0%)	

* $p<0.007$ was considered significant given Bonferroni correction for seven comparisons (tests are one-tailed unless otherwise stated).

Table 3.5

Content categories identified in intrusive obsessional images, in decreasing order of frequency

Category	Codes	Example Image
Harm (Intentional, accidental and by omission)	Aggressive and violent images Impulsive harm towards others/self Accidents involving others/self Death or suicide Causing a fire/accident Being responsible for a break in	*"My son laying on a pavement after being hit by a car - he's 8 years old. Police and paramedics are all around. I'm running towards him."*
Contamination and illness	Disease and illness Germs and dirt Chemicals and toxins Bodily waste	*"I see germs in the air that fall onto my hands and my body, and then spread onto everything around me. Everything is red and then my mum touches something and she turns red with germs. I hear dull screams."*
Sexual	Unwanted sexual images Concerns about sexual orientation Fears about sexual urges	*"When I sit in the car in the passenger's seat with my father driving, I often get the unwanted mental image that as I sit there, I reach out my hand to grab his crotch."*
Religious/ immoral	Concerns about blasphemy Images of God Demonic images Behaving immorally	*"A formless image of an angry god, like a sort of big shadow slowly growing and covering everything, I 'see' it coming from above…there's images of religious figures and I see myself swearing at them"*
Relationships	Doubts about relationships (e.g., attractiveness, desirability, compatibility of partner)	*"Images of my partner losing his hair and me not being attracted to him anymore. Being in a situation where I need to sort his hair out to a way I am more comfortable with, I cannot do so as I am sitting at a family dinner so have an image of me lunging over the table at my partner"*
Losing control	Being publicly shocking or embarrassing Loss of control / 'going crazy'	*"Image of myself being mentally ill, alone and understood by nobody in perpetual limbo, having frequent mental breakdowns and being so unstable I need to be committed."*

Other/ miscellaneous	Nonsensical images Perfectionism/perceived failure Doubts about memory or perception	*"A silver marble stuck on a silver, round (vertically placed, like a roller coaster's loopty-loop) track, endlessly looping."* *"It becoming true that I've failed, and the smart person I thought I was is actually lazy and a failure…my family and friends figuring out the reality of things, of me and my terrible work ethic."* *"Images of things being different to how it is in real life. Seeing how it is in my memory and having to call people to find out because I can't trust myself".*

TAF-Like Appraisals of Intrusive Images. Compared to the Low-OC group, participants in the High-OC group endorsed stochastically stronger beliefs that experiencing their image would increase the risk of the image coming true (i.e., likelihood-TAF; U=1007.50, p=0.003; r=0.29, a small-medium effect), and that having the image come to mind was morally as bad as what happens in the image (i.e., moral-TAF; U=1019.50, p=0.002; r=0.30, a medium effect).

Discussion

The primary aim of this study was to test a mediation model, in which – based on the assumptions of the cognitive-behavioural model of OCD (Salkovskis, 1985) - it was hypothesised that TAF would mediate the relationship between mental imagery use and OC symptoms. Using a percentile bootstrapping method, evidence of an indirect effect was found which supported this hypothesis. This effect appeared to be driven by likelihood-TAF appraisals, as moral-TAF did not emerge as a significant mediator when entered separately

into the model. This is consistent with literature that suggests likelihood-TAF may be implicated in OCD with greater specificity than moral-TAF (Rassin et al., 2001; Shafran et al., 1996; Berle & Starcevic, 2005; Shafran & Rachman, 2004). It should be highlighted when considering this finding that the SUIS was designed to capture an individual's tendency towards using mental imagery generally (Kosslyn et al., 1998), thus the findings suggest individuals who generally tended towards using mental imagery to a greater extent were more likely to endorse TAF and, in turn, more likely to report higher levels of OC symptoms. Nevertheless, participants also endorsed TAF appraisals (both likelihood- and moral-TAF) in relation to their idiosyncratic intrusive obsessional images, with individuals in the High-OC group found to report stronger TAF appraisals of intrusive imagery than those in the Low-OC group in both regards. These findings support previous literature suggesting an association between mental imagery and TAF in OCD (Lee et al., 2019; 2020; Coughtrey et al., 2013). With respect to the role of TAF, a partial mediation effect was found. Baron and Kenny (1986) suggest complete mediation is rarely obtained in psychological research due to the incidence of multiple mediators, thus it should be considered that additional mediators may be able to contribute further understanding with regards to the role of mental imagery within OCD.

Concerning idiosyncratic experiences of intrusive imagery, the current findings largely replicate the limited previous literature on intrusive imagery in OCD (Speckens et al., 2007; Lipton et al., 2010; Rachman, 2007). Consistent with the findings of Lipton and colleagues (2010), images relating directly to themes of harm were the most reported by participants in this study, although to a lower degree (48% compared to 75% estimated by Lipton and colleagues). Other themes (e.g., relationship doubts, losing control or religious images) were present, although much less frequently reported. No differences were found in the sensory modalities involved in images across subgroups. However, as predicted,

participants in the High-OC group reported more frequent, vivid, and distressing intrusive images, which were perceived as more uncontrollable, than participants in the Low-OC group. This supports research which suggests individuals with clinical versus subclinical levels of OC symptoms would be expected to vary mostly in terms of their subjective experience of imagery intensity (e.g., Gibbs, 1996; Morillo et al., 2007). These findings support the dimensional view that intrusions are experienced across the full continuum of OC experience (Rachman & de Silva, 1978), replicating in images findings previously described in terms of intrusive cognitions in general (Rachman & de Silva, 1978; Rassin & Muris, 2006; Morillo et al., 2007).

A positive association between having a tendency towards mental imagery use and OC symptoms was found in the current sample. Dale (2017) similarly found higher levels of OC symptoms to be related to a more imagery-based cognitive style; yet other studies have found no significant differences between general imagery use or ability in participants with OCD and healthy controls (Finnk-Lamotte et al., 2018; Hermans et al., 2003). In the current sample, a significant between-groups difference was observed in trait ability to generate vivid mental imagery, which previous research suggests may represent a related construct to trait imagery use (Nelis et al., 2019; Reisberg et al., 2003). Thus, it should perhaps be considered that group differences in trait imagery ability may have been a factor contributing to between-groups differences in intrusive imagery in this study.

Theoretical Implications

The current findings align with the key assumptions of cognitive-behavioural models of OCD (Rachman, 1997; Salkovskis, 1985; Salkovskis et al., 1999), which propose that misappraisals play a crucial role in the association between intrusions and OC symptoms. Applying this to intrusive imagery, the current findings support an understanding that

intrusive images may contribute towards OC symptomatology through an indirect pathway involving TAF (specifically, likelihood-TAF) misappraisals. In other words, imagery may act as a mechanism via which obsessions come to seem more real, potentially increasing the believability of misappraisals regarding the likelihood that a given obsession will come true. This aligns with research in the wider mental imagery literature which provides evidence that the distinctive sensory properties of mental images may make imagery feel more realistic than other forms of cognition (i.e., verbal thoughts and urges; Holmes et al., 2008; 2010; Matthews et al., 2012; Pearson et al., 2015) and potentially even experienced 'as-if-real'.

It could also be that a tendency towards a visual cognitive style in general may play a role in predisposing individuals to the formation and development of general TAF assumptions. However, such conclusions about causal relationships between these variables cannot be drawn from the current findings due to the cross-sectional design of this study, and it cannot be ruled out that the direction of the relationships investigated in this study may be different to that proposed by cognitive-behavioural models of OCD. Further research is needed to corroborate and explore these and other possibilities further.

Clinical implications

The current findings lend tentative support to existing research which suggests mental imagery may play an important contributary role in the development and maintenance of OCD symptomatology (Speckens et al., 2007; Lipton et al., 2010; Rachman, 2007; Coughtrey et al., 2007). However, current psychological interventions have been developed to intervene with OCD-related appraisals using predominantly *verbal* methods (Rachman, 2007), and evidence suggests clinicians are not always trained to ask about mental imagery (Holmes et al., 2016). Nevertheless, the distinction between mental imagery and other forms of cognition may be of importance in therapy. Currently, imagery rescripting is the most studied imagery-

specific therapeutic technique in relation to OCD, though previous investigations have reported mixed results (Veale et al., 2015; Mpavaenda, 2016; Maloney et al., 2019). In this regard, it has been suggested that imagery rescripting may be more effective for individuals whose intrusions stem from previous adverse experiences (Mpavaenda, 2016); yet, this is not always the case for images in OCD, which for some individuals feature primarily imagined content (e.g., Potik, 2007; de Silva, 1986; Speckens et al., 2007). If metacognitive beliefs such as TAF are indeed found to be implicated in the relationship between mental imagery and OC symptoms, it may be a useful avenue for future research to consider alternative imagery-specific techniques which may have greater utility in addressing such image-related appraisals.

Strengths and Limitations

This study used a cross-sectional design, which limits the causal inferences that can be drawn in relation to relationships between mental imagery use, TAF and OC symptoms. This design was chosen as this was a preliminary investigation aiming to probe the mechanism underpinning the role of mental imagery in OCD. It is hoped that the current results will inform future mediation-by-design investigations adopting longitudinal or experimental designs. The internet-based methodology offered a potentially more inclusive investigation of mental imagery in OCD than has previously been conducted, and a degree of anonymity, not present when completing an interview with a researcher, which may have reduced social desirability bias in the context of an area previously suggested to provoke feelings of shame (e.g., Weingarden & Renshaw, 2015). However, this also meant it was not possible to use a gold-standard diagnostic tool such as the Structured Clinical Interview for DSM Disorders (SCID; First et al., 1996) to inform allocation of participants into subgroups. Also, participants were self-selected, and the study relied on retrospective recall of imagery,

which may have represented sources of bias in the reporting of images; although, it should be noted that the prevalence of intrusive imagery in the current sample was comparable to those of previous investigations (Speckens et al., 2007; Lipton et al., 2010). Finally, despite efforts to recruit widely from across the UK, the sample was mostly white-British, which limits generalisability of the findings to other ethnic groups.

Conclusions

This was the first study to directly investigate the relationship between mental imagery, TAF and OC symptoms. Emerging evidence suggests mental imagery may play an important role in the formation of TAF, and the current findings aligned with this. Overall, the findings demonstrated that Likelihood-TAF may mediate the relationship between mental imagery use and OC symptoms, providing a potential mechanism underpinning the role of mental imagery in OCD. Although the findings should be interpreted cautiously due to methodological limitations, they provide interesting avenues for future research.

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Executive Summary

Thought-Action Fusion as a Mediator of the Relationship Between Mental Imagery and Obsessive-Compulsive Symptoms

It is well known that cognitions can take the form of mental imagery (or '*pictures in your mind'*), as well as verbal thoughts, and troubling mental imagery is increasingly understood to be an important feature of many mental health problems. As such, mental imagery has represented an important target for treatment in some mental health problems, notably including post-traumatic stress disorder and social anxiety. Intrusive mental imagery is also commonly reported by individuals with obsessive-compulsive disorder (OCD) and, along with intrusive thoughts and urges, the experience of intrusive imagery forms a central part of the diagnostic criteria for OCD. However, to date there has surprisingly been limited research investigating the role of intrusive mental imagery in OCD.

Contemporary cognitive-behavioural models of OCD are based on an observation that unwanted intrusive cognitions are commonly experienced in some form (i.e., thoughts, images, or urges) by most people. According to these models, misappraisals (i.e., incorrect interpretations) of these cognitions, rather than the cognitions themselves, play a crucial role in the development and maintenance of obsessive-compulsive (OC) symptoms. One potentially relevant proposed type of misappraisal is thought-action fusion (TAF), which refers to two beliefs about the meaning of intrusive cognitions: (1) that simply having a thought is morally equivalent to acting on the thought ('moral-TAF'), and (2) that having a thought makes it more likely that the content of the thought will actually happen ('likelihood-TAF'). Emerging evidence suggests that visual mental imagery may play an important role in the development of TAF, however the literature does not currently contain any studies which investigate the relationship between mental imagery, TAF and OC symptoms.

The primary aim of this study was to test whether TAF mediates (i.e., explains all or some of) the relationship between mental imagery use and OC symptoms. The study further aimed to explore whether the experience of intrusive imagery would be different in individuals reporting different levels of OC symptoms; based on previous research, it was expected that individuals who report higher levels of OC symptoms would report more frequent, uncontrollable, vivid, and distressing intrusive images than those who report lower levels of OC symptoms.

A mixed-methods cross-sectional questionnaire design was used in this study. One-hundred-and-thirty-one participants were asked to complete online questionnaires that asked about mental imagery use (the Spontaneous Use of Imagery scale), TAF beliefs (the Thought-Action Fusion scale) and OC symptoms(the Obsessive-Compulsive Inventory-Revised Version). The main analysis looked at scores on these questionnaires to probe the relationship between the use of mental imagery, TAF and OC symptoms. For this, mediation analyses were conducted using a percentile bootstrapping method. Two models were constructed, one which considered the role of TAF appraisals overall, and a second in which the effects of likelihood- and moral-TAF were considered separately. Participants were also asked questions about their personal lived experience of intrusive obsessional imagery. Secondary analyses (using a mix of quantitative and qualitative methods) compared participants' responses to these questions across two groups: participants who scored high for OCD, and participants who scored low for OCD.

Across the whole sample, greater use of mental imagery was associated with higher levels of TAF beliefs and higher OCD symptoms. Evidence of an indirect effect was found which supported the hypothesis that TAF mediated (partially) the relationship between mental imagery use and OCD symptoms. It was found that this effect appeared to be driven

by likelihood-TAF beliefs, as moral-TAF did not emerge as a significant mediator when entered separately into the model. As expected, in terms of participants' experience of idiosyncratic intrusive obsessional imagery, participants who scored high for OCD reported more frequent, vivid, and distressing intrusive images, which were perceived as more uncontrollable, than participants who scored low for OCD. Participants scoring high also reported stronger TAF appraisals of their images than those who scored low, both for likelihood- and moral-TAF appraisals.

Overall, the current findings are in line with the key assumptions of cognitive-behavioural models of OCD, which propose that misappraisals such as TAF play a crucial role in the association between intrusions and OC symptoms. Applying this to intrusive imagery, the current findings support an understanding that imagery may act as a mechanism via which obsessions come to seem more real, increasing the believability of misappraisals regarding the likelihood that a given obsession will come true. It is possible that imagery techniques aimed at undermining the perceived reality of an image, such as metacognitive imagery strategies, may be a helpful adjunct in the treatment of OCD for certain individuals, theoretically providing an avenue to assist in challenging likelihood-TAF beliefs as they relate to obsessions in the form of intrusive mental images. Future research should follow up these findings using experimental or longitudinal designs, to further test the relationship between mental imagery and TAF within OCD.

Connecting Narrative

I entered training with limited research experience, so found the prospect of completing this portfolio daunting at first. I enjoy reading research but found scoping topics and generating ideas for the projects a challenge, particularly as I did not have a clear sense of my research interests when I started training. I knew I wanted to take the opportunity to broaden my research skills and explore a range of ideas and topics; my pre-training experiences were almost entirely within CAMHS settings, and whilst my experiences on training overall have confirmed my passion for working with children and families, I knew there may be limited other opportunities to explore and develop other research interests. Therefore, each of my projects focussed on a different clinical area and drew on different research methodologies. I was extremely lucky to benefit from my supervisors' support and guidance in helping me focus my initial ideas and interests into feasible and relevant research questions and develop suitable methodologies to address them. Below are a few reflections on the process of completing the projects presented in this portfolio.

Systematic Review of the Literature

Multiple Concussions and Later-Life Cognitive Functioning

I was keen to take the opportunity with one of my projects to improve my ability to engage with and understand neuropsychological research and concepts. In some ways I found this the most demanding project to complete, as I had to learn the systematic review methodology and complete the review in parallel, in a research area that was very new to me. This felt a steep learning curve and took a lot of time and patience. However, my understanding of issues relating to research and research methodology have developed hugely through undertaking this review, which I feel has helped me to become a more effective critical consumer of research in my clinical practice - and I would not hesitate to do one again.

Service Improvement Project

Psychosocial Needs of Patients Living with Dialysis

I enjoyed the process of designing this project in collaboration with the service and found it exciting to undertake a project with real potential to have clinical implications that would be of benefit to people using the service. This project was my first opportunity to use qualitative research methodology, which I found a refreshing and rewarding way of approaching research. For this project particularly, I felt it resulted in a richly detailed exploration of care, directly from the perspective of patients, which wouldn't have been easily achievable using quantitative methods. This was the project I had the most opportunity to engage in service user involvement. I was very fortunate to benefit from the expertise of two people with personal experience of dialysis, who contributed towards several stages of the research process. I learnt so much from this and feel it resulted in a more relevant and useful project. In future clinical posts, I will aim to develop links with local participation groups to continue to meaningfully build my involvement activities when undertaking research and service development. I feel this will be especially important to consider working in CAMHS settings, where the 'voice' of young people in research and within services can be underrepresented.

Theoretically Driven Research Project

Mental Imagery and Thought-Action Fusion in Obsessive-Compulsive Disorder

My interest in mental imagery started following a lecture by Dr Susie Hales about the role of imagery in psychological conditions and the potential imagery may represent for psychological treatment innovation. The project initially was designed to explore the role of mental imagery in OCD using an experimental design. However, due to unforeseen recruitment issues, we had to take the difficult decision to restart using an entirely questionnaire-based design. Whilst this was disappointing and undoubtedly introduced methodological weaknesses, the experience did give me a greater awareness for the different ways research questions can be addressed; that it is not necessarily about there being one

'right' approach in research, but perhaps understanding that different methodologies have relative strengths and weakness and may offer different ways of thinking about a topic. I had to tolerate uncertainty when we were redesigning the project, not knowing whether I would encounter similar difficulties a second time. However, recruitment actually turned out to be one of my favourite parts of the research process, as I found I greatly enjoyed sharing the research and developing relationships with organisations and individuals supporting my recruitment. Several participants got in touch during the recruitment period and told me how important they felt imagery was in their experience of OCD. Some also noted that it was something they had not previously been asked about. This highlighted to me how important clinical research is, and I was pleased that people found the project relevant to their experiences. Doing this project has also informed my own clinical practise, where I increasingly endeavour to ask clients about intrusive imagery, it's meaning, and the impact it has for them.

Hopes for Future Research

Completing this portfolio has been the most challenging aspect of training, particularly undertaking research in the context of the Coronavirus-19 pandemic, and the pressures, delays, and obstacles this caused. However, it has also challenged me to think creatively, be adaptable, and overcome barriers, and I hope these are things I can carry with me going forwards. Although challenging, I found my experiences of clinical research during training hugely interesting and rewarding. I am deeply proud of the work described in this portfolio - and how my research skills have evolved throughout the process of research design, ethics application, data collection, data analysis, and write up. In the future, I plan to submit each of the papers to their target journals and aim to find a qualified clinical post that will support me to continue to be actively involved in research activities and further develop my skills as a clinical researcher.

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Appendices

Appendix A

SRL: Author guidelines for Brain Injury

About the Journal

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Please use double quotation marks, except where “a quotation is ‘within’ a quotation” Please note that long quotations should be indented without quotation marks.

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   For multiple agency grants
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Appendix B

SRL: Example search strategy and details of search results across databases

Example full search strategy with thesaurus terms and database-specific syntax (translated across databases for subsequent searches):

Database: PsycINFO (Final searches run 1st May 2021)

Population terms:

1 exp sports/ OR exp athletes/ OR exp military personnel/ OR combat experience/ OR domestic violence/ OR intimate partner violence/ OR dating violence/ OR battered females/ OR physical abuse/ OR head banging/ OR self-injurious behaviour/ OR whiplash/ OR falls/

2 ("sport-related" OR sport* OR athlet* OR box* OR football* OR soccer OR "american football" OR "australian rules football" OR rugby OR basketball OR "contact sport*" OR hockey OR lacrosse OR cricket OR baseball OR rac#?et OR tennis OR squash OR volleyball OR softball OR "martial arts" OR judo OR "tae kwon do" OR wrestling OR cycli* OR bik* OR BMX OR skiing OR skier* OR snowboard* OR "snow sport*" OR "extreme sport*" OR driv* OR rac* OR skating OR diving OR climb* OR mountaineering OR equestrian OR jockey* OR horse).ti,ab.

3 (military OR "military-related" OR army OR nav* OR "air force" OR marine OR combat* OR soldier* OR veteran* OR blast OR explosi*).ti,ab.

4 ("domestic violence" OR "intimate partner violence" OR "family violence" OR "physical abuse" OR "head banging" OR "self-injurious behavio?r" OR whiplash OR fall*).ti,ab.

5 1 OR 2 OR 3 OR 4

Exposure terms:

6 exp brain concussion/ OR traumatic brain injury/

7 (concussions OR ((multiple OR repeated OR repetitive OR recur* OR cumulative) ADJ3 ("mild traumatic brain injur*" OR "mild TBI*" OR MTBI* OR concuss* OR "head injur*" OR "brain trauma*" OR "head impact*"))).ti,ab.

8 6 OR 7

Outcome terms:

9 neurodegeneration/ OR cognitive impairment/ OR exp neurocognitive disorders/ OR neurodegenerative diseases/ OR cognitive ability/

10 (neurodegenerati* OR ((neuropsycholog*) ADJ2 (test* OR measure*)) OR neurocogniti* OR neurobehavio?r* OR ((cogniti* OR learn* OR memory OR recall OR attention OR language OR "visuo-spatial" OR psychomotor) ADJ3 (function* OR deficit* OR impairment* OR disorder* OR outcome*)) OR "executive function" OR "verbal fluency" OR intelle*).ti,ab.

11 ((("mild cognitive") ADJ (impairment* OR disorder*)) OR MCI OR dementia OR alzheimer* OR "chronic traumatic encephalopath*" OR CTE).ti,ab.
12 9 OR 10 OR 11
13 5 AND 8 AND 12
14 exp animals/ NOT human/
15 13 NOT 14
16 limit 15 to English language

Table B1

Search hits across databases

Database	**PsycINFO**	**EMBASE**	**MEDLINE**	**Web of Science**	**SportDISCUS**	**Total**
Number of results	*1626*	*4261*	*1762*	*2658*	*735*	11042

Appendix C

SRL: Blank data extraction template

1. General Information:

Title:	
Study authors:	
Year of publication:	
Date data extracted:	
Person extracting data:	
Author contact address:	
Notes:	

2. Study Characteristics:

Study location:	
Start and end date:	
Setting: *(e.g. sports, military, general population)*	
Study aim(s):	*Research question(s):*
Study design:	
Recruitment methods:	
Eligibility Criteria:	*Inclusion criteria:* *Exclusion criteria:*
Method of determining concussion history:	*Concussion definition used:*
Notes:	

3. Participant characteristics:

Sample details:	
Sample size:	
Comparison group: *Source, number of participants etc*	
Age:	*Sample mean age (SD):* *Sample age range:* *Controls mean age (SD):* *Controls age range:*
Gender:	
Ethnicity:	
Concussion history:	*Sample mean no of concussions (SD):* *Range:* *Mean years since last concussion:* *Controls mean no of concussions (SD):* *Range:* *Mean years since last concussion:*
Notes:	

4. Ethical standards:

Was ethical committee approval obtained?	
Was informed consent gained?	
How were ethical issues addressed?	
Conflicts of interest:	
Source of funding:	

Notes:	

5. Outcomes:

Cognitive domains /outcomes assessed:	
Cognitive measures used:	*Administered by:*
Details of other outcomes reported:	
Potential confounders matched/adjusted for:	
Baseline imbalances:	
Statistical methods used:	*Details of withdrawals/exclusions/missing data:*
Subgroups reported:	
Findings and key conclusions of authors:	
Notes:	

Appendix D

SRL: Newcastle-Ottawa Scale (modified from Alshabanat et al, 2015).

Selection

1. Representativeness of the sample:
    a) Truly representative of the average in the target population (all subjects or random sampling) **
    b) Somewhat representative of the average in the target population (non-random sampling) *
    c) Selected group.
    d) No description of the sampling strategy.

2. Sample size:
    a) Justified and satisfactory. *
    b) Not justified.

3. Selection of the comparison group (parameter taken from NOS for cohort studies)
    a) Drawn from the same community as the exposed group/internal comparison. **
    b) Drawn from a different source or population norms used. *
    c) No description of the derivation of the comparison group.

4. Ascertainment of the exposure:
    a) Medical record. *
    b) Structured interview or validated measurement tool. *
    c) Self-report questionnaire.
    d) No description.

Additional parameter not in NOS:

5. Exposure definition:
    a) Objective, standard definition of concussion used. *
    b) No description.

Comparability

1. The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.
    a) Study controls for age *
    b) Study controls for any additional factor *
    c) Unclear or no description.

Outcome

1. Assessment of the outcome:
    a) Objective neuropsychological assessment tool. **
    b) Validated self- or observer-report measure. *
    c) Non-validated self- or observer-report measure.
    d) No description.

2. Statistical test:
    a) The statistical test used to analyse the data is clearly described and appropriate, and reported fully. *
    b) The statistical test is not appropriate, not described or incomplete.

Selection /7
Comparability /2
Outcomes /3
Total score /12

Appendix E

SRL: Comparison of concussion definitions used across included studies

			Time of injury				Specific concussion symptoms												
Definition	**Studies** *First author (year)*	**Injury Characteristics**	Loss of consciousness	Alteration in mental status	Loss of memory of events before / after injury	Focal neurological deficits	Headache	Nausea	Vomiting	Dizziness / balance problems	Fatigue	Difficulty sleeping	Drowsiness	Sensitivity to light / noise	Blurred vision	Memory difficulty	Difficulty Concentrating	Seizure	**Notes**
American Academy of Neurology (68)	*[Fields, 2020; Strain, 2017; Strain, 2015; Hart, 2013]; Coughlin, 2015;*	Blow to the head		✓				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		‘1 or more’ specific symptoms needed
American Congress of Rehabilitation Medicine (71)	*[Terry, 2019; Terry, 2018; Terry, 2015]*	Traumatically induced	✓ <30 min	✓	✓ <24h	✓													Impairment ‘may or may not be transient’
2009 Zurich Consensus Statement of Concussion in Sport (88)	*[Tremblay, 2013; Tremblay 2014]*	Traumatic biomechanical forces	✓ or no LOC			✓													Impairment has ‘rapid onset’ and is ‘short-lived’
2013 Zurich Consensus Statement of Concussion in Sport (69)	*[Terpstra, 2019; Misquitta, 2018; Tarazi, 2018; Goswami, 2016];*	Blow to the head or body					✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		‘1 or more’ specific symptoms needed

	Esopenko, 2018; Clark, 2018																		
Centres for Disease Control and Prevention (75)	*Amen, 2011*	Head trauma	✓ or no LOC	✓															Temporary
Department of Veterans Affairs & Department of Defence (73).	*Kaup, 2017*		✓ <30 min		✓ w/o LOC														
a	*Guskiewicz, 2005*	blow to the head		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		1 or more symptoms needed
a	*McMillan, 2017*	blow or injury to the head	✓ or no LOC		✓	✓	✓	✓						✓		✓			Symptoms may not be 'noticeable straight away'
a	*Roberts, 2019*	blow to the head, neck, or upper body	✓	✓		✓	✓		✓					✓	✓		✓		Alteration in mental status incl disorientation and confusion

LOC = loss of consciousness

[a] In Guskiewicz (63), McMillan (57) and Roberts (45), definitions given to participants were detailed, but the source of the definition was not given.

Note. Due to unclear reporting, definitions used in Ruiter et al. (46) and Decq et al. (58) could not be assessed.

Appendix F

SRL: Results of risk of bias assessment

	Selection					Comparability	Outcome		Total Score /12
Study (first author)	**Representative-ness of the sample**	**Sample size**	**Selection of the comparison group**	**Ascertainment of the exposure**	**Exposure definition**	**Control of confounding factors**	**Assessment of the outcome**	**Statistical test**	
Fields (2020)[67]	Convenience and snowball sampling (*)	Not justified	Internal comparison (**)	Interview (*)	American Academy of Neurology Guidelines (1997) (*)	Unclear; partial correlations to control for depressive symptoms. Demographics considered but not adjusted for	Neuropsychological testing (**)	Correlational analysis between concussion exposure and cognitive variables (*)	8
Roberts (2019)[45]	Sampling frame identified but response rate low (25%) (*)	Not justified	Internal comparison (**)	Self-report questionnaire	Standard description of concussion (*)	Analysis adjusted for age, ethnicity, pain, non-head injury (**)	Self-reported using validated measure (*)	Relative risk analysis of concussion exposure and cognition (*)	8
Ruiter (2019)[46]	No clear description	Not justified	healthy controls recruited from the general population (*)	self-report questionnaire	No description	Controls matched for age (*)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	5
Terpstra (2019)[47]	Volunteer and snowball sampling (*)	Not justified	Internal (high/low concussion exposure) and external comparisons (**)	Unclear, self-report	American Academy of Neurology Guidelines (1997) (*)	Controls matched for age and gender (**)	Neuropsychological testing (**)	Examines between-group/subgroup differences in cognitive variables (*)	9

Terry (2019)[51]	Volunteer and convenience sampling (*)	Not justified	Internal comparison (**)	Self-report questionnaire and interview using ACE (Gioia & Collins, 2006) (*)	American Congress of Rehabilitation Medicine definition (1993) (*)	Unclear; no differences between groups on age, education, estimated pre-morbid IQ and current concussion symptomatology	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	8
Clark (2018)[54]	Stratified random sample (**)	Justified and satisfactory for main effects (*)	Internal comparison within strata (**)	Self-report questionnaire	Consensus statement on concussion in sport definition (McCrory et al, 2013) (*)	Unclear; participants matched, but across career-duration strata.	Neuropsychological testing (**)	Examines between-group/strata differences in cognitive variables (*)	9
Terry (2018)[52]	Volunteer and convenience sampling (*)	Not justified	Internal comparison (**)	Self-report questionnaire and interview using ACE (Gioia & Collins, 2006) (*)	American Congress of Rehabilitation Medicine definition (1993) (*)	Unclear; no differences between groups on age, education, estimated pre-morbid IQ and current concussion symptomatology	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	8
Misquitta (2018)[48]	No clear description	Not justified	Healthy controls recruited from the general population (*)	Semi-structured interview (*)	Consensus statement on concussion in sport definition (McCrory et al, 2013) (*)	Controls matched for age and education (**)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	8

Tarazi (2018)[49]	No clear description	Not justified	Healthy controls recruited from the general population (*)	SCAT3, validated concussion assessment tool used (*)	Consensus statement on concussion in sport definition (McCrory et al, 2013) (*)	Controls matched for age and education (**)	Neuropsychological testing and subjective self-report using non-validated measure (**)	Examines between-group differences in cognitive variables (*)	8
Esopenko (2017)[55]	Volunteer and snowball sampling (*)	Not justified	Healthy controls recruited from the general population (*)	Unclear, self-report	Consensus statement on concussion in sport definition (McCrory et al, 2013) (*)	Controls matched in study design, and regression analysis adjusted for age (*)	Neuropsychological testing and self-report using validated measure (**)	Examines between-group differences in cognitive variables, and regression analysis of relationship between concussion exposure to cognitive variables (*)	7
Kaup (2017)[56]	Convenience sample (*)	Not justified	Internal comparison (**)	Structured interview and medical records (*)	Department of Veterans Affairs & Department of Defence definition (2009) (*)	Analysis adjusted for age, gender, race, education, study site and medical/psychiatric/substance use history (**)	Neuropsychological testing (**)	Examines linear trend effects between level of concussion exposure and cognitive variables (*)	10
McMillan (2017)[57]	Sampling frame identified but response rate low (22%) (*)	Not justified	Friends and family of participants, schoolteachers and people from community groups recruited as controls (*)	unclear, self-report on 'structured assessment form administered at interview'	Standard description of concussion (*)	Main analysis adjusted for age, deprivation, and education (**)	Neuropsychological testing and self-report using validated measure (**)	Examines between-group/subgroup differences in cognitive variables and correlations between overall concussion exposure and cognitive variables (*)	8

Strain (2017)[66]	Convenience, volunteer and snowball sampling (*)	Not justified	Cognitively normal controls recruited from prior aging studies (*)	Unclear, self-report	American Academy of Neurology Guidelines (1997) (*)	Controls matched for age, education and estimated pre-morbid IQ (**)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	8
Decq (2016)[58]	sampling frame identified, response rate 46% (*)	Not justified	Other sportsmen not expected to be exposed to multiple concussions used as controls (*)	Self-report questionnaire	Unclear	Multivariate analysis used to adjust for potential confounders (*)	Self-reported using validated measure and neuropsychological test (**)	Examines between-group differences in cognitive variables, and regression analysis of relationship between concussion exposure and cognitive variables (*)	6
Goswami (2016)[50]	No clear description	Not justified	Healthy controls recruited from the general population (*)	Self-report questionnaire followed by structured interview (*)	Consensus statement on concussion in sport definition (McCrory et al, 2013) (*)	Controls matched for age, gender and education (**)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	8
Coughlin (2015)[59]	Convenience and snowball sampling (*)	Not justified / under-powered	Controls did not participate in neuropsychological assessment, former players' scores standardised based on normative data (*)	Standardised interview (*)	American Academy of Neurology Guidelines (1997) (*)	No comparison group used	Neuropsychological testing (**)	No statistical analysis	6

Strain (2015)[65]	Convenience, volunteer and snowball sampling (*)	Not justified	Healthy controls recruited from the general population (*)	Unclear, self-report	American Academy of Neurology Guidelines (1997) (*)	Controls matched in study design for education and estimated premorbid IQ (*)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	7
Terry (2015)[53]	Volunteer sample (*)	Not justified	Internal comparison (**)	Self-report questionnaire and interview using ACE (Gioia & Collins, 2006) (*)	American Congress of Rehabilitation Medicine definition (1993) (*)	Controls matched for age, education and estimated pre-morbid IQ (**)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	10
Tremblay (2014)[61]	No clear description	Not justified	Internal comparison (**)	Standard questionnaire taken from imPACT	Consensus statement on concussion in sport definition (McCrory et al, 2009) (*)	Age only controlled for in neuroimaging analyses	Neuropsychological testing (**)	Examines between-group differences in cognitive variables. Statistical test not reported fully therein, but previous paper with full analysis is cited (*)	6
Hart (2013)[64]	Convenience, volunteer and snowball sample (*)	Not justified	Healthy controls recruited from the general population (*)	Unclear, self-report	American Academy of Neurology Guidelines (1997) (*)	Controls matched for age, education and estimated pre-morbid IQ (**)	Neuropsychological testing (**)	Examines between-group differences in cognitive variables and correlation between concussion exposure and cognitive variables (*)	8

Tremblay (2013)[60]	No clear description	Not justified	Internal comparison (**)	Standard questionnaire taken from imPACT	Consensus Statement on Concussion in Sports definition (McCrory et al., 2009) (*)	Age only controlled for in neuroimaging analyses	Neuropsychological testing (**)	Examines between-group differences in cognitive variables (*)	6
Amen (2011)[62]	Convenience and snowball sampling (*)	Not justified	Microcog scores compared with MicroCog standardised sample (*)	Unclear, self-report	Centres for Disease Control and Prevention definition (1997) (*)	No description	Neuropsychological testing and validated self-report measure (**)	Descriptive statistics only. Inferential statistics performed only in relation to neuroimaging outcomes.	5
Guskie-wicz (2005)	Sampling frame identified, response rate 43.2% (*)	Not justified	Internal comparison, and population norms comparison in sub-analysis (**)	Self-report questionnaire	Standard description of concussion in line with AAN (1997) and McCrory (2013) (*)	No description	Validated self- and observer-report measure (*)	Examines subgroup differences in cognitive variables and associations between concussion exposure and self-/spouse-reported cognition (*)	6

AAN = American Academy of Neurology; ACE = Acute Concussion Evaluation; imPACT = Immediate Post-Concussion Assessment and Cognitive Testing; SCAT3 = Sport Concussion Assessment Tool.

Appendix G

SRL: Details of cognitive testing and list of abbreviations of cognitive tests used in included studies

Table G1

Cognitive tests used in included studies, organised by cognitive domains.

Cognitive Domain (# unique studies)	**Cognitive Tests Used**	**Study Citations**
Complex Attention (9)	CBS, CS, Digit Span (forwards), EFT, ImPACT, MicroCog, PASAT, RBANS, SART, SDMT, Spatial Span (forwards), TMT, WAIS-IV Coding, WAIS-R Digit Symbol, WMS-R Digit Span	46,47,49,51,52,55-57,60-62,64,67
Learning and Memory (11)	BVMT-R, CVLT-II, ImPACT, MicroCog, RAVLT, RBANS, ROCFT, RVDLT, SRTT, TCFT, WMS-IV	46-49,51-53,55-57,59-65,66
Executive Function (5)	CBS, CS, Digit Span (backwards), NIH-EXAMINER, SART (go/no-go), Spatial Span (backwards), TMT B, WCST	47,49,50,55-57,64
Language (5)	Animal Fluency, BDAE, BNT, COWAT, Isaac Set Test, RBANS, Semantic and Phonemic Verbal Fluency, SORT	51,52,56,58,60,61, 64,66,67
Perceptual-motor Function (7)	CBS, GPT, JLO, MicroCog, RBANS, ROCFT	46,49,51,52,55,57, 62,64
General Cognition/Intelligence (7)	MCIS, MMSE, MOCA, Neuro-QOL, RBANS, SILS, TICS-m, WAIS-III	45,47,54,57,58,60-62

Note. Please see overleaf for a list of abbreviations.

Table G2

List of abbreviations of cognitive tests used in the included studies

Abbreviation	Test Name
BDAE	Boston Diagnostic Aphasia Examination
BNT	Boston Naming Test
BVMT-R	Brief Visuospatial Memory Test-Revised
CBS	Cambridge Brain Sciences computerised battery
COWAT	Controlled Oral Word Association Test
CS	CogState computerised battery
CVLT-II	California Verbal Learning Test-II
EFT	Eriksen Flanker Test
GPT	Lafayette Grooved Pegboard Test
ImPACT	Immediate Post-Concussion Assessment and Cognitive Test
JLO	Judgement of Line Orientation Test
MCIS	Mild Cognitive Impairment Screen
MMSE	Mini Mental State Exam
MOCA	Montreal Cognitive Assessment
Neuro-QOL	Quality of Life in Neurological Disorders: Applied Cognition–General Concerns
NIH-EXAMINER	National Institutes of Health Executive Abilities: Measures and Instruments for Neurobehavioral Evaluation and Research
PASAT	Paced Auditory Serial Addition Task
RAVLT	Rey Auditory Verbal Learning Test
RBANS	Repeatable Battery for the Assessment of Neuropsychological Status
RVDLT	Rey Visual Design Learning Test
ROCFT	Rey-Osterrieth Complex Figure Test
SART	Sustained Attention to Response Task
SDMT	Symbol Digit Modalities Test
SF-36	Short Form Health Survey
SILS	Shipley institute of living scale
SOPT	Self-Ordered Pointing Task
SORT	Semantic Object Retrieval Test
SRTT	Serial Reaction Time Task
TCFT	Taylor Complex Figure Test
TICS-m	The Modified Telephone Interview for Cognitive Status
TMT	Trail Making Test
WAIS-III/IV	Wechsler Adult Intelligence Scale–Third/Fourth Edition
WAIS-R	Wechsler Adult Intelligence Scale-Revised
WCST	Wisconsin Card Sorting Task
WMS-IV	Weschler Memory Scales – 4th Edition

Appendix H

SIP: Author guidelines for Journal of Renal Care

Aims and Scope

The *Journal of Renal Care (JORC)*, formally the EDTNA/ERCA Journal, is the official publication of the European Dialysis and Transplant Nursing Association – European Renal Care Association (EDTNA/ERCA). It publishes a broad range of peer-reviewed clinical, research and educational papers for health care professionals working in kidney care. The JORC seeks to provide content that is relevant to, and reflective of, the growing diversity of the renal care community.

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Muller D., Harns P. & Watley L. (1986). *Nursing Children: Psychology Research and Practice*. London: Harper Row.

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Appendix I

SIP: Semi-structured interview schedule

Introduction

- Introduce self and thank participant for agreeing to take part
- Recap of information sheet relevant to participant interviews incl. confidentiality and data storage.
- Explain format of interview (up to 45 minutes, questions relate to experiences of being on dialysis and of receiving support as a dialysis patient, can take breaks or end the interview at any time)
- Give opportunity for participant to ask questions
- Seek verbal consent to audio record the interview for transcribing purposes, and to use quotes in the written report.

[Start of interview – begin recording]

Warm up question:

1. Could you describe what happens in dialysis, in your own words?

Experience of dialysis:

2. I'd like to know more about what it is like to be on dialysis. Can you tell me about what being on dialysis has been like for you?

   <u>Probes:</u> How has it impacted your everyday life? affected the way you see yourself? How about your relationships with others, or how others see you? Can you tell me about any challenges you have faced on dialysis in terms of your emotional and mental wellbeing?

3. Day-to-day, what helps you cope with being on dialysis?

   <u>Probes:</u> any strategies?

4. What makes it harder to adhere to your treatment and the restrictions that come with treatment?

Experience of support/service improvement questions:

5. What support are you aware of that is available to dialysis patients for the emotional and mental impact of dialysis at [name of service]?
6. What has been your experience of receiving support as a dialysis patient?

   <u>Probes:</u> what has been most helpful? least helpful? What was helpful/unhelpful about it?
7. What are the stages in your dialysis journey that support has been/would have been most helpful?
8. What, if anything, gets in the way of accessing support or asking for help?
9. Could we be doing anything different to better support patients with the emotional and mental impact of dialysis?

   <u>Probes:</u> type of support (e.g., formal, informal?), when? From whom?

10. Is there anything else you would like to add, or anything important you think we haven't already covered?

[end of interview]

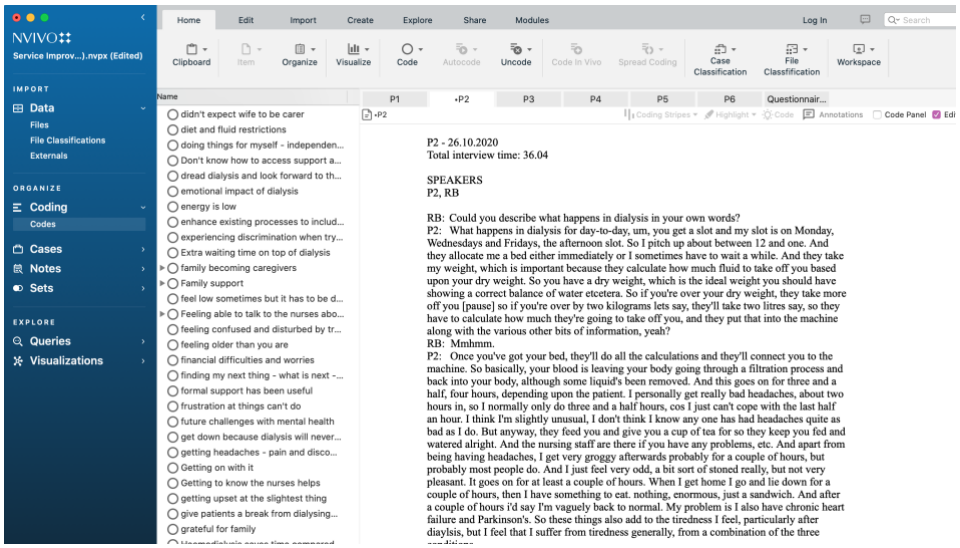
Debrief

Appendix J

SIP: Images demonstrating the stages of analytic process.

Picture 1.

Initial line-by-line coding of transcripts using NVivo.



Picture 2.

Initial clustering of codes into potential themes by hand using post-it notes.



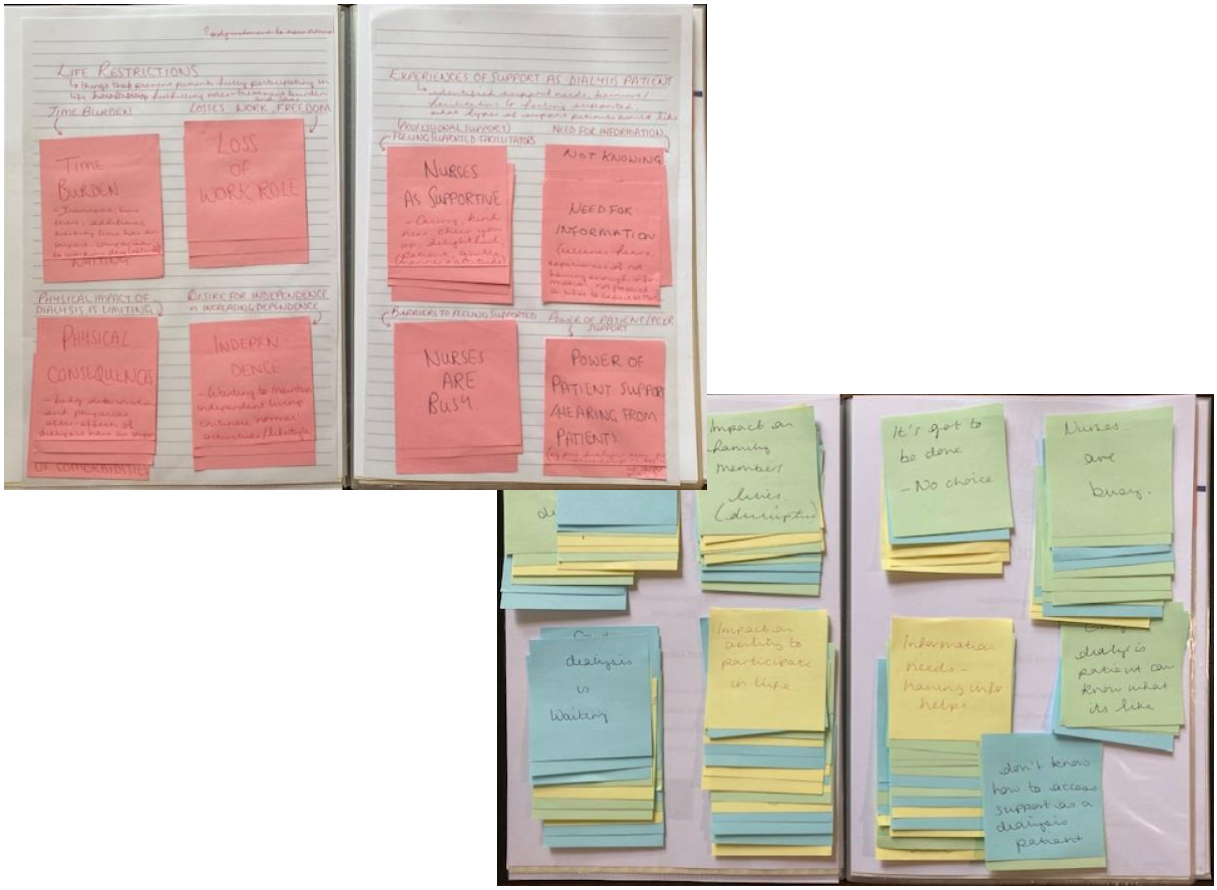
Picture 3.

Further organising initial themes based on patterns of similarity and dissimilarity



Pictures 4 and 5.

Reviewing and refining theme structure and clarifying subthemes; and continuing to refine and re-grounding themes in the data by returning to codes and data extracts



Appendix K

SIP: Confirmation of Trust registration as clinical audit

Email from Clinical Audit Lead (Oxford University Hospitals Clinical Audit Team) confirming registration of the project as a clinical audit

Date: 12/03/2020 11:00 GMT
To: Rachael Beale <rachael.beale@hmc.ox.ac.uk>
From: Jane Kilbey <Jane.Kilbey@ouh.nhs.uk>
Subject: Re: Service Improvement Project

Dear Rachael,

Please find enclosed the registered audit form DATIX 5948

Regards
Jane

Attached: <02.03.2020 – R. Beale – Renal unit Service Improvement Project – Clinical Audit Project Proposal Form_.docx>

Appendix L

SIP: Participant information sheet and consent form [4]

Oxford Institute of Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Rachael Beale
Trainee Clinical Psychologist
Rachael.beale@hmc.ox.ac.uk

PARTICIPANT INFORMATION SHEET

Are you a patient currently receiving dialysis at the Oxford Kidney Unit at Churchill Hospital, or its satellite units in Banbury, High Wycombe, Milton Keynes, Aylesbury or Swindon?

We would like to invite you to take part in an online service improvement project we are running. Please read through this information before deciding whether or not you would like to take part.

General Information

This project aims to improve the psychological support offered to patients of the Oxford Kidney Unit. It will do this by using information from questionnaires and interviews with current patients to help the unit develop a better understanding of the emotional and psychological needs and issues facing its patients – and whether the psychological service is fully meeting these. The findings from the project will help guide future developments in the service.

We are looking for up to 50 people currently receiving dialysis to complete a small set of questionnaires online. The questionnaires will ask you about your experience of a range of common psychological symptoms and other issues you might be facing while on dialysis. It is important that we hear from a full range of patients, so we are interested in hearing from you whether or not you consider yourself to be experiencing any psychological symptoms currently. The questionnaires should take about 20-30 minutes to complete.

At the end of the questionnaires, you will be asked whether you would be interested in taking part in an interview to talk further about your experience of being on dialysis. This is an additional part of the project, and you do not have to agree to take part in an interview to participate in answering the questionnaires. Interviews will be arranged at a later date with a small number of people who have expressed an interest in taking part in this, at their convenience. The interview would last approximately 30-40 minutes and would take place via video call.

Do I have to take part?

No! It is completely up to you if you would like to take part in either part of the project. You can ask questions about the project before deciding whether or not to take part by emailing rachael.beale@hmc.ox.ac.uk.

If you do decide to take part, you may withdraw at any point during the questionnaire for any reason before submitting your answers by pressing the 'Exit' button/closing the browser. If you exit the survey before submitting your response, your data will not be stored. As the questionnaire data is collected anonymously, once you submit your responses, we will not be able to withdraw your responses retrospectively. If you express interest in being contacted to arrange an interview, you will be able to withdraw from this at any time, without giving a reason, until the point that responses have been collated and the project is written up.

What are the possible benefits of this project?

I will analyse the data collected from the questionnaires and interviews and summarise the findings in a written report. The report will be shared with the Oxford Kidney Unit, to help them better understand the emotional and psychological needs of their patients and guide future developments in the psychological support they offer.

How will my data be used?

Your answers to the questionnaires will be completely anonymous, and we will take all reasonable measures to ensure that they remain confidential. Your name and computer's IP address **will not** be stored. All data will be stored securely in line with University and NHS information governance guidelines and will only be retained for as long as we need it for this project.

If you take part in an interview, please know that this will be recorded. This is so that the interviewer can write a transcript of the interview. The recording will be deleted after this has been done. With your permission, written quotes from the interview may be included in the written report. Any quotes used would be anonymised, and we would discuss this further with you at the interview.

The written report from this project will form part of Rachael Beale's doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives. You will not be identified in the written report.

Who do I contact if I have questions or concerns about the project?

This project has been approved by Oxford University Hospitals NHS Trust's Audit department (DATIX 5948).

If you have a question or concern about any aspect of this project, please don't hesitate to contact me (rachael.beale@hmc.ox.ac.uk) or my supervisor Dr Louise Hankinson (louise.hankinson@ouh.nhs.uk) and we will do our best to answer your query.

If you have read the information above and agree to participate in the project, please tick the boxes below.

☐ I understand that my participation is voluntary and that I am free to withdraw, without giving any reason, and that doing so will not affect my care.

☐ I understand what will happen to the data I provide.

☐ I agree to take part.

Name _____

Signed _____

Date _____

4. Adapted for this study from University of Oxford Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) templates and examples provided by the Oxford Institute of Clinical Psychology Training course.

Appendix M

SIP: Supplementary data analysis – Investigating the prevalence of depression and anxiety symptoms in patients undergoing hospital-based haemodialysis treatment

Overview

As an additional aim of the service improvement project, the service was interested in using data collection to provide a preliminary investigation of the prevalence of depression and anxiety in their patients living with haemodialysis. A cross-sectional questionnaire design was used to provide a 'snapshot' of depression and anxiety symptoms in patients receiving haemodialysis.

Additional data collection

In addition to the qualitative data collected (see main report for full details of recruitment and data collection), 43 participants completed the Patient Health Questionnaire (PHQ-9; Spitzer et al., 1999) and General Anxiety Disorder scale (GAD-7; Spitzer et al., 2006) either online (n=7) via the platform *JISC Online Surveys*, or on-paper (n=38) during a dialysis session. The PHQ-9 was used to assess the presence and severity of depression symptoms. The PHQ-9 has been found to demonstrate high correlation with diagnosis by mental health professionals and other standardised measures for depression (Lowe, 2004), and has been shown to demonstrate good internal consistency (Kroenke et al., 2001). The GAD-7 was used to assess the presence and severity of anxiety. The GAD-7 has been shown to be valid and demonstrate excellent internal consistency and good test-retest reliability (Spitzer et al., 2006). When used as screening tools with individuals from haemodialysis populations, the recommended clinical cut-off for both the PHQ-9 and GAD-7 is scores of 10 or greater (Watnick et al., 2005; Picariello et al., 2018).

Data Analysis

Exploratory data analysis was performed using Microsoft Excel (Version 16.44) and R (Version 4.0.3). Demographic characteristics (i.e., age, gender, and time on dialysis) and

scores on quantitative measures were explored using visual methods and descriptive statistics. Data across all variables were examined for normality, skew, and kurtosis and several variables were seen to not be normally distributed, thus it was felt percentages and median averages with 25-75% interquartile ranges (IQR) best characterised the data. Box plots, histograms, and scatterplots were utilised to visually inspect the data across all variables. An a priori decision was made to use person-mean imputation to substitute missing questionnaire data in cases where two or fewer items were missing due to participant non-response. Overall, 0.8% of the questionnaire data was missing and person-mean imputation was performed for the following measures: PHQ-9 (2 cases) and GAD-7 (2 cases).

Results

Demographic characteristics of the sample

Table M1 presents demographic characteristics. The most commonly reported age group was 65-74, followed by 45-54, and the majority of participants (67%) were male. This is comparable to the demographic distribution of the general hospital-haemodialysis population in the UK, which, according to the most recent prevalence estimate, consists of 61.9% of males, with a median age of 67.2 years (MacNeill & Ford, 2018).

Depression and anxiety

A summary of scores obtained on the PHQ-9 and GAD-7 is presented in Table M1, and the distribution of scores in relation to measure-specific cut-offs in Table M2. Overall, 21 participants (49%) met criteria for depression or anxiety based on a PHQ-9 or GAD-7 score of ≥10, with six (14%) meeting criteria for both. Visual inspection of the data did not suggest an effect of any demographic variables (i.e., gender, age, or time on dialysis) on the prevalence or severity of either depression or anxiety symptoms (see Table M3 for a breakdown of depression and anxiety scores according to demographic variables, and Figures M1-3); no further exploration of this data was indicated.

Table M1

Demographic and medical characteristics of participants, and summary of scores on self-report measures.

Variables	*N*	% [a]	Median	IQR	Range
Gender [a]					
Male	29	67.4			
Female	13	30.2			
Age [a]					
35-44	1	2.3			
45-54	11	25.6			
55-64	8	18.6			
65-74	13	30.2			
75+	9	20.9			
Time on Dialysis (months)[a]			30.0		1 – 168
Aetiology					
Unknown cause	10	23.3			
Diabetes	7	16.3			
Medication	4	9.3			
Autoimmune disorders	4	9.3			
Urinary tract blockages	3	7.0			
Infections	2	4.7			
Polycystic kidney disease	2	4.7			
Cancer	2	4.7			
Congenital cause	2	4.7			
Hypertensive disease	2	4.7			
Liver failure	1	2.4			
Acute kidney injury	1	2.4			
Glomerular diseases	1	2.4			
Transplant failure	1	2.4			
Drugs and alcohol	1	2.4			
PHQ-9 total score			8.0	3-14	0-24
GAD-7 total score			4.0	0.5-8	0-21

Note. PHQ-9 = Patient Health Questionnaire, GAD-7 = Generalised Anxiety Disorder scale, IQR = interquartile range

[a] Data were missing for gender (n=1), age (n=1), and time on dialysis (n=1). It was assumed that these data were missing at random. Missing demographic and medical data were not substituted in any way, thus percentages for these variables do not all add up to 100.

Table M2

Distribution of depression and anxiety severity, based on PHQ-9 and GAD-7 scores.

	Severity category (range of scores)	***N***	***%***
Depression	None (0-4)	15	35.0
	Mild (5-9)	8	18.6
	Moderate (10-14)	12	27.9
	Moderately severe (15-19)	6	14.0
	Severe (20-27)	2	4.7
Anxiety	None (0-4)	25	58.1
	Mild (5-9)	11	25.6
	Moderate (10-14)	5	11.6
	Severe (15-21)	2	4.7

Note. The recommended clinical cut-off for both the PHQ-9 and GAD-7 is scores of 10 or higher.

Table M3

Scores on self-report measures according to demographic characteristics

	Total	**Gender**		**Age group [years]**				
		Male	**Female**	**<45**	**45-54**	**55-64**	**65-74**	**75+**
	[n = 43]	[n = 29]	[n = 13]	[n = 1]	[n = 11]	[n = 8]	[n = 13]	[n = 9]
Depression (PHQ-9)								
Median Score (0-27)	8.0	7.0	10.0	4.0	10.0	10.5	6.0	8.0
IQR	3-14	3-13	3-14	N/A	7-12	3-16	3-11	3.4-10
Depression indicated [≥10]	45%	41%	54%	Younger (≤65) = 52%			Older (>65) = 38%	
Anxiety (GAD-7)								
Median Score (0-21)	4.0	4.0	3.0	0.0	7.0	6.5	1.0	3.0
IQR	0.5-8	0-9	2-8	N/A	5-10	3.8-8.2	0-4	1-4
Anxiety indicated [≥10]	17%	21%	8%	Younger (≤65) = 19%			Older (>65) = 14%	

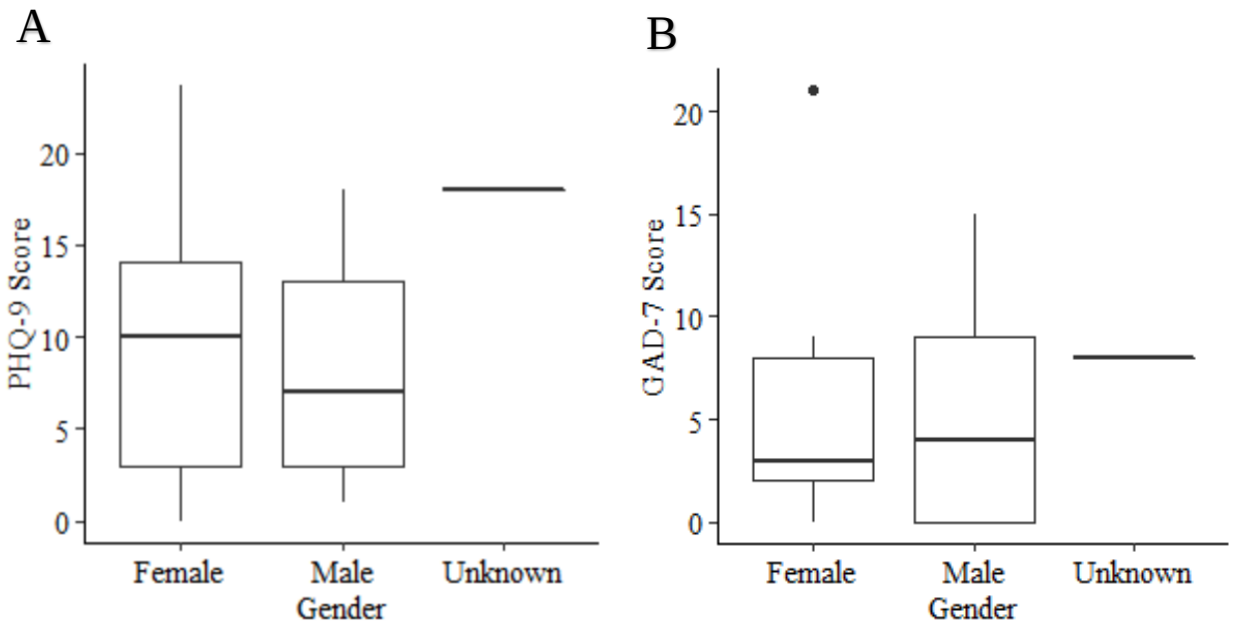


Figure M1.

Distribution of depression and anxiety scores by gender. (A) Boxplot of PHQ-9 scores by gender, and (B) boxplot of GAD-7 scores by gender. Box = 25th and 75th percentiles, bars = min and max values. 'Unknown' indicates scores for participants who selected I'd prefer not to say *when reporting their gender (n=1).*

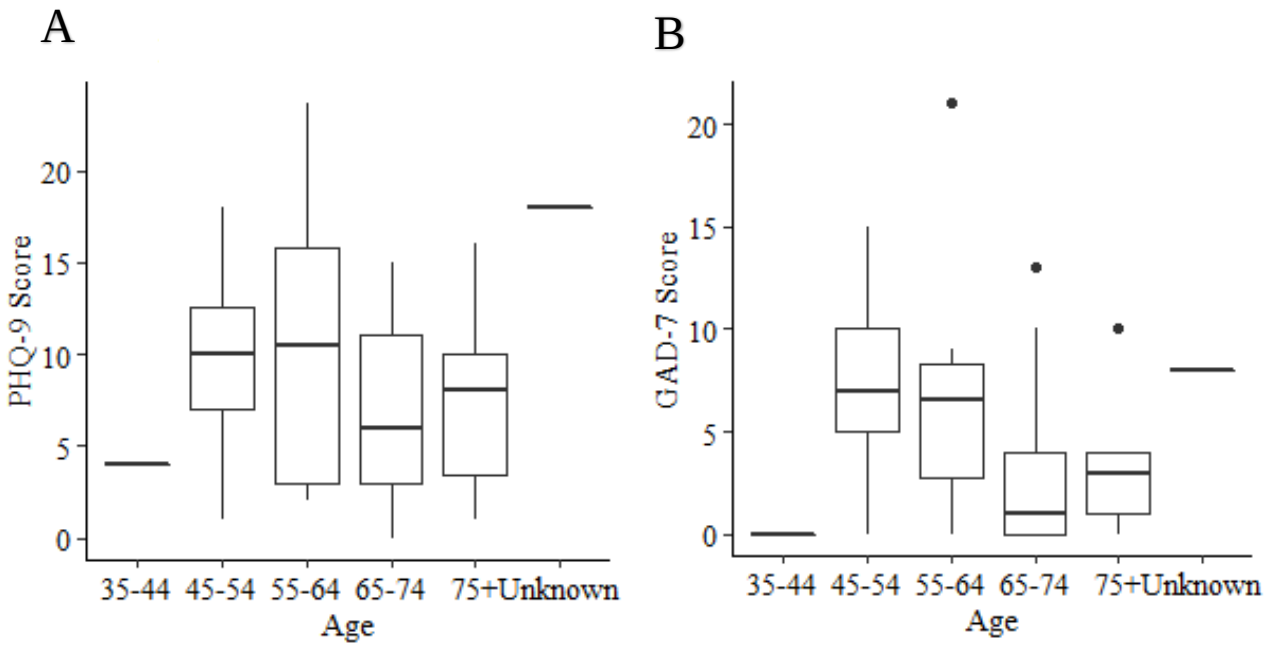


Figure M2.

Distribution of depression and anxiety scores by age group. (A) Boxplot of PHQ-9 scores by age group, and (B) boxplot of GAD-7 scores by age group. 'Unknown' indicates participants with missing data for age group (n=1).

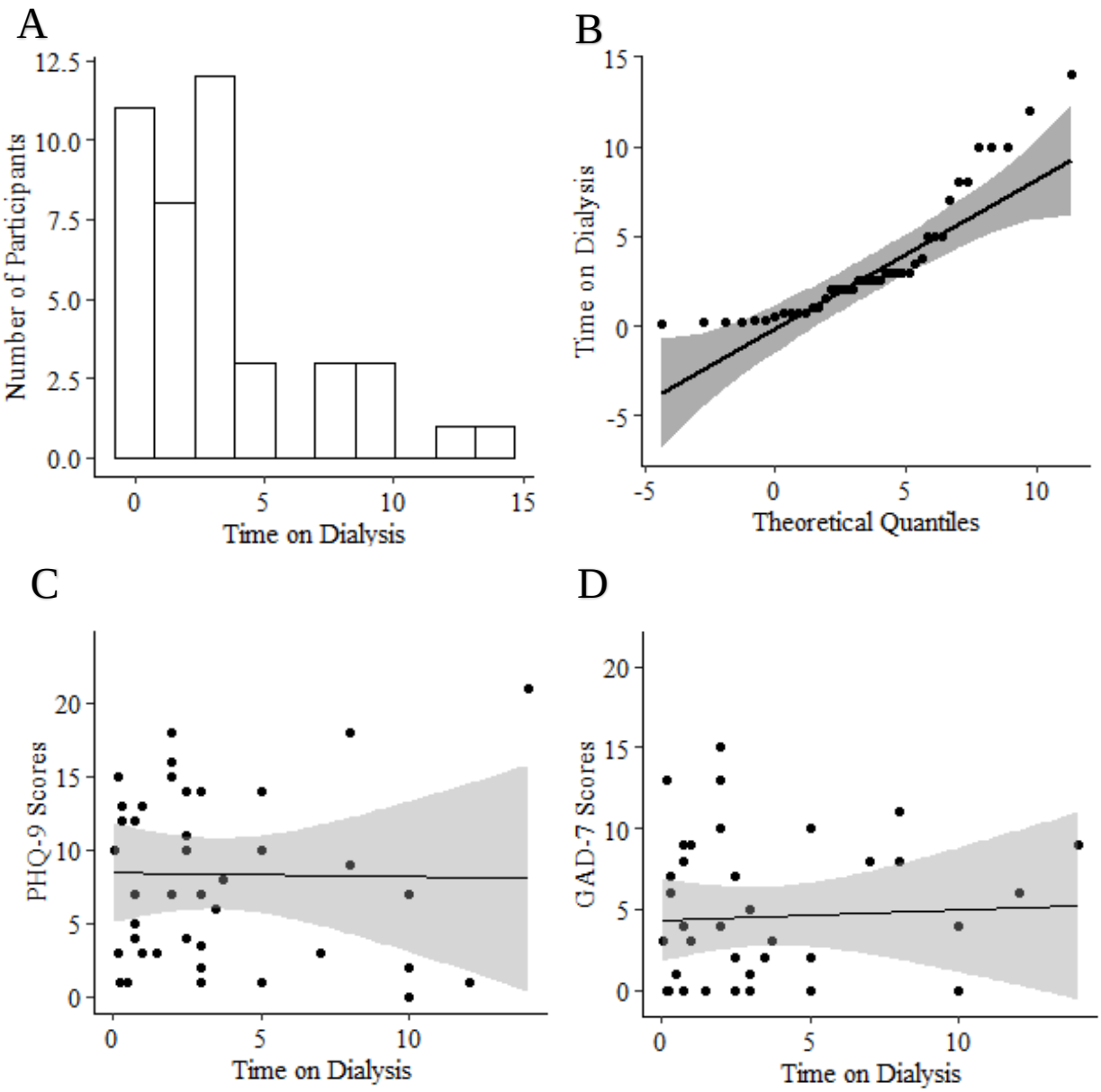


Figure M3.

Distributions of time on dialysis (years) and effect of time on dialysis on PHQ-9 and GAD-7 scores. (A) histogram showing frequency distribution of time on dialysis in years, skew=1.43, kurtosis=1.09 (right skewed), (B) Normal Q-Q plot showing distribution of time on dialysis, (C) scatterplot showing the relationship between time on dialysis and PHQ-9 score, (D) scatterplot showing the relationship between time on dialysis and GAD-7 score.

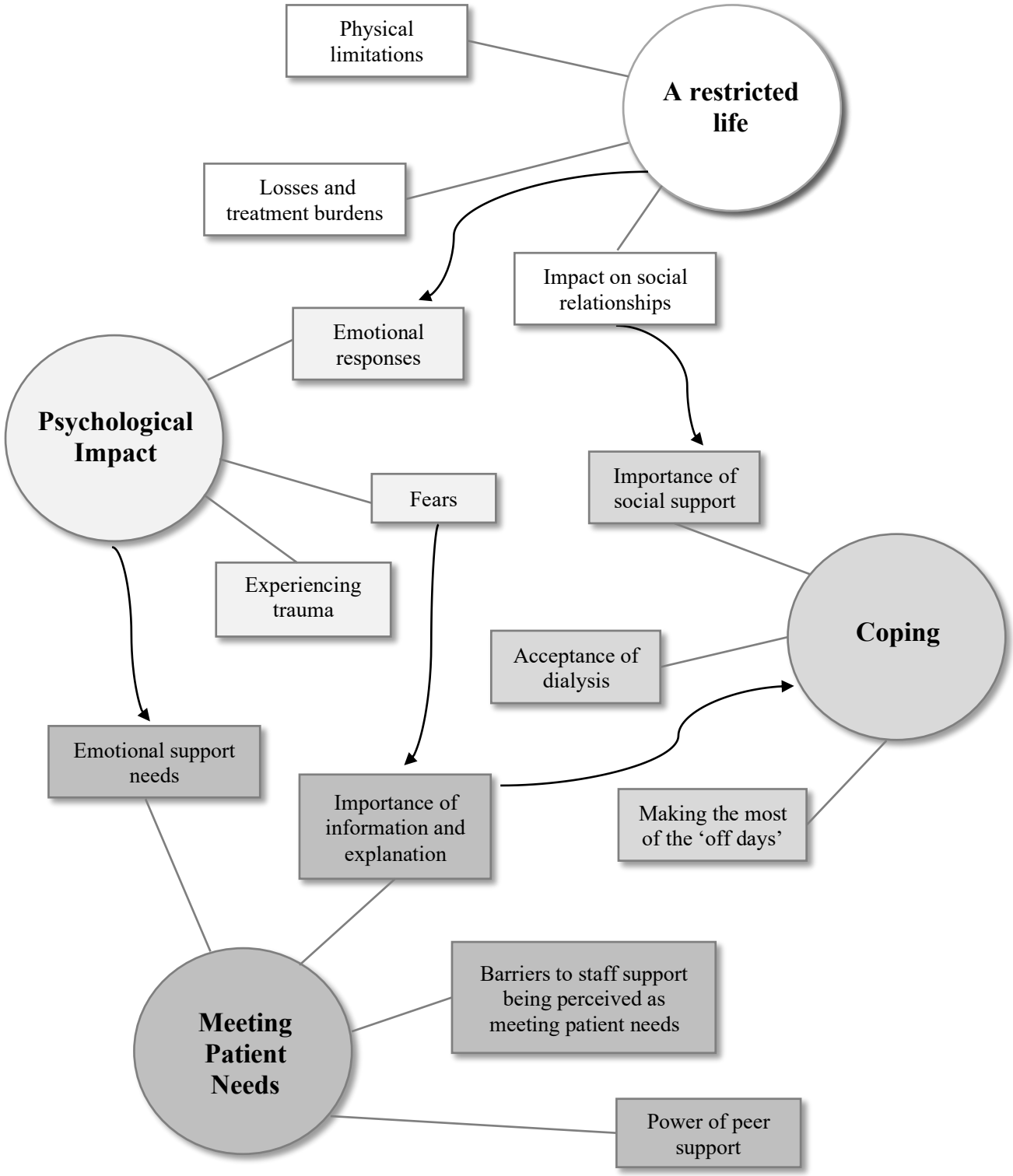
Discussion

It was found that almost half of participants reported above-threshold symptoms of depression or anxiety, suggesting a high prevalence of psychological distress in this sample. The incidence of both depression and anxiety were comparable to previous findings in the literature (Palmer et al., 2013; Murtagh et al., 2007; Schouten, 2019), although at 47%, the proportion of participants scoring above the cut-off for depression was slightly higher than expected compared to a meta-analysis estimating the prevalence of depression in patients with ESRD across the literature (using screening measures) to be 39.3% (Palmer et al., 2013). There was no clear evidence to suggest any relationships between gender, age, or time since dialysis initiation, and either the presence or severity of depression or anxiety symptoms. This is consistent with some previous literature (e.g., Cukor, 2007), but contradicts other studies that have reported associations between distress and these sociodemographic variables in dialysis populations (e.g., Damery et al., 2019; Goh & Griva, 2018). Given the relatively small sample size used in this study, it would be warranted to explore this further in future work. Overall, findings suggest that there may be unmet psychological needs in this group and that some patients may benefit from additional support. Nevertheless, it should be noted that this was a relatively small sample with an exploratory approach to data analysis, thus above reported findings are tentative, and generalisations should not be made beyond this study.

In terms of clinical implications, given the observation of the service that patients often present for psychological support already experiencing high levels of distress, and given the high prevalence of patients in this sample identified by screening measures as being at risk for psychological difficulties, there would be value in implementing routine psychological screening within the dialysis pathway. This would aid timely identification of patients who may benefit from psychological intervention. Multidisciplinary team members should be trained to screen patients for anxiety and depression and refer patients at high-risk of either for further assessment and treatment.

Appendix N

SIP: Final thematic map and prevalence of themes and subthemes across participants



Note. circles denote themes, rectangles denote subthemes, lines represent hierarchical relationships between themes and subthemes, and arrows represent tentative relationships between themes and subthemes.

Table N1

Prevalence of themes and subthemes across participant interviews and qualitative questionnaire responses.

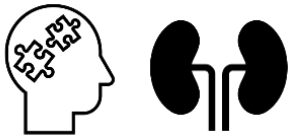
	Participant							
Themes and Subthemes	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Q** [a]
A restricted life								
Physical limitations	*	*	*	*		*	*	*
Losses and treatment burdens	*	*	*	*	*	*	*	*
Impact on social relationships	*	*	*	*	*	*	*	*
The psychological impact								
Emotional responses	*	*	*	*		*		*
Fears		*	*	*	*	*	*	*
Experiencing trauma	*	*	*	*	*	*		
Coping								
Importance of social support	*	*	*	*	*	*		*
Acceptance of dialysis	*	*	*		*		*	*
Making the most of the 'off days'	*	*			*	*	*	
Meeting patient needs								
Importance of information and explanation	*	*	*	*	*	*	*	*
Emotional support needs	*	*	*	*	*	*	*	*
Barriers to staff support being perceived as meeting patient needs	*		*	*	*	*		*
Power of peer support		*		*	*	*		

[a] *'Q' indicates that the theme was supported by the qualitative questionnaire data.*

Appendix O

SIP: Lay summary

Improving the Emotional and Psychological Support Offered for Haemodialysis Patients



Project Summary

This is a summary of our study and its results. It will tell you what the study tried to learn, how we went about it, and what we found.

What was this study about?

We know that living with dialysis doesn't just affect patients' physical health. It also brings a range of changes and difficulties into peoples' lives which can be hard to adjust to. This may create difficult feelings and worries, and previous research has suggested that patients on dialysis may be more likely to develop depression and anxiety than people who do not have long-term health conditions. Because of this, it is important for renal services to be able to offer emotional and psychological support to their patients.

This study was a service improvement project. We aimed to improve our understanding of the emotional and psychological needs of patients getting haemodialysis treatment. We also asked patients about their experiences of getting support from the service. The service was interested in learning more about these things so that it can improve the emotional and psychological support it offers to patients.

What did we do?

We asked a group of 45 patients to complete questionnaires asking about common depression and anxiety symptoms. We also invited them to give written feedback or take part in an interview to talk more about their experiences of living with dialysis and receiving support as patients. Seven patients agreed to take part in interviews, and 27 more gave written feedback. All of this this took place between September and December 2020.

What did we find out?

Almost half (49%) of patients that took part in the project reported symptoms that suggested they may have been experiencing depression or anxiety. This suggested that

patients in the service may have unmet psychological needs as well as their physical health needs and may benefit from some extra support.

We learned more about the impact of dialysis on patients' quality of life. For example, patients spoke about haemodialysis getting in the way of them being able to carry on with roles and activities in their lives that were important to them. This was commonly because of physical limitations like pain, weakness, and fatigue, experiencing losses and burdens to do with treatment, and the impact of dialysis and kidney disease on social relationships.

Patients experienced a range of emotions while adjusting to living on dialysis, including feeling low, anxious, stressed, angry and hopeless. Some also talked about having fears to do with treatment and going through scary or upsetting experiences related to dialysis which made it harder for them to feel able to cope with treatment. Patients felt that they had been less well prepared for the emotional and psychological impacts of haemodialysis treatment and suggested that information support is a key area the service should develop. They also felt that more support should be given to patients around the time of being diagnosed and starting dialysis treatment.

Patients talked about several things that helped them to cope with dialysis treatment, such as making the most of the days they do not have dialysis sessions, having support from their friends and family, and reaching a place of accepting dialysis as part of life. Positive relationships between staff and patients, and informal day-to-day support where patients felt the focus was on themselves as people, rather than on their kidney disease, also helped patients to cope with treatment. Finally, we learned that patients valued having opportunities to learn from other patients' experiences and wanted the service to increase peer-led support.

Conclusions and next steps

This study added to the evidence about psychological wellbeing in people living with dialysis. The above findings were shared with the service to recommend areas where they can develop the emotional and psychological support that they offer to patients living with haemodialysis. The service found the study helpful and felt it had met its aims. Future work will be needed to test out whether the recommended improvements make a positive difference for patients living with haemodialysis.

Appendix P

TDRP: Author guidelines for Behaviour Research and Therapy

The major focus of *Behaviour Research and Therapy* is an experimental psychopathology approach to understanding emotional and behavioral disorders and their prevention and treatment, using cognitive, behavioral, and psychophysiological (including neural) methods and models. This includes laboratory- based experimental studies with healthy, at risk and subclinical individuals that inform clinical application as well as studies with clinically severe samples. The following types of submissions are encouraged: theoretical reviews of mechanisms that contribute to psychopathology and that offer new treatment targets; tests of novel, mechanistically focused psychological interventions, especially ones that include theory-driven or experimentally-derived predictors, moderators and mediators; and innovations in dissemination and implementation of evidence-based practices into clinical practice in psychology and associated fields, especially those that target underlying mechanisms or focus on novel approaches to treatment delivery. In addition to traditional psychological disorders, the scope of the journal includes behavioural medicine (e.g., chronic pain). The journal will not consider manuscripts dealing primarily with measurement, psychometric analyses, and personality assessment.

The Editor and Associate Editors will make an initial determination of whether or not submissions fall within the scope of the journal and/or are of sufficient merit and importance to warrant full review.

Early Career Investigator Award

This award is open to papers where the first author on the accepted papers is within 7 years of their PhD. By endorsing candidature for the annual Early Career Investigator Award, your manuscript will be reviewed by the Associate Editors/Editor-in-Chief for an annual award for the most highly rated paper. The winner will be announced in print, and will have the option of being spotlighted (photo and short bio).

The CONSORT guidelines (http://www.consort-statement.org/?) need to be followed for protocol papers for trials; authors should present a flow diagramme and attach with their cover letter the CONSORT checklist. For meta-analysis, the PRISMA (http://www.prisma-statement.org/?) guidelines should be followed; authors should present a flow diagramme and attach with their cover letter the PRISMA checklist. For systematic reviews it is recommended that the PRISMA guidelines are followed, although it is not compulsory.

Contact details

Any questions regarding your submission should be addressed to the Editor in Chief:
Professor Michelle G. Craske
Department of Psychology
310 825-8403
Email: brat@psych.ucla.edu

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:
One author has been designated as the corresponding author with contact details:
• E-mail address
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All necessary files have been uploaded:
Manuscript:
• Include keywords
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• All tables (including titles, description, footnotes)
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• Journal policies detailed in this guide have been reviewed
• Referee suggestions and contact details provided, based on journal requirements For further information, visit our Support Center.

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Please see our information pages on Ethics in publishing and Ethical guidelines for journal publication.

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If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans; Uniform Requirements for manuscripts submitted to Biomedical journals. Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.
All animal experiments should comply with the ARRIVE guidelines and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, EU Directive 2010/63/EU for animal experiments, or the National Institutes of Health guide for the care and use of Laboratory animals (NIH Publications No. 8023, revised 1978) and the authors should clearly indicate in the manuscript that such guidelines have been followed.

Conflict of Interest
All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also http://www.elsevier.com/conflictsofinterest. The Conflict of Interest form can be found

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Registration in a public trials registry is a condition for publication of clinical trials in this journal in accordance with International Committee of Medical Journal Editors recommendations. Trials must register at or before the onset of patient enrolment. The clinical trial registration number should be included at the end of the abstract of the article. A clinical trial is defined as any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects of health outcomes. Health-related interventions include any intervention used to modify a biomedical or health-related outcome (for example drugs, surgical procedures, devices, behavioural treatments, dietary interventions, and process-of-care changes). Health outcomes include any biomedical or health-related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. Purely observational studies (those in which the assignment of the medical intervention is not at the discretion of the investigator) will not require registration.

As of October 2016, registration in a public trials registry is a condition for publication of clinical trials in this Journal. In the event that patient enrollment began in a trial that was not pre-registered prior to September 2016, authors may still submit their manuscript to this Journal but will be asked to retrospective register (i.e., registration after patient enrolment begins) their study in a public trials registry. This exception to pre-registration will cease in October 2019.

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Appendix Q

TDRP: Confirmation of ethical approval

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ethics@medsci.ox.ac.uk



CONFIDENTIAL

Rachael Beale
Oxford Institute for Clinical Psychology Training
(OxICPT)
Isis Education Centre
Warneford Hospital
Oxford

9 September 2020

Dear Rachael

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R70783/RE001

Study title: Investigating the Role of Intrusive Mental Imagery in Obsessive-Compulsive Disorder: an Experimental Study

Short title: Mental Imagery and Obsessive-Compulsive Disorder

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

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on **9th September 2020**.

Approval is **subject to:**

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

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

Amendments

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

Please do not hesitate to contact me if you have any queries.

Yours Sincerely

H. Barnby-Porritt

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

Appendix R

TDRP: Intrusive obsessional imagery questionnaire

I would like to ask you a few questions about the mental imagery you have experienced in the past month. Please select the most frequent and unwanted image that you experience and answer the following questions:

Can you describe the content of this image? (brief summary of 25-30 words; it may help to describe what happens in the image as if you were explaining a picture or a film clip to someone who is unable to see it)

Do you experience this image mainly as a visual picture, an impression (i.e. a vague notion or awareness) or a sensation (e.g. taste, smell, sound or body sensation)?

Visual pictures

Impression

Sensation

Do you experience any other sensations when you experience the image? (select all that apply)

Sounds

Smell

Taste

Touch

Other (please specify)

None

How frequently have you experienced this intrusive image in the past week?

Not at all

Once

2-5 times

5-10 times

10-20 times

More than 20 times

How controllable is this image when it comes to mind?

Not at all

Slightly

Moderately

Very

Completely

How vivid is this image when it comes to mind?

No image at all, I only 'know' I am thinking of it

Dim and vague

Moderately realistic and vivid

Realistic and reasonably vivid

Perfectly realistic, as vivid as my normal senses

How distressing is this image when it comes to mind?

Not at all

Slightly

Moderately

Very

Extremely

Finally, to what extent do you agree with the following statements?

Experiencing this image increases the risk that what happens in the image will come true

Disagree Strongly
Disagree
Neutral
Agree
Agree Strongly

Having the image come to mind is morally almost as bad as doing what happens in the image

Disagree Strongly
Disagree
Neutral
Agree
Agree Strongly

Appendix S

TDRP: Participant information sheet and consent [5]

Oxford Institute of Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Rachael Beale
Trainee Clinical Psychologist
Rachael.beale@hmc.ox.ac.uk



PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R70783/RE001

Thank you for taking the time to look at this information sheet. Before you decide whether or not to take part in this research, it is important that you understand why the research is being done and what taking part would involve for you. Please take time to read this participant information sheet and feel free to discuss the research with others if you wish. We recognise there is a lot of information in this document - If there is anything that is not clear, or if you would like more information, please ask us by emailing the researcher at rachael.beale@hmc.ox.ac.uk – I will be happy to discuss the information sheet and answer any questions that you may have.

1. *What is the purpose of the study?*

In this study, we are interested in the different types of thoughts that can run through our minds, and the form that these thoughts can take. In particular, we are interested in the role that mental images – or 'pictures in your mind' - might play in the extent to which people do or do not have experiences often called obsessions or compulsions.

Mental images are the pictures, sounds, smells, and other sensory information that run through our minds when we have a thought or feeling. Troubling mental imagery is understood to be an important feature of many mental health problems. It is commonly reported by people who experience obsessive-compulsive disorder - however, to date there has been little research investigating the potential role that intrusive mental imagery plays in obsessive-compulsive disorder. Understanding more about this could help future research improve treatments for people experiencing obsessive-compulsive disorder.

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

For this study, we would like to hear from people who identify with experiencing obsessional and compulsive traits, and we would also like to hear from those who do not. You can take part if you are aged 18 years or over and live in the UK – and we are interested in hearing from you whether or not you consider yourself to be someone who thinks in mental images. You will also need to be able to speak and read in the English language and be able to use a computer or touchscreen device with internet access.

3. *Do I have to take part?*

No! It is completely up to you if you would like to take part in this study. You can ask questions about the research before deciding whether to take part by emailing rachael.beale@hmc.ox.ac.uk. If you do decide to take part, you can choose to stop taking part in the study at any time before submitting your answers by closing the browser.

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

At the end of this information sheet, you will be provided with contact details should you wish to ask any questions about the study. If you choose to click 'next' at the bottom of this page, you will be invited to give your consent to take part in the study by completing an online consent form. You will then proceed to complete a series of questionnaires online. The questionnaires will include some questions about demographic details (such as age, gender etc), about common mental health symptoms and about your experiences of mental imagery. We estimate the questionnaires will take you between 20 and 30 minutes to complete, and then you will be thanked and debriefed. While completing the study, you can take a break at any time and return to the questionnaires later on.

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

The questionnaires chosen for the study are widely used in psychological research and in clinical practice, but it is possible that some people may find answering the questionnaires upsetting. You can either take a break from the study and return to it later or withdraw from the study at any point. At the end of the study, you will be provided with contact details of services and third-party organisations that are able to offer support and guidance should you experience distress.

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

There will be no direct or personal benefit to you from taking part in this research, but we hope that your participation in this study will help us better understand the role that mental imagery plays in obsessional and compulsive problems and help future research to improve treatments for people experiencing OCD.

In acknowledgement of your time and contribution, we will donate £2 of our research funds on your behalf to either OCD Action or OCD UK. These are established charities in the UK that provide information, support and advice for individuals distressed by obsessional and compulsive problems.

7. *What happens to the data provided?*

We will not collect any data that could directly identify you. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential. The responses you provide will be stored securely, in line with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, on Nexus OneDrive for Business, Microsoft's storage service for hosting files in the "cloud". Research data (including consent records) will be stored in this way for the duration of the project, and then transferred to the University network to be stored securely for 3 years after publication or public release of the work of the research. This information will then be permanently deleted and destroyed.

8. *Will the research be published?*

We hope to publish our findings in an academic publication and present them to relevant charities. You will not be identified in any reports or publications arising from the study.

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

This research will be written up as Rachael Beale's doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the final thesis will be openly accessible. It will not be possible to identify you or your individual data from anything written up within the thesis.

9. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (ethics approval reference: R70783/RE001).

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

If you have a concern about any aspect of this study, please contact Rachael Beale (rachael.beale@hmc.ox.ac.uk), or one of her research supervisors Professor Craig Steel (craig.steel@hmc.ox.ac.uk) or Brynjar Halldorsson (brynjar.halldorsson@psych.ox.ac.uk), by email and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

11. *Further Information and Contact Details*

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

Rachael Beale
Trainee Clinical Psychologist, Oxford Institute of Clinical Psychology Training
Email: rachael.beale@hmc.ox.ac.uk

Thank you for taking the time to read this information sheet and for your interest in the project.
Please note that you may only participate in this survey if you are 18 years of age or over.

☐ I certify that I am 18 years of age or over

If you have read the information above and agree to participate with the understanding that the data you submit will be processed accordingly, please check the relevant box below to get started.

☐ Yes, I agree to take part

5. Adapted for this study from University of Oxford Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) templates and examples provided by the Oxford Institute of Clinical Psychology Training course.

Appendix T

TDRP: Supplementary details of data analysis and statistical outputs

1.1 Data Screening and Descriptive Data for Main Study Variables

Data were imported into SPSS and checked for quality by examining survey completion times, and distribution and range of responses. These checks did not highlight any reasons to exclude any responses. Scores were calculated for each measure and relevant subscales. The online survey was designed such that participants were prevented from missing any items on questionnaire measures; therefore, there were no missing data. This decision was made in recognition that it is not possible to use multiply imputed data with the PROCESS macro plug-in (Hayes, 2017). Data were screened for outliers, and parametric assumptions were explored using visual methods including histograms and quantile-quantile plots. Skewness and kurtosis were also checked for each variable (see Table T1). Significant

Table T1

Descriptive data for study variables

	Whole Sample (n=131)			**High-OC** (n=84)			**Low-OC** (n=47)		
	Mean *(SD)*	**Skew**	**Kurtosis**	**Mean (SD)**	**Skew**	**Kurtosis**	**Mean (SD)**	**Skew**	**Kurtosis**
OCI-R	28.46 *(17.32)*	0.25	-0.87	38.82 (12.20)	0.45	-0.53	9.94 (5.66)	0.27	-1.32
TAF total	28.95 *(21.30)*	0.36	-0.85	37.95 (19.94)	-0.07	-0.69	12.87 (12.35)	0.84	-0.37
Likelihood	10.02 *(9.88)*	0.42	-1.34	14.31 (9.31)	-0.23	-1.19	2.34 (5.07)	2.70	6.58*
Moral	18.94 *(13.85)*	0.30	-0.98	23.64 (13.47)	-0.04	-0.95	10.53 (10.12)	0.80	-0.39
SUIS	38.37 *(10.44)*	-0.16	-0.66	42.26 (8.89)	-0.13	-0.65	31.43 (9.42)	0.11	-1.04
VVIQ	39.62 *(13.63)*	0.33	0.02	37.10 (12.84)	0.33	0.29	44.13 (13.97)	0.25	-0.29
DASS Total Score	53.86 *(34.99)*	0.14	-1.21	72.64 *(26.89)*	-0.24	-0.71	20.30 *(19.04)*	2.19*	7.72*
DASS Depression	9.16 *(6.83)*	0.27	-1.29	12.25 (6.01)	-0.20	-1.22	3.64 (4.27)	1.73*	3.50*
DASS Anxiety	7.32 *(6.24)*	0.48	-1.10	10.49 (5.42)	-0.00	-1.04	1.66 (2.49)	3.61*	17.67*

OCI-R = Obsessive-Compulsive Inventory-Revised; TAF = Thought-Action Fusion scale; SUIS = Spontaneous Use of Imagery scale; VVIQ = Vividness of Visual Imagery Questionnaire; DASS = Depression, Anxiety, and Stress scale; * $p<0.05$

levels of skew or kurtosis (i.e., with *z*-scores over 3.29 [$p < 0.001$] for the whole sample and over 2.58 [$p < 0.01$] for the smaller High- and Low-OC subgroups; Kim, 2013; Field, 2009), indicated the following variables were not adequately normally distributed: TAF Likelihood subscale (Low-OC subgroup only), and DASS total score (Low-OC subgroup only), Depression and Anxiety subscales (Low-OC subgroup only). Appropriate transformations were tried; however, these did not resolve the issues with the distributions of variables that were not normal. Potential outliers were identified using boxplots for TAF Likelihood scores in the Low-OC group. Individual responses were inspected and there was no reason to suspect these were data entry errors or otherwise erroneous responses, thus no data points were removed. It was considered that due to the proportion of adequately normally distributed variables and overall sample sizes (i.e., in accordance with the central limit theorem; Tabachnick & Fidell, 2001), the potential impact of the deviation from normal was small and it was appropriate to proceed using parametric tests.

1.2 Additional Details of Comparisons between High- and Low-OC Groups on Demographic and Questionnaire Data

Table T2

Comparisons between High- and Low-OC groups on sociodemographic variables

	High-OC (n=84)	**Low-OC** (n=47)	**Test Statistic**
Gender *(n, %)*			
Female	52 (62%)	24 (51%)	FET = 1.71, $p = 0.453$
Male	30 (36%)	22 (47%)	
Non-Binary	2 (2%)	1 (2%)	
Age (years; *mean, SD)*	31.4 (11.89)	39.3 (15.24)	$t(77.7) = 3.08$, $p = 0.003$*
Ethnicity *(n, %)*			
White	73 (87%)	44 (94%)	FET = 1.48, $p = 0.599$
Another ethnic group	10 (12%)	3 (6%)	
Prefer not to say	1 (1%)	0 (0%)	
Employment status *(n, %)*			
Employed	54 (64%)	41 (87%)	$\chi^2(1) = 7.96$, $p = 0.005$*
Unemployed	30 (36%)	6 (13%)	
Education *(n, %)*			
No formal qualifications	13 (15%)	3 (6%)	$\chi^2(2) = 3.68$, $p = 0.159$
School leaving qualifications	25 (30%)	11 (24%)	
Further education	46 (55%)	33 (70%)	

Table T3

Comparison between High- and Low-OC groups on questionnaire measures, using t-tests

	High-OC (n=84)	**Low-OC** (n=47)	**Test Statistic**
OCI-R	38.82 (12.20)	9.94 (5.66)	$t(125.58) = -18.43$, $p = 0.000$*
TAF total	37.95 (19.94)	12.87 (12.35)	$t(127.60) = -8.88$, $p = 0.000$*
Likelihood	*14.31 (9.31)*	*2.34 (5.07)*	$t(128.94) = -9.53$, $p = 0.000$*
Moral	*23.64 (13.47)*	*10.53 (10.12)*	$t(118.10) = -6.30$, $p = 0.000$*
SUIS	42.26 (8.89)	31.43 (9.42)	$t(129) = -.66$, $p = 0.000$*
VVIQ	37.10 (12.84)	44.13 (13.97)	$t(129) = 2.91$, $p = 0.004$*
DASS Depression	12.25 (6.01)	3.64 (4.27)	$t(121.72) = -9.53$, $p = 0.000$*
DASS Anxiety	10.49 (5.42)	1.66 (2.49)	$t(125.25) = -12.731$, $p = 0.000$*

* $p<0.05$. These results remain significant when Bonferroni correction is applied to control for increased risk of type I error due to conducting multiple comparisons between the groups (Field, 2009).

Further clinical information is presented in Table T4. Seventy-five percent of the High-OC group reported having been given a diagnosis of OCD from a mental health professional, and 20% reported other mental health diagnoses, including anxiety (n=12), attention-deficit hyperactivity disorder (n=6), major depressive disorder (n=4), eating disorders (n=3), post-traumatic stress disorder (n=1), agoraphobia (n=1), panic disorder (n=1), and emotionally unstable personality disorder (n=1). Three participants reported they had autism. No participants assigned to the Low-OC group self-reported having been given diagnoses of any mental health conditions (although it should be noted that four participants in this group self-reported taking medication to manage anxiety, and two reported current engagement with psychological therapy).

1.3 Attrition Rate

Information on respondent progress provided by the online survey platform used for the study showed that a further 98 individuals initially gave consent to take part but withdrew before submitting their response (an attrition rate of 42.8%). There is no information available about the characteristics of those who did not submit their response, and so no comparison between those who completed the study and those that withdrew is possible.

Table T4

Additional clinical information

	Whole Sample (n=131)	**High-OC** (n=84)	**Low-OC** (n=47)
OCD diagnosis *(n, %)*			
Yes	61 (48%)	61 (75%)	0 (0%)
No	67 (52%)	20 (25%)	47 (100%)
I prefer not to answer	3 (2%)	3 (4%)	0 (0%)
Current talk therapy *(n, %)*			
Yes	46 (35%)	44 (52%)	2 (4%)
No	85 (65%)	40 (48%)	45 (96%)
Current medication for anxiety *(n, %)*			
Yes	44 (34%)	40 (48%)	4 (9%)
No	87 (66%)	44 (52%)	43 (91%)

2.1 Further Data Screening for Mediation Analyses

In addition to the data screening procedures outlined above, assumptions for the mediation analysis were checked using linear regression methods. Alongside scatterplots, residuals statistics were examined to assess for potential outliers, using Leverage values, Mahalanobis, and Cook's distances. Using criteria of two of these three values being above critical values as indication of a significant outlier, no multivariate outliers were identified. Visual inspection of scatterplots suggested linear relationships between the independent variables and outcome variable. Multivariate normality was assessed visually using a histogram and normal probability-plot of the regression standardised residuals (Figure T1) and deemed to be sufficiently normal. Multicollinearity was assessed using exploratory correlation coefficients (with 0.9 correlation or above indicating unacceptably high levels of relatedness between variables; Table T5; Hayes, 2017) alongside variation inflation factors (VIF). All VIF values were below ten (range 1.05-2.29), and therefore considered within acceptable limits (Field, 2009). Homoscedasticity was checked using visual analysis of the scatterplot of residuals against predicted values (Figure T2). Overall, no assumptions were found to be violated, thus no adjustments to the data were made.

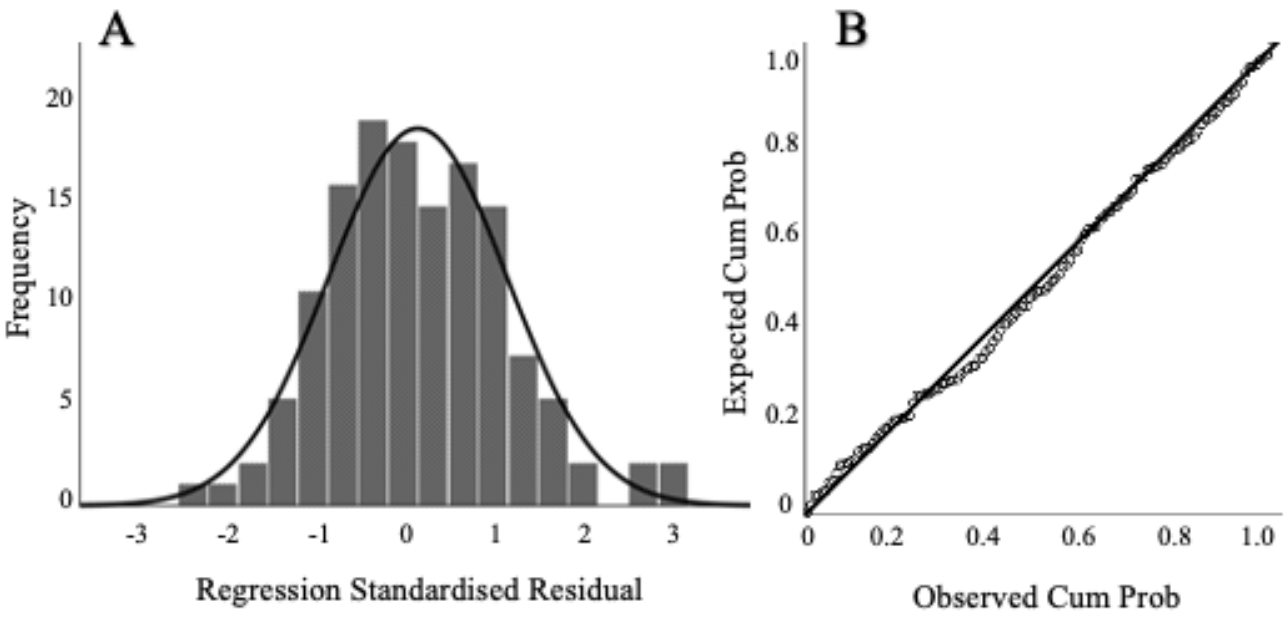


Figure T1

(A) Histogram and (B) normal P-P plot showing distribution of regression standardised residuals.

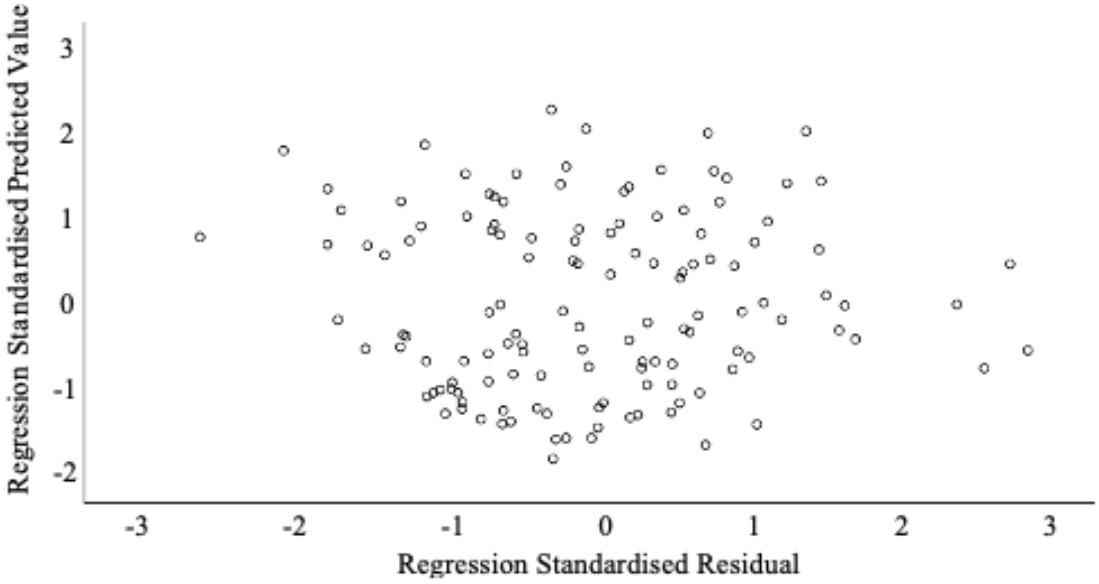


Figure T2

Scatterplot of residuals against predicted values

Table T5

Correlation matrix of main variables of interest

Variable	OCI-R	TAF total	*Likelihood*	*Moral*	SUIS	Depression
OCI-R	-					
TAF total	0.62**	-				
Likelihood	0.68**	0.86**	-			
Moral	0.47**	0.93**	0.60**	-		
SUIS	0.57**	0.51**	0.51**	0.42**	-	
DASS Depression	0.66**	0.49**	0.49**	0.42**	0.32**	-
DASS Anxiety	0.77**	0.65**	0.66**	0.53**	0.47**	0.75**

* p<0.05, ** p<0.01 (two-tailed). These results remain significant at Bonferroni corrected confidence level of p<0.002 (i.e., correcting for 21 comparisons).

Table T6

Correlations of planned covariates with OCI-R score

Variable	OCI-R
Age	-0.28**
DASS Depression	0.66**
DASS Anxiety	0.77**

* p<0.05, ** p<0.01 (two-tailed). These results remain significant at Bonferroni corrected confidence level of p<0.0167 (i.e., correcting for 3 comparisons).

2.2 Supplementary Details of Mediation Analyses

Figure T3 presents a conceptual diagram representing the proposed mediation effect being tested). Tables T6 and T7 present full details of the statistical output in relation to both models.

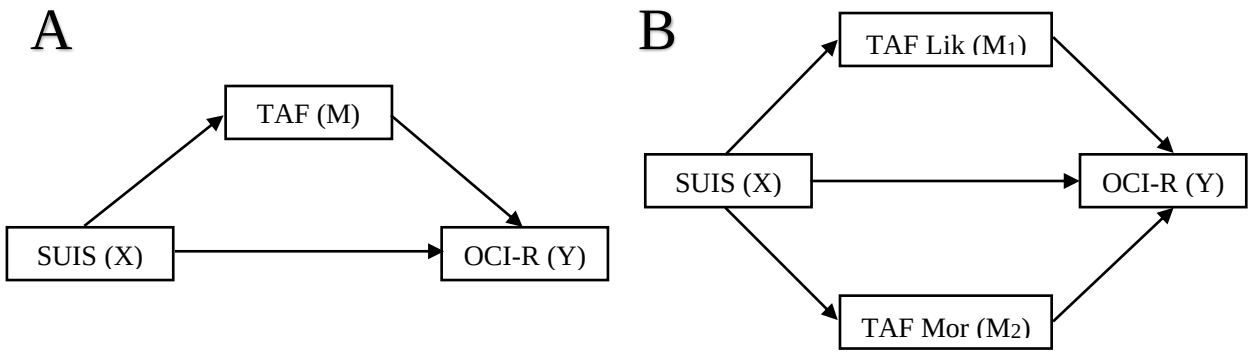


Figure T3

Conceptual diagrams of mediation analyses testing the potential mediating effect of (A) TAF total score and (B) TAF likelihood and moral subscale scores.

Selection of Covariates. Given previous literature that suggests associations between sociodemographic variables and psychopathology with the severity of OCD symptoms (e.g., Ruscio et al., 2010), it was planned to statistically control for age, gender, and depression and anxiety (as measured separately by the DASS) in the mediation analyses. However, at r=0.75, anxiety and depression symptoms were highly correlated. Guidance in the literature recommends that when two covariates are highly related (above 0.50), one will not adjust the dependent variable over and above the other, and therefore including both becomes statistically redundant (e.g., Bonate, 1999). Therefore, the DASS total score was included as a covariate as a measure of core psychological symptoms, to capture both depression and anxiety subscales. Age, gender, and DASS total score were controlled for in the final mediation analyses, with dummy variables created to represent gender.

Table T6

Results of single mediation analysis with total TAF score, controlling for age, gender, and depression symptoms

	OCI-R (Y): OCD Symptoms			95% CI for b		TAF (M)			95% CI for b	
	b	**SE**	**p**	**Lower**	**Upper**	**b**	**SE**	**p**	**Lower**	**Upper**
SUIS: Imagery use (X)	0.398***	0.1	0.000	0.200	0.596	0.614***	0.155	0.000	0.307	0.922
TAF (M)	0.119*	0.054	0.030	0.012	0.227	-	-	-	-	-
Age (CV)	-0.089	0.067	0.189	-0.221	0.044	-0.088	0.11	0.426	-0.306	0.130
Gender 2 (CV)	-1.059	1.807	0.559	-4.635	2.517	0.162	2.978	0.957	-5.732	6.056
Gender 3 (CV)	3.65	5.893	0.537	-8.013	15.314	-9.314	9.678	0.338	-28.468	9.839
DASS total score (CV)	0.28***	0.033	0.000	-8.013	15.314	0.272***	0.048	0.000	0.177	0.367
Regression model	$R = 0.832^{***}$, $R^2 = 0.693$ $F(131,6) = 46.59$, $p = 0.000$					$R = 0.666^{***}$, $R^2 = 0.444$ $F(131,6) = 19.93$, $p = 0.000$				
Indirect effect of X on Y	0.073	0.044	-	0.001	0.175	*CI doesn't contain 0, reject the null hypothesis*				

SUIS = Spontaneous Use of Imagery scale, TAF = Thought Action Fusion scale, OCI-R = Obsessive Compulsive Inventory-Revised Version, SE = standard error, CI = confidence interval

*p<0.05, ***p<0.001

Table T7

Results of parallel mediation analysis with likelihood- and moral-TAF, controlling for age, gender, and depression symptoms

	OCI-R (Y): OCD Symptoms			95% CI for b		TAF Likelihood (M1)			95% CI for b		TAF Moral (M2)			95% CI for b	
	b	**SE**	**p**	**Lower**	**Upper**	**b**	**SE**	**p**	**Lower**	**Upper**	**b**	**SE**	**p**	**Lower**	**Upper**
SUIS: Imagery use (X)	0.397***	0.098	0.000	0.203	0.591	0.304***	0.07	0.000	0.165	0.443	0.332**	0.11	0.003	0.114	0.550
TAF Likelihood (M1)	0.503***	0.125	0.000	0.256	0.750	-	-	-	-	-	-	-	-	-	-
TAF Moral (M2)	-0.084	0.08	0.293	-0.242	0.074	-	-	-	-	-	-	-	-	-	-
Age (CV)	-0.124	0.066	0.063	-0.254	0.007	0.006	0.051	0.911	-0.094	0.106	-0.094	0.079	0.237	-0.251	0.063
Gender 2 (CV)	-1.791	1.78	0.316	-5.314	1.732	0.907	1.37	0.509	-1.805	3.619	-0.963	2.146	0.654	-5.211	3.284
Gender 3 (CV)	3.399	5.785	0.558	-8.052	14.850	-1.914	4.456	0.668	-10.734	6.905	-6.653	6.979	0.342	-20.465	7.159
DASS total score (CV)	0.696***	0.093	0.000	0.513	0.880	0.383***	0.062	0.000	0.260	0.505	0.409***	0.097	0.000	0.217	0.601
Regression model	$R = 0.841^{***}$, $R^2 = 0.707$ $F(131,6) = 42.348$, $p = 0.000$					$R = 0.673^{***}$, $R^2 = 0.453$ $F(131,6) = 20.682$, $p = 0.000$					$R = 0.563^{***}$, $R^2 = 0.317$ $F(131,6) = 11.625$, $p = 0.000$				
Indirect effect of X on Y															
Total	0.125	0.056	-	0.022	0.24	*CI doesn't contain 0, reject the null hypothesis*									
TAF Likelihood (M1)	0.153	0.052	-	0.062	0.263	*CI doesn't contain 0, reject the null hypothesis*									
TAF Moral (M2)	-0.028	0.028	-	-0.091	0.023	*CI contains 0, unable to reject the null hypothesis*									

SUIS = Spontaneous Use of Imagery scale, TAF = Thought Action Fusion scale, OCI-R = Obsessive Compulsive Inventory-Revised Version, SE = standard error, CI = confidence interval

*p<0.05, ***p<0.001