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Abstracts:

(1) Critical Review of the Literature: Facilitators and barriers to mental health disclosure and help-seeking among doctors: a systematic review

Background: Doctors experience high rates of mental ill-health. Effective treatments and specialist services exist, yet there are significant barriers to disclosure and help-seeking. These barriers are concerning given the negative impact on doctors' health and recovery, staff turnover and the quality of care provided. It is therefore important to understand these barriers and facilitators in more detail to improve access to support and services.

Objectives: To ascertain barriers and facilitators to mental health disclosure and help-seeking among UK doctors.

Data sources: PubMed, Embase, PsycInfo and CINAHL

Study eligibility criteria: Studies were eligible if they referred to i. doctors working in the UK NHS ii. experiences of disclosure or help-seeking for mental health difficulties and iii. facilitators or barriers to this. Studies had to be published in a peer-reviewed journal between 2000-2022. Studies with medical students or other health professionals were excluded.

Participants: UK doctors of all specialties and grades (from foundation training to consultants).

Study appraisal/ synthesis methods: A systematic mixed studies review was conducted. The quality of included studies was assessed and a narrative synthesis conducted to synthesise both qualitative and quantitative findings.

Results: A total of 3650 studies were identified; 29 meeting inclusion criteria (10 quantitative, 17 qualitative and 2 mixed). The most common barrier to disclosure and help-seeking was the professional medical culture (including perceived stigma). Other

themes included doctors' difficulty recognizing/accepting illness in themselves, reactions from others and inadequate services.

Conclusions: Significant barriers remain to doctors disclosing and help-seeking for mental health difficulties. There is need to shift the professional medical culture (including doctors' perceived sense of invulnerability to illness), strengthen support from colleagues to create an approachable workplace for disclosing difficulties and further promote the availability of specialist services.

(2) **Service Improvement Project:** Difficulties in transitioning to dialysis; possible reasons and potential psychological interventions.

Introduction: Depression and anxiety are prevalent among those with chronic kidney disease (CKD) and lead to delay starting dialysis and poor prognosis. The current study assessed the prevalence of these difficulties among patients in Oxford and five satellite Low Clearance Clinics (LCCs), identified why patients experience difficulties transitioning to dialysis and explored how services can best support with managing this transition.

Method: Twenty-nine patients completed self-report questionnaires on mood (PHQ-9, GAD-7), quality of life (KDQoL) and illness perceptions (IPQ-R). Self-reported numbers of missed appointments and kidney-related hospitalisations were collected. Eight carers completed a qualitative survey on their loved one's experiences of transitioning to dialysis. Interviews were also conducted with seven patients and six staff on their experiences of approaching dialysis and supporting patients respectively.

Results: On the self-report measures 55% of patients (n=16) reported low mood and 28% reported anxiety (n=8). Illness perceptions were similar to previous findings, however the current sample experienced a higher emotional impact of living with

CKD. Nonetheless, numbers of missed appointments and hospitalisations were low. Qualitative experiences reported by patients, staff and carers included fear/denial and difficulties adjusting to the lifestyle changes involved. Reasons for delay in starting dialysis included a lack of knowledge about symptoms/ dialysis, being torn about the need for dialysis with good/ bad symptom days and at times 'just following medical advice'. All groups provided recommendations for service provision including the importance of family involvement in pre-dialysis support, the pros/ cons of peer support and need for appropriately tailored information.

Discussion: Recommendations for psychological support in LCCs are suggested. Therapeutic approaches focused on (i) adjusting to CKD (such as Cognitive Behavioural Therapy and Acceptance and Commitment Therapy), (ii) symptom reduction (e.g. pain-management or mindfulness-based interventions) and (iii) systemic-focused interventions may be particularly helpful.

(3) **Theoretically Driven Research Project:** The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD

Introduction: Despite readily available and effective treatments for Obsessive Compulsive Disorder (OCD) there are still barriers to treatment readiness, engagement and outcomes. Past studies indicate self-compassion correlates with OCD symptom severity. The current study therefore explored whether those low v high in self-compassion differed on readiness to engage in treatment and treatment outcomes. It also assessed whether self-compassion predicted treatment readiness and outcomes above other factors such as symptom severity.

Method: Eighty patients were recruited from the OCD treatment waiting list in three Improving Access to Psychological Therapies (IAPT) services. They completed study

questionnaires on their obsessive beliefs (OBQ), treatment readiness (TAQ) and self-compassion (SCS). IAPT routine measures were also collated on low mood (PHQ-9), anxiety (GAD-7) and OCD (OCI) symptom severity; subscale scores were not available. A median split was used to create 2 groups (those low in self-compassion v high in self-compassion). The 2 groups were compared on readiness to engage in treatment. A hierarchical regression examined whether self-compassion predicted treatment readiness above initial low mood/ anxiety/ OCD symptom severity.

Results: Those low in self-compassion rated themselves as significantly less ready to engage in treatment (with greater concerns about starting treatment). They also experienced significantly higher symptom severity and obsessive beliefs. Self-compassion significantly predicted readiness to engage in treatment, even after accounting for symptom severity on the OCI, PHQ-9 and GAD-7. It explained 6.1% additional variance in treatment readiness.

Discussion: Future research is needed to investigate additional factors which might contribute to explaining variance in treatment readiness and explore whether baseline low self-compassion/ treatment readiness predicts later treatment outcomes.

Critical Review of the Literature

Title: Facilitators and barriers to mental health disclosure and help-seeking among doctors: a systematic review

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Internal Supervisor: Dr Helen Jenkins

Journal: BMJ Open. This journal has been chosen due to its readership covering a range of medical disciplines, allowing dissemination to a wide medical audience who the findings are likely to be applicable to. It has also published many of the papers on barriers to doctors help-seeking for their mental health.

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Abstract:

Background: Doctors experience high rates of mental ill-health. Effective treatments and specialist services exist, yet there are significant barriers to disclosure and help-seeking. These barriers are concerning given the negative impact on doctors' health and recovery, staff turnover and the quality of care provided. It is therefore important to understand these barriers and facilitators in more detail to improve access to support and services.

Objectives: To ascertain barriers and facilitators to mental health disclosure and help-seeking among UK doctors.

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Conclusions: Significant barriers remain to doctors disclosing and help-seeking for mental health difficulties. There is need to shift the professional medical culture (including doctors' perceived sense of invulnerability to illness), strengthen support from colleagues to create an approachable workplace for disclosing difficulties and further promote the availability of specialist services.

Introduction:

Doctors are known to experience high rates of mental health difficulties including work-related stress/ burnout, anxiety, depression, and suicide.[1] A recent systematic review identified rates of psychiatric morbidity between 17-52% among UK doctors with burnout rates from 31-54%.[2] This has been exacerbated by the covid-19 pandemic where 40% of National Health Service (NHS) doctors reported experiencing work-related stress; the highest rate in the past 5 years.[3] Furthermore, work-related stress and burnout are often associated with suboptimal patient care and high rates of absenteeism, presenteeism and turnover.[1]

The high levels of psychological distress identified in this population are often compounded by significant, multifactorial barriers to disclosure and help-seeking for mental health difficulties ([4-5]) including:

i. Individual factors (eg. self-stigma)
ii. Organisational factors (eg. long hours and high workload)
iii. The professional culture (eg doctors' perceived invulnerability to illness)
iv. Fear of the consequences of disclosure or help-seeking
v. Stigma within the profession

vi. The availability of services

There is suggestion that doctors may require specialist services that address possible concerns about confidentiality and difficulties with transitioning to a patient role.[6] In the UK there are now specialist services for doctors accessible through organisations such as the British Medical Association (BMA), including the specialist mental health service (Practitioner Health).[7] In recent meta-analyses, mindfulness, psychoeducation on self-confidence and communication, and cognitive behavioural interventions were shown to reduce burnout and anxiety among doctors.[8 9] In order to benefit however doctors must first overcome existing barriers to disclosure and help-seeking and be aware of services, which reportedly remains an issue.[10]

Relevant theory

Existing theories aim to explain the stages leading to an individual's choice to disclose or seek help for difficulties. Two key theories (the disclosure process model and theory of planned behaviour), were used to interpret the findings of the current review, regarding at what stage doctors experienced barriers/facilitators to disclosure and help-seeking.

The disclosure processes model[11] suggests that there are five main components to choosing whether to disclose hidden identities such as mental health difficulties (*see table 1)*. The current review explores whether barriers/ facilitators exist for doctors at any of these stages.

Table 1:

The disclosure process model

1.	**Weighing up the initial goals of disclosing (either to pursue positive outcomes (eg understanding/ acceptance from others) or avoid negative outcomes (eg social rejection, anxiety))**
2.	**Disclosure itself- with choices made regarding what to disclose and how.**
3.	**Mediating factors including** • Overcoming no longer suppressing personal information • Social support (allowing people to either gain this or experience further stigmatisation) and • Changes in social information (i.e. by sharing their concealed identity this impacting future interactions with others both positively and negatively).
4.	**Outcomes to disclosure (both positive and negative) potentially including psychological and behavioural benefits such as reduced anxiety, relationship changes (eg. increased trust) and changing norms for disclosure**
5.	**Lastly a feedback loop after initial disclosure feeding back into the perceived benefits or costs of future disclosures**

The theory of planned behaviour[12] suggests a number of influences on help-seeking behaviours, which include: i. attitudes to help-seeking, ii. subjective norms and iii. perceived behavioural control. More recently stages specific to mental health help-seeking have been identified including: i. recognition and awareness of the problem, ii. the decision to seek help and iii. acceptance of help from a relevant provider.[13 14]

A few reviews have explored barriers to disclosure and help-seeking within doctors. In a mixed-methods systematic review of help-seeking among doctors for both physical and mental health difficulties,[5] this identified issues around embarrassment, time, and a professional culture where doctors are expected to be invulnerable to illness with confidentiality being a particular concern for disclosing and help-seeking for mental health difficulties. In addition, a narrative review[6] investigated further barriers to disclosure and help-seeking including a lack of knowledge about where to seek help, doctors' concerns about implications for their

professional future, worries about confidentiality, embarrassment with mental health being viewed as a weakness and difficulties with transitioning to a patient role.

The current review is the first to focus specifically on mental health disclosure and help-seeking among doctors, where there are likely to be specific barriers. In addition, these reviews date back over 10 years, during which further research has been published and an update is needed. The current review will therefore focus on papers published within the last 21 years. To date no reviews have yet scrutinised the methodology and quality of such studies. Therefore, a systematic review is timely to explore the quality of existing research in this area and consider the extent to which conclusions can be drawn or future research is needed. The review will allow us to consider existing disclosure and help-seeking theories and draw conclusions about relevant factors among this population. This will be important to provide recommendations to better promote access to, and shape development of, interventions for doctors.

This review aims to examine the facilitators and barriers to doctors disclosing or seeking help for mental health difficulties where intervention is indicated. The review focuses on UK doctors within one healthcare system (the NHS) to account for its unique context and to aid applicability of the findings. Furthermore, this is a mixed studies review in order to integrate the depth of themes from qualitative studies, alongside the numbers endorsing these particular themes from larger quantitative studies.

Method:

Study registration-

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The review was registered on Prospero in September 2020 (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=200621).

Types of studies-

Studies were eligible if they referred to doctors' experiences of mental health disclosure or help-seeking and facilitators or barriers to this. All types of mental health problems were included. Studies also had to include the following for eligibility:

- identify at least 1 mental health disclosure or help-seeking barrier or facilitator
- focus on UK NHS doctors or junior doctors of all specialties and grades, not medical students due to them likely having different contextual factors
- be published in a peer-reviewed journal from 2000 onwards

Studies that included doctors in any capacity were included, even if in combination with medical students or other professionals, provided results were reported separately for doctors. Studies focused exclusively on healthcare professionals other than doctors (eg allied health professionals) were excluded due to different professional support networks being available to them.

Studies were also excluded that:

- were not published in English
- consisted of a medical review/ opinion piece

- investigated barriers to help-seeking or disclosure for difficulties other than mental health.

Search strategy-

A combination of search terms was used to capture eligible studies. The key parts were that studies included all of the following categories:

- doctors
- help-seeking and disclosure barriers/ facilitators and
- mental health problems

For the full search strategy see *appendix A*. The search was run across PubMed, Embase, PsycInfo and CINAHL. The date was filtered to studies published between 2000-2022. The search was conducted on 31st May 2022. Qualitative and quantitative studies were included. Reference lists of the final included studies were hand searched to conduct forward and backward citation searching. An expert clinician in the field was also consulted to identify any additional studies not found by online databases.

Study selection-

Two researchers (AP and VE) independently screened the identified titles and abstracts using the above criteria. 25% of papers were double coded to ensure reliability and the criteria were refined where appropriate. Agreement between the two raters at abstract stage was $\kappa = 0.85$. One researcher (AP) screened the rest of the papers. If a study was included by either author it was taken to the full text stage. Full text articles were then screened independently in the same way as above (by two researchers (AP and VE) for 25% of the studies, with agreement at $\kappa = 0.90$ and one

researcher (AP) for the remaining studies). Where there was discrepancy a third reviewer (HJ) independently reviewed the relevant study.

Data extraction-

Two researchers (AP and VE) independently extracted the data from 50% of the studies in line with a pre-specified form developed. This form was developed guided by items used in the literature (ie. wider systematic reviews regarding barriers/ facilitators to help-seeking for mental health difficulties), with some items applicable to quantitative studies only eg those regarding power and the statistical significance of findings. This included details on study methodology, design, sample size and characteristics (eg. doctor specialty, age), barrier/ facilitator identified, intervention type (disclosure/ help seeking and from which service type) and mental health problem type. Demographic data about the studies was also extracted. Where discrepancies were identified, these were discussed to reach a consensus and a third researcher (HJ) reviewed these where necessary. One researcher (AP) extracted data from the remaining studies. Each study was given a contribution to the review score (small, medium, or large; in line with a previous similar review[15]) based on the amount of extractable data on specific barriers/ facilitators to help-seeking or disclosure (ie. whether this was the focus of the study (large), explored as a secondary question with some information (medium) or contained a small amount of information on this (small).

Quality assessment-

The quality of studies was assessed using the quality rating checklist developed by Kmet, Lee and Cook.[16] Items that were not relevant to the current

studies were removed (eg those related to blinding/ randomisation). The final quantitative checklist consisted of 11 items and the qualitative of 10 items (*see appendix B*). Mixed methods studies were coded under both. Items were rated on a 3-point scale as to whether they satisfied criteria (0- no, 1- partial, 2-yes). A summary score was then calculated by summing the total score obtained across relevant items and dividing by the total possible score and studies grouped into low, medium, and high quality. This was based on criteria used in a prior similar review[15] as follows:

- quantitative studies: >7.5 = high quality, 5–7.5 = medium quality, and <5 = low quality; and
- qualitative studies: >7 = high quality, 4.5-7 = medium quality, and <4.5 = low quality).

Due to the heterogeneous nature and medium-high quality of all studies in the current review this was not used as an exclusion criterion. 30% of studies were reviewed independently by two researchers (AP and VE), and the remaining by one researcher (AP). Discrepancies were discussed to reach agreement and a third researcher (HJ) consulted where necessary.

Data synthesis-

A narrative synthesis was conducted based on the framework outlined by Popay et al.[17] Quantitative and qualitative data were synthesised separately at first. Studies were tabulated, grouped by common factors (help-seeking/disclosure) and patterns identified. Thematic analysis was used to translate the data into specific facilitators/ barriers to i. help-seeking and ii. disclosure (following Braun and Clarke's 6 stages of thematic analysis[18]). This included familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes

and writing up themes. An inductive data analytic approach was used, based on a social constructionist epistemological stance. Self-reflexivity, supervision and triangulation with two other researchers (HJ and VE) were used throughout the process to increase credibility of the analysis. Qualitative studies were analysed first to develop an initial coding framework. This was then used to code the quantitative studies, with additional themes being subsequently added to the coding framework. A single coding framework was used to combine the overall qualitative and quantitative findings. Figures on the level of endorsement of particular themes were noted from the quantitative findings. Relationships were explored within and between studies. Two of the researchers (AP and HJ) reviewed and discussed the themes and subthemes in order to maximize reliability and credibility. Due to the heterogeneous nature of the data, it was not possible to derive overall scores for the themes from the quantitative studies. Therefore in line with a prior similar review[15] the barriers/ facilitators were labelled by level of endorsement (low (<30% participants endorsed), medium (30–60% endorsed), or high (>60% endorsed)). Qualitative and quantitative data were synthesised to give an overall picture of the information provided across the studies.

Results:

Study selection-

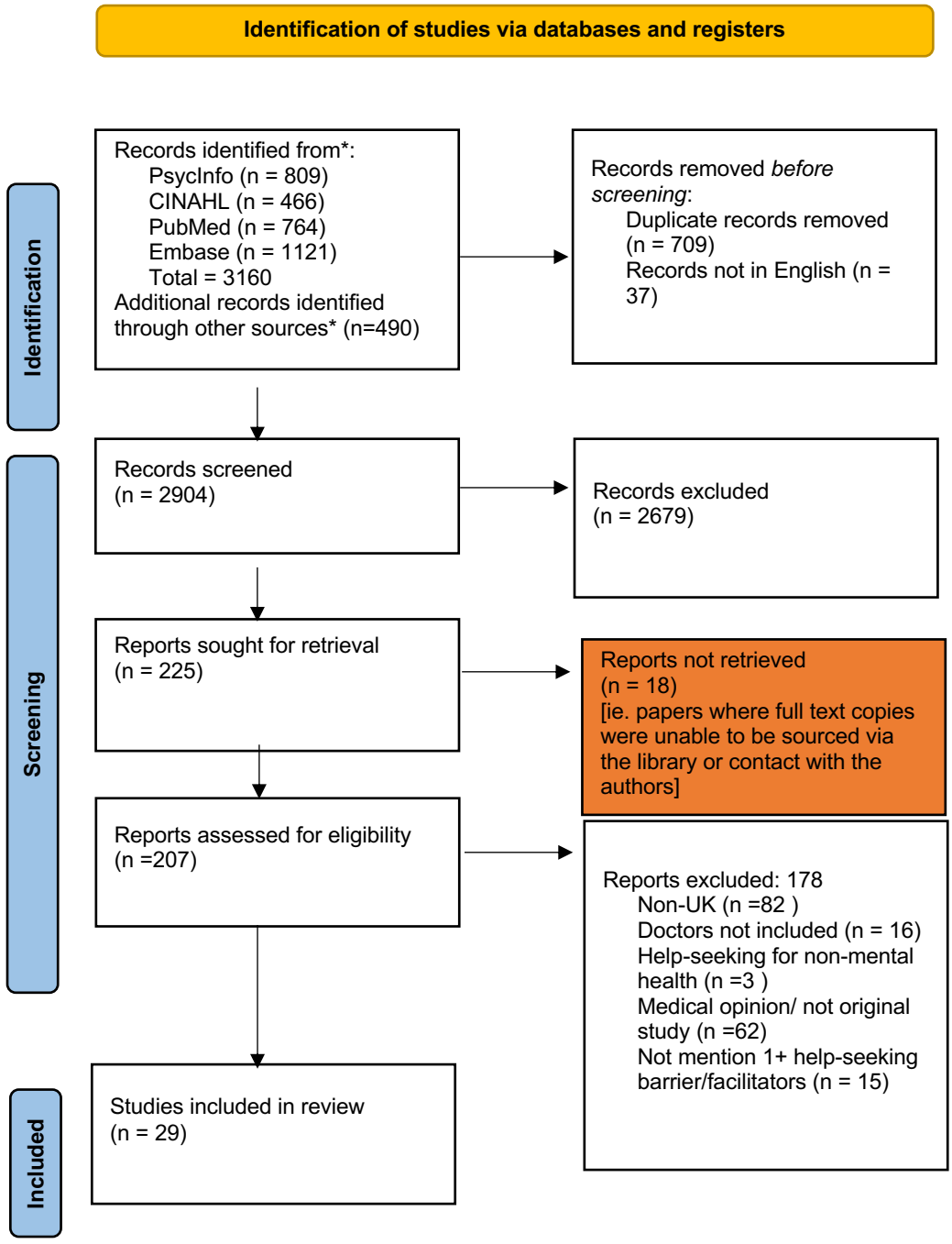
The study selection process is shown in *figure 1*. The database search identified 3160 studies. Hand-searching of forward and backward citations and recommended papers by the expert clinician in the field found 490 further articles. When duplications and papers not in English were removed the total was 2904. Following abstract screening 225 studies remained for full text screening. In total 29

studies met inclusion criteria: 10 quantitative[19-28], 17 qualitative[29-45] and two mixed[46 47]. Five of these (all qualitative) were papers by the same authors on the same sample so these were viewed collectively as one paper[31] with the key paper on barriers being the focus and only additional themes/ subthemes being included from the others. The same occurred for two other overlapping qualitative papers on the same sample which were viewed collectively as one paper[44]. Therefore this review considers 24 distinct studies.

The quantitative studies used survey data whist qualitative studies included individual interviews and focus groups. All studies presented data from the UK; 10 recruited nationwide[31 38 40 20 42 23-25 44 47] whilst 14 were focused on specific regions of the UK[29-31 36 19 21 22 26-28 39 41 43 46]. The majority focused on barriers/facilitators to help-seeking or disclosure as a secondary research question[20 26 30 36 37 40 44 46 47]. 14 studies focused on help-seeking[19-24 29-31 36-38 46 47], 6 on disclosure[25-27 39-41] and 4 on both[28 42-44]. Most studies (n=18) recruited a range of doctors including General Practitioners (GPs) (n=12), junior doctors (n=9), consultants (n=7), associate specialists (n=4), registrars (n=3) and senior house officers (SHOs) (n=2). Whilst some (n=6) focused on a particular specialty including psychiatrists (n=2) and anaesthetist trainees (n=1). Included studies covered a range of mental health difficulties including anxiety/stress (n=11), depression (n=9), burnout (n=5), substance misuse (n=5), bipolar (n=3), schizoaffective disorder (n=3), eating disorders (n=3), Post-Traumatic Stress Disorder (PTSD) (n=2), psychological distress as a result of experiencing domestic violence (n=1) and Obsessive-Compulsive Disorder (OCD) (n=1).

Figure 1:

Study selection: Prisma Flow diagram



Key: | *Other sources included records identified from the expert clinician in the field and backward/forward citation tracking.

Data quality assessment-

All studies were rated as medium-high quality. 10/12 qualitative studies were rated high quality[29-31 36 37 40-44] and 2/12 medium quality[38 39]. 7/10 quantitative studies were rated high quality[20-22 24 25 27 28] and 3/10 medium quality[19 23 26]. 1/2 mixed methods papers was rated as high quality[47] and 1/2 medium quality[46] . Strengths across studies included clearly reported and appropriate study design and suitable conclusions being drawn from the results. Limitations however included suboptimal control of confounding variables in several studies and the qualitative papers often minimally reporting on a key theoretical framework or the authors' reflexivity on their impact on the results (often pertinent as they were also doctors). See *tables 2-3* for detailed quality ratings. Characteristics of the included studies are given in *table 4*.

Regarding the extent to which studies contributed to the review; of the quantitative findings 3 made a large contribution[19 25 28], 2 medium[20 26] and 5 a small contribution[21-24 27]. Of the qualitative findings 5 made a large contribution[29 31 39 42 43], 5 medium[30 36 37 40 44] and 2 a small contribution[38 41]. Both mixed method papers made a medium contribution[46 47].

Table 2:

Quality assessment ratings (qualitative studies)

Study	1 Question / objective sufficiently described	2 Study design evident and appropriate	3 Context for the study clear	4 Connection to a theoretical framework / wider body of knowledge	5 Sampling strategy described, relevant and justified	6 Data collection methods clearly described and systematic	7 Data analysis clearly described and systematic	8 Use of verification procedure(s) to establish credibility	9 Conclusion supported by the results	10 Reflexivity of the account
1 Bianchi, E; Bhattacharyya, M; Meakin, R[29]	Y	Y	Y	P	P	Y	P	Y	Y	Y
2 Brooks, S; Gerada, C; Chalder, T[30]	Y	Y	Y	N	Y	Y	Y	Y	P	N
3 Spiers et al.[31] **Overlap with: (1) Riley, R; Spiers,**	Y	Y	P	N	Y	Y	Y	Y	Y	P

J; Buszewicz, M, et al., 2018[32], **(2) Riley, R; Spiers, J; Chew-Graham, C, et al., 2018[33],** **(3) Spiers et al., 2019[34],** **(4) Spiers et al., 2020[35]**										
4 Wainwright et al[36]	P	Y	Y	P	P	P	Y	Y	Y	P
5 Fox et al[37]	Y	Y	Y	P	Y	Y	Y	Y	Y	Y
6 Looseley et al[38]	Y	P	P	N	Y	P	Y	Y	Y	N
7 Rees et al[39]	Y	Y	P	P	P	Y	Y	P	P	N

8 Henderson et al[40]	Y	Y	P	P	P	Y	Y	Y	Y	N
9 Thompson, N; Corbett, S; Welfare, M[41]	P	Y	P	Y	P	P	Y	Y	Y	Y
10 Donovan et al[42]	Y	Y	Y	N	P	Y	Y	Y	Y	P
11 Fox et al[43]	Y	Y	Y	P	P	Y	P	Y	Y	N
22 Hanson et al[46]	Y	Y	P	P	P	Y	Y	Y	Y	P
23 Slade et al[47]	Y	P	Y	P	Y	Y	P	Y	Y	N
24 Riley, R; Kokab, F; Buszewicz, M, et al[44] **Overlap with: Riley, R; Buszewicz, M; Kokab,**	P	Y	P	P	Y	Y	P	Y	Y	P

F, et al., 2021[45]	

Key: | Abbreviations: N - No, P - Partial, Y - Yes

| Mixed methods papers are captured in both tables.

Table 3:

Quality assessment ratings (quantitative studies)

Study	1 Question / objective sufficiently described	2 Study design evident and appropriate	3 Method of subject/ comparison group selection or source of information/ input variables described and appropriate	4 Subject (and comparison group, if applicable) characteristics sufficiently described	5 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias | Means of assessment reported	6 Sample size appropriate	7 Analytic methods described/ justified and appropriate	8 Some estimate of variance is reported for the main results	9 Controlled for confounding	10 Results reported in sufficient detail	11 Conclusion supported by the results
12 Adams et al[19]	P	Y	P	P	P	Y	N	P	P	P	Y
13 Bhugra et al[20]	P	Y	Y	Y	Y	Y	N/a	N/a	N/a	P	Y
14 Brooks, S; Chalder, T & Gerada, C[21]	P	Y	Y	P	Y	Y	P	Y	N/a	Y	Y
15 Meerten et al[22]	Y	Y	P	Y	Y	Y	Y	Y	P	Y	Y

16 Miller, L[23]	N	P	N/a	P	P	Y	P	N/a	N/a	P	Y
17 Smith, F; Goldacre, M & Lambert, T[24]	Y	Y	Y	P	P	Y	Y	P	P	Y	Y
18 Cohen, D; Winstanley, S; Greene, G[25]	P	Y	Y	Y	P	Y	Y	Y	N/a	P	Y
19 White et al[26]	Y	Y	P	P	P	Y	Y	N	N/a	P	Y
20 Mukherjee et al[27]	P	Y	N/a	Y	P	Y	N/a	Y	P	Y	Y
21 Hassan et al[28]	P	Y	P	P	Y	Y	Y	P	N/a	Y	Y
22 Hanson et al[46]	P	Y	P	P	Y	P	P	P	N/a	P	Y
23 Slade et al[47]	P	Y	P	Y	Y	Y	P	Y	P	Y	P

Key: | Abbreviations: N/a - Item not applicable, N - No, P - Partial, Y - Yes

| Mixed methods papers are captured in both tables.

Table 4:

Study characteristics of included studies

	Author	Year	Study design	Participants, n (response rate (RR)), demographics	Setting	Specialty	Help-seeking or disclosure	Type of mental health difficulties	Quality assessment score	Contribution to the review
1	Bianchi, E; Bhattacharyya, M; Meakin, R[29]	2016	Semi-structured interviews	N=14 86%M 36-65yrs	Single-centre: North London	Senior doctors: hospital consultants, senior academic GPs	Help-seeking	General mental health	High	Large
2	Brooks, S; Gerada, C; Chalder, T[30]	2017	i. Semi-structured interview ii. Written feedback	N=9 Interviews (75% RR) N=87 Feedback forms (65% RR) 56%M 27-65yrs	London	Not reported	Help-seeking	General mental health (incl substance misuse)	High	Medium
3	Spiers et al.[31] Overlap with: (1) Riley, R; Spiers, J; Buszewicz, M, et al., 2018[32], (2) Riley, R; Spiers, J; Chew-	2017	Semi-structured interview	N=47 (39% RR) 30%M 20-59yrs	UK national	GPs	Help-seeking	I Anxiety I Depression I Stress I Burnout	High	Large

	Graham, C, et al., 2018[33], (3) Spiers et al., 2019[34], (4) Spiers et al., 2020[35]									
4	Wainwright et al[36]	2017	Semi-structured interview	N=8 (50% RR) 100%F	Single-centre: Bath	Junior doctors from first postgraduate year to year below consultant status	Help-seeking	General mental health	High	Medium
5	Fox et al[37]	2009	Semi-structured interview	N=17 59%M 36-58yrs	Multi-centre: West England	GPs	Help-seeking	l General mental health difficulties l Chronic medical conditions l Malignancies l Trauma l Surgical l Undiagnosed	High	Medium
6	Looseley et al[38]	2019	Semi-structured interview	N=397 Questionnaires (64% RR) N=209 Consented to interviews (53% RR)l N=12 Total interviews	UK national	Anaesthetic trainees	Help-seeking	l Stress l Burnout l Depression	Medium	Small

				conducted (33%M)						
7	Rees et al[39]	2019	Semi-structured interview	N=46 24%M 19-73yrs old	Single centre: Cardiff	l Medical students l Doctors in training l Consultants l GP l Specialists	Disclosure	General mental health	Medium	Large
8	Henderson et al[40]	2012	Interview	N=19 (25% RR) 48%M 27-67yrs	UK national	Doctors (not specified)	Disclosure	General mental health: l Depression l Anxiety l Bipolar l Alcohol dependence) l Physical health difficulties	High	Medium
9	Thompson, N; Corbett, S; Welfare, M[41]	2013	Semi-structured interview	N=10 (29% RR) 20%M	Single centre: Northumbria	FY1 doctors	Disclosure	Stress	High	Small
10	Donovan et al[42]	2021	Semi-structured interview	N=21 100%F 32-62yrs White British majority	UK national	l GPs l Consultants l FY1/2 doctors l Registrars	Both	Domestic violence	High	Large
11	Fox et al[43]	2011	Semi-structured interviews	N=8 38%M 22-35yrs	Single centre: Bath	FP trainees (2yrs post qualification)	Both	Significant illness: l Psychiatry l Acute & chronic l Physical illness	High	Large
12	Adams et al,[19]	2010	Piloted questionnaire on demographics,	N=1256 (77% RR) 60.7%M	Multi-site: Devon and Cornwall	l GPs l Psychiatrists	Help-seeking	l Depression l stress	Medium	Large

			depression history, help-seeking behaviours, and stigma							
13	Bhugra et al[20]	2019	Questionnaire (Oldenburg burnout inventory & Office of National Statistics (ONS) 4 questions on wellbeing)	N=4347 70% F <25-64yrs 75% White, 13% Asian/ Asian British, 3% Mixed/multiple ethnic group, 2% Black/ Black British	UK national	l Junior doctors l GPs l Associate specialists l Consultants l Medical students	Help-seeking	l Burnout- exhaustion and disengagement from work l Wellbeing	High	Medium
14	Brooks, S; Chalder, T & Gerada, C[21]	2011	Questionnaires: l CORE Outcome Measure (CORE-OM) l Social adjustment scale l Fast alcohol screening test	N=200 (81% RR) 56.5%M 24-67yrs	Single-centre: London	l Doctors (not specified) (95%) l Dentists	Help-seeking	General mental health: l Depression l Alcohol dependence l Mental health problems only l Comorbid problems l Anxiety l Stress l Bipolar l Adjustment disorders l Other: eating disorder, PTSD, ADHD, psychoses, self-harm, post-natal depression.	High	Small

15	Meerten et al[22]	2011	Questionnaires: | CORE-OM | Brief symptom inventory | Maslach burnout inventory | 20-item bespoke questionnaire to assess views of attending service	N=121 (98%) 50%F 24-64yrs 65% Caucasian, 20% Asian	Single-centre: London	| Consultants | Specialist registrar | SHOs | Pre-registration house officers | Unknown | Associate specialists | Staff grade | GP	Help-seeking	General mental health (most prevalent): | Depression | Anxiety | Interpersonal difficulties | Work-related issues	High	Small
16	Miller, L[23]	2009	Piloted questionnaire asked qualitative and quantitative questions about the doctor's personal experience of mental ill-health, its impact on their careers and the strategies that helped their recovery	N=116 (35% RR) 37%M 26-68yrs	UK national	GP (9% non-principals)	Help-seeking	General mental health: | Depression | Bipolar | Anxiety | Burnout | Schizoaffective disorder | Eating disorder | OCD | Addictions	Medium	Small
17	Smith, F; Goldacre, M & Lambert, T[24]	2017	Medical Careers Research Group (MCRG) survey	N=3550 (85% RR)	UK national	| GP | Hospital medical specialties | Surgery | Other hospital specialties	Help-seeking	General mental health	High	Small

18	Cohen, D; Winstanley, S; Greene, G[25]	2016	Questionnaire on experiences of ill health and whether doctors would disclose	N=1946 59%F (N=1048 answered disclosure questions) 18-65+yrs 87% White, 7% Asian, 1% Black, 2% Mixed, 1% Chinese, 2% Other	UK national	Not reported (qualified doctors only)	Disclosure	General mental health	High	Large
19	White et al[26]	2006	Survey	N=370 (72.6% RR)	Multi-centre: West Midlands	Psychiatrists	Disclosure	General mental health	Medium	Medium
20	Mukherjee et al[27]	2002	Questionnaire based on national survey by Crisp et al- piloted.	N=520 (41% RR) 48%M 64% Caucasian, 11% Indian, 25%Other	Single-centre: London	l Medical students yrs 1-5 l Permanent doctors of all grades/ specialties	Disclosure	General mental health: l Severe depression l Panic attacks l Schizophrenia l Dementia l Eating disorder l Drug addiction l Alcohol addiction	High	Small
21	Hassan et al[28]	2009	9-item questionnaire (piloted) on perception of mental illness prevalence in doctors compared to the general	2462 (70% RR)	Multi-centre: Birmingham	l Consultants (27.5%) l Specialist registrars (11.1%) l SHOs (17.9%) l GPs (22%)	Both	General mental health	High	Large

			population & psychiatrists, who doctors are most likely to disclose mental illness to, preference of treatment in outpatient & inpatient settings, grade of doctor and if have experienced mental illness in the past.			| Other doctors (21.5%)				
22	Hanson et al[46]	2020	i. Questionnaires: | Oldenburg burnout inventory | Brief resilience scale | Warwick-Edinburgh mental wellbeing scale ii. Focus group (semi-structured)	N=47 surveys (39% RR) N=14 focus group 40%M	Single centre: Coventry/ Warwickshire	GP trainees (2/3rd year)	Help-seeking	Stress/ burnout	Medium	Medium
23	Slade et al[47]	2020	i. Survey developed with Royal College of Obstetricians & Gynaecologists (RCOG) on the frequency and impact of traumatic work-related events and PTSD & burnout prevalence | ii. Interviews	N=1095 Surveys (18% RR) N=43 Interviews 88%F Average age: 45yrs 81.4% White British	UK national	| Trainee/staff grades | Consultant/ associate specialist | RCOG members outside of obstetrics and gynaecology	Help-seeking	Trauma, PTSD	High	Medium

24	Riley, R; Kokab, F; Buszewicz, M, et al[44] Overlap with: Riley, R; Buszewicz, M; Kokab, F, et al., 2021[45]	2021	Semi-structured interview	N=21 24%M 20-39yrs 10% Asian, 5% Bangladeshi, 5% Chinese, 15% Indian, 62%White British, 5% White (other)	UK national	Foundation/ junior (pre-consultant doctors)	Both	I Stress I Distress I Anxiety I Depression I Suicidal thoughts	High	Medium

Key: | PTSD - Post-traumatic stress disorder, ADHD - Attention deficit hyperactivity disorder, OCD - Obsessive-compulsive disorder, SHO - Senior house officer

Data synthesis- summary of results

Tables 5 and 6 provide an overview of the qualitative study findings with themes and example quotes for both barriers and facilitators to disclosure and help-seeking. *Figures 2 and 3* show the number of studies (both qualitative and quantitative) endorsing particular themes. There was significant overlap between help-seeking and disclosure barriers and facilitators therefore joint barriers and facilitators are discussed first then separate themes for disclosure and help-seeking are outlined.

Table 5:

Themes and example quotes [Disclosure]

Theme	Subthemes	Example quote
Difficulty Recognising/ Accepting Illness	Normalise/ Trivialise Or Deflect Experiences Of Stress	'I think stress comes alongside responsibility and if you didn't have any responsibility in the job it would be boring and you wouldn't enjoy it and it wouldn't be rewarding so you have to take the responsibility so you have to take a certain amount of stress with that' (#108) (s9)
	Difficulty Recognising Or Accepting Illness/ Denial	'I think in the earlier years I didn't really realise that I was depressed, I just thought I wasn't coping, you know, and I was a bit useless' (#4) (s7)
Career Implications (+/-)	Negative Career Implications/ Fear Of Repercussions	'I was really scared that it might finish off my career' (#22) (s9)
	Sense Of Responsibility To Disclose	'my constant fear was that I was going to reach a point where I'd be too tired or just couldn't work out what was wrong with the patients, I was going to have to call on a lot of help, so I wanted people to be aware of sort of what's going on' (#7) (s11)
	Identity As Doctor [Importance Of Work]	'But once you try and put that doctor persona aside, I realised there wasn't much left of me. I realised I was kind of a doctor, but what else do I do' (#18) (s8)

Medical Culture	Stigma	'If you see that attitude towards patients who have got those problems, it doesn't make you want to be particularly forthcoming about your own' (#4) (s11) 'It's far easier to tell people that you know you've got arthritis or ..cancer than you've got de- pression and I think to talk about any mental health things, there is still that stigma attached in medicine' (#19) (s24)
	Impact Of Disclosure On Self/ Others	'I wouldn't want to worry my current practice partners… I'm one of the older partners there and I wouldn't want them to think that I'm falling to bits or you know, or that they have to worry about me' (#19) (s9)
Responses From Others (-/+)	Responses From Colleagues	(+)'I used to leave the house in the morning in tears and walked to work in tears. Honestly, I got to work sometimes and cried to my ODP [operating department practitioner], you know, and they were amazing. And that's what got me through it' (#14) (s10) (-)'I mean we're meant to be caring people [laughs] but we don't, don't seem to care about each other at all in my experience' (#3) (s8)
	Responses From Others	(+)'My friends were very supportive. I think they put up with a lot really in a sense because I was very unwell on and off' (#14) (s8) (-)'I think — there was — professional courtesy as well, because the health visitor knew there was more going on, that I talked about … and a couple of times the health visitor looked at me and she said, if you say any more, I'm going to need to involve the relevant agencies. So I stopped talking' (#8) (s10)

	Change Relationships With Family/Friends	'My relationship with my children has changed very much and that's an ongoing thing which I'll have to face as they get older and learn more about me and what I can and can't do. And obviously even my wife has completely changed, as you can imagine. But I've been fortunate in the fact that they've all been very accepting and supportive of me' (#11) (s8)
(+)To Aid Help-Seeking	To Aid Help-Seeking	'When I was a house officer, within six weeks of starting the job, I had a really um almost life-threatening um depressive episode, precipitated by just by being thrown in at the deep end, not having a team, not having support, and I went to Human Resources every single day saying that I couldn't cope and I needed somebody to help' (#1) (s7)
	Wanting To Share Experiences	'I kind of came to the conclusion that this is how things are, and you know I no longer need to make a big secret of it. I was quite proud of the fact that I'd sort of um, recovered and got back to work and you know, I wanted to tell people about it I suppose really' (#11) (s7)
Confidentiality/ Privacy Concerns	/	'I would rather they didn't know about me and you know, my personal life and the things I struggle with but… if they don't know about it, it just kind of probably makes things worse' (#36) (s7)

Key: | # - participant number, s – study number

Table 6:

Themes and example quotes [Help-seeking]

Theme	Subthemes	Example quote
Medical Culture/ Stigma	Doctors Attitudes To Mental Health (Stigma)	'There is a sort of an unwritten rule that you don't admit to mental illness in any way in general practice, I think. Even though everybody knows that everybody has it, it's just not talked about' (#9) (s3) 'you don't want to be seen by your colleagues or managers as someone who can't cope' (#7) (s4)
	Vulnerability/ Perceiving Self As Weak	'To me it feels, talking to my colleagues out there, there's probably a tranche of people that feel that going to the professional support unit is a sign of failure or a sign of weakness' (#4) (s6)
	Fear Of Judgement From Others	'It was about all the voices I've heard from GPs saying, you know: "They just need to pull themselves together." Or, you know: "All they ever want is pills"' (#20) (s3) 'I fought and fought and fought not to go off sick, because the guilt associated with going off sick is so huge. […] Everybody's struggling, so if I go off sick I will just make everybody else struggle even more. But it got to the point where it was making me quite ill' (#24) (s3)
	Changing Attitudes/Medical Culture Shift	'I think ... encouraging medical students to realise that they're only human, and doctors can get ill like anyone else and to ... seek help ... is a common-sense thing to do' (#12) (s5)
Career Implications (-)	Negative Career Implications/ Fear Of Repercussions	'I mean professionally you might be looking at being drawn off the line, so you're no longer able to operate,

		you're not able to work…I think you're also looking at an income that's lost. And you know, if you're no longer able to work for years that's quite a substantial income that you're losing. How can I put it? An incentive to carry on working and to not acknowledge that these things are going on' (#2) (s1) 'I've had my appraisal, I'm going to have my revalidation tomorrow, and the health-related part is a simple self-assessment 'I am in good health'—yes or no. So I don't think it's very thorough' (#2) (s1)
Difficulty Recognising/ Accepting Illness		'The hardest thing is to acknowledge that you've got a problem' (#30) (s3) 'nobody feeds this back to you in person at the time. Which is when you need it actually. You need to be able to sit down in a room and, you know, talk about things' (#3)(s6) 'I was in a position where I was either going to give up medicine, because I felt that it was negatively impacting my own health, or I was going to try and find a better way of me doing it' (#2) (s4)
Self-Management	Accessing Alternative Support	'I'm just thoroughly enjoying myself. I've never had time to myself in my life. So I'm seeing friends, I'm going for runs, I'm walking the dog, I'm interested in cooking and, yeah, for the first time in my life I'm actually relaxed and happy' (#49) (s3)
Organisational Support From Colleagues (+/-)		(+)'I do think peer support is very important and I think that's probably the first line for a lot of people, like even with some stigma and embarrassment about mental health, I think most people would usually turn to a colleague first' (#16) (s24)

		(-)'One of my colleagues went off with depression […] and then died by suicide, which was really devastating to the practice. But it was a bit like, 'Well, we've just got to carry on. We've got this job to do,' and there was no time to (pause) even really acknowledge it, you know, beyond having the usual things like funerals and stuff. So it was almost swept under the carpet like, 'Well, you know, let's just carry on. Let's not address what perhaps might have contributed to it at work' (#31) (s3)
Awareness Of Services/ Where To Seek Help		'It's that connection, that network of finding appropriate advice which I think is very missing (. . .) you're not taught about it at medical school, there's no mention of what happens if your life goes wrong' (#7) (s2) 'There is the Practitioner Health Programme... I've been seeing a GP, that lives down the road from me, who's absolutely amazing... I didn't feel comfortable being treated in the mental health trust here..being able to move my care completely away from that is very important. I didn't know that was there at the beginning. That's when I ran into some of my problems and when I wasn't seeking the help I needed' (#22) (s24)
Adequacy of External Psychological Support- Need For Independent, Specialist Services	What Doctors Want From Services- Therapy Qualities	'They [PHP] always trusted me, that the story I am telling them is right' (#2) (s2) 'it's just nice knowing that I wasn't the first trainee that had ever been through this sort of thing' (#7) (s4)
	What Doctors Want From Services- Service Qualities	'I still think that the personal approach might be the better way. You know, using your own existing net of contacts might be the first step and that first step might lead you to another source of help' (#4) (s1)

		‘You need an unconditional relationship where a friendship is not at risk if you say something that’s not going to be acceptable’ (#13) (s1) ‘It’s very difficult for doctors to get help which is why people end up with so many problems. Most GPs have got very little experience of addiction’ (#9) (s2)
	Being Treated Differently Due To Their Doctor Status (+/-)	(+)‘I had to really pull rank in order to get my bed that day which I found a bit sad because nobody was saying “He’s a doctor, you do something about it”. Whenever I see patients who are related to the profession I always do my little bit extra’ (#7) (s5) (-)‘She [GP] said: “Well, what do you do?” “I’m a GP.” “Well, we’re all stressed, aren’t we?” was the answer’ (#45) (s3)
Confidentiality/ Privacy Concerns	/	‘It was very difficult (. . .) getting help in the same hospital I worked at. Just kind of embarrassment’ (#5) (s2) ‘I knew all these GPs in [location], and it was a close-knit community. And, suddenly, all my colleagues that were training to be GPs were training in all the different practices in [location], which potentially had — could have — wherever I was registered would have access to my notes and know exactly what was going on with me’ (#5) (s3) ‘If you went to like a counselling group, you’d be worried you’d bump into one of your patients’ (#26) (s3)

Key: | # - participant number, s – study number

Figure 2:

Disclosure barriers and facilitators by percentage endorsement of individual themes across and within studies

*For *figures 2 and 3* the bars represent the number of studies endorsing that particular theme (negative numbers represent barriers, and positive numbers facilitators to disclosure and help-seeking). The specific study numbers are listed within the bar. As below study numbers are colour coded based on their endorsement of the theme for quantitative studies (red, orange, green) and qualitative studies are simply listed in black.

Key: | Study number colours: black - qualitative studies, colour - quantitative studies (red: low (<30% endorsement), orange: medium (30-60% endorsement), green: high (>60% endorsement), blue: not reported endorsement).

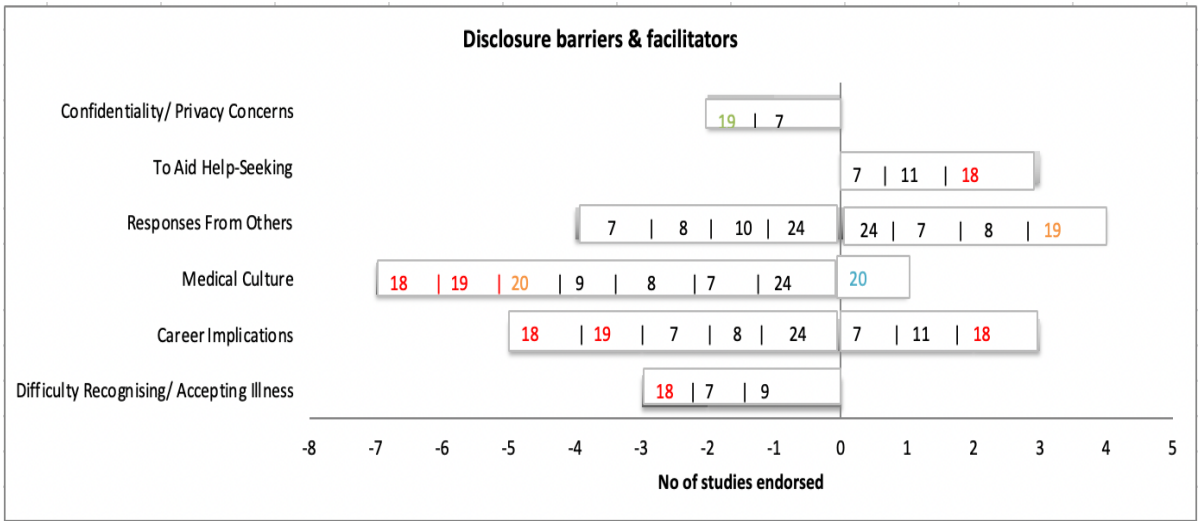
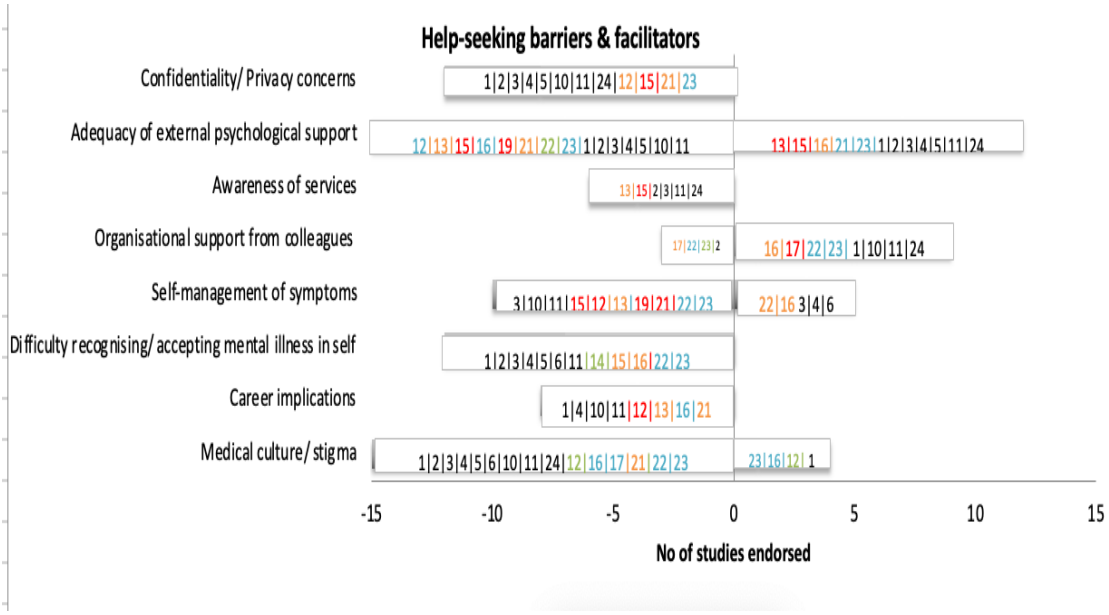


Figure 3:

Help-seeking barriers and facilitators by percentage endorsement of individual themes across and within studies



i. Both:

Medical culture/ stigma around mental health difficulties (positive and negative)

Disclosure-

Most studies[25-27 39-41 44] reported on a perceived medical culture of doctors being invulnerable to illness and the perceived/ anticipated stigma from others (including colleagues and supervisors) around mental illness but particularly around doctors experiencing these difficulties. There was also a self-stigma in feeling a failure for becoming mentally unwell and seen as not coping. Others talked of the fear of letting colleagues down if needing to take time off or feeling a pressure to keep working after disclosure. In addition quantitative findings among doctors of all specialties showed

that among more than 50% of doctors there was feeling that people with depression, dementia and schizophrenia may be difficult to talk to, whilst this general mental health stigma appeared to reduce as doctors gained more clinical experience[27].

Help-seeking-

The majority of studies[19 23 24 28-31 36-38 42-44 46 47] noted the stigma associated with doctors experiencing mental health difficulties and this disrupting their identity as a doctor. Similarly to disclosure doctors noted both a perceived stigma from colleagues and supervisors, including a culture of colluding with presenteeism when doctors are unwell, and self-stigma including feeling ashamed, labelling themselves as weak and having difficulty transitioning from their doctor-patient role. This, alongside fear of judgement from others including fear of being blamed/ seen as not coping, labelled as less clinically competent or needing to remain in work due to staff shortages and not let colleagues down, served as significant barriers to help-seeking. Quantitative findings noted further differences between groups with one study among GPs and psychiatrists finding women were more likely to perceive high levels of stigma (OR = 1.31, 95% CI 1.01-1.23) alongside those with a history of depression (OR = 1.55, 95% CI 1.23-1.95); resulting in both of these groups being significantly less likely to report help-seeking[19]. Some papers suggested that medical culture was starting to shift with doctors noticing reduced stigma within the profession and in their own practice and others wanting to share their experiences to help shape this culture shift[19 23 29 47].

Considering career implications (positive and negative)

Disclosure-

Some studies[25 26 39 40 44] reported doctors fearing the implications on their career of disclosing mental ill-health. Quantitative studies revealed this as one of the most frequent reasons for failing to disclose mental illness (eg. for 34.7% of psychiatrists) and being significantly more likely to be cited as a barrier for those who had not experienced prior mental illness (X^2=8.395, df 3, p = .039, Cramer's v = 0.154)[26]. This included fears of needing to take time off work, General Medical Council (GMC) involvement or feeling conflicted by the fear of losing their positive identity as a doctor. Other studies[25 39 43] noted that some doctors felt a sense of responsibility to disclose, and this was a facilitator to doing so, as they felt a duty to adhere to their professional registration guidance and wanted to forewarn colleagues if this may impact their work performance.

Help-seeking-

Some studies[19 20 23 28 29 36 42 43] noted fears of help seeking having implications for doctors, such as impacting their medical registrations or experiencing losses including financial (due to taking time off work) and promotional (in being not considered for promotional opportunities) losses. This appeared supported by the quantitative findings with one study indicating around 87.1% of GPs and psychiatrists agreed 'doctors are less likely to appoint a doctor with a history of depression'[19]. Others noted that doctors often felt that professional bodies such as the GMC or internal appraisal/ re-validation processes were inadequate at detecting mental illness or managing/ following up on such issues in a sensitive and timely manner.

Difficulty recognising/ accepting mental illness in themselves

Disclosure-

A few studies[25 39 41] reported doctors' normalising/ trivialising experiences of stress and seeing this as part of their job. This often led to difficulty recognising or accepting they were experiencing mental health difficulties and often waiting till crisis point before disclosure. In the quantitative findings around 25% of qualified doctors noted lacking insight and not seeing the relevance of symptoms, therefore feeling able to deal with these alone[25]. It may be that this further relates to the overall medical culture described by doctors in their perceived invulnerability to illness and a need to carry on working.

Help-seeking-

Similarly most help-seeking papers[21-23 30 31 36-38 43 46 47] mentioned the difficulty of doctors accepting mental illness in themselves. They noted this being linked to denial at times and again waiting till crisis point or increased symptom severity before help-seeking. In the quantitative findings scores were typically high when accessing specialist services, indicating delayed help-seeking, with women scoring significantly higher than men on the wellbeing dimension of the CORE Outcome Measure (CORE-OM) (indicating higher wellbeing) ($Z = 72.116$, df 1, $p = .034$)[21]. Additionally studies reported doctors finding their mental health symptoms interfered with being able to access help such as a significant lack of motivation with depression.

Confidentiality and privacy concerns

Disclosure-

A few studies[26 39] reported doctors' fears about confidentiality with some doctors wanting to have 'off the record' conversations to disclose mental ill health in order for their difficulties not to be noted centrally where others may have access to

this. In the quantitative paper when psychiatrists were asked where they would seek inpatient treatment if required 46% chose a local private facility, with the largest factor behind this being confidentiality (cited by 66% of doctors)[26].

Help-seeking-

One of the most commonly reported barriers to doctors' help-seeking was confidentiality concerns[19 22 28-31 36 37 42-44 47]. Doctors reported fears of their employer/ occupational health being made aware or colleagues due to their role having increased access to medical records and similar. Some also reported the fear that they may see their patients whilst accessing mental health support locally. Quantitative studies indicated confidentiality was a key barrier to help-seeking for around 53.4% of GPs and psychiatrists, whilst this was also cited as an issue by around half (46%) of those self-prescribing indicating this may be turned to if individuals have confidentiality concerns[19]. This was particularly an issue for women who were more likely to cite confidentiality as a reason for self-prescribing (OR = 1.37, 95 % CI 1.09–1.72)[19]. Of those doctors accessing specialist support, service improvement feedback indicated 4% wanted more information about confidentiality processes[21].

The following theme emerged from the quantitative findings only.

Demographic differences including the impact of intersectionality, specialty, and type of difficulties

Disclosure-

Specialty- There was some suggestion in studies of differences between specialties with trainees (51%) and locum staff (49%) being less likely to disclose mental ill health than other groups such as consultants (62%) or GPs (61%)[25]. Whilst

other findings suggested minimal differences eg there being no significant differences between non-psychiatrists and psychiatrists about to whom they would disclose their mental illness[28].

Type of mental health difficulty- This could also act as a barrier to disclosure with conditions such as substance misuse being less likely to be disclosed by qualified doctors[25]. Some studies noted the above meant doctors may make choices about selective disclosure including how much to share, who to and in what setting.

Help-seeking-

Gender- Some papers reported on a gender difference with female doctors agreeing with more reported barriers to help-seeking and often instead turning to family or friends or external support rather than colleagues. This was particularly highlighted in one study (of GPs, surgeons and hospital medical specialities) where women were more likely to disagree that the NHS was a good employer when doctors become ill themselves (49%) than men (40%)[24].

Age- Some studies (on junior doctors, GPs, associate specialists and consultants) reported on the average age of those accessing services with the majority of doctors seeking specialist support being under 50 years. There was suggestion that being older (>64) was linked to being least likely to access support if offered, in part due to self-medicating (15%)[20].

Type of mental health difficulty- Some papers reported on those accessing specialist services (including junior doctors, GPs, associate specialists and consultants) often having co-morbid difficulties (26%) eg mental health difficulties, substance misuse and physical health difficulties[20]. This appears to fit with the notion that doctors only seek help when their symptoms become severe.

History of mental health difficulties- GPs and psychiatrists with a history of mental health difficulties were reported to be more likely to endorse barriers to help-seeking, particularly not turning to colleagues (OR = 0.58, 95% CI 0.46–0.72) or family/friends (OR = 0.67, 95% CI 0.46–0.97)[19].

ii. Disclosure

Barrier/ facilitator themes specific to disclosure included:

Responses from others (positive and negative).

Some studies[39 40 42 44] noted negative responses from colleagues and others (in passing about patients/ other colleagues with mental health difficulties or following doctors' disclosure) resulted in a significant barrier to doctors' opening up in future. This likely stems from the medical culture and stigma several doctors described towards experiencing mental health difficulties. Some also noted early disclosures resulting in significant changes to relationships with family/friends such as others becoming more detached or doctors fearing further stigma. Positive responses from colleagues and others however facilitated disclosures[26 39 40 44], highlighting the role that this could have and quantitative papers supported this notion in that 30.9% of psychiatrists would choose informal professional advice as first preference if requiring treatment for moderate depression[26].

To aid accessing/seeking help

A few studies[25 39 43] reported that disclosure could be facilitated by a desire to access help. In the quantitative papers around 11% of qualified doctors noted disclosing due to wanting to access emotional support or treatment[25]. This included both wanting external support (such as a diagnosis/ therapy) and internal support (eg.

wanting to facilitate workplace adjustments or take time off). Some doctors noted that they wanted to help create a culture of openness regarding talking about mental health difficulties and help other colleagues who may be experiencing similar difficulties to them.

iii. Help-seeking

Barrier/ facilitator themes unique to help-seeking included:

Self-management of symptoms (positive and negative)

Many papers[19 20 22 23 26 28 31 36 38 42 43 46 47] reported of doctors turning to self-managing symptoms with a number describing doctors self-prescribing for their symptoms. Quantitative findings among junior doctors, GPs, associate specialists and consultants revealed around 1 in 3 doctors used alcohol, drugs, self-medication or self-prescribing occasionally or regularly to cope with their mental health condition, particularly men (38%) and older doctors (31%)[20]. One study showed GPs and psychiatrists most commonly self-prescribed sleeping tablets (11.5%), antidepressants (7.4%) or anxiolytics (3.2%)[19]. Others noted a preference for turning to family/friends rather than accessing more formal support. Some GP trainees noted that finding their own way of managing symptoms could be helpful eg finding more of a work-life balance or practicing mindfulness (34%)[46]. Some papers reported that a lack of time contributed to not help-seeking from more formal services.

Organisational support from colleagues (positive and negative)

Some papers[24 44 46 47] noted that doctors had received negative comments or a lack of support fr[44 46 47]om colleagues resulting in being less likely to seek help. In addition there was note of inadequate support and training in managing mental health

within the workplace. Others however reported positive support from colleagues and workplace adaptations (eg flexible working patterns) promoting further help-seeking[23 24 29 42-44 46 47]. In the quantitative findings around 32% of GPs noted benefiting from flexible working practices[23].

Awareness of services and where to find them

Some studies[20 22 30 31 43 44] reported that doctors were unaware of services available to them and where to seek help for their own mental health difficulties. Quantitative findings suggested around 4% of those accessing specialist services (including doctors of all grades from pre-registration to consultant level) felt these needed better publicity[22].

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Adequacy of external psychological support and the need for independent, specialist services (positive and negative)

The majority of studies[19 20 22 23 26 28-31 36 37 42 43 46 47] reported on doctors perceiving inadequate psychological support for doctors with it not being possible to access support in a timely way or services not being tailored to their specific needs. In the quantitative findings of those accessing support around 54% of doctors from junior doctor to consultant level felt the support partially met their needs and whilst those under 25 years were the most likely to accept support they were also most likely to find the support offered unacceptable[20].

Nevertheless of those papers reporting on doctors' feedback of specialist services this was largely positive [20 22 23 28-31 36 37 43 44 47]. Studies reported that services which normalise doctors' difficulties, involve them in treatment and are aware of issues specific to doctors (eg GMC involvement, the stigma accessing help and tailoring around doctors

working hours) were considered the most valuable. Doctors also noted the importance of the service being independent with no conflict of interest with their employer and having a longstanding relationship with their GP/ therapist being important for improving access to help-seeking. Lastly doctors noted being treated differently due to their doctor status and at times this not working in their favour but at other times being able to use their status when help-seeking to improve access to services.

Discussion:

Summary

This review highlights the significant barriers that doctors experience both disclosing and help-seeking for mental health difficulties. Key themes across both areas were the existing medical culture involving perceived invulnerability to illness, collusion with presenteeism and stigma around doctors' mental health. The mental health stigma described includes perceived stigma from colleagues and self-stigma in perceiving themselves as weak/ a failure if experiencing mental ill-health. Similarly, many doctors fear that disclosing and help-seeking for mental ill-health may have negative career implications including impacting their medical registrations, and involvement from bodies such as the GMC. Doctors also described perceived need to continue working as part of their identity. Other common themes when disclosing and help-seeking for mental health difficulties involved confidentiality concerns and difficulty recognising or accepting mental health difficulties in themselves. There were also however facilitators which can be drawn upon including positive reactions and support from colleagues, with factors such as openness, workplace adjustments and flexible working facilitating doctors to open up about their difficulties and access appropriate help.

Existing literature

This review provides further support of the ongoing barriers that exist for doctors when disclosing and accessing help for their own mental health difficulties. Concerns about medical culture with doctors needing to be seen as invulnerable to illness and associated fears around confidentiality and shame when accessing support mirrors previous findings.[5] Furthermore doctors' difficulty transitioning to the role of a patient and viewing themselves as weak when experiencing mental health difficulties with concerns about their professional future[6] were themes also found in the current review. These barriers appear particularly prominent around doctors experiencing mental health difficulties. Despite several years since these reviews unfortunately a significant stigma still exists within the medical profession both from others and doctors themselves which affects their confidence disclosing and help-seeking for mental health difficulties.

In line with the disclosure processes model,[11] it was apparent that for doctors barriers lay at each part of the disclosure process.

i. Doctors when weighing up the decision to disclose had significant fears about the reactions of others and therefore often continued to conceal their mental health difficulties to avoid negative repercussions. This appeared particularly informed by the medical culture described of doctors being invulnerable to illness and the self-stigma and perceived/anticipated stigma from others of doctors experiencing mental health difficulties.

Ii. During disclosure doctors often made decisions to selectively disclose parts of their difficulties to specific people, with this often not being to colleagues due to confidentiality fears and fear of being labelled (in line with past research).[25]

iii. Regarding mediating factors sharing information appeared difficult due to fears around the implications of doing so, such as on their career and working identity. This review found particular support for the mediating role of social support with doctors noting mixed reactions from others- some positive with colleagues being increasingly supportive, prompting likely further disclosure, and some negative, resulting in further concealment of difficulties. Some studies discussed changes in relationships such as family and friends becoming more distant since disclosure and this subsequently having a negative impact on doctors' wellbeing.

iv. As above outcomes were both positive and negative with some noting the benefits of feeling less guilt from not concealing difficulties, feeling more supported and helping to shift the medical culture, whilst others noted experiencing bullying or doubts regarding their ability since disclosure resulting in decreased wellbeing.

V. This appeared to involve a feedback loop where doctors noted the above affected their decisions about whether future disclosures were likely to be helpful.

This review, in line with the different types of stigma[48] impacting on disclosure decisions, highlighted doctors experiencing not only internalised self-stigma and perceived/ anticipated stigma from colleagues but also experiencing direct stigma on occasion in the negative reactions of others. This was noted to impact on perceived likelihood of further disclosures and mirrors previous findings about the types of stigma that exist within a professional medical culture of being invulnerable to illness.[25] In the review one of the key reasons for choosing to disclose mental health

difficulties was in order to access appropriate help and therefore the following theory was also of relevance. In line with previously identified stages for mental health help-seeking[13], the review was able to map specific barriers and facilitators at the three different stages of i. recognising the problem, ii. deciding to seek help and iii. accepting help.

i. Problem recognition

Barriers identified previously about doctors needing to live up to a professional identity and appear well to patients and colleagues whilst observing high rates of presenteeism were also mirrored in the current review.[49 50] Since this can lead to burnout and suboptimal patient care[1] there is a need to normalise the importance of initially recognising difficulties and taking the appropriate time needed to seek help for these.

ii. Decision to seek help

Stigma attached to mental health difficulties within the profession remained a significant factor across multiple studies in the current review and previously.[29 51]As above changes to the medical culture and doctors' attempts to shift this by being open about mental health difficulties provide hope for future. It was also highlighted in the current review how supportive colleague and workplace environments could be particularly helpful for increasing disclosure and appropriate help-seeking for mental health difficulties among doctors. A recent guideline has outlined recommendations for improving doctors' work cultures (eg leaders listening to doctors' difficulties, facilitating compassionate team cultures and facilitating access to appropriate pastoral support.[52]

iii. Accepting help

Prior findings that doctors experience specific barriers to accessing mainstream services including time constraints given their working pattern and not always feeling treatment would be effective[4] were similarly shown in the current review. As noted, this can lead to self-managing psychological difficulties or preferring to speak to friends/ family due to confidentiality concerns.[53] The current review echoed that doctors often utilised self-management strategies, some unhelpful such as self-medicating (as there is no overseeing physician ensuring an objective or timely treatment nor offering ongoing monitoring for medication side effects or ongoing symptoms of mental ill-health which may impact their health and work performance)[54] and others more helpful, such as restoring a work-life balance and using mindfulness. Specialist services offer the opportunity to overcome some of these barriers such as being more aware of and tailored to meet doctors' specific needs including an awareness of the shame associated with seeking help, having flexible availability around working patterns and being independent and confidential. It appears there may still be some barriers such as increasing awareness of where to seek help[10] to help make most use of these services, however studies reporting on those who accessed help were largely positive about the outcomes.

Strengths

All of the included studies were of medium-high quality, including in the appropriateness and quality of study methods and robustness of the findings, which supports the current review. Nevertheless future studies may benefit from more inclusion of authors' reflexivity, connection to a key theoretical framework and control of confounding variables to strengthen the research quality further. In addition a rigorous, systematic review was used which involved two raters at each stage of the

process including abstract and full text screening, data extraction and quality assessment. A third rater was also involved for disagreements to be resolved, increasing objectivity of the process. This review provided an up-to-date review of studies in this area, which was well-needed as despite reported improvements in medical culture and available services significant barriers and facilitators appear to remain for doctors disclosing and accessing help. The use of mixed studies (both qualitative and quantitative) allowed integration of both the depth of specific themes and endorsement numbers of these across larger studies.

Limitations

It is acknowledged that studies varied considerably in the extent to which they contributed to the review, particularly regarding qualitative studies, with barriers and facilitators often being studied as secondary questions in research. Furthermore whilst there is likely to be some overlap between different specialties in the barriers they experience disclosing and help-seeking it may be helpful for further studies to explore similarities and differences between specialties in the barriers and facilitators they experience, particularly as factors such as age and training stage have been suggested to be relevant and the current review did not include medical students as a comparison. This would help to widen generalisability across the medical profession.

Further research is required focused on ways to overcome barriers to doctors help-seeking and disclosing mental health difficulties. It would be valuable to explore different stakeholders' views on how to tackle these barriers to disclosure and help-seeking to provide alternative perspectives. As medical culture was a particular barrier in the current review more evaluation of interventions aimed to reduce stigma

and unhelpful aspects of medical culture may be a particular focus. It may be that, due to increased discussion around mental health difficulties among doctors during the covid pandemic, this has begun to shift some of this culture in normalising disclosure and help seeking Furthermore it is notable that over covid-19 there has been greater investment in staff mental health with further tailored mental health support hubs being opened for NHS staff which deliver confidential evidence-based support with qualified clinicians.[55] These are available by both self-referral and the hubs proactively contacting staff groups identified as being most at risk. Guidance has also emerged regarding meeting the psychological needs of healthcare staff since covid-19 with recommendations regarding individual, management and organisational support initiatives (eg. visible leadership, encouraging staff communication, establishing peer/ team support, normalising psychological responses and delivering psychological care in a stepped-care way).[56] Further reviews focused on merging findings from other countries may be beneficial for learning about facilitators or support structures, particularly in similar healthcare systems, that could be extrapolated to benefit doctors in the UK.

Conclusions

This review suggests that doctors continue to experience barriers to disclosing and help-seeking for mental ill-health.

i. There is need for a shift in the medical culture of doctors perceived sense of invulnerability and the stigma associated with mental ill health within the profession, which reportedly stems from early in training.[43] There is suggestion that anti-stigma interventions such as hearing from other doctors with lived experience may be effective.[57]

ii. One of the most common facilitators to help-seeking and disclosure in the review was support from colleagues and supervisors and an approachable working environment, which is adaptable (eg offering time off or flexible working when needed). Creating this culture of openness and flexibility may serve as both a facilitator for help-seeking and preventing further difficulties where teams work well collectively.

iii. There are specialist services available for doctors, which appear highly valued by those who have used them in understanding and meeting the needs of doctors. As barriers such as lack of awareness still exist there is need to further promote the availability of these services and focus on reassuring doctors of their concerns eg regarding confidentiality.

(See appendices C-E for reflections on the systematic review process, further detail on the step-by-step analysis strategy and author guidelines for the target journal (BMJ Open)).

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Project: Service Improvement Project

Title: Difficulties in transitioning to dialysis; possible reasons and potential psychological interventions.

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

Internal Supervisors: Prof Myra Cooper | Dr Sarah Lack

External Supervisor: Dr Louise Hankinson

Journal: Journal of Health Psychology. This was chosen because this is a leading international journal which reports on research within the field of health psychology. The current article may have findings generalisable to wider health settings, hence wishing to reach a broader audience.

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Abstract:

Introduction: Depression and anxiety are prevalent among those with chronic kidney disease (CKD) and lead to delay starting dialysis and poor prognosis. The current study assessed the prevalence of these difficulties among patients in Oxford and five satellite Low Clearance Clinics (LCCs), identified why patients experience difficulties transitioning to dialysis and explored how services can best support with managing this transition.

Method: Twenty-nine patients completed self-report questionnaires on mood (PHQ-9, GAD-7), quality of life (KDQoL) and illness perceptions (IPQ-R). Self-reported numbers of missed appointments and kidney-related hospitalisations were collected. Eight carers completed a qualitative survey on their loved one's experiences of transitioning to dialysis. Interviews were also conducted with seven patients and six staff on their experiences of approaching dialysis and supporting patients respectively.

Results: On the self-report measures 55% of patients (*n*=16) reported low mood and 28% reported anxiety (*n*=8). Illness perceptions were similar to previous findings, however the current sample experienced a higher emotional impact of living with CKD. Nonetheless, numbers of missed appointments and hospitalisations were low. Qualitative experiences reported by patients, staff and carers included fear/denial and difficulties adjusting to the lifestyle changes involved. Reasons for delay in starting dialysis included a lack of knowledge about symptoms/ dialysis, being torn about the need for dialysis with good/ bad symptom days and at times 'just following medical advice'. All groups provided recommendations for service provision including the importance of family involvement in pre-dialysis support, the pros/ cons of peer support and need for appropriately tailored information.

Discussion: Recommendations for psychological support in LCCs are suggested. Therapeutic approaches focused on (i) adjusting to CKD (such as Cognitive Behavioural Therapy and Acceptance and Commitment Therapy), (ii) symptom reduction (e.g. pain-management or mindfulness-based interventions) and (iii) systemic-focused interventions may be particularly helpful.

Introduction:

Chronic kidney disease (CKD) is a condition with few symptoms initially but in later stages patients can notice fatigue, swelling, shortness of breath and nausea (NHS, 2019). Management includes lifestyle/ dietary changes, medication and in later stages dialysis or transplant (Jha et al., 2013), which patients typically access through low clearance clinics (LCCs) when they reach end-stage renal failure (ESRF). However, treatment can be onerous, and symptoms affect functioning, leading to mixed adherence to treatment and missed appointments (Clark et al., 2014).

Depression is prevalent among patients with CKD, alongside lower quality of life (QoL) and perceived symptom burden, regardless of the stage of the condition (Abdel-Kader et al., 2009). A recent meta-analysis found depression in 21-39% of patients with higher rates in ESRF (Palmer et al., 2013). Other studies estimate anxiety and depression in 31-72% of patients, linked with poorer outcomes, e.g. hospitalisation (Loosman et al., 2015; Shafi & Shafi, 2017). Mood difficulties are typically associated with poorer prognosis, with patients who also experience a major depressive episode being more likely to be hospitalised with CKD in a shorter timeframe and experience longer hospital stays (Hedayati et al., 2005; Hedayati et al., 2008; Hedayati et al., 2010). Furthermore, depression may contribute to difficulties in

treatment engagement (including adherence to dialysis), alongside substance misuse, and pain, leading to frequently missed appointments and increased hospital admissions (Chan et al., 2014). There is thus a need to investigate how best to support patients with CKD psychologically, to improve treatment engagement and wellbeing.

The self-regulatory model of illness perceptions (Leventhal et al., 1997) explains how patients' beliefs about their condition drive their behaviour (e.g. engagement with treatment).

The model proposes that patients hold:

i. Cognitive perceptions of the illness regarding its identity, timeline, cause, controllability (by themselves/ an expert) and consequences
ii. Coping behaviours which seek to control the illness. These are informed by an individual's prior history and knowledge about the illness. There must be coherence between their illness perceptions, behaviour, and the belief that their efforts can effectively control symptoms.
iii. Emotional perceptions of the illness and behaviours to cope with this.

The patient will then appraise the outcome of their coping style and continue with this or adapt it as necessary. The model subsequently predicts illness and emotional outcomes.

O'Connor et al. (2008) found the model predicted engagement with diet and medication changes, with emotion-focused coping leading to more variation in treatment adherence in ESRF. Illness perceptions can change across the course of the illness and provide a focus for intervention as they link with anxiety, depression and disease progression (Clarke et al., 2016). Beliefs about treatment and self-efficacy in

managing symptoms are also important. Grubbs et al. (2017) found nephrologists perceived public misconceptions about dialysis and lack of time to discuss these as a barrier to engagement in dialysis. Furthermore self-efficacy in relation to managing CKD symptoms was found to partially mediate the relationship between symptoms and QoL (Chan et al., 2011). Therefore, helping individuals to adjust their coping style, illness perceptions, treatment beliefs and self-efficacy may be beneficial.

Service context

LCCs support those typically in or approaching ESRF, and likely to require renal replacement therapy, within 12 months. In LCCs it is important to support patients to attend regular appointments for monitoring and preparing for dialysis, as this leads to better prognosis and QoL (Getting it Right First Time (GIRFT), 2021).

Oxford and its five satellite LCCs consist of nurses, doctors, and the wider multidisciplinary team (MDT) including dieticians, surgeons, pharmacists, psychiatrists, and psychologists. Approximately 400 patients are under the care of the LCCs. A psychologist is funded (0.7wte) and offers a flexible needs-based service based on an Acceptance and Commitment Therapy (ACT) approach. In the wider clinic patients are offered an informative seminar, opportunity to visit the dialysis unit, and follow up appointments with nurses and consultants who offer psychoeducation, medical reviews and ongoing support.

The service does not collect baseline data regarding rates of low mood/ anxiety, so it is currently not possible to ascertain whether numbers referred to psychology reflect the level of need in this population. The service acknowledges that

patients miss appointments and delay dialysis, however it has yet to conduct a systematic consultation with patients on reasons for this and to review the extent of this costly problem. The service was also keen to review what psychological support may be most appropriate to offer patients, carers, and staff to support individuals transitioning to dialysis as intervention at this early stage of treatment, might lead to better long-term outcomes.

Service improvement

Patients and carers are ideally positioned to help improve services, through sharing their range of experiences accessing National Health Service (NHS) services. Guidelines state patients and carers should be involved in care decisions and service design (NHS, 2009). Experience-based co-design includes collating this with staff feedback. The five-step improvement approach (NHS, 2014) includes: preparation, launch, diagnosis, implementation, and evaluation phases. This project conducted the first three phases exploring the extent of the problem and developing recommendations for future implementation.

Study rationale

To the author's knowledge there is no existing study qualitatively exploring psychological reasons for difficulty transitioning to dialysis among UK patients and carers, nor investigating the type of psychological intervention that they view likely to be most beneficial at this time. This study uses mixed methods to identify the extent of mood (PHQ-9, GAD-7) and QoL (KDQoL) difficulties and missed appointments in clinic. As illness perceptions (IPQ-R) have been linked with mood difficulties and treatment non-adherence these were also explored to inform potential therapeutic

recommendations. Qualitative interviews/ surveys were conducted with patients, staff, and carers to identify experiences of transitioning to dialysis and what psychological support may be helpful for this. This information was designed to inform the development of psychological intervention(s) to support individuals pre-dialysis with their mood, QoL, and treatment adherence. This would then hopefully influence prognosis and patient experience and safety. It may also provide cost savings by reducing the number of missed appointments and hospital admissions due to treatment non-adherence. The recommendations may be generalisable across similar settings nationwide.

Study questions

1. What are baseline rates in clinic of low mood, anxiety and QoL pre-dialysis?
2. What illness perceptions are prevalent amongst this group? How does this compare to previous research?
3. To what extent do patients miss appointments or require hospitalization pre-dialysis?
4. What are patients' experiences of transitioning to dialysis? What reasons may patients have for delaying dialysis?
5. What support do carers of these patients need?
6. How may the service better support patients transitioning to dialysis; what might a brief psychological intervention consist of, given the responses gathered from patients, carers, and staff?

Method:

Service user involvement

The service identified the need for exploring more closely the accessibility of psychology for pre-dialysis patients and whether more could be done for this group at this early stage of transitioning to dialysis. Dialysis patients, carers and staff were consulted to shape the study design and interview questions.

Participants

[i] All pre-dialysis patients attending Oxford LCCs between January 2021-July 2021 were asked to complete measures about their mood and QoL where possible. A subset of patients (n=20) who had consented to be contacted were invited to a telephone/ online interview to discuss their experiences of transitioning to dialysis and how services could best support them psychologically during this period.
[ii] All carers were asked to complete a carers survey where possible.
[iii] A range of staff members across all six clinics (N=20) were invited to a focus group to discuss their experiences of patients transitioning to dialysis and how services could improve to best meet the psychological needs of patients.

Setting

The study was conducted across Oxford LCCs in the south-east of England; Banbury, High Wycombe, Swindon, Milton Keynes and Stoke Mandeville.

Measures

[1] The following patient questionnaires were completed and collected:

-Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001)- this 9-item measure assesses symptoms of depression.

-Generalised Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006)- this 7-item measure assesses symptoms of generalised anxiety.

Both measures have been shown to be valid and reliable screening tools within primary care.

-Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002)- this measures the five illness representations in Leventhal's self-regulatory model. It asks patients about their symptoms, perceived causes of the condition and how much they agree on a 5-point Likert scale with items regarding illness identity, consequences, timeline, coherence, and emotional responses.

It has been found to be valid and reliable for assessing illness perceptions.

-Kidney Disease Quality of Life Instrument (KDQoL-36) (RAND, 2000)- this 36-item measure asks about health-related QoL, including how much kidney disease and emotional difficulties affect different aspects of patients' lives (e.g. activities, socialising) and how bothered they are by symptoms. It has been shown to be valid and reliable for assessing QoL in dialysis patients (Peipert et al., 2018).

-Screening questionnaire (provided in *appendix L*)- this included questions about:

i) demographics – including age/sex/ethnicity

ii) mental health history – including past psychological therapy or psychotropic medication and whether patients perceived this to be linked to their kidney disease

iii) kidney disease – including any prior renal treatment and the numbers of relevant (kidney-related) hospital admissions and missed appointments within the past 12 months.

(*See appendix G for copies of the following)*

[2] The structured interview questions for a subset of pre-dialysis patients were developed and reviewed with a pilot group of four individuals with CKD. Questions were focused on experiences of transitioning to dialysis and how services could best support this transition.

[3] A carers survey was developed focusing on their experiences and how the service may best support them. This was reviewed by a pilot group of two carers of those with CKD.

[4] The staff focus group questions were developed and reviewed by two clinic staff members. These focused on experiences of patients transitioning to dialysis, and what they felt may facilitate/hinder this transition.

Procedure

The project was approved by the Oxford University Hospitals research classification committee and University course and registered with the trust clinical audit team [No: 6344] (*see appendix J*). Patients and carers were asked to complete the self-report questionnaires in clinic, by post or online via Qualtrics. Recruitment occurred across six months between January 2021- July 2021. A subset of the pre-dialysis patients was invited (with consent) to participate in a structured 30-minute interview. A 1-hour staff focus group was also held. Information gathered from patients, carers and staff was used to inform the development of potential psychological intervention(s) that may be helpful for this population.

Data analysis

Descriptive statistics were used to report on the prevalence of mood difficulties, missed appointments and hospitalisations. KDQoL and IPQ-R scores were compared to existing data sets in this area for people with CKD. This was because group clinical cut offs do not exist on the measures, and it was important to ascertain whether our sample were scoring similarly to others with CKD or scoring higher/ lower than expected on these measures. A 1-sample t-test was conducted to compare the KDQoL and IPQ-R scores in the current sample with recent published data sets in this area; the KDQoL scores were compared to a US dialysis sample (as to the authors' knowledge no pre-dialysis norms exist) (Peipert et al., 2018) and the IPQ-R scores to a pre-dialysis Dutch sample (Meuleman et al., 2015).

Demographic differences were explored using t-tests (or Mann-Whitney for non-parametric data).

Thematic analysis (following Braun and Clarke's 6 stages, 2006) was conducted by AP. This included familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and writing up themes. Key themes and subthemes were identified from the carer surveys and transcribed patient and staff interviews, until no new themes were found. All themes were checked by multiple researchers and discrepancies were resolved before themes were finalised.

Results:

[1] Questionnaires

Thirty-one patient questionnaire sets were returned (two were excluded as repeats). Eight carer surveys were returned.

Demographics

See *table 1* for summary demographics of the sample.

Table 1:

Demographic data

Demographic data (N=29)	**N (Frequency)**	**%**
Age (years)		
18-30	3	10
31-43	0	0
44-56	3	10
57-69	11	38
70-82	9	31
83-95	3	10
Sex		
Male	16	57
Female	12	43
Ethnicity		
White British/ White other	25	89
Black African/ Black Caribbean/ Other Black, African or Caribbean Background	1	4
Other *Included Irish and Asian	2	7
Low Clearance Clinic		
Oxford	15	52
Banbury	4	14
Milton Keynes	3	10
Stoke Mandeville	3	10
Swindon	3	10
High Wycombe	1	3
Previous kidney disease-related treatment		
Haemo/ peritoneal dialysis	2	12
Transplant	1	6
'Other' care	4	24
None	10	58

Key: | Percentages may not add up to 100% where small amounts of missing data exist or some percentages were rounded up to the nearest whole number.

Hospitalisations and Missed Appointments

89% (N=25) of participants reported no hospital admissions within the past year, whilst 11% (N=3) noted having 1-4 admissions[1]. 93% (N=26) reported not missing any kidney-related appointments, whilst 7% (N=2) noted missing 2-5 appointments.

Mood

8/29 participants noted prior mental health history, including anxiety and depression with 50% feeling these were related to their kidney condition. 63% had prior treatment including medication and psychological therapy (internal and external to the renal clinic) with 38% currently taking psychotropic medication.

Current rates of depression and anxiety severity were low overall as indicated by scores on the PHQ-9 (*M*= 7.17, *SD*= 6.84) and GAD-7 (*M*= 4.07, *SD*= 5.63). These reflected mild levels of depression and sub-clinical levels of anxiety respectively. However, 55% of participants reported experiencing mild-severe depression, and 28% mild-severe anxiety. This reflects 45% and 72% of participants being in the sub-clinical range for symptoms of depression and anxiety respectively.

QoL

See table 2 for a summary of QoL scores. Subscale scores were calculated with kidney-specific QoL mean scores of 61.4-71.6. KDQoL scores[2] were compared to those in a US paper with 70,786 dialysis patients (Peipert et al., 2018). There was a

[1] Numbers and percentages reflect the total number of participants completing each question so these may not add up to the total sample size where small amounts of missing data exist.
[2] Parametric assumptions were met for all measures excluding the GAD-7, PHQ-9 and timeline cyclical subscale of the IPQ-R.

significant difference in QoL symptom rating ($t(27) = 2.059, p<.049$) with the current sample reporting lower QoL regarding symptoms (95% CI [-14.690, -.026][3]. There was no significant difference between the two samples in QoL regarding the effect or burden of CKD nor in physical or mental composite scores.

Table 2:

QoL Scores

Subscale	Current sample		Score range	Peipert (2018) comparison sample	
	M	SD		M	SD
KIDNEY-SPECIFIC QoL					
Symptoms of KD	71.6	18.9	35-100	79	16.0
Effects of KD	73.8	20.5	9-100	74	22.0
Burden of KD	61.4	26.9	0-100	52	30.0
GENERAL HEALTH-RELATED QoL					
Physical composite	33.7	12.2	16-55	38	10.0
Mental composite	47.9	12.9	24-66	51	10.0

Key: | Abbreviations: M - Mean, SD - Standard Deviation, QoL - Quality of Life, KD - Kidney Disease

| Higher scores indicate higher QoL

Illness perceptions

See *table 3* for a summary of IPQ-R scores. Subscale scores were calculated with mean scores of 4.4-25.5. IPQ-R scores were compared to a Dutch paper with 416 pre-dialysis patients (Meuleman et al., 2015). There was no significant difference between samples for illness identity. However the current sample scored significantly higher on the perceived emotional impact of the condition ($t(26) = 13.203, p<.001$)

[3] Statistics are reported for significant results only to aid readability.

(95% CI [12.98, 17.77]) and consequences of CKD *(t*(25) = 27.179, *p*<.001) (95% CI [17.09, 19.89]). The current sample scored significantly higher for perceived personal control, indicating they felt more in control of managing their CKD (*t*(24) = 19.473, *p*<.001) (95% CI [13.41, 16.59]) and on perceived treatment control (*t*(25) = 22.919, *p*<.001) indicating they more strongly believed treatment would be effective. Lastly the current sample scored significantly higher on believing the condition would have a long duration (*t*(25) = 24.152, *p*<.001) (95% CI [19.54, 23.18]) and on illness coherence (*t*(25) = 17.323, *p*<.001) with the current sample reporting a better understanding of the condition (95% CI [13.56, 17.21]). For Pearson correlations between illness perceptions on the IPQ-R and the other self-reported mood and QoL measures *see appendix I* (*table I1*).

Table 3:

IPQ-R Scores

Subscale	Current sample		Score range [in sample]	Possible score range [original measure]	Interpretation of current sample scores	Meuleman (2015) comparison sample	
	M	SD				M	SD
Identity	4.4	3.8	0-13	0-14	Participants scored towards the low end of the scale (M=4.4, indicating they experienced relatively few symptoms	3.0	2.5
Consequences	21.9	3.5	12-28	6-30	Participants generally scored high on the scale (M=21.9) indicating strong beliefs of CKD having negative consequences for them and family	3.4	0.7
Timeline acute	25.5	4.5	16-30	6-30	Participants scored towards the high end of the scale (M=25.5) indicating strongly held beliefs that CKD would have a long duration.	4.1	0.7
Timeline cyclical	8.8	4.2	4-16	4-20	Participants scored low on the scale (M=8.8) and were unlikely to believe CKD was cyclical	2.8	0.8

Emotional impact	18.1	6.1	6-30	6-30	Participants scored in the middle of the scale (M=18.1) regarding the emotional impact of CKD.	2.7	0.9
Personal control	18.0	3.9	10-25	6-30	Participants scored in the middle of the scale (M=18.0) in feeling they had some control of their CKD.	3.0	0.7
Treatment control	16.8	3.1	12-23	5-25	Participants generally scored towards the high end of the scale (M=16.8) and therefore felt treatment was effective for CKD	3.0	0.6
Coherence	18.9	4.5	9-25	5-25	Participants scored on the high end of the scale (M= 18.9) indicating a good understanding of the condition.	3.5	0.8

Key: | Abbreviations: M - Mean, SD - Standard Deviation, CKD - Chronic Kidney Disease

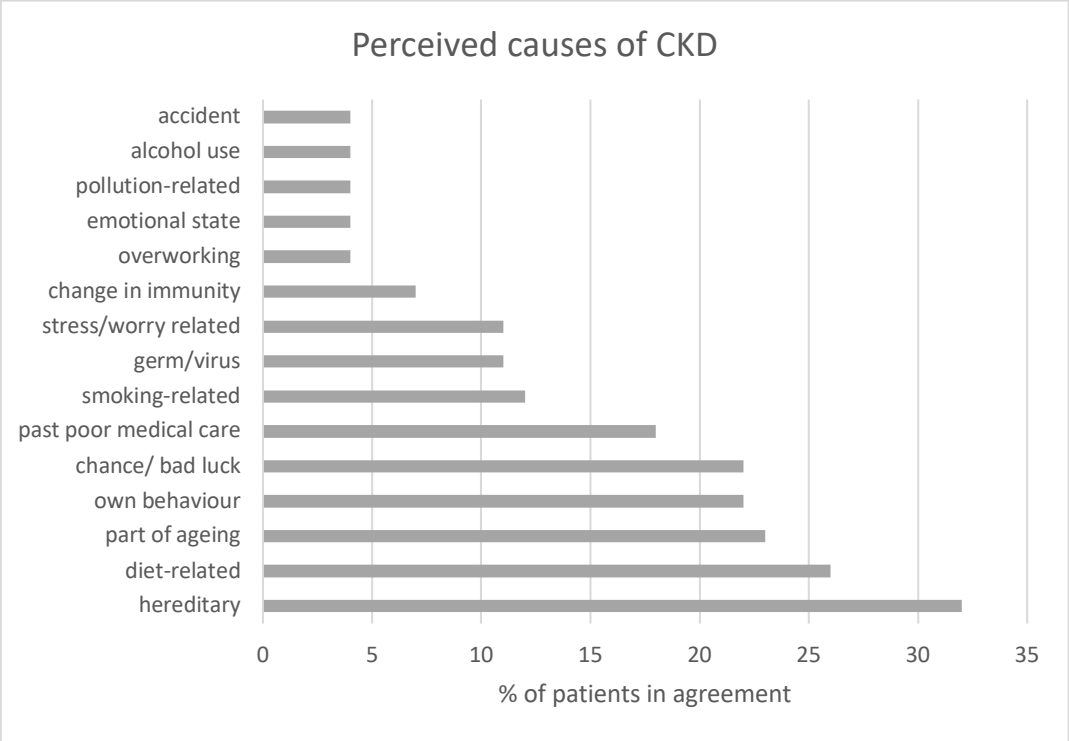
| Higher scores indicate more strongly held beliefs

| Interpretation is based on where the mean falls within the subscale score range.

See *figure 1* for a list of perceived causes of CKD. In the current sample the most common perceived causes of CKD were it being hereditary, diet-related or part of ageing.

Figure 1:

Perceived causes of CKD



Demographic differences

There were no significant sex or age[4] differences on the PHQ-9, GAD-7 nor KDQoL. On the IPR-Q women ($t(23)=.387$, $p<.001$) and younger people ($t(23)=2.704$, $p<.006$), scored significantly higher on perceived personal control over CKD. Younger people also perceived higher consequences of the condition

[4] Age was split between those under and >70 years so there was roughly half of the sample in each group.

($t(24)=3.571$, $p<.001$). There were no other sex or age differences on the IPQ-R subscales.

[2] Interviews:

Six staff members attended the focus group. Seven patient interviews were conducted. See *table 4* for participants' demographic data. Thematic analysis (in line with Braun and Clarke, 2006) was conducted on the patient and staff interviews and carer qualitative surveys. This identified the following overarching themes: i. Experiences of transitioning to dialysis, ii. Reasons for delay, iii. How the service can best support patients transitioning to dialysis. Key subthemes identified by staff, patients and carers were combined (*see figures 2-4*) with example quotes provided in *table 5*. For further quotes and the author's reflections see *appendix H*.

Table 4:

Demographics of qualitative sample (Patients, Staff, Carers)

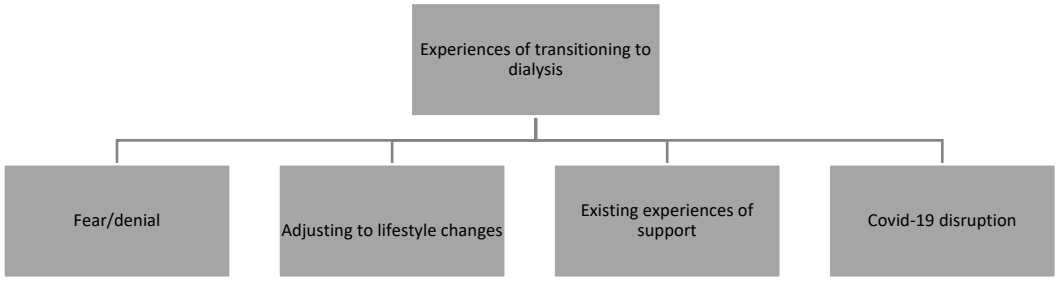
Patients		
Sex	Male	4
	Female	3
Age	44-56	2
	57-69	2
	70-82	2
	83-95	1
Staff		
Sex	Female	6
Profession	Pre-dialysis nurse	3
	Dialysis nurse	1
	Psychologist	1
	Clinical researcher	1
Carers		
Sex	Male	5
	Female	3
Relationship to person transitioning to dialysis	Husband	5
	Wife	3

Experience of transitioning to dialysis:

See *figure 2* for a list of the subthemes identified across all groups.

Figure 2:

Summary of subthemes identified for 'experiences of transitioning to dialysis'



Fear/denial

All groups noted fears of starting dialysis including feeling it was a waiting game, fearing the unknown and fears about complications or needing to self-manage dialysis at home. Patients and carers noted timing of the news being important (i.e. whether this was expected or a shock) with the latter invoking more fear. Staff acknowledged that fear could dissipate once starting treatment, whilst for others fear of mortality increased as they approached treatment, and some remained fixed on alternative treatments (e.g. transplant).

Adjusting to lifestyle changes

All groups noted difficulty adjusting to dialysis (often having little time to prepare for this), therefore whilst understanding the benefits, acknowledging it may significantly impact family life and lead to loss of/adaptation to activities. Patients acknowledged the financial repercussions/ time commitment and chronicity of dialysis, and for some, how this might impact their family roles /confidence.

Existing experiences of support

Despite the above patients and carers noted positive healthcare experiences and benefits of an MDT. They valued information on diet, dialysis machinery and treatment options and 1:1 sessions to ask questions. Staff noted the importance of having time to build rapport with patients.

Some patients reported negative experiences with information being given or not communicated between services. Some experienced difficulties with medical terminology and information not tailored to them. Staff also acknowledged difficulty with tailoring information to differing patient needs and language barriers. Some carers identified a lack of information or emotional support or preferred to use their own coping strategies.

Covid-19 disruption

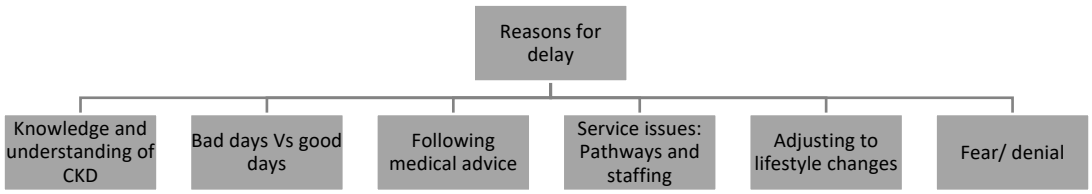
All groups reported covid-19 impacted on pre-dialysis support. Patients lacked their usual support networks, relatives were unable to attend appointments and groups/home visits were not offered. Staff also noted some patients were fearful of attending hospital appointments.

Reasons for delay:

The above led to some patients delaying dialysis. Common subthemes were identified among all groups (*see figure 3*).

Figure 3:

Summary of subthemes identified for 'reasons for delay'.



Knowledge and understanding of CKD

Some patients reported lack of knowledge of CKD, leading to uncertainty/being unaware of the need for dialysis, and typically only detecting a health decline when receiving medical results or comparing present to past functioning. Others acknowledged existing knowledge could inform their beliefs about dialysis, both positively and negatively.

Bad Vs good days

All groups noted that patients could have good days when they felt OK, and bad days when symptoms flared up. It was therefore hard on a good day to accept they might need dialysis. Others experienced few symptoms, so were unaware of their poor kidney function and unlikely to want to start dialysis.

Following medical advice

All groups reported some patients engaged in dialysis to follow medical advice, take control of their condition, and relieve symptoms. Some patients however used their own knowledge or resources to adjust to needing dialysis or due to treatment beliefs wished to try alternative strategies first.

Service issues: Pathways and staffing

Staff acknowledged issues in the referral pathway with a lack of/late referrals for some groups who require a tailored pathway (e.g. young adults) and difficulty arranging cover for staff holiday/sickness.

Adjusting to lifestyle changes

Staff and patients acknowledged some wished to delay dialysis due to prioritising other commitments (e.g. holidays, other health conditions).

Fear/ denial

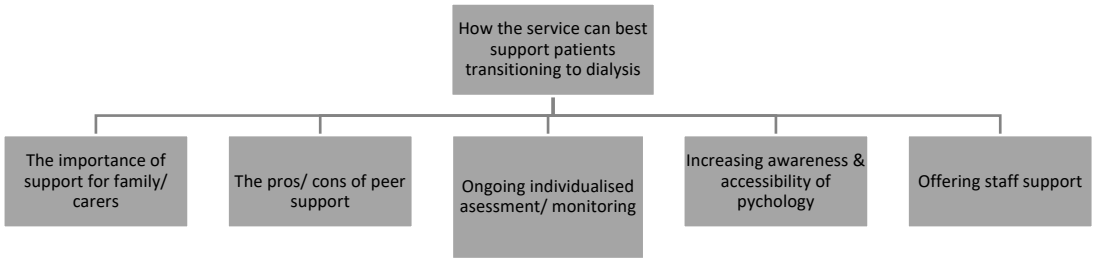
Staff identified denial of being unwell and needing dialysis, alongside treatment fears (e.g. dialysis being painful) as barriers to engagement with dialysis.

How the service can best support patients transitioning to dialysis:

Following their experiences, all groups identified recommendations for improving support (*see figure 4*).

Figure 4:

Summary of subthemes identified for 'how the service can best support patients transitioning to dialysis'



The importance of support for family/carers

Patients highlighted the importance of supporting families including processing family stories about CKD, recognition of different coping styles and the condition's heritability (where this is a factor). Families noted difficulty navigating role changes, expectations and impact on family life, with a need for mutual support in adjusting to caring responsibilities. Carers noted a session on adjusting to life post-dialysis would be helpful. Staff felt carers required a separate space to normalise their experiences but also identified the value of family providing information and support at appointments.

The pros/cons of peer support

Some patients wanted to meet others with CKD, whilst others were unsure this would be helpful. Staff perceived value in peer support when patients were matched on characteristics e.g. age and symptom profile. They acknowledged past therapeutic

groups had not always been well attended, nor reached those needing it most. Staff noted however the benefit of sharing patient perspectives at seminars, or potentially online which could then be shared more widely. They expressed how previously patients found offering their perspective mutually beneficial.

Ongoing individualised assessment/ monitoring

All groups acknowledged the importance of ongoing individualised assessment and monitoring to facilitate opportunities to discuss dialysis concerns. Staff noted the importance of picking up on mood difficulties in clinic and of normalising difficult emotions. Patients further highlighted the importance of having space to discuss the emotional aspects of dialysis as, for some, past appointments had focused more on physical aspects. Some patients felt staff had differing professional roles or preferred their own ways of coping, therefore emotional aspects did not always feel relevant to discuss within the LCC context. Follow up appointments were an opportunity for staff to provide information (including showing people the dialysis unit, offering home visits or answering questions). Staff queried whether a webpage introducing patient perspectives, the staff team and offering dialysis information might be helpful.

Increasing awareness and accessibility of psychology

All groups reported increased awareness of psychology was important. Some patients and carers were unaware psychological support was available while those that had accessed this found it beneficial. Some patients felt regular opportunities for follow up with psychology such as drop-in sessions might improve access for hard-to-reach groups or those at risk of developing emotional difficulties. Staff identified the

value of patients accessing psychological support, acknowledging there is still stigma around this for many people.

Offering staff support

Staff felt support in managing difficult conversations about mood/engaging in dialysis may be beneficial, particularly for patients not accessing psychology.

Table 5:

Summary of patient quotes for themes and subthemes

Subtheme	Quote
THEME 1: EXPERIENCES OF TRANSITIONING TO DIALYSIS	
Fear/denial	'you know- it's just one of those things you just don't know what's going to happen from one day to the next' #P2 'anxious that I will be able to deliver the care and support they deserve' #C8 'it's all fear of the unknown..once they've started dialysis that kind of disappears cause they're there' #S3
Adjusting to lifestyle changes	'So you have to be subject to..rituals, processes, time schedules, so your life becomes if not governed, but heavily influenced by.. the new scenario which is dialysis' #P6 'You can't just plan to go away for the weekend. And things like that. So.. all that will have to be in place, which is where the apprehension is' #P7 'Once the decision is made it is irreversible curtailment of freedom' #C8
Existing experiences of support	'I went to a seminar which I found really helpful..cause before I went for the seminar I wasn't too keen on peritoneal dialysis but at the seminar this lady.. showed us herself doing the dialysis and I thought gosh that looks good' #P5 'if.. one form of dialysis is.. not suitable for somebody who has a heart problem, then you have to say that… there's a certain..mental strain.. in rethinking everything that you think you know' #P4 'no one has actually sat us down and had a good chat' #C2
Covid-19 disruption	'I didn't have my husband with me then cause of the covid so..that was quite distressing for me' #P5

	‘Support is limited by the pandemic’ #C3
THEME 2: REASONS FOR DELAY	
Knowledge and understanding of CKD	‘my elder brother had already been on dialysis, so I had a reasonable knowledge of dialysis’ #P1 'if I hadn’t have had a blood test I wouldn’t have known I’d got a dodgy kidney’ #P3 ‘We have been given plenty of high-quality information and explanation’ #C3
Bad days vs good days	‘on the head side.. the body needs dialysis..the tail side of the coin..it’s actually just making that change to start that dialysis' #P1 ‘people just get used to the way they feel on a day-to-day basis…it's a gradual decline.. that that just becomes their new normal I think’ #S1 ‘I think that really is hard to come in and start using a machine when you don’t actually feel very unwell’ #S4
Following medical advice	‘if you’re ill in other ways you take the medicine don’t you, so it’s the same with dialysis, it’s a kind of medicine isn’t it’ #P3 ‘No he knows when the time comes that he will have dialysis’ #C2 ‘I'm thinking about somebody that I've seen recently..who's chosen not to start and not engage, because he doesn't feel he's tried everything himself..he feels that there’s changes he could make to his lifestyle, that might stave it off’ #S4
Service issues: Pathways and staffing	‘..looking how we can support one of those groups such as young adults, they don't tend to come through the low clearance clinic at the moment, so we don't give them the support from our perspective that they would otherwise have... to support that group of patients..maybe in a separate way altogether’ #S2 ‘where there'll be problems is if ..somebody is off sick..or annual leave’ #S2

Adjusting to lifestyle changes	'we've got quite a lot of young patients who have problems with families, and jobs and childcare and all of these issues..prevent people from starting' #S1
Fear/Denial	'the fear of it being painful or unpleasant when you're doing it' #S1' 'Almost denial that they are 'sick' or unwell especially if they were healthy to begin with' #S5 'Uh in my fantasyland, .. I don't think that I need absolutely anything' #P6
THEME 3: HOW THE SERVICE CAN BEST SUPPORT PATIENTS TRANSITIONING TO DIALYSIS	
The importance of support for family/ carers	'One thing that I always thought.. that'd be good.. a couple of sessions where you could listen to the family' #P6 'my wife still expects me to be the male of..,the head of..and also the leader of the family' #P1 'if they (carers) could see that other people were seeing..similar things.. I could tell there was a lot of guilt..and it..helped .. to..express..that its normal to feel.. how they were feeling' #S2
The pros/cons of peer support	'wouldn't mind..maybe meeting more people .. with the condition..(but) if you meet more people going through it you could..end up.. feeling quite depressed really' #P5 'they get to talk to people who are in the same situation, which is really helpful.. like.. I'm not alone in this' #S6 'when she [previous patient] spoke at it [seminar] it was fantastic .. because .. if I'd have said what she was trying to say nobody would have listened but because she was saying it everybody listened' #S2
Ongoing individualised assessment/monitoring	'For me, what is really useful? The fact that you have different point of contact.. so then I got different people.. that you can access to and ask questions if something comes up suddenly. Also I think the element of feeling that you are not alone, that is extremely useful' #P6

	'often, we would show patients around the dialysis unit.. they've even visited their homes' #S2 '(its) always been about the practicalities of dialysis rather than the emotional side of it... really it's about recognition isn't it, that there's an emotional element to you know, otherwise, medical things' #P4
Increasing awareness and accessibility of psychology	'Every so often to actually check that the person's OK.. not everybody is willing to talk about their feelings, so sometimes that persistence and for them people to know that there actually.. is that support..if.. people are aware that support is there, they're more likely to use it or even if they don't use it, it would be that..psychological..confidence to say OK if I do need that help, it's there' #P7 'for some patients, they're very delightful to be referred to a psychologist.. but there's .. some resistance to that as well because people say I don't need that- I'm not mad, there is a stigma'#S1 'a webpage with information and links, I mean..should we as a service do more like that. here's a video of the psychologist, its normal to feel this and here's a link to a mindfulness exercise' #S4
Offering staff support	'I can think of a few patients who we feel like they really need input but..they will be the ones who will not engage.. they will have like a 'why did it happen to me.' but then they're the ones who would say..if we refer you to somebody (psychologist) would you talk to them, no' #S6

Key: | Abbreviations: CKD - Chronic Kidney Disease

| # number - participant number, # letter - participant group (P - patient, C - carer, S - staff)

Discussion:

Mood & QoL

55% of patients attending clinic experienced depressive symptoms and 28% anxiety symptoms; highlighting a need for ongoing psychological support. This is similar to past research (Abdel-Kader et al., 2009; Shafi & Shafi, 2017), but higher than some estimates. which may be due to current patients having experienced CKD for longer, which is associated with higher depression prevalence (Palmer et al., 2013).

Patients reported similar QoL to prior research (Peipert et al., 2018). Given the comparison sample being on dialysis, this may suggest QoL remains similar across illness duration. However, QoL was significantly more affected by symptoms suggesting potential for symptom-focused interventions. A biomarker (eg Glomerular Filtration Rate (GFR) which indicates the kidney's filtration rate) may have supplemented interpretation of symptom severity here.

Illness perceptions

The current sample experienced higher perceived chronicity, emotional impact, and consequences of CKD than a previous sample (Meuleman et al., 2015). This may in part be explained by more younger people and women partaking in the current study as significant age/sex differences were found with these groups scoring higher on perceived consequences and control of CKD. This highlights the need for psychological support with emotional adjustment to CKD in UK settings such as the current one.

Patients had better understanding and higher perceived personal and treatment control over CKD than in other research (Meuleman et al., 2015). This may in part reflect the current clinic offering educational sessions early on post-referral to the clinic. High perceived self-efficacy managing symptoms may help explain the finding that mood difficulties did not appear to lead to high rates of missed appointments/hospitalisations here (Chan et al., 2011; Chan et al., 2014). This is promising for engagement in psychological support and treatment. However, ongoing MDT assessment is crucial as illness perceptions may change across the course of the illness (Clarke et al., 2016). Longitudinal studies would thus be beneficial.

Past research has suggested that, in line with the self-regulatory model of illness perceptions (Leventhal et al., 1997), emotion-focused coping may lead to more variation in treatment adherence (O'Connor et al., 2008). This did not appear the case however for the current sample, as despite perceiving a higher emotional impact of living with CKD than previous samples (Meuleman et al., 2015) this did not appear to influence treatment adherence as rates of missed appointments and hospitalisations were low. Qualitatively, cognitive illness perceptions and subsequent coping behaviours here appeared to influence adherence as patients noted their prior knowledge of CKD impacted their decision to delay dialysis. Further research could explore whether the model predicts engagement with specific parts of dialysis treatment (O'Connor et al., 2008).

Pre-dialysis support experiences and recommendations

Missed appointments and hospitalisations were generally low. Common experiences across all groups included fear/ denial of dialysis and difficulty adjusting to the lifestyle changes of dialysis. Service support addressing patient fears, preparing for dialysis, and supporting emotional adjustment to CKD may therefore be beneficial.

For some patients delaying dialysis was due to lack of knowledge about CKD, being torn by the experience of good and bad symptom days and at times engaging in treatment to just 'follow medical advice'. This supports previous professionals' views that lacking time to discuss dialysis misconceptions may lead to treatment delay (Grubbs et al., 2017). It is important to explore barriers with patients to improve knowledge and collaboratively decide when to start dialysis.

All groups acknowledged the importance of family support and pros/cons of peer support. Systemic approaches and groups may therefore be beneficial for some. Patients valued a coherent MDT approach and tailored information provision, suggesting this is important to continue.

Research supports offering psychological therapies such as CBT for depression in CKD indicating this as lower risk than medication (Gregg and Hedayati, 2020; Zalai et al., 2012). Symptom-management focused interventions such as stress management/relaxation techniques may also be efficacious (Jhamb and Steel, 2021; Picariello et al., 2017), particularly as in the current study patients scored higher on the perceived impact of symptoms subscale of the KDQoL than in previous samples (Peipert et al., 2018). Psychological approaches like ACT, may support adjustment to

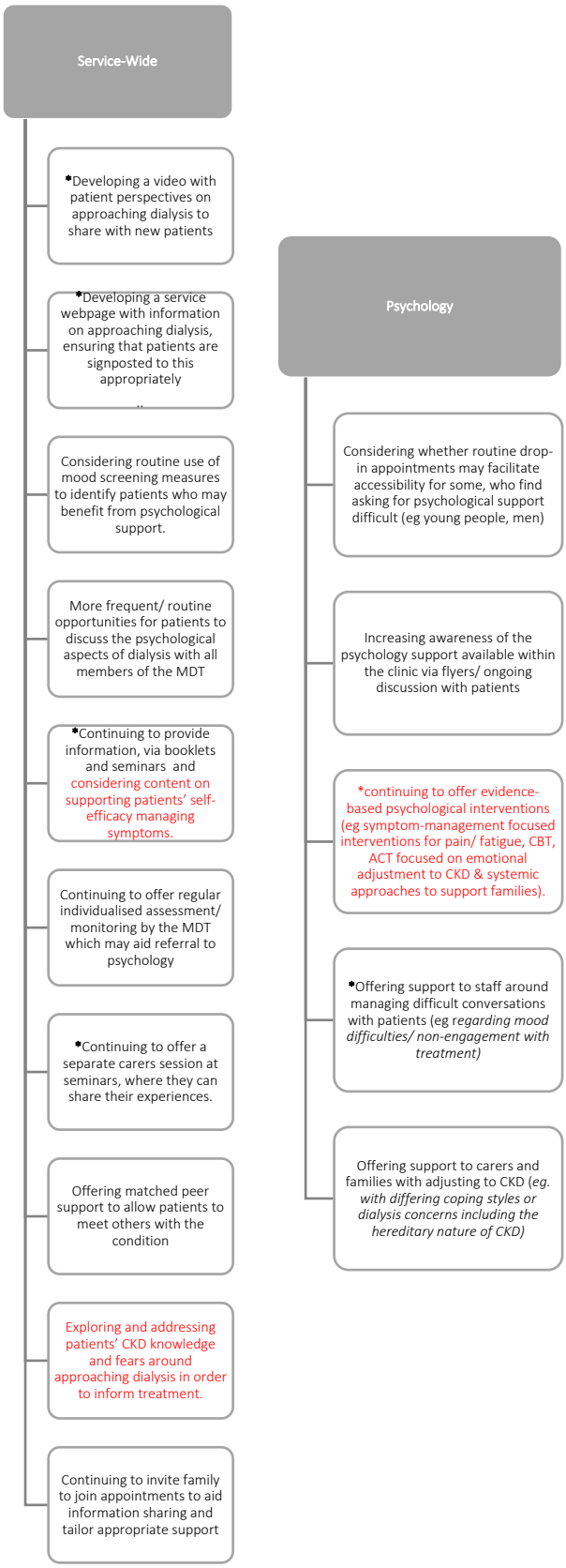
chronic physical conditions (Brassington et al., 2016). This may be beneficial as all groups noted difficulties accepting the need for and impact of dialysis could lead to treatment delays. Given family support was highlighted there may be a need for systemic approaches. Future studies exploring the mechanisms behind change within these treatments in renal settings are indicated. In sum, evidence-based approaches for psychological support include CBT, ACT, symptom-reduction based, and systemic-focused interventions.

Service feedback

Findings will be shared with the service via a verbal presentation in the team meeting (which all staff are invited to attend (including the renal nurses and doctors)). An electronic copy of the slides will also be circulated afterwards to the team. A summary of the results will be shared by email with patients who expressed an interest in this. See *figure 5* for recommendations given to the service for consideration in order to inform service improvement.

Figure 5:

Summary of Recommendations for Consideration for Service Improvement



Key: | Abbreviations - CBT - Cognitive Behavioural Therapy, ACT - Acceptance and Commitment Therapy, CKD - Chronic Kidney Disease, MDT - Multidisciplinary Team | Red text - recommendations from existing literature based on the findings. | * - Recommendations viewed by the psychologist as feasible to consider implementing

Strengths/limitations:

-To the authors' knowledge, this study was the first to qualitatively explore reasons for difficulty transitioning to dialysis among UK pre-dialysis patients, using interviews to understand patients' experiences and then to make recommendations for potential psychological intervention.

-Opportunistic sampling was used leading to potential for a self-selecting bias, representing those more likely to attend appointments and less likely to be experiencing mood/QoL difficulties. This is likely reflected in the low rate of missed appointments/ hospitalisations, however as 55% of patients acknowledged experiencing depression and patients generally perceived a higher emotional impact of CKD than previous samples, it is likely some of those experiencing difficulties were captured.

-It was beneficial to compare KDQoL and IPQ-R scores to comparison samples to aid interpretation of the scores and the generalisability of the conclusions from the sample. Nevertheless comparison to other samples may have limitations. For example, the KDQoL scores being compared to those of a dialysis sample, who were at a later stage of treatment, and both samples were from non-UK countries, where differing healthcare systems exist. As such this might complicate interpretation of our scores and potentially introduce some unknown biases'

-A low sample size is acknowledged, alongside it not being possible to ascertain the completion rate (given staff handing out measures) limiting ability to draw

conclusions about the representativeness of the sample. However the use of mixed methods involving carer, staff and patient feedback across multiple clinics is likely to aid generalisability.

Further research would benefit from exploration with a larger sample (representing a wider demographic) as 86% of the sample were from a white ethnic background and sex and age differences were noted in perceived control over and consequences of the condition. There is increasing recognition of the need to adapt psychological intervention to meet the needs of wider demographic groups, therefore further analysis is required. In addition, evaluation after implementing the above recommendations is important to explore their feasibility and effectiveness in delivering optimal patient outcomes, not least in a longitudinal study.

In conclusion, this study indicates that psychological intervention is likely to be important for those with CKD, with resulting benefits for QoL, adherence and prognosis. Recommendations are provided here, informed by patient, staff, and carer perspectives. The study highlights the value of involving multiple stakeholders in understanding a psychological issue in a renal service and laying the foundations for the development of psychological intervention(s) to improve patient experience and health.

(See appendix F for a lay summary of the service improvement project, appendix K for the participant information sheets and consent forms, and appendix M for author guidelines for the target journal (Journal of Health Psychology)).

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Project: Theoretically Driven Research Project

Title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD

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

Internal Supervisors: Prof Paul Salkovskis

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Journal: British Journal of Clinical Psychology. This journal was chosen because it publishes original research including on the assessment and treatment of a range of psychological disorders.

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Abstract:

Introduction: Despite readily available and effective treatments for Obsessive Compulsive Disorder (OCD) there are still barriers to treatment readiness, engagement and outcomes. Past studies indicate self-compassion correlates with OCD symptom severity. The current study therefore explored whether those low v high in self-compassion differed on readiness to engage in treatment and treatment outcomes. It also assessed whether self-compassion predicted treatment readiness and outcomes above other factors such as symptom severity.

Method: Eighty patients were recruited from the OCD treatment waiting list in three Improving Access to Psychological Therapies (IAPT) services. They completed study questionnaires on their obsessive beliefs (OBQ), treatment readiness (TAQ) and self-compassion (SCS). IAPT routine measures were also collated on low mood (PHQ-9), anxiety (GAD-7) and OCD (OCI) symptom severity; subscale scores were not available. A median split was used to create 2 groups (those low in self-compassion v high in self-compassion). The 2 groups were compared on readiness to engage in treatment. A hierarchical regression examined whether self-compassion predicted treatment readiness above initial low mood/ anxiety/ OCD symptom severity.

Results: Those low in self-compassion rated themselves as significantly less ready to engage in treatment (with greater concerns about starting treatment). They also experienced significantly higher symptom severity and obsessive beliefs. Self-compassion significantly predicted readiness to engage in treatment, even after accounting for symptom severity on the OCI, PHQ-9 and GAD-7. It explained 6.1% additional variance in treatment readiness.

Discussion: Future research is needed to investigate additional factors which might contribute to explaining variance in treatment readiness and explore whether baseline low self-compassion/ treatment readiness predicts later treatment outcomes.

Introduction:

Obsessive-compulsive disorder (OCD) is characterised in the DSM-5 (APA, 2013) by the presence of i) obsessions (i.e., intrusive and persistent thoughts, images or urges that cause distress, that the individual attempts to neutralise or suppress) and/or ii) compulsions, which are repetitive/ ritualistic behaviours the individual feels driven to perform, aimed at reducing distress or preventing negative outcomes. Specific OCD symptom dimensions have been identified for contamination, symmetry, unacceptable thoughts, and responsibility of harm with associated compulsions including cleaning, ordering, mental rituals, and checking (Wheaton et al., 2010). OCD affects approximately 1.1% of the UK population (Torres et al., 2006). It is often time-consuming, causing significant distress, impacting individuals' functioning and quality of life (QoL) and can be longstanding without appropriate treatment. There is need to provide suitable treatment in a timely way. The current study therefore explores the role of self-compassion in readiness to engage in treatment and treatment outcomes to see whether this may provide focus for tailoring intervention to meet the needs of more individuals with OCD.

Theory underpinning treatment

Early behavioural models (Roper & Rachman, 1976) suggested a neutral event (e.g., an intrusive thought) became associated with fear through conditioning when it was repeatedly presented together with a distressing event, with this fear leading to

escape/avoidance behaviours to reduce the anxiety (such as compulsions/ rituals). Several experiments evidenced that obsessions increased and compulsions subsequently reduced distress (Rachman, De Silva & Roper, 1976; Roper, Rachman & Hodgson, 1973) in the short term, but that distress increased as a result. By contrast, refraining from the compulsion reduced distress longer-term. These findings linked with early behavioral interventions focused on Exposure with Response Prevention (ERP) where individuals were gradually exposed to their feared situation(s) (Rachman, Marks & Hodgson, 1973; Rachman, Hodgson & Marks, 1971).

The cognitive model of OCD (Salkovskis et al., 1998) later proposed it is the interpretation of intrusive thoughts that maintains OCD e.g., the individual misinterpreting that they are responsible for preventing harm, leading to anxiety/ low mood, attention biases, engaging in neutralizing behaviours (e.g., rituals/ reassurance seeking) and safety strategies (e.g., avoidance/thought suppression), which reinforce the initial appraisals. Misinterpretations may relate to inflated responsibility, overestimated threat, perfectionism, intolerance of uncertainty, and the importance/ control of thoughts (Obsessive Compulsive Cognitions Working Group (CCWG), 2005). This model has obtained significant support (Wheaton et al., 2010; Abramowitz et al., 2007); however, research suggests that variance in OCD symptom severity is not fully explained by level of endorsement of obsessional beliefs, suggesting other factors may also contribute to maintaining OCD symptoms, warranting future exploration (Abramowitz, Lackey & Wheaton., 2009).

National Institute for Health and Care Excellence (NICE) guidelines (2005) recommend offering selective serotonin reuptake inhibitors (SSRIs) or psychological therapies such as cognitive behavioural therapy (CBT) for adults with OCD. CBT focuses on ERP (with individuals gradually facing their fears without conducting compulsions) and cognitive therapy challenging their misappraisals regarding harm (NICE, 2005; Salkovskis, 1985, 1996). Previous meta-analyses provide support for these approaches, indicating large effect sizes compared to controls (Ost et al., 2015; Rosa-Alcazar et al., 2008). However approximately 4-15% of patients refuse treatment initially, with a mean dropout rate of 15% (Ost et al., 2015; Ong et al., 2016). Some studies estimate dropout rates up to 25-30% for ERP (Abramowitz, Taylor & McKay., 2009). This appears more pronounced for ERP which is known to be more challenging as patients engage in anxiety-provoking situations. Difficulties with treatment engagement typically lead to poorer outcomes (Leeuwerik et al., 2019; McKay et al., 2015) with ongoing variability in recovery rates (approximately 43-58%) for CBT (Kyrios et al., 2015; Ost et al., 2015). There is therefore need to explore factors that contribute to low readiness to engage in treatment and poorer treatment outcomes in order to tailor effective treatments.

Readiness to engage

Whilst effective treatments are available, many people may delay help-seeking or do not seek support for OCD, often waiting until symptoms are severe and significantly impacting daily life with one study suggesting only 40% of adults with OCD had received treatment (Goodwin et al., 2002). Individuals' readiness to engage in treatment is likely due to multiple factors. Reasons for help-seeking delay may include significant shame about difficulties, particularly if experiencing severe or

'unacceptable thought' (eg sexual/ violent/ religious) obsessions (Glazier et al., 2015). Marques et al. (2010) similarly found that stigma and shame were barriers to accessing treatment with worry what others may think, beliefs that treatment may not work/ take too much time and practical concerns about where to access treatment. Further barriers included internal factors (eg. reluctance to accept there was a problem/ feeling symptoms weren't bad enough/ they didn't deserve treatment), concerns about what treatment involved (eg. whether they could tolerate this), stigma (being ashamed to tell doctors about symptoms) and lack of knowledge about what symptoms were (Robinson, Rose & Salkovskis, 2017). There are therefore significant barriers to accessing treatment promptly.

Early readiness to engage in treatment may affect subsequent treatment adherence and outcomes. Individuals may have concerns about psychological therapy (eg. that it may increase symptoms, will fail, or have negative consequences) (Rowa et al., 2014) which impact treatment adherence and outcomes in CBT for OCD (Keeley et al., 2008; Leeuwerik, 2019). Past findings are mixed however with some suggesting readiness to engage (alongside the therapeutic alliance, specific obsessional beliefs, and depression) predicts adherence to CBT for OCD (Dowling et al., 2016; Maher et al., 2012) and others suggesting it has no significant link to treatment outcome (indicated by symptom severity) (Monaghan et al., 2015; Pinto et al., 2007). Boswell et al. (2012) proposes that readiness to engage may moderate the relationship between initial symptom severity and treatment outcome, with those more ready for treatment and experiencing greater symptom severity showing greater change during treatment. Prior studies have typically been limited to residential settings and therefore further research is needed to explore the generalisability of

these findings among community samples. In the present study, a measure of readiness to engage (the Treatment Ambivalence Questionnaire (TAQ)) will be used. This measure has been shown to assess treatment concerns in individuals awaiting psychological therapy for anxiety disorders (with 3 key domains measured: the personal consequences of treatment, adverse reactions to treatment and the inconvenience of treatment) (Rowa et al., 2014). Rowa et al found some of these concerns were more prominent among people with OCD than conditions such as panic and may be helpful to predict future treatment acceptance, retention and drop out.

Self-compassion

Self-compassion is defined as comprising i.) self-kindness in being understanding towards oneself in instances of pain/ failure, ii.) common humanity in perceiving one's experiences as part of the larger human experience rather than isolated to them, and iii.) mindfulness in holding painful thoughts and feelings in balanced awareness without over-identifying with these (Neff, 2003b). Low self-compassion is commonly seen among people with psychological difficulties, including anxiety disorders, depression, and Post-Traumatic Stress Disorder (PTSD) with a strong relationship between compassion and psychopathology (MacBeth & Gumley, 2012). Specifically Wetterneck et al. (2013) found a negative correlation between self-compassion and OCD severity with patients with moderate-OCD reporting below average levels of self-compassion. They hypothesized low self-compassion may link with difficulties viewing experiences with self-kindness and being able to cope with thoughts without over-focusing on them and therefore relate to higher OCD symptom severity. Systematic reviews highlight that studies are often

unclear of the causality of this link (Athanasakou et al., 2020). In sum lower self-compassion is linked with higher severity of mental health difficulties, including anxiety disorders.

There may be several ways in which low self-compassion could link to barriers to readiness to commence treatment for OCD. (1) Low self-compassion may link to experiencing high levels of shame regarding obsessional beliefs about the controllability of thoughts and concern about their meaning (Weingarden & Renshaw, 2015; Shapiro & Steward, 2011). Furthermore individuals may perceive others do not experience such difficulties. Therefore individuals may have significant concerns about sharing their difficulties with healthcare professionals due to shame/ fear of judgement. (2) Treatment beliefs regarding symptoms not being bad enough or being undeserving of treatment (Robinson et al., 2017) may be more prevalent for those with low self-compassion as they may find it difficult to be understanding (rather than judging/ disapproving) towards difficulties or respond to these compassionately (eg by help-seeking). (3) Lastly concerns about what treatment involves and whether they can tolerate this may be greater if low in self-compassion due to difficulties being mindful of difficult emotions, such as those raised in treatment, without becoming over-focused on these.

Low self-compassion may also lead to barriers in treatment engagement and subsequent treatment outcomes: (1) If there are difficulties during treatment people with low self-compassion may see these as a personal failure, become self-critical and discouraged/ disengage from treatment before completion. (2) Where individuals with low self-compassion have difficulties tolerating distress or being mindful of initial

urges before deciding how to respond, this may make engaging in ERP more difficult without promptly engaging in compulsions. Low self-compassion may therefore pose a barrier to readiness to engage in treatment due to worries about sharing difficulties with professionals, treatment beliefs regarding being undeserving of treatment or treatment being intolerable and becoming self-critical about difficulties during assessment and treatment in CBT.

Treatment outcomes

Two recent studies showed self-compassion was significantly negatively correlated with OCD symptom severity, with those low in self-compassion experiencing more severe OCD symptoms. Eichholz et al. (2020) found among 90 inpatients that OCD symptom severity and obsessive beliefs negatively correlated with self-compassion. In addition, Leeuwerik et al. (2020) found among 1871 patients in National Health Service (NHS) Improving Access to Psychological Therapies (IAPT) services that those with OCD had lower self-compassion rates than those with depression/ anxiety or healthy controls and a medium-large association between self-compassion and OCD symptoms. However, methodological issues (e.g., using single time-point data) limit the ability to draw clear conclusions about the link between self-compassion and OCD symptom severity over time and potential mediators (e.g., obsessive beliefs). As there is a link between self-compassion and OCD severity there is need to explore whether low self-compassion pre-treatment may predict poorer treatment outcomes (indicated by symptom severity).

Study aims

In sum a candidate for the link between OCD symptom severity and self-compassion is readiness to engage in treatment. It is also possible that self-compassion may predict OCD treatment outcome longitudinally. The present study was therefore designed to investigate whether level of self-compassion pre-treatment was negatively associated with readiness to engage in treatment in relation to other variables. As a secondary aim, longitudinal data was planned to be used to ascertain whether level of self-compassion was associated with treatment outcome (as measured by OCI severity) once initial severity has been accounted for. The study was conducted among adults with OCD accessing treatment via IAPT services to consider whether adaptations to CBT or alternative stand-alone/ augmentation treatments may improve outcomes.

Research Questions

Is self-compassion negatively associated with readiness to engage in treatment for OCD?

Do baseline rates of self-compassion predict treatment outcomes (i.e., OCD symptom severity post-treatment)?

Method:

Design

For the main study question a cross-sectional independent groups design was used, with level of self-compassion as an independent variable and treatment readiness as the dependent variable, to investigate whether self-compassion (measured by the SCS) affected readiness to engage in treatment (measured by the

TAQ). Group differences between those low and high in self-compassion were also explored regarding mood symptom severity measures and obsessive belief subtypes (which may further explain variance in treatment readiness). A longitudinal repeated measured design was used with measures taken pre- and post-treatment.

Patient and Public Involvement

Individuals (*N*=3) with lived experience of OCD were involved in reviewing the study design. They shaped the wording and formatting of study materials, number of measures to aid engagement, and range of options for questionnaire completion to aid accessibility.

Participants

Participants were adults assessed as experiencing OCD (by the assessing IAPT clinician and an OCI score within the IAPT clinical range ≥40) who were treatment-seeking through IAPT services in Berkshire, Buckinghamshire, and Oxfordshire. *n*=4 participants did not score in this clinical range however as IAPT do not include OCI subscales and for some groups (eg people who ruminate) the total score does not fully reflect the clinical picture; these participants were included. Adults were included if over 18, assessed and starting treatment in IAPT and with OCD labelled as their primary presenting problem. Exclusion criteria were those who had declined or started treatment prior to the study or those receiving treatment where OCD was not the primary target.

Setting

In the UK IAPT services typically offer treatment in the first instance for OCD with low intensity guided self-help (via telephone/online/face to face) or high intensity intervention via CBT groups or 1:1 sessions.

Power

G-power was used to calculate optimal sample size. There was no existing research paper directly exploring these variables to calculate effect size from however when considering wider research on self-compassion and treatment readiness (eg Maher et al., 2012) a medium effect size was estimated. When input to G power (with power at 0.8, alpha level at 0.05 and effect size at f = 0.25) an estimated sample size of 86 was found. For the longitudinal part of the study approximately 50 participants were estimated to be needed based on 4 predictors (rule of 10 participants per variable, Harrell, 2001) and a potential dropout rate of 20%.

Measures

The following measures are routinely collected in IAPT pre and post treatment:

-*Patient Health Questionnaire-9 (PHQ-9)* (Kroenke et al., 2001)- this is a 9-item questionnaire used to assess depression severity.

-*Generalised Anxiety Disorder-7 (GAD-7)* (Spitzer et al., 2006)- this 7-item questionnaire is used to assess symptoms of generalized anxiety.

Both measures are rated on a 4-point scale (from 0 [not at all] – 3 [nearly every day]) and have been shown to be valid and reliable screening tools within primary care (PHQ-9 ($\alpha = 0.89$) (Kroenke et al., 2001), GAD-7 ($\alpha = .92$) (Spitzer et al., 2006)).

-*Obsessive-Compulsive Inventory (OCI)* (Foa et al., 1998)– this measure assesses OCD symptom severity. It has 42 items rated on a 4-point scale indicating level of distress (from 0 (not at all) – 4 (extremely)). It includes 7 subscales for washing, checking, doubting, ordering, obsessions, hoarding and neutralising which are not available from the IAPT database. The measure has shown to be valid and reliable (α = .92-.93 (Foa et al., 1998)). As individual items are not accessible in the IAPT database, it was not possible to determine the internal consistency for these measures in the present sample.

The following additional measures were collected for the current study:

-*Obsessive Beliefs Questionnaire (OBQ-20)* (Moulding et al., 2011)- this 20-item questionnaire is a shortened form of the original OBQ-87. Items are rated on a 7-point scale (from 1 (disagree very much) – 7 (agree very much). It assesses four subscales of obsessive beliefs including i. overestimation of threat, ii. Inflated responsibility, iii. over-importance of controlling thoughts and iv. perfectionism/ intolerance of uncertainty. The 20-item measure has been shown to be reliable and valid within clinical samples (α = .85-.86) (Fergus & Carmin, 2014). In the current sample the subscales: threat (α = .75), perfectionism/ intolerance of uncertainty (α = .83), inflated responsibility (α = .89) and importance/ control of thoughts (α = .82) and overall scale were reliable (α = .91). This measure was included to assess obsessive belief subtypes to explore whether these differed between those low and high in self-compassion.

-*Treatment Ambivalence Questionnaire (TAQ)* (Rowa et al., 2014)- this 26-item measure assesses concerns of commencing psychological treatment for anxiety-based disorders. Items are scored from 0 (strongly disagree) to 7 (strongly agree). The three

subscales have differing numbers of items so total subscale scores are as follows: fear of personal consequences (T=91), fear of negative/ adverse reactions (T=56),and concerns about inconvenience (T=35). It has been shown to have good internal consistency (α = .80-.90) (Rowa et al., 2014). In the current sample the fear of personal consequences (α = .89), fear of negative/adverse reactions (α = .89) and concerns about inconvenience subscales (α = .66) and total scale (α = .92) demonstrated reliability.

-*Self-compassion Scale (SCS)* (Neff, 2003a)– this 26-item measure is used to assess self-compassion using a 5-point scale (from 1 (almost never) – 5 (almost always)). It comprises 6 subscales: self-kindness, self-judgment, common humanity, isolation, mindfulness and over-identification. The measure and subscales have been shown to be reliable and valid (α =.92 (Neff, 2003a). In the current sample the self-kindness subscale (α = .84), self-judgement (α = .71), common humanity (α = .73), isolation (α = .63), mindfulness (α = .80), overidentification (α = .62), and total scale (α = .85) demonstrated reliability.

Demographic characteristics (e.g., ethnicity, sex, age etc.) were collated alongside clinical data (including treatment type/ duration, dropout rates, condition duration and prior treatment) from the participant's clinical notes.

Procedure

IAPT services asked all eligible patients referred to the service and on the waiting list for OCD treatment post-assessment whether they were willing to be contacted by the research team. All eligible patients added to the waiting list during the study duration (November 2021-May 2022) were included. If they consented, they were sent the study information sheet (*see appendix O)* and written informed consent

sought by the research team. The IAPT clinician collected routine measures as is standard procedure (PHQ-9, GAD-7, OCI) pre- and post- treatment. The research team collected the additional measures (OBQ, TAQ, SCS) via an online survey on Qualtrics survey software, postal/ email questionnaire or by phone also pre- and post-treatment. Confidentiality was maintained and scores on the additional measures were not shared with the individual's IAPT clinician so that treatment was not affected in any way. The study was approved by NHS ethics (Preston Research Ethics Committee, IRAS: 289268) and sponsored by Oxford University Clinical Trials and Research Governance (CTRG) (*see appendix N*).

Data Analytic Plan

A mixed model ANOVA was used to compare readiness to engage scores (on the TAQ subscales) between the two groups (those high v low in self-compassion). Participants were assigned to 2 groups using an enhanced median split (i.e. divided at the median score plus or minus the standard error of measurement for the mean total score) based on their level of self-compassion. Group 1 were those low in self-compassion, group 2 were high in self-compassion. Demographic and descriptive factors were examined between these groups using t-tests, ANOVA (or chi square for nominal data). Hierarchical regression was used to determine the amount of variance in treatment readiness explained by self-compassion, above symptom severity measures (OCI, PHQ-9, GAD-7).

Hierarchical multiple linear regression was originally planned to determine predictors of treatment outcome (indicated by OCD severity on the OCI). The following variables were planned to be entered in sequence: baseline OCD symptom

severity; baseline self-compassion (SCS); treatment type (step 2, 3); readiness to engage (TAQ).

Results:

Sample demographics and characteristics

Eighty participants took part in the study (23.3% response rate) (*see figure 1*). The sample reflected more women (*n*=58, 72.5%) than men (*n*=22, 27.5%), however a large age range was captured from 18-71 years (*M*=32.05, *SD*= 12.51) (*see table 1*). The majority of people were from a White British background (*n*= 69, 87.3%). There was missing data regarding OCD duration and prior treatment however the majority had experienced OCD for 1-5 years (*n*=33, 47.1%) and received past treatment (*n*=56, 76.7%). It was often unspecified whether past treatment had focused on OCD.

Figure 1:

Participant flow diagram, outlining the number of participants included/excluded at each stage of the recruitment process

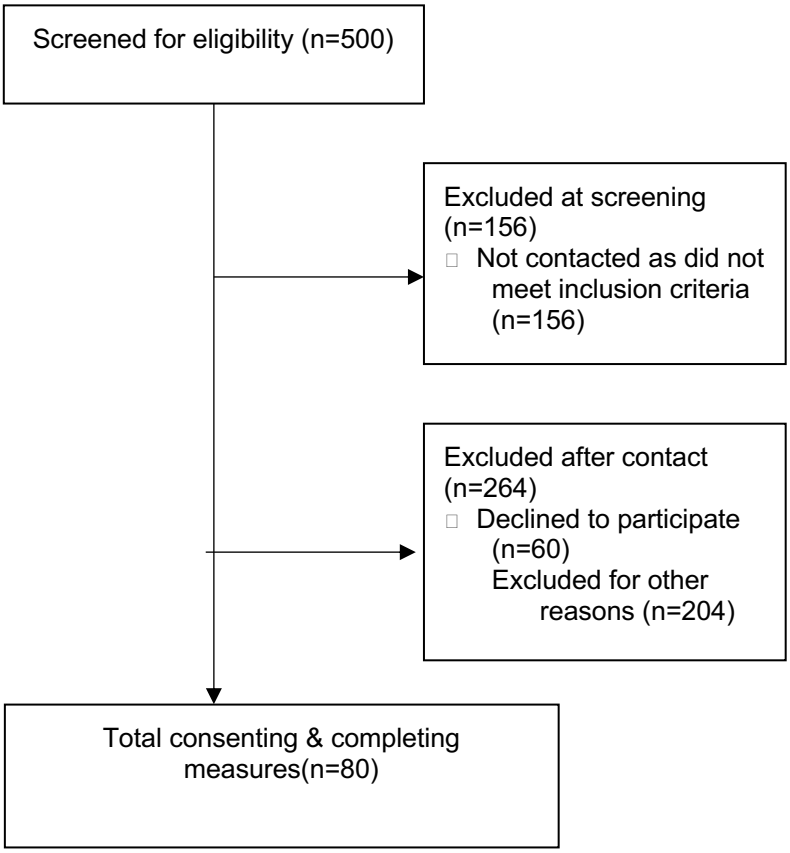


Table 1:

Demographic and descriptive data in the total sample and between the two groups

	Low self-compassion (*n*=37)		**High self-compassion (*n*=37)**		**Total (*N*=80)**	
	N	%	N	%	N	%
Age	M=32.00, SD=12.17		M=32.11 SD= 13.39		M=32.05 SD=12.51	
Sex						
Male	8	21.6	14	37.8	22	27.5
Female	29	78.4	23	62.2	58	72.5
Ethnicity						
Asian/ Asian British	2	5.5			2	2.5
Black/ Black British- Caribbean	1	2.8			1	1.3
Other Ethnic	1	2.8			1	1.3
White British	30	83.3	31	83.8	69	87.3
White Other	2	5.5	6	16.2	6	7.6
Duration of OCD **(years)**						
<1	2	6.1	2	6.1	4	5.7
1-5	14	42.4	19	57.6	33	47.1
6-10	6	18.2	3	9.1	10	14.3
11-15	1	3.0	1	3.0	4	5.7
16-20	1	3.0			1	1.4
<20	5	15.2	4	12.1	10	14.3
'Years' not specified	4	12.1	4	12.1	8	11.4
Past treatment						
Yes	27	84.4	23	65.7	56	76.7
No	5	15.6	12	34.2	17	23.3
Treatment types						
IAPT	10	37.0	10	43.5	21	37.5
IAPT + other treatment	2	7.4	3	13.0	5	8.9
Private	2	7.4	1	4.3	3	5.4
Not specified/ other	4	14.8	6	26.1	13	23.2
University counselling	5	18.5	2	8.7	8	14.3
Counselling	2	7.4			3	5.4
AMHT	1	3.7			1	1.8
CAMHS	1	3.7	1	4.3	2	3.6

Key: | Abbreviations: M - Mean, SD - Standard Deviation, OCD - Obsessive-Compulsive Disorder, IAPT - Improving Access to Psychological Therapies, AMHT - Adult Mental Health Team, CAMHS - Child and Adolescent Mental Health Services.

| Numbers and Percentages represent the total number of participants for which data was available for each question so these may not add up to the total group size where small amounts of missing data exist.

| The total sample (*N*=80) includes 6 additional participants who were excluded from the self-compassion grouping due to the median split *(n*=5) and missing data (*n*=1).

| Due to small numbers of other ethnicities any ethnicity other than White British was grouped as 'Other' during analysis to allow sufficient group sizes.

Measures of psychopathology and other psychological variables

Mean PHQ-9 score was 11.63 (*SD*=5.77) and GAD-7 score 13.49 (*SD*= 4.59) indicating moderate levels of low mood and anxiety respectively. The OCI mean score was 82.08 (*SD*=28.40).

Assumptions were met for all t-test/ANOVA tests, regarding normal distribution, Levene's test being non-significant indicating equal variance between groups and no significant outliers being present. Mauchley's sphericity test was significant for the ANOVA models, so the Greenhouse-Geisser correction was used. For the regression analysis PP and homoscedasticity scatterplots were examined; both passing assumptions with a tolerance and VIF below 10 suggesting no evidence of multicollinearity.

An enhanced median split divided the sample into two groups based on their total mean self-compassion score; low (*n*=37) v high *(n*=37) self-compassion (*see table 2*). Five participants were excluded from analysis with a cut off of 2.18 (2.16-2.20 when accounting for plus or minus at least 2SD from the standard error (*SE*= .05)).

Table 2:

Descriptive data on the Self-Compassion Scale (SCS) total and subscales for the 2 groups (low v high self-compassion) and the total sample

	Low self-compassion (*n*=37)		**High self-compassion (*n*=37)**		**Total (*n*=79)**	
	M	SD	M	SD	M	SD
SCS total mean	1.77	.29	2.53	.27	2.15	.46
SCS self-kindness	1.82	.49	2.63	.78	2.22	.75
SCS self-judgment	1.57	.50	2.30	.69	1.93	.69
SCS common humanity	1.99	.67	2.82	.65	2.39	.77
SCS isolation	1.67	.46	2.30	.79	1.99	.71
SCS mindfulness	2.09	.67	3.03	.66	2.54	.80
SCS overidentification	1.47	.48	2.09	.74	1.78	.68

Key: | Abbreviations: M - Mean, SD - Standard Deviation, SCS - Self-Compassion Scale

| Mean scores are out of 5 (as per the SCS scale).

| N was based on the number of participants completing each measure so this may not add up to the total group N in all cases where small amounts of missing data exist.

| The total sample (*n*=79) includes 5 additional participants who were excluded from the self-compassion grouping.

A t-test found no significant difference between the low and high self-compassion groups on age ($t_{(72)} = -.03$, $p=.978$). Chi square tests further revealed no significant differences between both groups on gender ($X^2_{(1, N = 74)} = 2.33, p=.127$) or ethnicity ($X^2_{(2, N = 74)} = 1.54, p=.462$).

T-tests showed there was a significant difference between those low and high in self-compassion on the following mood questionnaires; there was a medium effect on the PHQ-9 ($t_{(70)} = 2.22, p = .030, d = .523$, 95% *CI* [.051,.992]), large effect on the GAD-7 ($t_{(70)} = 3.64, p < .001, d = .859$, 95% *CI* [.373, 1.340]) and medium effect on

the OCI ($t_{(70)} = 2.67, p = .010, d = .629$, 95% *CI* [.153-1.100]). Those low in self-compassion scored higher across all measures indicating greater symptom severity for low mood, anxiety, and OCD symptoms respectively (*see table 3*).

Table 3:

Descriptive data on mood severity (PHQ-9, GAD-7, OCI) for the 2 groups (low v high self-compassion) and the total sample

	Low self-compassion (*n*=37)		**High self-compassion (*n*=35)**		**Total (*n*=78)**	
	M	SD	M	SD	M	SD
PHQ-9	12.92	6.23	9.91	5.18	11.63	5.77
GAD-7	25.11	4.23	11.40	4.40	13.49	4.59
OCI	90.89	28.13	73.14	28.34	82.09	28.49

Key: | Abbreviations: M - Mean, SD - Standard Deviation, PHQ-9 - Patient Health Questionnaire-9, GAD-7 - Generalised Anxiety Disorder-7, OCI - Obsessive-Compulsive Inventory

| N was based on the number of participants completing each measure so this may not add up to the total group N in all cases where small amounts of missing data exist.

| The total sample (*n*=78) includes 5 additional participants who were excluded from the self-compassion grouping.

A mixed model omnibus ANOVA compared the effect of self-compassion level on obsessive beliefs (across the 4 OBQ subscales). There was a significant main effect of subscale (within subjects) ($F_{(2, 163)} = 9.57, p < .001, \eta p^2 = .122$). There was a significant main effect of group (between subjects: low v high self-compassion) ($F_{(1, 69)} = 15.26, p < .001, \eta p^2 = .181$) (*see table 4*). There was no significant interaction between self-compassion level and the 4 OBQ subscales, indicating self-compassion group differences were similar across the subscales ($F_{(2, 163)} = .17, p = .878$).

Table 4:

Descriptive data on the Obsessive Beliefs Questionnaire (OBQ-20) and subscales for the 2 groups (low v high self-compassion) and the total sample

	Low self-compassion (N=36)		**High self-compassion (N=36)**		**Total (N=79)**	
	M	SD	M	SD	M	SD
OBQ-20 threat	28.97	4.67	24.67	5.32	27.04	5.32
OBQ-20 perfectionism	28.80	3.95	24.86	6.66	26.97	5.83
OBQ-20 inflated responsibility	29.91	4.33	25.86	6.33	28.18	5.59
OBQ-20 importance/ control of thoughts	25.89	7.10	22.56	5.54	24.51	6.32

Key: | Abbreviations: M - Mean, SD - Standard Deviation, OBQ-20 - Obsessive Beliefs Questionnaire-20.

| The total sample (*n*=79) includes 5 additional participants who were excluded from the self-compassion grouping.

| N was based on the number of participants completing each measure so this may not add up to the total group N in all cases where small amounts of missing data exist.

Primary variable

A mixed model omnibus ANOVA compared the effect of self-compassion level on treatment readiness (across the 3 TAQ subscales). There was a significant main effect of treatment readiness subscales ($F_{(2, 122)} = 176.38, p<.001, \eta p^2 = .713$). There was a statistically significant main effect of group ($F_{(1, 71)} = 6.22, p = .015, \eta p^2 = .081$). The interaction effect was non-significant, indicating self-compassion group differences were similar across the 3 subscales ($F_{(1, 122)} = 1.79$, p = .177). Thus, those low in self-compassion scored higher for treatment concerns across all subscales (*see table 5*).

Table 5:

Descriptive data on the Treatment Ambivalence Questionnaire (TAQ) and subscales for the 2 groups (low v high self-compassion) and the total sample

	Low self-compassion (*n*=36)		**High self-compassion (*n*=37)**		**Total (*n*=78)**	
	M	SD	M	SD	M	SD
TAQ total	98.89	26.70	82.27	26.80	90.23	28.18
TAQ fear of negative/ adverse reactions	43.00	10.06	35.24	10.46	38.52	11.03
TAQ fear of personal consequences	41.11	17.10	34.32	14.89	37.46	16.29
TAQ fears of inconvenience	15.89	5.58	13.70	6.37	14.87	6.27

Key: | Abbreviations: M - Mean, SD - Standard Deviation, TAQ - Treatment Ambivalence Questionnaire

| The total sample (*n*=78) includes 5 additional participants who were excluded from the self-compassion grouping.

| N was based on the number of participants completing each measure so this may not add up to the total group N in all cases where small amounts of missing data exist.

A 3-stage hierarchical linear regression was used to test if SCS scores independently predicted treatment readiness, above OCI, PHQ-9 and GAD-7 scores (*see table 6*). At stage 1 OCI score significantly predicted total TAQ score ($F_{(1, 73)}$ = 8.87, p = .004) and accounted for 9.6% of the variation in treatment readiness. At stage 2 introducing the PHQ-9 and GAD-7 variables explained an additional 5.8% of the variation in treatment readiness however this change was not significant *(*p = .093). At stage 3 adding self-compassion total mean score explained an additional 6.1% of the variation in treatment readiness which was significant ($F_{(1, 70)}$ = 5.54, p = .021). In this final stage self-compassion was the only significant predictor when

included with PHQ-9, GAD-7 and OCI scores. The total model (with all predictors) explained 18.3% of the variance in treatment readiness.

Table 6:

Hierarchical regression models run with predictors of total score for treatment readiness (TAQ)

Model		Standardised co-efficient (B)	Significance	Adjusted R^2	R^2 change	Significance
1	OCI	.329	.004**	.096	.108	.004**
2	OCI	.239	.069	.131	.058	.093
	PHQ-9		.031*			
	GAD-7		.290			
3	OCI	.219	.086	. 183	.061	.021*
	PHQ-9	.279	.070			
	GAD-7	-.207	.172			
	SCS	-.270	.021*			

Key: | * p<.05, **p<.01

| Abbreviations: OCI = Obsessive Compulsive Inventory, PHQ-9 = Patient Health Questionnaire, GAD-7 = Generalised Anxiety Disorder-7, SCS = Self-Compassion Scale, TAQ = Treatment Ambivalence Questionnaire

There was insufficient data (only 10 participants) to address whether baseline rates of self-compassion and treatment readiness predict treatment outcomes due to covid-related treatment delays.

Discussion:

This study was designed to examine whether low levels of self-compassion are associated with a measure of readiness to engage in treatment for those at the beginning of treatment for OCD in IAPT. Findings indicated that those scoring lower on self-compassion scored higher on treatment concerns as measured by the TAQ

(likely indicating lower treatment readiness) than those higher in self-compassion. Other between group differences were also found, however. Low and high self-compassion groups also differed significantly in terms of OCD symptom severity, obsessive beliefs, depression, and particularly anxiety levels. As these differences may potentially confound the primary variable the regression analysis aimed to clarify this with treatment readiness as the dependent variable and severity of OCD, anxiety and depression entered ahead of self-compassion level. Self-compassion significantly accounted for a further modest proportion (6.1%) of independent variance. The secondary research question: whether baseline rates of self-compassion predict treatment outcome, could not be evaluated with the data obtained.

The differences in symptom severity between those with low and high self-compassion are consistent with previous reports of a relationship between compassion and psychopathology (MacBeth & Gumley, 2012) including specifically within OCD (Wetterneck et al., 2013; Eichholz et al., 2020; Leeuwerik et al., 2020). However the use of single time point data limits the ability to draw conclusions about the causality of this link (i.e., whether symptom severity is worse pre- or post- developing low self-compassion) (Athanasakou et al., 2020). Longitudinal work regarding changes in self-compassion and symptom severity may help to shed light on this. From a theoretical stance the cognitive model of OCD (Salkovskis et al., 1998) has obtained significant support regarding the role of misinterpretations of intrusive thoughts in maintaining OCD symptoms however given that variance in OCD symptom severity is not fully explained by level of endorsement of obsessional beliefs (Abramowitz, Lackey & Wheaton., 2009), there is need to explore additional factors, with the current study suggesting self-compassion may be one potential such variable for further

exploration. There was no interaction effect between self-compassion level and obsessive belief subtypes (on the OBQ-20) suggesting that it may be symptom severity rather than specific obsessive beliefs that link with low self-compassion. This provides promise for treating OCD as interventions may be generalisable across different subtypes of obsessive beliefs (regarding overestimation of threat, inflated responsibility for harm, importance of/ need to control thoughts, perfectionism/ intolerance of uncertainty). However it may be important to explore further whether OCD symptom subtypes (on the OCI) are evenly distributed also across the self-compassion groups.

The notion that many people may delay help-seeking or do not seek support until symptoms are severe, appeared partially supported here, as the majority of individuals had experienced OCD for several years. Rates of prior treatment were higher (62.5%) than previous estimates (Goodwin et al., 2002) however Goodwin's study was conducted in the US where services such as IAPT do not exist, limiting comparability. This may also partially be explained by our sample engaging with a service currently, therefore reflecting a more active help-seeking population. Nevertheless there were still significant concerns about starting treatment, with high scores on the TAQ. As those in the low self-compassion group scored significantly higher (i.e., experienced significantly more concerns about commencing treatment) this may support research suggesting that significant stigma/shame (often associated with low self-compassion) about difficulties leads to barriers accessing treatment with worry about what others may think (Glazier et al., 2015). Furthermore past barriers identified regarding beliefs that treatment may not work/be impractical or concerns

about what treatment involves (assessed by the TAQ) appeared to be replicated here for people with OCD (Marques et al., 2010; Robinson et al., 2017).

Due to limited follow up data, it will be important for future research to explore whether self-compassion impacts treatment outcomes longitudinally. It may be particularly helpful to explore whether low self-compassion leads to high rates of treatment refusal or drop out. Research would benefit from identifying more of the variance in self-rated readiness to engage in treatment and importantly later treatment engagement. Using other validated measures such as the University of Rhode Island Change Assessment Scale (URICA) (McConnaughy et al., 1983) (measuring readiness to change) may further help to define treatment readiness. If self-compassion further predicts treatment engagement and outcomes this would help to draw firmer conclusions about whether potential interventions may be needed to address early readiness to engage or low levels of self-compassion (eg. allowing consideration of trialling self-compassion enhanced CBT for OCD or similar). It was not possible to compare OCD subtypes (due to OCI subscales being unavailable in the IAPT database), so exploring whether these are evenly distributed across the self-compassion groups and comparing differently self-stigmatised groups (eg those with sexual/harm obsessions vs those with checking/cleanliness obsessions) may be important to see whether further differences in self-compassion and readiness to engage in treatment exist. Lastly future research may benefit from exploring whether the link between low self-compassion and readiness to change is replicated among other mental health conditions (e.g., depression/ anxiety) and in different settings such as GP surgeries (where individuals may be at an earlier stage of readiness to engage). This would help to understand the generalisability of the issue.

Clinical implications

As the low self-compassion group were significantly less ready to engage in treatment (with greater concerns about starting treatment), targeting those with low self-compassion may be an initial focus for intervention, as this predicted readiness to engage, even after accounting for symptom severity. The provision of OCI subscale information is likely to be helpful to consider if OCD subtypes are evenly distributed across the self-compassion groups.

In the current study treatment delays in IAPT due to covid-19 meant that insufficient longitudinal data were collected in the time frame to answer the second research question. Several participants had not yet completed treatment due to long waiting lists, which likely reflects the current reality of NHS services meaning there are delays in treatment access. As early readiness to engage in treatment is likely to affect subsequent treatment adherence (Keeley et al., 2008; Leeuwerik, 2019) it will be important to see whether further barriers exist for those low in self-compassion when it comes to engaging in treatment and receiving comparable treatment outcomes. This is particularly important when considering mixed past findings with some suggesting no significant link to treatment outcome (Monaghan et al., 2015; Pinto et al., 2007).

Strengths/ limitations

The study benefited from collecting data across 3 IAPT services with a range of demographics captured aiding generalisability. One notable limitation is the lack of longitudinal data, limiting the ability to draw conclusions about the relationship between self-compassion and later treatment engagement/ outcomes however the

cross-sectional findings provide interesting preliminary findings that self-compassion may be an important variable to explore. Furthermore the sample size was slightly smaller than estimated to be needed for sufficient power, however main effects were detected suggesting that sufficient power was obtained to identify such effects.

Conclusions

In summary those low in self-compassion were significantly less ready to engage in treatment with self-compassion significantly accounting for a modest proportion (6.1%) of independent variance, after accounting for symptom severity. Further research is needed to explore whether low self-compassion/readiness to engage predicts later treatment outcomes. If so, this may provide focus for future interventions, such as screening for self-compassion at assessment or offering interventions focused on improving treatment readiness (eg. motivational interviewing techniques) or self-compassion (e.g. compassion-focused interventions). However, the results may also reflect the established association between OCD symptom severity and other psychopathology, and in turn with TAQ scores due to the severity difference.

(See appendix P for author guidelines for the target journal (British Journal of Clinical Psychology)).

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Executive summary:

The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD

Why was the study conducted: Obsessive Compulsive Disorder (OCD) is a condition characterised by having obsessive thoughts (eg. distressing intrusive thoughts/images/urges) and compulsive behaviours (eg. repeated behaviours an individual feels driven to perform to reduce distress). This can impact individuals' functioning and quality of life, so it is important they access suitable treatment promptly. Current treatments (such as Cognitive Behavioural Therapy (CBT)) focus on individuals gradually facing their fears without completing compulsions and challenging their interpretations of the intrusive thoughts (e.g. believing they are responsible for preventing harm). Effective treatments exist for OCD however there remain barriers to how ready people feel to engage in treatment and how well treatment works. Research estimates approximately 15% of people decline treatment initially or drop out. If there are difficulties engaging in treatment, this typically leads to poorer outcomes, with 43-58% of people currently recovering with CBT for OCD. There is a need to explore what factors contribute to people feeling less ready to engage in treatment and poorer treatment outcomes to inform effective treatments. Research suggests people with OCD may wait until symptoms are severe before seeking help. Reasons for delay help-seeking include shame about their difficulties/ worry about what others may think, feeling they don't deserve treatment/ their symptoms aren't severe enough and beliefs that treatment may not work/ be too difficult or take too much time. People's readiness to engage in treatment is likely to affect how well treatment works. There is need to explore what factors mean someone

is less ready to engage in treatment as this could provide a focus before starting OCD treatment to improve outcomes.

It has been suggested that self-compassion (i.e., the ability to be kind to oneself, to understand that distress is a common human experience and to tolerate difficult experiences) may be important in OCD. Low self-compassion is commonly seen in people with mental health difficulties such as anxiety/ depression. In OCD, studies suggest a link between how self-compassionate someone is and how severe their OCD symptoms are (with those low in self-compassion experiencing more severe symptoms). It may be that those low in self-compassion experience barriers to feeling ready to engage in treatment and how well treatment works because they may: (1) Experience more shame about their symptoms and feel that others do not experience these so worry about sharing their difficulties with professionals, (2) Find it hard to be understanding towards their difficulties so have more beliefs that they are undeserving of treatment/ their symptoms aren't bad enough, (3) Have more concerns about what treatment involves and if they can tolerate this as they may find it difficult to tolerate difficult emotions, (4) Become self-critical if there are difficulties during treatment and (5) Have difficulty tolerating distress when facing their fears. This study therefore looked to see whether self-compassion plays a role in how ready people feel to engage in treatment and how well treatment works.

What was done: Participants were adults seeking treatment for OCD through local IAPT (Improving Access to Psychological Therapies) services in Berkshire, Buckinghamshire and Oxfordshire. In the UK IAPT services typically offer treatment in the first instance for OCD with low intensity guided self-help (via

telephone/online/face to face) or high intensity intervention via CBT groups or 1:1 sessions.

IAPT services asked all eligible patients on the waiting list for OCD treatment after an initial assessment whether they were willing to be contacted, and if so, the research team sent the study information sheet to seek informed consent. Eighty people completed questionnaires before treatment on their obsessive beliefs, how ready they felt to start treatment and their self-compassion level. They also completed questionnaires on their mood (low mood, anxiety and OCD symptoms) as is routine when they attend their local IAPT service. The IAPT clinician collected the three measures taken routinely in IAPT (on mood symptoms) and the researcher collected the three other measures (on their obsessive beliefs, how ready they felt to start treatment and their self-compassion level) via an online survey or by email. It was planned to collect these same measures after treatment also. Data on their demographics (e.g. age/gender) and clinical characteristics (e.g. duration of OCD, past treatment type) were pulled from their patient record with consent.

What was found: Two groups were formed for those high v low in self-compassion (based on their scores on the self-compassion questionnaire). People low in self-compassion felt significantly less ready to engage in treatment (i.e.. had more concerns about starting treatment). They also experienced more severe symptoms of low mood, anxiety and OCD and had more obsessive beliefs. When exploring what factors predicted how ready people felt to engage in treatment, people's self-compassion level marginally predicted how ready they felt to start treatment above how severe their symptoms of low mood, anxiety and OCD were. Due to too smaller numbers completing the after-treatment questionnaires at the time of the study being

written up (due to treatment delays), it was not possible to analyse results on whether self-compassion predicts how well treatment works.

Implications: Overall self-compassion appears to marginally affect how ready people feel to engage in treatment with those low in self-compassion feeling less ready to engage in treatment. Further research is needed however to see whether this impacts how well people later engage with treatment and how well treatment works. If so, it may be that using a questionnaire to assess people's self-compassion level before treatment or considering treatment focused on improving their readiness for treatment or self-compassion level first may be helpful. Future research would be needed to see what types of treatments do this best and which ones may be realistic to offer in IAPT services.

Connecting reflective narrative:

I entered training with a broad range of interests including health psychology, staff wellbeing and primary care, meaning initially scoping three projects was challenging. Through discussions I discovered a passion for improving service accessibility. It has been rewarding to see all projects having positive clinical implications regarding improving service accessibility.

The value of critical examination

This was my first systematic review however reading around methodology has helped me take a more critical approach to reading academic papers, regarding their quality/applicability given the sample size/ characteristics. Later, in my TDRP when exploring the evidence base, I noted whilst psychologists were interested in this area the research was in its infancy. In consultation with supervisors I learnt the importance of needing to tailor the research question to first identify whether something (eg. low self-compassion) is an issue with this population before trialling potential intervention.

The importance of PPI

In my SIP I enjoyed developing a project that would be meaningful to the service with clear clinical implications. I was fortunate to consult individuals on dialysis and carers to shape the study design. This provided great insight into the participant experience of completing measures, potential issues, and the importance of separate patient/ carer feedback. It was also valuable in my TDRP having service users review the design; noticing condition-specific issues (eg. questionnaire formatting/timing), alongside increasing accessibility (eg. offering postal measures).

There appeared a high prevalence of comorbid ASD during screening and therefore postal/telephone options for completion were helpful, highlighting the importance of service user consultation. I am increasingly mindful of consulting service users before implementing research/ service changes.

Impact of self on research

My CRL focused on barriers to doctors help-seeking due to personal connections with several doctors. This became increasingly pertinent during the pandemic, when there was heightened media focus on doctors' mental health/burnout. Hearing these perspectives helped to resonate with the literature around professional medical culture and stigma. I checked all stages with my supervisor/ another trainee, to reduce this biasing the themes extracted, highlighting the need to conduct research collaboratively. Similarly in my SIP when balancing the views of patients, carers and staff, supervisors reviewing the themes and ensuring these represented all groups helped to aid credibility. Later working in a medical team I observed some of the barriers disclosing mental health difficulties (eg. a culture of invulnerability), emphasising the need to disseminate my findings widely across doctor specialities to highlight existing barriers and promote future exploration of ways to overcome these.

In my SIP using mixed-methods I found the patient interviews insightful to supplement the quantitative findings; collating detailed lived experiences of CKD. I was drawn in teaching to the idea that people without lived experience typically underestimate the QoL of people living with conditions and could identify this initial bias myself. It was important in the interviews and analysis to create space for positive experiences of living with CKD. In clinical work I now ask more about QoL

and coping strategies, being mindful not to make assumptions. It may be interesting to consider whether staff views on ill-health further affect patients' engagement with services.

My pre-existing IAPT experience appeared to support negotiations setting up my TDRP across the three IAPT sites in understanding their processes/treatment pathways etc. Throughout however I was reminded of the importance of ongoing collaboration (maintaining relationships and communication) particularly in a multi-site study, to shape and conduct meaningful research.

Challenges of NHS research

Recruitment was difficult at times, influenced by the pandemic. During my SIP I observed staff difficulty offering questionnaires in time-pressured services alongside participants' potential burden completing multiple questionnaires. In future I would engage all staff from the outset to aid study engagement and minimise the questionnaire number for participants whilst still capturing the data needed to answer the research question(s). Furthermore for my TDRP a longitudinal aspect was envisaged to collect treatment outcomes, however unforeseen treatment delays meant this was not possible to collect in a timely way, with many people not completing treatment by write up (as initially hoped). I have learnt the need to be adaptable, particularly during time-limited projects, and consider feasibility with services. This highlights the need for research like this to improve treatment accessibility and outcomes. I will continue collecting longitudinal data for publication.

Being new to NHS ethics, sponsorship, local Research and Development (R&D) and service-level approvals I gained skills navigating these and collating multiple perspectives to inform a shared protocol, whilst at times needing to be more decisive (initially challenging as a trainee). I will continue to work collaboratively with services to conduct meaningful research, whilst now considering a more realistic timeframe from scoping research ideas to data collection. These experiences have provided insight into the challenges conducting NHS-based research and how these may hamper potential future development, highlighting the need for psychologists to continue promoting research.

Future research opportunities

I have seen the benefits across all projects advocating for different groups and working to address systemic barriers to treatment access/ outcomes. It was interesting similar themes arose with the stigmatised culture across healthcare services, when mental health help-seeking, being an access barrier. This existed among healthcare providers (doctors) and service users with varying difficulties, highlighting the breadth of the issue. It would be interesting to explore whether healthcare provider stigma is a further barrier to services' accessibility.

I aim to continue collating service users' voices via research/audit, questioning why existing approaches are used and identifying access gaps via service evaluation. I acknowledge this may require persistence given the tension changing things in time- and resource-pressured services where differing views on priorities may exist. My projects have taught skills in adaptability and thinking creatively, which are likely valuable in conducting future research within NHS services. I will continue critically

evaluating the evidence base, considering if the research characteristics allow generalisability to specific patient groups in clinical practice. I have learnt the increasing importance of dissemination via journals/ conferences, service user groups and clinical teams and will source opportunities to share the above findings here.

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Appendices:

Appendix: Critical review of the literature

Appendix A: Search strategy

Line 1- (doctor? OR medic? OR physician? OR practitioner OR consultant OR registrar OR GP OR surgeon)

Line 2- [+synonyms of doctor]

Line 3- ("mental health" OR burnout OR stress OR depress* OR anxiety OR "mental illness" OR trauma* OR substance? OR "mental disorder?")

Line 4-[+synonyms of mental disorders]

Line 5- ((help-seek*) OR (help ADJ3 (seek* OR access*)) OR disclos*) ADJ7 (barrier? OR obstacle? OR facilitat* OR access* OR attitude? OR prevent*))

Line 6-[+synonyms of help-seeking behaviour]

Line 7- (line 1 OR 2) AND (line 3 OR 4) AND (line 5 OR 6)

Appendix B: Quality appraisal tool (Kmet et al., 2004)

Quantitative studies were assessed as follows:

1 Question / objective sufficiently described?

2 Study design evident and appropriate?

3 Method of subject/comparison group selection or source of information/input variables described and appropriate?

4 Subject (and comparison group, if applicable) characteristics sufficiently described?

5 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias?

Means of assessment reported?

6 Sample size appropriate?

7 Analytic methods described/justified and appropriate?

8 Some estimate of variance is reported for the main results?

9 Controlled for confounding?

10 Results reported in sufficient detail?

11 Conclusions supported by the results?

Qualitative studies were assessed as follows:

1 Question / objective sufficiently described?

2 Study design evident and appropriate?

3 Context for the study clear?

4 Connection to a theoretical framework / wider body of knowledge?

5 Sampling strategy described, relevant and justified?

6 Data collection methods clearly described and systematic?

7 Data analysis clearly described and systematic?

8 Use of verification procedure(s) to establish credibility?

9 Conclusions supported by the results?

10 Reflexivity of the account?

Appendix C: Reflective paragraph

The research question stemmed from the supervisor and trainee identifying the absence of an up-to-date systematic review collating UK findings regarding barriers/ facilitators to doctors help-seeking for mental health. The trainee acknowledged, in selecting this topic and interpreting the data, personal experience of observing doctors' barriers to mental health help-seeking and disclosure which may have led in data synthesis to focusing more on representing barriers than facilitators. However she used an interpretive data analytic approach, based on her epistemological stance (regarding multiple versions of reality/ experiences existing and a social constructionist approach) and immersed herself in the data to identify common themes that emerged from the qualitative and quantitative studies and that resonated with the research questions posed. Self-reflexivity, supervision, and triangulation with two other researchers (HJ and VE), one with professional experience working with doctors and another more neutrally involved as a trainee psychologist, were used throughout the process to increase credibility of the analysis (eg. selecting papers reflective of the topic and checking themes and subthemes to aid these accurately reflecting the data set). The themes were refined over several attempts ensuring that the data accurately reflected the range of experiences of doctors (with systemic, personal, and professional barriers identified). The trainee's clinical view has been shaped by the analysis in observing the range of experiences reported (both positive and negative) by doctors, from an early stage and throughout training. This has aided understanding when working in medical teams of the existing culture. Throughout write up all authors checked that themes represented a wide range of quotes and experiences.

Appendix D: Step by step analysis strategy (in line with Popay et al., 2006)

1.Data extraction forms were used to collate information on quantitative and qualitative studies separately. These forms were completed with data extracted for each study type or mixed methods coming under both forms. Data was extracted on study characteristics (eg type of mental health difficulties studied), participant demographics (eg age, sex), sample size, recruitment method, study design (eg measures used, setting) and whether the focus was on help-seeking or disclosure. For both types of study barriers and facilitators were identified from the results section using an inductive approach and researchers were careful to preserve the original use of language and contextual meaning by keeping words identical to those used in the papers to aid validity.

2.The quality of included studies was checked using the Kmet et al (2004) quality rating checklist. Qualitative and quantitative papers were rated on separate checklists with mixed methods coming under both. It was acknowledged that a limitation of this tool appeared at times differentiating between 'partial (1)' and 'yes (2)' ratings. There was sufficient agreement between the two raters (AP and VE) on the above two stages and where disagreements were present HJ was consulted to reach consensus. An overall quality assessment score was calculated in line with Kmet et al (2004)'s scoring. It is acknowledged that the criteria used to subsequently rate studies as low, medium, and high quality was based on a similar previous paper (O'Brien et al, 2016) to aid replicability, however this could benefit from further psychometric testing to ensure these are suitable cut off criteria for ranking the studies in this way. It was also of note in the current study that all papers were of medium-high quality. This was discussed among reviewers however agreement was reached that this did appear reflective of the overall literature in this area, which was

conducted to a high standard. Nevertheless there were implications for improving research in the area regarding more evidence of authors' reflexivity and connection to a key theoretical framework and better control of confounding variables. The contribution to the review score (small, medium, large) was also allocated at this time which helped to distinguish papers which had only a small mention of barriers and facilitators compared to those where this was the focus of the paper. The decision to include all of these papers was based on these all being of medium-high quality and therefore all mentions of barriers/ facilitators whether small or large were likely to be informative. In the subsequent narrative synthesis those contributing more to the review provided further exemplar quotes and therefore had slightly more influence on the overall themes. However, where possible equal weighting was given to the different studies to aid generalisability of the findings.

3. A narrative synthesis was then conducted (Popay et al., 2006). Quantitative and qualitative data were tabulated and synthesised separately initially and grouped according to common factors; in this case whether they focused on help-seeking or disclosure. Thematic analysis (following Braun and Clarke's 6 stages, 2006) was conducted including familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and writing up themes. Qualitative data was analysed in excel first with discussions held between AP and HJ to identify and refine codes and provide a single coding framework. The quantitative data was then analysed using this initial coding framework and codes were amended or added where appropriate, such as the inclusion of demographic differences. Key themes and subthemes were then identified from the papers, until no new themes were found. All themes were checked by multiple researchers (AP and HJ) and discrepancies were resolved before themes were finalized, to enhance credibility of

the analysis. This approach was chosen (qualitative to quantitative) to allow the depth of the themes to emerge and the quantitative data to then provide insight into the percentage of doctors endorsing these themes.

4.In displaying the data tables were chosen to represent the qualitative data by summarising the themes and subthemes and providing exemplar quotes to aid the reader. Figures were chosen to display the merged qualitative and quantitative findings by showing i.the number of studies endorsing each particular theme and ii.within each quantitative study the percentage of doctors endorsing this particular theme. This was colour coded to show those studies where small, medium, and high numbers of individuals endorsed the themes. This ranking criteria was also taken from a previous systematic review exploring barriers and facilitators to managing child/ adolescent mental health problems (O'Brien et al, 2016). Whilst this aids replicability, this method may also benefit from further study to set objective cut off criteria, when subject to psychometric testing.

Appendix E: Author guidelines for BMJ Open

Original research

Research submissions should have a clear, justified research question. We strongly encourage you to register your study. Prospective registration is mandatory for any clinical trials. Acceptable registries for trials include clinicaltrials.gov. We recommend Prospero for registration of systematic reviews. All articles should include the following:

- **The article title should include the research question and the study design**. Titles should not declare the results of the study.
- **A structured abstract** (max. 300 words) including all the following where appropriate (please note that for RCTs there is a specific CONSORT extension for abstracts):
    - **objectives:** clear statement of main study aim and major hypothesis/research question
    - **design:** e.g. prospective, randomised, blinded, case control
    - **setting:** level of care e.g. primary, secondary; number of participating centres. Generalise; don't use the name of a specific centre, but give geographical location if important
    - **participants:** numbers entering and completing the study; sex and ethnic group if appropriate. Clear definitions of selection, entry and exclusion criteria
    - **interventions:** what, how, when and how long (this can be deleted if there were no interventions)
    - **primary and secondary outcome measures:** planned (i.e. in the protocol) and those finally measured (if different, explain why) - for quantitative studies only

- **results:** main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks
- **conclusions:** primary conclusions and their implications, suggest areas for further research if appropriate. Do not go beyond the data in the article
- **where applicable, trial registration:** registry and number (for clinical trials and, if available, for observational studies and systematic reviews)

- **Please include a 'Strengths and limitations of this study' section after the abstract.** This section should be no more than 5 bullet points relating specifically to the methods - not the results of the study. This will be published as a summary box after the abstract in the final published article.
- **The original protocol for the study**, as a supplementary file.
- **A funding statement** preferably worded as follows. Either: 'This work was supported by [name of funder] grant number [xxx]' or 'This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors'. You must ensure that the full, correct details of your funder(s) and any relevant grant numbers are included.
- **A competing interests statement**. See the BMJ Author Hub for details on what to include as competing interests.

- **Articles should list each author's contribution individually at the end**; this section may also include contributors who do not qualify as authors. Please visit the ICMJE website for more information on authorship.
- **Any checklist and flow diagram for the appropriate reporting statement**, e.g. STROBE (see below).

- **A patient consent form:** any article that contains personal medical information about an identifiable living individual requires the patient's explicit consent before we can publish it. We will need the patient to sign our consent form, which requires the patient to have read the article. This form is available in multiple languages.
- **A data sharing statement**, such as: "Technical appendix, statistical code, and dataset available from the Dryad repository, DOI: [include DOI for dataset here].
- **Word count,** we recommend your article does not exceed 4000 words, with up to five figures and tables. This is flexible but exceeding this will impact upon the paper's 'readability'. Authors are encouraged to submit figures and images in colour - there are no colour charges. We require that you upload your figures as separate files rather than embedding them in the manuscript.
- **Supplementary and raw data** can be placed online alongside the article although we prefer raw data to be made publicly available and linked to in a suitable repository (e.g. Dryad, FigShare). We may request that you separate out some material into supplementary data files to make the main manuscript clearer for readers.

We also recommend, but do not insist, that the discussion section is no longer than five paragraphs and follows this overall structure (you do not need to use these as subheadings): a statement of the principal findings; strengths and weaknesses of the study; strengths and weaknesses in relation to other studies, discussing important differences in results; the meaning of the study: possible explanations and implications for clinicians and policymakers; and unanswered questions and future research. At upload you will be asked to choose one general subject area that applies to your article - it will be published under this banner on the main table of contents. You will also be asked to select further subject headings to be used for the 'Browse by topic' section, and specific keywords for help with identifying reviewers. Following the lead of The BMJ and its patient partnership strategy, *BMJ Open* is encouraging

active patient involvement in setting the research agenda. As such, we require authors of Research Articles to add a Patient and Public Involvement statement in the Methods section. Please see more details above.

Appendix: Service Improvement Project

Appendix F: Lay summary of the project

Lay summary:

Introduction: Depression and anxiety are common among those with chronic kidney disease (CKD), at times leading to delays starting dialysis treatment and poorer outcomes.

The current study aimed to assess how common mood difficulties were among kidney clinics in the UK. It interviewed patients, carers and staff to identify why patients experience difficulties approaching dialysis and how services can best support them.

Method: Patients completed questionnaires on their mood, quality of life and beliefs about kidney disease. They also reported how many kidney-related missed appointments and hospital visits they had had. Carers completed a survey and interviews were conducted with patients and staff; all on their experiences approaching dialysis.

Results: Approximately half of patients in the current study experienced depression, whilst anxiety rates were lower. The current sample experienced a higher impact emotionally of having kidney disease however numbers of missed appointments and hospitalisations were low. Patients' prior knowledge of the illness appeared to have an impact on choosing when to start dialysis. Reasons for delay included a lack of knowledge about symptoms/ dialysis, being torn about the need for dialysis with good/bad symptom days and at times 'just following medical advice'. Common themes among patients, staff and carers included fear/denial about dialysis, adjusting to the lifestyle changes involved in dialysis, the importance of family involvement, the pros/cons of meeting others with the condition and needing appropriate personalised information.

Discussion: Recommendations for supporting people emotionally in kidney clinics are provided. Existing psychological therapies which focus on adjusting to living with kidney disease, reducing symptoms, or supporting families may be helpful.

Appendix G: Interview Scripts

Patient interview questions:

- What have been your experiences in first being told you may need dialysis?
- What sort of information are you given at appointments? Is this helpful? Is there opportunity to ask questions?
- How do you feel about starting dialysis? Are you feeling low or anxious about dialysis? What specific concerns do you have (if any)?
- Do you feel the service pays attention to your mood (eg low mood/ anxiety)? Do you feel the service talks to you enough about the emotional aspects of starting dialysis?
- Are there any factors you feel may lead you to delay dialysis or make the transition difficult?
- Is there anything you feel has helped you in transitioning to dialysis?
- Do you feel you understand enough about the benefits it will bring and the associated lifestyle changes?
- Do you have any concerns about the impact of dialysis on different aspects of your life? What aspects of your life are you most concerned about?
- Do you ever feel like you don't really need dialysis?
- What support would you like to be offered/do you feel would be most helpful to be offered by the psychology service in easing the transition to dialysis?

Carer's survey:

1a.What is your relationship to the individual transitioning to dialysis (eg husband/wife, parent, sibling) ? ……

1b.Has the person you care for previously had any of the following treatments for their renal problems? [Tick all that apply]

… Haemodialysis ~ Dates [in years eg 1993-1997]:

… Peritoneal dialysis ~ Dates [in years]:

… Transplant ~ Dates [in years]:

… Other ~ Dates [in years]:

2.What have been your experiences of the person you care for being told they might need dialysis?

3.What sort of information and support are you given at appointments? Is this helpful? How would you rate the amount of information offered for you and the person you care for?

4a.How do you feel about the person you care for starting dialysis? Are you feeling any of the following, in relation to them transitioning to dialysis? (eg. anxiety, guilt, sad/low, frustrated/angry)?

4b.What specific concerns do you have about the person you care for moving closer to needing dialysis (if any)?

5. Do you feel that the service has been supportive in relation to the emotional aspects of approaching dialysis, both for you and the person you care for? Do you feel the service talks to you enough about the emotional aspects of starting dialysis?

6. Do you think that the person you care for might put off starting dialysis for any reason? What might disrupt the transition to dialysis or make it difficult?

7.What has helped you and the person you care for as they transition to dialysis?

8.Do you have any concerns about the impact of dialysis on different aspects of your life as a relative/carer? Or on your relationship with the person starting dialysis?

9.What support would you like to be offered/might be helpful to be offered by the psychology service for relatives/carers of those transitioning to dialysis ? Would you attend this if it was offered?

Staff focus group questions:

1. Do you think there are any issues/barriers to patients engaging in

   i.low clearance clinic

   ii.dialysis?
2. If so, what are those issues/barriers?

[prompt- i. patient-related, ii. staff-related, iii.service-related]

3. Do you notice some patients delay or do not attend their pre-dialysis appointments and follow-ups? If so, have you any thoughts on why this may be?
4. What may be possible reasons for patients delaying dialysis?
5. Have you picked up any indications that patients may be low/anxious pre-dialysis? What do you observe in clinic that tells you a low-clearance patient may be experiencing anxiety or depression?
6. Why do you think patients think/feel this way?
7. If patients are anxious/low pre-dialysis;

i.What support do you currently offer them?

ii.What support do you think may be helpful for them?

iii.Are there any obstacles for offering this? What factors affect what is offered?

[Prompt- eg. service pressures, staff beliefs]

8. What support are patients offered in clinic when transitioning to dialysis generally? Eg. information, groups.

[prompt: how similar or different across clinics?]

9. What factors do you think help or hinder a patient approaching dialysis?/ What do you think may facilitate patients in engaging with dialysis?
10. Is there anything the psychology service could offer to help patients stay engaged with low-clearance clinic and with dialysis?
11. Is there anything the psychology service could offer to help patients, carers and staff in coping with the transition to dialysis?
12. What do you think the wider service could improve upon in relation to the above & how?
13. Is there anything not covered today that you feel is relevant for supporting patients approaching dialysis?

Appendix H: Qualitative Analysis (Reflective paragraph and additional quotes)

Reflective paragraph:

The research questions stemmed from the psychologist and trainee identifying these as gaps in current understanding at a service level. The trainee acknowledged, in setting these questions and interpreting the data, experience in health psychology and understanding of experiences commonly reported by those with other health conditions (eg diabetes/chronic pain). She used an interpretive data analytic approach however and immersed herself in the data to identify common themes that emerged from the interviews and questions and that resonated with the research questions posed. Self-reflexivity, supervision and consultation with two other researchers with clinical health psychology backgrounds were used throughout the process (LH and SL) to increase credibility of the analysis (eg. checking the themes and subthemes to aid these accurately reflecting the data set). The themes were refined over several attempts ensuring that the data accurately reflected the views of all groups (staff, patients and carers). The themes will be triangulated with staff, carers and patients to further check that these are reflective of the meaning intended by participants. The trainee acknowledged no prior lived experience of CKD. Her clinical view has been shaped by the analysis in observing the range of experiences reported (both positive and negative) by patients/ carers and staff of living with a chronic condition. Throughout write up all authors checked that themes represented a wide range of staff, patient and carer quotes and a range of healthcare experiences.

Table H1:

Additional quotes

THEME 1: EXPERIENCES OF TRANSITIONING TO DIALYSIS	
Fear/ denial	'I mean I'm not somebody who enjoys the medical world so, I have some trepidation about sticking tubes in myself and so on.. it came as a complete and total shock' #P4 'fear of spending a lifetime on dialysis' #P1
Existing experiences of support	'the doctors and the nurses and everybody else just use the word fistular as an everyday word' #P1 'when you're an inpatient the information doesn't get given to outpatients.. I've had letters asking me to come for those tests and..I'm sure I've had this done before' #P2 'they ultimately have to trust the person putting them on dialysis..they have never met the nurses before' #S5
THEME 2: REASONS FOR DELAY	
Knowledge of CKD	'is this problem that I've got at this moment, to do with my kidneys or is it to do with my age or what? And there are no answers' #P1
THEME 3: HOW THE SERVICE CAN BEST SUPPORT PATIENTS TRANSITIONING TO DIALYSIS	
Pros/ cons of peer support	'the ones that we'd really want to come (to a group).. just aren't there, unfortunately they tap into the people that are probably the people that need it least' #S4
Ongoing individualised assessment/ monitoring	'there are people that are expected to look after your emotional..wellbeing..but..I don't think that everybody in the team is expected to play the same role' #P6 'I think we all just have to think about what we'd feel like, don't we, that it kind of makes sense, doesn't it?' #S4 'it's very palpable, I think.. the anxiety' #S6
The importance of support for family/ carers	'all my friends and family who have been rooting for me all this..time, would feel very let down if I said.. I don't think I want to have .. dialysis' #P2 'how couples cope and continue to enjoy life together when one partner transitions to dialysis' #C3 'it..has a mental impact on you, the fact that you've..passed it onto your children' #P1

Appendix I: Supplementary Analysis (Correlations with illness perceptions)

Pearson correlations (or Spearman's rank for non-parametric data) were used to explore relationships between illness perceptions on the IPQ-R and the other self-report questionnaire measures[5].

Table I1:

Correlations between self-report measures

	PHQ-9	GAD-7	KDQoL Symptoms of KD	KDQoL Effect of KD	KDQoL Burden of KD	KDQoL Physical composite	KDQoL Mental Composite
Identity	*.281*	.227	*** -.563**	***-.385**	-.319	-.212	-.076
Consequences	**.394*	*** .441**	-.266	*** -.439**	*** -.434**	-.152	-.357
Timeline acute	*-.082*	-.124	-.097	.278	.254	-.035	.025
Timeline cyclical	*.268*	.294	-.370	-.348	-.360	-.078	-.131
Emotional impact	**** -.467***	*** .553**	*** -.379**	*** -.456**	*** -.545**	.070	***-.467**
Personal control	.111	.202	-.073	-.054	-.273	-.207	.013
Treatment control	-.048	-.032	.130	-.170	-.072	-.265	.330
Coherence	.179	.207	.137	-.115	-.051	.322	-.376

Key: | * p<.05

| Abbreviations: PHQ-9 - Patient Health Questionnaire-9, GAD-7 - Generalised Anxiety Disorder-7, KDQoL - Kidney Disease Quality of Life Instrument, KD - Kidney Disease

| Spearman-rank correlations were conducted for measures not meeting parametric assumptions, as indicated in blue

[5] Correlations were conducted as illness perceptions have been previously shown to contribute significantly to distress levels in those with CKD (Muscat et al., 2021)

Appendix J: Clinical Audit Trust Approval

From: Franklin Jo (RTH) OUH <Jo.Franklin@ouh.nhs.uk>
Sent: 17 September 2020 15:16
To: Alice Parfitt <alice.parfitt@hmc.ox.ac.uk>
Subject: Starting Dialysis; reviewing current challenges around this transition, and potential psychological interventions to address this within low clearance clinics in Oxford.

Re: Starting Dialysis; reviewing current challenges around this transition, and potential psychological interventions to address this within low clearance clinics in Oxford.

Dear Alice
The classification committee reviewed your project today and agreed the activity could be classed as service evaluation/improvement. Therefore no regulatory approvals are required.
You should ensure you have approval from the relevant departmental leads to undertake the project and you may need to register the project with the clinical audit team in the trust – clinical.audit@ouh.nhs.uk
Please let me know if you have any questions in the meantime regarding this.
With best wishes
Jo

In relation to the latest guidance from the Government and from the Trust in response to the developing COVID-19 pandemic, the R&D teams are currently working from home (from 18th March 2020) until further notice. Therefore, please contact the R&D teams by email in the first instance (rather than by phone). Many thanks for your understanding at this time.

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NHS Foundation Trust

Joint Research Office
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Appendix K: Participant information sheets and consent forms

Questionnaires:



Service Evaluation Project: Transitioning to Dialysis

Information sheet

Title:
Starting Dialysis; what are the challenges for people moving towards dialysis, and how can we best support them and their families with this within low clearance clinics in and around Oxford.

As part of our continual efforts to monitor and improve our service, you are being invited to complete some questionnaires for us. This will allow us to look closely at how we can best support individuals who are transitioning to dialysis, as this is known to be a difficult time for many. Everyone who is approaching the start of dialysis is being asked to take part.

Please take 10-20 minutes to complete the questionnaires, which are about your mood and quality of life. You can do this on paper copies, or online, and they can be done in clinic, or at home.

You can also opt to take part in a follow-up interview, where we will ask you more about your experiences of transitioning to dialysis, and your thoughts on how we might improve the service and the support we offer.

Relatives / Carers
We would also like to get the views of relative / carers, about their experience of supporting you at this time. Please pass on the Carers Questionnaire to anyone who you know, who might be interested in taking part in this.

Confidentiality
Once the questionnaires are returned, **all data collected will be anonymised**. Only the trainee clinical psychologist researcher and a clinical psychologist will have access to the data at this stage. If anything on the questionnaires suggests that you or others are at risk, one of them will contact you to review this.

Once the data has been analysed, the findings will be fed back to the renal team, to help shape the service moving forward. The findings may be published in a peer-reviewed journal at a later date.

Name:
Contact number:
[This is in case there may be concerns around your safety or if you agree to take part in the follow up interview.]

Consent:
1. Are you happy for your anonymised data to be used for the purposes of audit/ service evaluation?
[Please note your treatment with the service will *not* be affected in any way by your answers.
You are also able to change your mind at any point by informing your clinician who will update our records accordingly]

Yes ~ No

2.Are you happy for the information collected about you to be anonymised and summarised together with other participants and used to support other research in future eg. by being shared in a peer-reviewed journal publication?

Yes ~ No

3. Are you happy to be contacted about taking part in a follow up interview (approx 30 mins) about your experiences of transitioning to dialysis?

Yes ~ No

If yes, please provide your contact details below for us to pass on to the trainee clinical psychologist researcher based at Oxford University:
Email –

If you have any questions about this project please contact Alice Parfitt (Trainee Clinical Psychologist) : alice.parfitt@oxfordhealth.nhs.uk or Dr Louise Hankinson (Clinical Psychologist) : Louise.hankinson@ouh.nhs.uk.

Please note you can also complete the following questionnaires online at:
https://psychiatryoxford.qualtrics.com/jfe/form/SV_9vOfO4w9RMa39iJ

Follow up interviews:

NHS Oxford University Hospitals NHS Foundation Trust

Service Evaluation Project: Transitioning to Dialysis

Information sheet

Title: Starting Dialysis; what are the challenges for people moving towards dialysis, and how can we best support them and their families with this within low clearance clinics in and around Oxford.

Interviews
You recently completed some questionnaires for us, as part of a service-related project looking to monitor and improve the service for those who are approaching dialysis. Many thanks for completing the questionnaires, which will be valuable for informing the above. We are contacting you now as you kindly agreed for us to contact you regarding taking part in a follow-up interview.

What does it involve?
We will conduct the interview by phone or online via Microsoft Teams. You can choose which method you would prefer. We estimate the interview to take up to 30 mins.
In the interview we will ask you about your experiences of transitioning to dialysis, and your thoughts on how we might improve the service and the support we offer.

What if I change my mind?

You may have decided since completing the questionnaires that you no longer wish to take part in the interviews. Taking part is optional so it is fine not to take part in this if you don't want to. We will contact you initially to agree a time when we can conduct the interview, and you can let us know at this time if you no longer wish to take part.

You can also withdraw at a later point if you change your mind without giving reason, including soon after you have taken part. However, you will not be able to withdraw your data after it has been transcribed (typically after 2 weeks).

Please note choosing not to take part in the interviews or to withdraw your data at any time will not affect your treatment in any way. If you no longer wish to take part, we encourage you to contact your local renal clinician who will update our records accordingly.

What are the possible benefits?

There are no direct benefits to taking part and unfortunately we are unable to reimburse participants for taking part in the study. However by taking part there is opportunity to contribute to shaping services locally, with regards to what psychological support may be available for kidney patients.

What are the possible risks of taking part?

We will be talking about your experience of transitioning to dialysis. As with discussing any healthcare experiences, both positive and negative, there is potential that this may cause some distress. If this occurs we would encourage you to let the interviewing clinician know. You can also contact local support services (including Samaritans – Tel: 116 123, NHS out of hours – Tel: 111 & your local crisis team).

If anything during the interview suggests you are at increased risk, we will discuss this with you during the call and if needed, may pass your details to the local renal team psychologist who will then make contact with you.

What will happen to my data?

We will ask to audio record the interview to help us in recording and analysing the data. This recording will be deleted as soon as possible after the data has been analysed (up to 2 years). Your recording will not be associated in any way with your name or personal details. Only the trainee clinical psychologist researcher and a clinical psychologist will have access to the data at this stage.

Once the data has been analysed, the findings will be fed back to the renal team, to help shape the service moving forward. The findings may be published in a peer-reviewed journal. We may use brief quotes from interviews in this publication, however this will not be personally identifiable in any way.

Name: | **Date:**

Consent:

1. I understand participation in this follow-up interview is voluntary and I am free to withdraw at any time without giving reason and without my medical care/ legal rights being affected.
2. I understand that the research team will hold my personal details (name, contact details) to contact me for interview, however the rest of my data will be anonymised and each participant assigned a unique code. Following completion of the study my data including the audio recording will be destroyed.
3. I have read the above information and had the opportunity ask questions
4. I am happy for the interview to be audio-recorded
5. I am happy for my anonymised data to be used for the purposes of audit/ service evaluation and written up as part of the trainee's course work and for a peer reviewed publication.

6. I am happy to take part in the interview

If you have any questions about this project please contact Alice Parfitt (Trainee Clinical Psychologist) : alice.parfitt@oxfordhealth.nhs.uk or Dr Louise Hankinson (Clinical Psychologist) : Louise.hankinson@ouh.nhs.uk.

Appendix L: Questionnaire on demographics and renal service use

Service Evaluation Project: Transitioning to Dialysis

The following questionnaire asks for some information about your demographics (age, sex etc) and your past use of services.

Demographics:

Age: 18-30 31-43 44-56 57-69 70-82 83-95 96+

Sex: Female ~ Male ~ Other ~ Prefer not to say

Ethnicity (please circle):
-White British ~ White Other
-White and Black Caribbean ~ White and Black African ~ White and Asian ~ Other mixed/ multiple ethnic background
-Asian Indian ~ Asian Pakistani ~ Asian Bangladeshi ~ Asian Chinese ~ Other Asian background
-Black African ~ Black Carribean ~ Other Black, African or Caribbean background
-Other ethnic group (please specify) ……

Where do you attend your appointments currently? (please circle): Oxford ~ Banbury ~ High Wycombe ~ Swindon ~ Milton Keynes ~ Stoke Mandeville

Do you attend a low clearance clinic? Yes ~ No

Kidney-related care:

1.Have you previously had any of the following treatments for your renal problems? [Tick all that apply]
… Hemodialysis ~ Dates [in years eg 1993-1997]:
… Peritoneal dialysis ~ Dates [in years]:
… Transplant ~ Dates [in years]:
… Other ~ Dates [in years]:

2.In the past year- approximately how many kidney-related hospital admissions have you had?

……...

3.In the past year- approximately how many kidney-related appointments have you missed?

……...

Mental health history:

1. Have you had any mental health difficulties in the past? Yes ~ No

If yes, please briefly summarise the nature of these difficulties

……..
……...

2.Do you feel these were related to your kidney condition? Yes ~ No

3. Have you had any previous treatment/ therapy for mental health difficulties? Yes ~ No

If yes, please briefly summarise the treatment you had eg. medication, psychological therapy, counselling, CMHT, inpatient, etc.

……..

……...

4. Are you currently taking any medication for your mood?
Yes ~ No

If yes, please write the name of the medication(s) you are taking **for your mood**

……..

……...

Appendix M: Author guidelines for Journal of Health Psychology

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Journal of Health Psychology, please ensure you have read the Aims & Scope.

1.2 Article Types

The Editorial Board of the Journal of Health Psychology considers for publication:

(a) Full-length reports on empirical studies (up to 8,000 words counting 500 words per table and figure for all study types including intervention studies and qualitative studies).

(b) Brief reports on empirical studies (up to 3,000 words counting 500 words per table and figure).

(c) Review articles including systematic reviews, narrative reviews, and theoretical contributions (up to 8,000 words counting 500 words per table and figure).

(d) Open peer commentaries on recent articles in this journal or topical issues (up to 2,000 words counting 500 words per table and figure).

(e) Commissioned guest editorials (up to 3,000 words counting 500 words per table and figure) approved in advance by the Editors (email hpq@sagepub.com with formal enquiries).

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online

2. Editorial policies

2.1 Peer review policy

Journal of Health Psychology operates a strictly anonymised peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Journal of Health Psychology requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the *Funding Acknowledgements* page on the SAGE Journal Author Gateway to confirm the format of the

acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Journal of Health Psychology to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript and on the title page, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here

Please see the ICMJE Form for Disclosure of Potential Conflicts of Interest for more information about what items should be referenced in a Conflict of Interest statement.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Reporting guidelines

These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

2.8 Research data

At SAGE we are committed to facilitating openness, transparency and reproducibility of research. From the 1st July 2020 *Journal of Health Psychology* requires authors to share only those data described in the publication and to submit a Data Sharing Statement alongside their submission. This should appear as a distinct sub-section at the end of the Method section of the manuscript.

The data must be uploaded to the SAGE Track submission system and will be uploaded to Figshare on publication. Please see section 3.4 for information on MIRD data sharing, data uploading and required files and the relevant Editorial for further details.

2.8.1 Data sharing statement

Data sharing statements must indicate the following: whether individual de-identified participant data (including data dictionaries) are shared; what data in particular are shared; additional, related documents that are available (e.g. study protocol and statistical analysis plan). The shared data should be useable and interpretable and include the following features:

1. If the data are in the form of a **statistical dataset**, variables must be labelled clearly, and variables that are stored as labelled numeric values must have associated value labels. The version of the software used to create the dataset must be stipulated (to clarify potential back-compatibility issues).
2. For data stored as a **spreadsheet, or delimited text**, an associated text file containing variable labels and, where appropriate, value labels for labelled numeric data.

3. **Missing data codes** should be documented, together with numbers of missing values for each variable. Ideally, missing data should be left blank, not assigned a pseudo-numeric code.
4. **Measurement units** and **measurement times** (where appropriate).
5. The dataset should be accompanied by a **codebook** giving means of continuous variables and frequencies of categorical variables, together with numbers of valid cases. This allows the use to check that they have read the data correctly into whatever software they are using.
6. Clearly spell out the **analytic procedures** upon which the submitted claims rely, and where possible provide access to all relevant analytic materials.
7. **Note** explaining the datasets will be available in Figshare and as supplementary material on the SAGE Journals platform.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway

3.1.1 Plagiarism

Journal of Health Psychology and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is

found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway

3.3 Open access and author archiving

Journal of Health Psychology offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please

visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

3.4 Transparency, Openness and Replication Policy

From the 1st July 2020, *Journal of Health Psychology* requires all authors to make their data fully accessible for all empirical research submitted to the journal for publication and will only consider manuscripts which follow an open publication model with M = Mandatory, I = Inclusion (of), R = Raw, D = Data (MIRD). According to the MIRD model, all contributions of new qualitative and quantitative studies must fully document and share the raw data collected by the author(s) or their data collection team together with full details of the analytical procedures used. All data and analytical procedures must be sufficiently well described to enable a third party with the appropriate level of expertise to replicate the data analyses.

Authors must include their raw data and disclose the key aspects of the research design to every extent possible. The raw data and associated contextual information will be sent to reviewers, revised alongside the paper in every round and published alongside the paper (as an appendix or online supplement). In addition to publishing the raw data with the article, the data must be shared through a digital repository. Authors have to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier, for example a Digital Object identifier (DOI).

The MIRD data sharing principle will be applied to all empirical studies, not only clinical trial report data:

1. As of 1 July 2020, manuscripts concerning clinical trials and other empirical studies that are submitted to *Journal of Health Psychology* must contain a data sharing statement as delineated in section 2.8 Research Data.
2. Any clinical trial that begins enrolling participants and is intended for later submission to *Journal of Health Psychology* must include a data sharing plan in the trial's registration.

It is *Journal of Health Psychology* policy that authors submit detailed information on empirical analysis alongside their written article. Authors should upload *at least* the first four files listed below when they submit their article.

- data set
- syntax file(s) from the software that has been used for the analysis;
- explanatory memo: explaining enclosed files/material and their content including help with regard to the analysis, which is important when non-standard techniques have been used; this may also apply to qualitative work; also some information on the software used for the analysis, including its version, is required;
- log file(s): output with results from the software that has been used for the analysis;
- Additional data analysis, including robustness analyses

Authors must provide a separate readme PDF listing all included files and documenting the purpose and format of each file provided, as well as instructing a user on how a replication can be conducted.

Making datasets publicly available is mandated by *Journal of Health Psychology* policy. Authors should ensure that they are uploading to the *Journal of Health Psychology* SAGE Track submission site, all data to do with their article. Once the article is accepted and published, it will be automatically uploaded to the Figshare repository.

The manuscript will not be moved through to Peer Review, or to Production until the editor is satisfied that all relevant data has been submitted alongside the manuscript. If cited data are restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors must notify the editor at the time of submission. The editor shall have full discretion to follow the journal's policy on restricted data, including declining to review the manuscript of granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

In addition to sharing the raw data, *Journal of Health Psychology* requires authors to delineate clearly the analytic procedures upon which their published claims rely and, where possible, provide access to all relevant analytic materials.

3.4.1 Replication studies

Journal of Health Psychology encourages the submission of replication studies regardless of whether or not the findings are statistically significant. Normally replication studies fall within of one or more of the following types:

Theoretical replication: The submitted article argues that the original theoretical model is missing at least one key element. The missing element(s) are addressed and included in the empirical analysis;

***Technical replication*:** The submitted article identifies faults in the original research design or analysis, thereby arguing that the original results might not hold; and/or

***Concept replication**:* The submitted article questions the validity of the original study. An alternative measurement or operationalisation is proposed which yields different substantive results.

3.4.2 Preregistration of Studies and Analysis Plans

Researchers conducting experimental studies are encouraged to consider pre-registering their research design in advance with an established registry. *Journal of Health Psychology* will publish papers where authors indicate the conducted research was preregistered with an analysis plan in an independent, institutional registry (e.g., http://clinicaltrials.gov/) of studies involves registering the study design, variables, and treatment conditions. Including an analysis plan involves specification of sequence of analyses or the statistical model that will be reported.

For preregistered studies, the following requirements apply:

1. Authors must, in acknowledgments or the first footnote, indicate that research was preregistered in an independent, institutional registry (with name and link to its location) with an analysis plan;
2. The author must:

    1. confirm in the text that the study was registered prior to conducting the research with links to the time-stamped preregistration(s) at the institutional registry, and that the preregistration adheres to the disclosure requirements of the

institutional registry or those required for the preregistered badge with analysis plans maintained by the Center for Open Science.

2. report all pre-registered analyses in the text, or, if there were changes in the analysis plan following preregistration, those changes must be disclosed with explanation for the changes clearly distinguish in text analyses that were preregistered from those that were not, such as having separate sections in the results for confirmatory and exploratory analyses (these changes are added as a separate document linked to the text of the main paper)

4. Preparing your manuscript for submission

Please ensure that your manuscript is suitable for publication and completely free of errors before you submit. Please pay particular attention to SAGE guidelines on Authorship and the SAGE Correction Policy.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Language and terminology

Authors must follow the Guidelines to Reduce Bias in Language of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

The language used in your manuscript should be inclusive and language that might be deemed sexist or racist should not be used. All submissions should avoid the use of pejorative terms and insensitive or demeaning language and submissions that use unacceptable language will be returned by the editor.

Useful websites to refer to for guidance

We recommend that authors consider looking at the below guidance:

- APA guidelines on Bias Free Language
- Words Matter
- Authors are encouraged to refer to land use any language guidelines that relate specifically to their research

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's *Manuscript Submission Guidelines*

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files

4.5 Reference style

Journal of Health Psychology adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use *EndNote* to manage references, you can download the SAGE Harvard EndNote output file.

4.6 English language editing services

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

5. Submitting your manuscript

Journal of Health Psychology is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts.
Visit http://mc.manuscriptcentral.com/jhealthpsychology to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the

end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which

significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any enquires about the manuscript submission process, the status of a submission, selecting the appropriate manuscript type, journal policies, or fit with the journal's aims and scope should be addressed to: hpq@sagepub.com

Appendix: Theoretically Driven Research Project

Appendix N: Ethical approval

Miss Alice Parfitt
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
The Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre | Warneford Hospital
Oxford
OX3 7JXN/A

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

27 May 2021

Dear Miss Parfitt

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

Study title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD

IRAS project ID: 289268

Protocol number: PID15428

REC reference: 21/NW/0124

Sponsor: University of Oxford ~ Clinical Trials and Research Governance

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

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

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

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

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

How should I work with participating non-NHS organisations?

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

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?

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

Your IRAS project ID is **289268**. Please quote this on all correspondence.

Yours sincerely,



Natalie Marking

Approvals Specialist

Email: approvals@hra.nhs.uk

Appendix O: Participant information sheet and consent forms

Participant information sheet

The Oxford Institute of Clinical Psychology
Training and Research
Isis Education Centre | Warneford Hospital
Oxford | OX3 7JX
Email: alice.parfitt@hmc.ox.ac.uk

PARTICIPANT INFORMATION SHEET

Study title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD

The above research is being undertaken as part of the lead researcher's Doctorate in Clinical Psychology qualification.

You are being invited to take part in a research study on the role of self-compassion within Obsessive Compulsive Disorder (OCD) treatment. This will be looking to see whether self-compassion plays a role in readiness to engage in therapy and how well treatment works, and if so provide a focus for future psychological treatments.

Before you decide, it is important for you to understand why the research is being done and what it involves. Please read this information sheet carefully and do ask if anything is not clear or you would like more information.
If you do decide to take part, we ask you to please sign the consent form below.

What is the purpose of the study?
Current research suggests that results of psychological treatment can vary for those with OCD, so we need to explore why this is and consider how best to improve future treatments to meet the needs of more individuals suffering with OCD.

It has been suggested that self-compassion (i.e., the ability to be kind to oneself, to understand that distress is a common human experience and to tolerate difficult experiences) may be important in OCD.

We therefore aim to explore with those seeking treatment for mild-moderate OCD whether self-compassion plays a role in readiness to engage in treatment and how well treatment works. If so, then focusing on self-compassion may help to improve how helpful OCD treatment is in the future.

Why have I been invited to take part?

You have been invited to take part, as we understand you are about to start treatment for OCD within your local Improving Access to Psychological Therapies (IAPT) service[6]. As before we are interested to explore the role of self-compassion with adults currently seeking psychological treatment for OCD. We are intending to involve 85 participants receiving treatment for OCD in the study.

Do I have to take part?
No, taking part in the research is optional. You can withdraw from the study if you later change your mind without giving a reason. Choosing to take part or not or choosing not to remain in the study will not affect your treatment in any way.

What is involved if I decide to take part?
As is standard in IAPT services you will be asked by your therapist to complete 3 questionnaires looking at your symptoms of depression, anxiety and OCD at the start and end of treatment. With your consent the researchers will be sent a copy of these scores.

1.The researchers will ask you after your first appointment to complete 3 additional questionnaires. These are looking at the content of your obsessive beliefs, your level of self-compassion and your readiness to engage in treatment.
You will be given the option to complete these yourself either via an online Qualtrics link, via questionnaires sent by email, questionnaires sent by post or by telephone with the researcher. Completing these questionnaires is estimated to take around 10-20 minutes in total, however if completing questionnaires by phone this may take up to 30 minutes.
2. At the end of your treatment we will ask you to again complete 2 of the additional questionnaires looking at the content of your obsessive beliefs and your level of self-compassion.

If you are a non-English speaker we will aim to offer the questionnaires in your chosen language provided a validated version of the questionnaire is available. If this is not possible, we apologise that it will not be possible to take part in the study on this occasion.

It is important for us to collect the first set of questionnaires before you start your treatment. If you do not complete the questionnaires by this time unfortunately you will be unable to continue in the study.

What are the possible disadvantages / risks of taking part?
As with completing any questionnaires on your mood there is the potential that these may cause some distress when completing the questionnaires or afterwards. If this occurs we would encourage you to contact the local support services listed on the questionnaires (including Samaritans – Tel: 116 123, NHS out of hours – Tel: 111 & your local crisis team). You can also contact your local IAPT service *[Tel: 01865 901222]* or the lead researcher at (alice.parfitt@hmc.ox.ac.uk).

What are the possible benefits of taking part?
There are no direct benefits to taking part. However by taking part there is the opportunity to contribute to shaping future treatments for individuals with OCD. At this time we are unclear what the results will be which is why we are conducting the research. The aim is to publish this research in a peer-reviewed journal to share the findings with other researchers and clinicians. We are unable to reimburse participants for taking part in the study.

Will my GP/ doctor be informed of my participation?
No, we will not let your GP know that you are taking part in the study, as your treatment will continue to be the same.

What data will be collected?
As above your answers to the above questionnaires will be collected. Data on demographics – (for example: age, gender and ethnicity) and minimal clinical data (eg duration of your OCD and type and

[6] Your local IAPT service may be called Talking Therapies, TalkingSpace Plus or Healthy Minds.

length of treatment) will also be collated from your medical records by the researcher with your consent.

The 3 questionnaires collected routinely by IAPT services will be stored on your patient notes and with your consent, both your therapist and researcher will have access to these scores. The 3 additional questionnaires will be collected and viewed by the researcher only. Your data will be anonymised with each participant being assigned a unique code.

Will my taking part in the study be kept confidential?
As above all data will be stored confidentially and only viewed by those you have given consent to view this. Your data will remain confidential and would only be shared with the relevant professional(s) if there were concern that you or others were at risk of imminent harm. Your data will be stored on a secure database in line with data protection laws. Any identifiable information (for example, your name and contact details) will be stored separately from the data collected during this study. Following completion of the study and fully anonymised publication of the findings your data will be destroyed.

Responsible members of the University of Oxford [and the relevant NHS Trust(s)] may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

What will happen to my data?
Data protection regulation requires that we tell you the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly.

We will be using information from you and your medical records in order to undertake this study and will use the minimum personally identifiable information possible. In line with university policy, we will keep the information you provide in the study (excluding your personal data) on a securely encrypted file for up to 3 years after publication of the results.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at: https://compliance.web.ox.ac.uk/individual-rights. You can find out more about how we use your information by contacting the lead researcher (alice.parfitt@hmc.ox.ac.uk)

What will happen if I don't want to carry on with the study?
Participation in the study is voluntary and you can later change your mind. If you change your mind during the study, you can stop being part of the research at any time without giving a reason. We will continue to use the data we have collected until this point.
We will, however no longer contact you about completing the second part of the study or collect any further data about you, unless you opt in to taking part in this part of the study by informing the researcher at the point of withdrawing. As above, this will not affect your treatment in any way.

What will happen to the results of the study?
We hope to publish the research findings in a peer-reviewed journal. We may also present the findings at national conferences. Please note you will not be identifiable from the data as this will have been grouped with others and anonymised.
The research will also contribute to the fulfilment of a doctoral thesis as part of the lead researcher's Doctorate in Clinical Psychology.
You will be asked if you are happy for the researchers to retain your contact details in order to send you a copy or link to the research findings. If you consent to this your contact details will be held for up to 1 year for this purpose alone.

What if there is a problem?
Should you wish to complain about any aspect of the way in which you were approached or treated, or how your information is handled during the course of this study please contact: Alice Parfitt (alice.parfitt@hmc.ox.ac.uk) or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 616480, or the head of CTRG, email: ctrg@admin.ox.ac.uk.
You can also contact your local Patient Advice and Liaison Service (PALS) team on [*Tel: 0800 328 7971] who are independent from the study.*

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

How have patients and the public been involved in this study?
Individuals with OCD have reviewed the research design and wording of the questionnaires. Changes have been made to ensure that questionnaires are easy to understand and the research process is as simple as possible.

Who is conducting and funding the research?
The research is being conducted by Alice Parfitt (Trainee Clinical Psychologist) at the University of Oxford as part of a Clinical Doctorate Training programme. This is being supervised by Dr Sarah Rakovshik (Senior Associate Tutor) and Prof Paul Salkovskis (Course Director) based at the University of Oxford and working for Oxford Health NHS Foundation Trust. The study is being funded by Oxford Health NHS Foundation Trust and sponsored by the Clinical Trials and Research Governance (CTRG) office based at University of Oxford.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Preston Research Ethics Committee.

Thank you for considering taking part.

<Participant Information Sheet>	**<Version: 1.1>**
<Title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD>	**<IRAS project number: 289268>**
<Chief Investigator: Alice Parfitt>	**<REC reference no: 21/NW/0124>**

Consent form (standard)

The Oxford Institute of Clinical Psychology
Training and Research
Isis Education Centre | Warneford Hospital
Oxford | OX3 7JX
Email: alice.parfitt@hmc.ox.ac.uk

Study code: *Site ID code:* *Participant identification number:*

CONSENT FORM

Study title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD
Researcher: Alice Parfitt

If you agree, please initial the box

1. I confirm that I have read the information sheet dated 20.5.21 (version 1.1) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and without my medical care/ treatment or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, University of Oxford, regulatory authorities and my local NHS trust (Berkshire Healthcare/ Buckinghamshire Healthcare or Oxford Health NHS Foundation Trust), where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I understand that the information collected about me will be anonymised and summarised together with other participants and used to support other research in future, for example by being shared in a peer-reviewed journal publication.	
5. I understand that the research team will hold my personal details (name, contact details) for the duration of the study in order to contact me for research purposes, however the rest of my data will be anonymised and each participant assigned a unique code. Following completion of the study my data will be destroyed.	
6. I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Additional questions:

1- … I agree to be prompted by the research team via text to complete these measures.

2- I would like to receive the measures:
… by post
… by email
… online link
… by phone

3- …. I agree for my contact details to be retained for up to 1 year so that the researchers can send me a copy or link to the research findings.

**The above form will be kept as follows: 1 copy for participant; 1 copy to be kept in medical notes, 1 (original) for researcher site file.*

<Consent form>	**<Version: 1.1>**
<Title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD>	**<IRAS project number: 289268>**
<Chief Investigator: Alice Parfitt>	**<REC reference no: 21/NW/0124>**

Consent form (verbal)

The Oxford Institute of Clinical Psychology
Training and Research
Isis Education Centre | Warneford Hospital
Oxford | OX3 7JX
Email: alice.parfitt@hmc.ox.ac.uk

Study code: *Site ID code:* *Participant identification number:*

VERBAL CONSENT FORM

Study title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD
Researcher: Alice Parfitt

If individual agrees, researcher to initial the box

1. Do you confirm that you have heard/ read the information for this study (as detailed in the information sheet dated xx (version 1.0))? Have you had the opportunity to consider the information, ask questions and have had these answered satisfactorily?	
2. Do you understand that your participation is voluntary and you are free to withdraw at any time without giving any reason and without your medical care/ treatment or legal rights being affected?	
3. Do you understand that relevant sections of your medical notes and data collected during the study may be looked at by individuals from the research team, University of Oxford, regulatory authorities and your local NHS trust (Berkshire Healthcare/ Buckinghamshire Healthcare or Oxford Health NHS Foundation Trust), where it is relevant to your taking part in this research. Do you give permission for these individuals to have access to your records?	
4. Do you understand that the information collected about you will be anonymised and summarised together with other participants and used to support other research in future, for example by being shared in a peer-reviewed journal publication?	
5. Do you understand that the research team will hold your personal details (name, contact details) for the duration of the study in order to contact you for research purposes, however the rest of your data will be anonymised and each participant assigned a unique code? Following completion of the study your data will be destroyed.	
6. Do you agree to take part in the above study?	

Name of Participant Date

Name of Researcher Date Signature

Additional questions:

1- … Do you agree to be prompted by the research team via text to complete these measures?

2- Would you like to receive the measures:
… by post
… online
… by phone

3- … Do you agree for your contact details to be retained for up to 1 year so that the researchers can send you a copy or link to the research findings?

**The above form will be kept as follows: 1 copy for participant; 1 copy to be kept in medical notes, 1 (original) for researcher site file.*

<Verbal Consent form>	**<Version: 1.1>**
<Title: The role of self-compassion in readiness to engage in treatment and treatment outcomes for OCD>	**<IRAS project number: 289268**
<Chief Investigator: Alice Parfitt>	**<REC reference no: 21/NW/0124>**

Appendix P: Author guidelines for British Journal of Clinical Psychology

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at http://www.editorialmanager.com/bjcp

Read more details on how to use Editorial Manager.

All papers published in the *British Journal of Clinical Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The *British Journal of Clinical Psychology* publishes original research, both empirical and theoretical, on all aspects of clinical psychology:

- clinical and abnormal psychology featuring descriptive or experimental studies
- aetiology, assessment and treatment of the whole range of psychological disorders irrespective of age group and setting
- biological influences on individual behaviour
- studies of psychological interventions and treatment on individuals, dyads, families and groups

For specific submission requirements, **read** the Author Guidelines.

The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers, provided that these are sufficiently related to empirical data;
- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;

- Brief Reports and Comments.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Papers describing quantitative research should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.

In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

Refer to the separate guidelines for **Registered Reports**.

All systematic reviews must be pre-registered.

4. PREPARING THE SUBMISSION

Free Format Submission

British Journal of Clinical Psychology now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including a data availability statement and your co-author details with affiliations. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)* You may like to use this template for your title page.

Important: the journal operates a double-blind peer review policy. Anonymise your manuscript and prepare a separate title page containing author details. *(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)*

- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*

To submit, login at **https://www.editorialmanager.com/bjcp/default.aspx** and create a new submission. Follow the submission steps as required and submit the manuscript.

If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

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