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

Victoria Edwards

Harris Manchester College

University of Oxford

August 2022

## Word Counts

| | |
|---|---|
| Critical Review of the Literature (CRL) | 7,031 |
| Service Improvement Project (SIP) | 4,996 |
| Theoretically Driven Research Paper (TDRP) | 5,500 |
| Executive Summary | 649 |
| Connecting/Reflective Narrative | 941 |

## Table of Contents

**Word Counts** ..... **2**

**Abstracts** ..... **6**

**Critical Review of the Literature** ..... **11**

Abstract ..... 12

Introduction ..... 14

Method ..... 17

Results ..... 24

Discussion ..... 49

References ..... 56

**Service Improvement Project** ..... **69**

Abstract ..... 70

Introduction ..... 72

Method ..... 75

Results ..... 79

Discussion ..... 87

References ..... 94

**Theoretically Driven Research Project** ..... **109**

Abstract ..... 110

Introduction ..... 111

Method ..... 115

Results ..... 123

Discussion ..... 141

References ..... 147

**Executive Summary ..... 155**

**Connecting/ Reflective Narrative ..... 158**

**Acknowledgments ..... 162**

**Appendices ..... 163**

Appendix A: CRL – Approvals ..... 163

Appendix B: CRL – Supplementary information on bracketing interview ..... 163

Appendix C: CRL – Search strategy ..... 164

Appendix D: CRL – Supplementary information on CASP ..... 165

Appendix E: CRL – Supplementary information on exclusion rationale ..... 165

Appendix F: SIP – Approvals ..... 166

Appendix G: SIP – Supplementary information on bracketing interview ..... 167

Appendix H: SIP – Information pack ..... 168

Appendix I: SIP – Debrief sheet ..... 172

Appendix J: SIP – Participant demographic and descriptive information ..... 173

Appendix K: SIP – Staff focus group interview schedule ..... 175

Appendix L: SIP – Patient semi-structured interview schedule ..... 176

Appendix M: SIP – Representative quotes from staff focus groups ..... 177

Appendix N: SIP – Representative quotes from patient interviews ..... 183

Appendix O: SIP – Agenda for service feedback ..... 190

Appendix P: SIP – Lay summary ..... 190

Appendix Q: MRP – Approvals ..... 191

Appendix R: MRP – Supplementary information on recruitment and procedure ..... 193

Appendix S: MRP – Study documentation ..... 195

Appendix T: MRP – Additional descriptive information ..... 205

Appendix U: MRP – Measures pack ..... 207

## Abstracts


### Critical Review of the Literature

**Background:** Chronic pelvic pain syndrome (CPPS) is a common condition that can reduce quality of life. To explore the psychosocial impact of CPPS, this review provided an up-to-date synthesis and assessment of qualitative papers. The review aimed to i) synthesise results from recent qualitative studies to identify themes regarding the lived experience and psychosocial impact of CPPS; ii) analyse the quality of the synthesised papers; iii) consider implications for clinical practice and research.

**Method**: The electronic databases Medline, Embase, PsycInfo, CINAHL, Web of Science, and Scopus were searched in June 2021 and updated in April 2022. Inclusion criteria consisted of qualitative results published in English from 2014 onwards in peer-reviewed journals that explored the psychosocial impact of urological and gynaecological CPPS in adults. Risk of bias was assessed using the CASP Qualitative Studies Checklist. A thematic approach described by Thomas and Harden (2008) was used for the meta-synthesis.

**Results:** Thirty-seven papers were identified; all were rated as medium or high quality. Greater reporting around participants' demographics and researchers' reflexive accounts would strengthen the evidence base. Only one paper with male participants was found, thus synthesis focused on women's experiences from 36 papers describing 34 datasets. Themes included: dominance of CPPS (impacting multiple aspects of life, disrupting life trajectories, unpredictability of symptoms); lack of understanding (lack of CPPS awareness, stigma); isolation (reduced social life, impact on sex and intimate relationships); negative sense of self (lost identity, self-blame) and psychosocial strategies (unhelpful and helpful). There were relatively consistent experiences across different CPPS subtypes and initial insights into differences depending on age, sexuality, and culture.

**Conclusions:** CPPS can have a significant impact on multiple life domains, supporting research on the significant impact of chronic pain conditions on quality of life. CPPS can be exacerbated by a lack of understanding (individual and societal), and misunderstanding. Stigma concerning pain associated with menstruation, genitalia, sex, and infertility can lead to isolation, shame, guilt, disrupted sense of identity, and reduced self-worth. Further research is required to facilitate the safe disclosure of 'embarrassing' symptoms, the potential underreporting of difficulties with incontinence and toileting, and the experiences of men and LGBTQ+ individuals. Multidisciplinary services, long-term management plans, access to peer support and psychological strategies are recommended. Overall, this paper highlights the significant psychosocial impact of CPPS and the need for greater awareness, education, and support to enable individuals to manage its multifaceted complexities.

***Keywords:*** Chronic pelvic pain syndrome; psychosocial impact; systematic review; qualitative synthesis

**Service Improvement Project**

**Background:** Chronic pelvic pain syndrome (CPPS) can reduce quality of life and increase healthcare utilisation. The John Radcliffe Hospital Gynaecology Department can find supporting CPPS patients particularly challenging due to prolonged and repeated admissions and limited treatment options. Patients have made formal complaints when discharged without medical treatments and staff can be unsure how to best provide care. This project aimed to gain a greater understanding of these challenges and generate user-informed service recommendations.

**Method**: Two staff focus groups were conducted using opportune sampling. Patients were interviewed individually if they were 18 years and above, had been an inpatient within the past three years, remained under the department and were able to provide informed consent. Exclusion criteria included pregnancy, upcoming or ongoing surgery or safeguarding concerns. Staff and patient data were gathered using semi-structured interviews and analysed separately using inductive thematic analysis.

**Results:** Eleven nurses formed the staff focus groups. Themes included a) difficulties understanding chronic pain, b) working with a condition with no clear fix and c) what helps the service respond well. Nineteen patients were sent information packs with eight interviewed (42% response rate). Themes included a) never knowing what is going to happen, b) feeling medically safe, and c) being sent home unequipped.

**Conclusions:** Staff and patients described uncertainties about how to understand and manage pain and the nature and purpose of admissions. Some differences in how staff and patients conceptualised admissions are noted. This study supports and builds upon research into invalidating discourses around ‘women’s problems’ and ‘hidden’ chronic pain conditions and highlights the need for collaborative, multidisciplinary approaches. Key recommendations include staff training about CPPS, facilitating conversations with

patients to provide holistic care, reducing uncertainties, and re-framing admissions as support through a crisis rather than a ‘fix’.

***Keywords*:** Chronic pelvic pain syndrome; thematic analysis; support; service improvement

**Theoretically Driven Research Paper**

**Background:** Unmet interpersonal needs may play a role in excessive emotional attachments to objects for people with hoarding difficulties (HD). Evidence of attachment difficulties stemming from childhood have been noted in HD and may be reflected in the extent of social networks. Previous research indicates that attachment difficulties may not be specific to HD but there are preliminary indications that the extent of social support may be specific.

**Aims**: To evaluate social networks and support in HD relative to clinical controls with obsessive compulsive disorder (OCD) and healthy controls (HC). The secondary aim was to explore the extent of loneliness and thwarted belongingness. Potential mechanisms for deficits in social support were also examined.

**Method:** A cross-sectional between-groups design was used to compare scores on measures in those with HD ($n$ = 37); OCD ($n$ = 31); and HCs ($n$ = 45).

**Results:** Whilst individuals with HD and OCD both report smaller social networks than HC, lower levels of social support appear to be specific to HD. The HD group also showed higher levels of loneliness and thwarted belonging compared to OCD and HC. No differences were found between groups for perceived criticism or trauma.

**Conclusions:** These results support the previous finding of lower levels of self-reported social support within HD. Loneliness and thwarted belongingness also appear significantly elevated within HD compared with OCD and HC. Further research is required to explore the nature of felt support and belonging, direction of effect and to identify potential mechanisms. Clinical implications include the importance of advocating and promoting support systems for individuals with HD and consideration of the role of personal supporters and professionals with healthcare, social care, and charitable sectors.

***Keywords:*** *Hoarding, OCD, social support, loneliness, thwarted belongingness*

**Critical Review of the Literature**

# Title: The Psychosocial Impact of Urological and Gynaecological Chronic Pelvic Pain Syndromes on Individuals' Daily Lives: A Systematic Review & Meta-Synthesis

Victoria Edwards

victoria.edwards@hmc.ox.uk

Department of Psychology, University of Oxford, Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

**Word Count:** 6,986

**Date:** May 2022

**Internal Supervisor:** Dr Matthew Knight

Senior Admissions Tutor, Clinical Tutor & Consultant Clinical Psychologist, Oxford Institute for Clinical Psychology Research and Training

**External supervisor:** Dr Emma Evans

Clinical Psychologist, Oxford University Hospitals NHS Foundation Trust

**Intended journal and rationale:** The British Journal of Pain. This is a peer-reviewed journal that is suitable for this review as it publishes research on all major aspects of pain and pain management and has a multidisciplinary readership.

## Abstract

**Background:** Chronic pelvic pain syndrome (CPPS) is a common condition that can reduce quality of life. To explore the psychosocial impact of CPPS, this review provided an up-to-date synthesis and assessment of qualitative papers. The review aimed to i) synthesise results from recent qualitative studies to identify themes regarding the lived experience and psychosocial impact of CPPS; ii) analyse the quality of the synthesised papers; iii) consider implications for clinical practice and research.

**Method**: The electronic databases Medline, Embase, PsycInfo, CINAHL, Web of Science, and Scopus were searched in June 2021 and updated in April 2022. Inclusion criteria consisted of qualitative results published in English from 2014 onwards in peer-reviewed journals that explored the psychosocial impact of urological and gynaecological CPPS in adults. Risk of bias was assessed using the CASP Qualitative Studies Checklist. A thematic approach described by Thomas and Harden (2008) was used for the meta-synthesis.

**Results:** Thirty-seven papers were identified; all were rated as medium or high quality. Greater reporting around participants' demographics and researchers' reflexive accounts would strengthen the evidence base. Only one paper with male participants was found, thus synthesis focused on women's experiences from 36 papers describing 34 datasets. Themes included: dominance of CPPS (impacting multiple aspects of life, disrupting life trajectories, unpredictability of symptoms); lack of understanding (lack of CPPS awareness, stigma); isolation (reduced social life, impact on sex and intimate relationships); negative sense of self (lost identity, self-blame) and psychosocial strategies (unhelpful and helpful). There were relatively consistent experiences across different CPPS subtypes and initial insights into differences depending on age, sexuality, and culture.

**Conclusions:** CPPS can have a significant impact on multiple life domains, supporting research on the significant impact of chronic pain conditions on quality of life. CPPS can be exacerbated by a lack of understanding (individual and societal), and misunderstanding.

Stigma concerning pain associated with menstruation, genitalia, sex, and infertility can lead to isolation, shame, guilt, disrupted sense of identity, and reduced self-worth. Further research is required to facilitate the safe disclosure of ‘embarrassing’ symptoms, the potential underreporting of difficulties with incontinence and toileting, and the experiences of men and LGBTQ+ individuals. Multidisciplinary services, long-term management plans, access to peer support and psychological strategies are recommended. Overall, this paper highlights the significant psychosocial impact of CPPS and the need for greater awareness, education, and support to enable individuals to manage its multifaceted complexities.

***Keywords:*** Chronic pelvic pain syndrome; psychosocial impact; systematic review; qualitative synthesis

## Introduction

Chronic pelvic pain syndrome (CPPS) is a condition involving persistent pain within the pelvis. Approximately 15% of women aged ≥25 years were found to have CPPS in a UK sample (Ayorinde et al., 2017). Worldwide prevalence rates are hampered by a paucity of population-based studies but are estimated at 5.7- 26.6% (Ahangari, 2014). CPPS has no single identifiable pathology and is a diagnosis of exclusion. Symptoms can vary greatly and may include urinary tract, sexual, bowel, pelvic floor, or gynaecological dysfunction and psychological, cognitive, behavioural, sexual and emotional consequences (European Association of Urology, 2022). The experience of pain itself can also vary between individuals regarding intensity, chronicity and affected areas (Drabble, 2020). This heterogeneity appears to contribute to underdiagnoses, and limited access to specialist services and pain management (Breivik et al., 2006). This is concerning given the detrimental impact CPPS can have on quality of life (QoL) and mental health (EAU, 2022). In a large European study of adults with chronic pain, the majority had reduced or stopped working due to pain and 21% were diagnosed with depression (Breivik et al., 2006). Given treatment relies on management strategies rather than a cure, it is important to explore patients' experiences of living with CPPS to understand and mitigate its consequences.

Exploration through qualitative research is appropriate given that chronic pain is a subjective experience that is personal and contextually situtated (Crowe et al., 2017). Yet qualitative research has been under-utilised within CPPS (Mellado et al., 2019). Research, clinical assessments and interventions have often focused on the biological components of CPPS but there is increasing acknowledgement of its psychological impact. To acknowledge these complexities, pain has been redefined as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020). There is increasing interest in qualitative

research to gain a holistic understanding of pain. This could enable management strategies and psychosocial interventions to be recognised as equally valuable and sit alongside biomedical models in promoting QoL.

As well as different components of pain, there is increasing research into the interaction between biological and psychosocial components (World Health Organization, 2017). As research mainly utilises cross-sectional data the direction of effect or presence of a bi-directional relationship remains unclear. Psychosocial factors may influence the onset, severity and persistence of CPPS (Chung & Lin, 2013; Laganà et al., 2017) and CPPS may increase depression and anxiety (Chen et al., 2016). One meta-analysis found higher levels of depression among women with endometriosis compared to controls, moderated by pain (Gambadauro et al., 2019).

Individual and contextual factors are likely to moderate the experience of CPPS, especially given the diversity of pain experiences and healthcare provisions (Gambadauro et al., 2019). Indeed, an individual's reaction to pain can impact the way they experience CPPS (Alappattu & Bishop, 2011). Psychological factors such as pain catastrophising are commonly associated with higher pain levels and decreased QoL in CPPS (Krsmanovic et al., 2014; Sewell et al., 2018). Individuals who felt they had "something more serious" than their doctor diagnosed, reported more severe pain, disability and distress (Roth et al., 2011). Lower self-esteem and emotional self-efficacy have also been associated with greater distress among individuals with endometriosis (Facchin et al., 2017). Further, Facchin et al. (2017) found that being in a stable, intimate relationship was associated with less rumination. This is consistent with other literature on the importance of social support as a protective factor (Van der Kolk, 2014).

Equally, a lack of social support may have negative consequences (Link & Phelan, 2006). A lack of social acceptance, or stigma, is defined as "labelling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised" (Link

& Phelan, 2001). Stigma can depend on the extent to which society deem conditions significant and relevant (e.g. bone fractures or cancer) or undesirable (e.g. AIDS or schizophrenia) (Link & Phelan, 2006). Health conditions such as chronic pain are commonly associated with stigma and may be exacerbated by additional mental health difficulties (Naushad et al., 2018). Stigma may be particularly prevalent in CPPS due to societal discourse around menstruation and the normalization of 'women's pains' (As-Sanie et al., 2019). Pain associated with reproduction may entail a heavier psychosocial burden compared with other chronic pain conditions due to implications for fertility, sexuality and romantic relationships (Bergeron et al., 2014). Therefore, increased understanding of the potential role of stigma is important in the development and implementation of tailored interventions and policies.

**Rationale for Proposed Review**

There is increasing interest in qualitative research to explore the psychosocial complexities of CPPS yet there are no recent reviews synthesising results. Although the EAU guidelines are revised annually, there has been no update of the "psychological aspects" of CPPS chapter since their 2014 review (Engeler et al., 2014). Further, it focuses specifically on the implications of experiencing pain, whereas this review aims to explore a holistic understanding of the impact of CPPS. One review that has examined the impact of CPPS included all published papers (including ones over 25 years old) that may not capture current experiences (Toye et al., 2014). It consisted only of "CPPS" and "endometriosis" despite many CPPS subtypes and patients often having overlapping and multiple diagnoses. A new review with a greater spectrum of subtypes would prevent the exclusion of minority subtypes that receive less research and could explore experiences across subtypes. Furthermore, there is increasing emphasis on systematically documenting risk of bias (Garner et al., 2016). A new review applying a formal quality appraisal tool

and synthesising recent research would promote understanding of the current literature base and implications for clinical practice and research.

### Objectives

i. Synthesise results from qualitative studies to identify themes regarding the psychosocial impact of living with CPPS.
ii. Analyse the quality of the synthesised papers.
iii. Consider implications for clinical practice and research.

## Method

This review aimed to synthesise qualitative studies that explored the experiences of adults with CPPS. Given that the latest EAU guidelines and systematic review on this topic were both in 2014, this review looked at studies published from 2014 onwards to gain a greater understanding of themes as well as the quality of the latest evidence base. In line with existing research, this review focused on urological and gynaecological subtypes. This was to inform clinical practice, as they are commonly grouped due to similar symptomology and treatment within the same clinical service (e.g., a Urogynaecologist within a Women's health centre). Other CPPS conditions, such as irritable bowel syndrome (IBS) within the gastrointestinal division, commonly entail separate clinical pathways and research (Shorey et al., 2020). The aim was to build upon pre-existing research to allow a comparison with other subtypes and pain conditions to enhance knowledge of potential transdiagnostic interventions and clinical pathways.

Before establishing the specific search criteria, a bracketing interview was conducted between the main researcher and an independent researcher to enhance reflexivity around how experiences, assumptions and biases may impact the research (see Appendix B). To increase transparency and validity, 'psychosocial impact' was defined in

line with the literature base. Psychological impact was defined as the influence on mood and affect (e.g. sadness), cognitions (e.g. worthlessness), behaviours (e.g. withdrawal) and somatic symptoms (e.g. apathy) (Drapeau et al., 2012). Cognitions could refer to the self, future and the world (Beck & Haigh, 2014). The concept of 'social' impact was guided by the Work and Social Adjustment Scale (Mundt et al., 2002). This identified key areas of life including work, home management, social and private leisure activities, and relationships. Alterations to any of the above domains due to CPPS were included in this review. This included adaptation/s to manage CPPS. The aim was to synthesise experiences of living with CPPS without a pre-defined stance and consider higher-order themes. The review did not include studies investigating lived experiences prior to developing CPPS.

## Eligibility Criteria

The review was conducted based on the following criteria:

### *Inclusion Criteria*

i. Adults with urological and gynaecological CPPS.
ii. Qualitative studies and mixed methods studies exploring the psychosocial impact of living with CPPS. For mixed-method studies, only qualitative results were included.
iii. Studies published from 2014 onwards.
iv. Papers published in peer-reviewed journals.

### *Exclusion Criteria*

i. Papers not written in English.
ii. Papers that do not report novel findings (e.g., review papers).
iii. Papers focusing on questionnaire development, interventions, or healthcare analysis.

## Information Sources

The following electronic databases were searched: Medline, Embase, PsycInfo, CINAHL, Web of Science, and Scopus on 13/06/2021 and updated 24/04/22. The update produced seven new papers highlighting the clinical importance of this topic and timeliness of this review. To ensure a comprehensive search, manual searches were completed of the references and papers that had referenced the papers meeting the final inclusion criteria.

## Search Strategy

The search strategy was developed by the reviewers in consultation with a research librarian. The search centred on terms relating to two concepts: CPPS and qualitative methodology. Limits included papers I) written in English; II) published 2014 onwards. See Appendix C for an example search strategy.

## Selection Processes

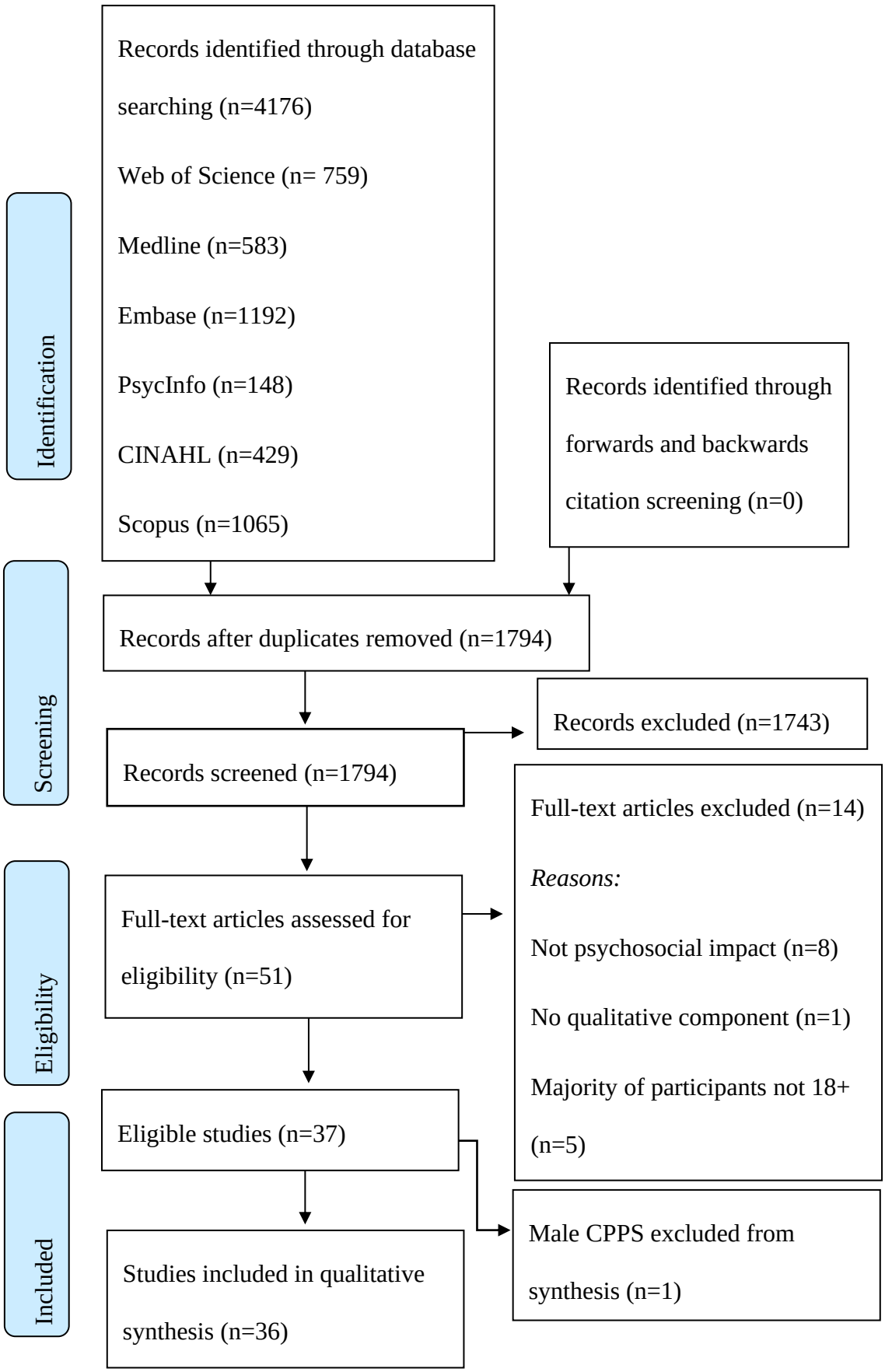
A Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow chart (Figure 1) describes the review process (Page et al., 2021). The combined electronic database search retrieved 4176 records. After removing duplicates, 1794 papers remained. All titles and abstracts were screened by one reviewer, with 25% being independently reviewed by a second. There was moderate agreement between the reviewers (k=0.820). If papers did not meet the criteria, they did not advance to the next stage. This excluded 1743 papers.

Fifty-one papers were reviewed through examining the full text. Fifteen papers (30%) were reviewed by a second reviewer. There was agreement on 13/15 papers signifying substantial agreement (k=0.700). The other two papers were discussed between reviewers with a third reviewer consulted to strengthen the final decision. From the full-

text review, 14 were excluded. Another reviewer (a Clinical Psychologist within a CPPS setting) reviewed the final papers to verify eligibility.

**Figure 1**

*Flow of Information during the Systematic Review based on the PRISMA 2020 Statement*



## Data Collection Process

Data was extracted by one reviewer, with a second reviewer independently checking a sample of 50% for correctness and completeness of data.

## Data Items

Data extraction included: title, author, publication year, country of origin, sample size, diagnoses, age, gender, ethnicity of participants, method of data collection, analytic approach, and themes. No assumptions were made regarding participant demographics when studies reported that they were representative of the local area.

## Study Risk of Bias Assessment

The methodological quality of studies was assessed using the CASP Qualitative Studies Checklist (CASP Qualitative Checklist, 2018) (see Appendix D). Whilst there can be contention around use of different assessment tools, structured instruments and transparent rationale allow reviewers to be explicit for the reasoning behind their judgements (Dixon-Woods et al., 2007).

Two reviewers independently assessed the quality of papers, with a second rater independently evaluating twelve papers (33%). There was 92% agreement between the first and second reviewer ratings. A third reviewer evaluated six papers, with 95% agreement between reviewers. Throughout the ratings, reviewers kept notes on their decision-making processes. Discrepancies and rationales were discussed before researching a consensus.

Whilst CASP does not suggest a specific scoring system, and caution is required regarding the arbitrary nature of cut-offs, classifying studies can aid reporting. This technique can be considered a preliminary stage to Thomas and Harden's approach (Long et al., 2020). It creates a transparent and systematic process to establish the quality of

papers prior to organising and synthesising papers. Scoring was completed based on the average quality score across reviewers. Categories included low (≤10), medium (11–15), and high (16-20) quality.

**Data Synthesis**

As only one paper was found with male participants it was not possible to reliably synthesise results about male experiences or explore cross-cutting themes regarding gender. Accordingly, this paper was not included in the synthesis (further information Appendix E).

Therefore, 36 papers were synthesised followed the thematic approach described by Thomas and Harden (2008). This data-driven method was chosen to enable an open exploration of individuals' experiences expressed within papers rather than imposing a pre-existing framework. It seeks to generate theory (generalisable explanations for social phenomena) using a systematic approach prominent within health research (Dixon-Woods et al., 2005). Firstly, the text was extracted from all papers and coded to identify key concepts within the data. Secondly, similarities and differences were examined between codes to group them, with new descriptions given to new groups of codes. An initial summary of findings was produced by the first reviewer and discussed and refined with two other reviewers in a cyclical process. Findings were reviewed and continually developed in a recursive process, with investigator triangulation helping to reflect on potential lenses and biases throughout the process. Codes were then translated into higher order themes to 'go beyond' the original data. For instance, codes around lost identity and self-blame led to the development of an overarching theme of negative sense of self. The aim of these concepts was to sufficiently describe and explain descriptive themes and create concepts that could link to healthcare and clinical interventions.

# Results

## Study Selection

Results included 36 papers reporting on 34 datasets as there were two occasions where datasets were analysed twice based on different research questions. In one case, the data was analysed regarding a) changes affecting body and mood (paper 6 in Table 1) and b) experienced restrictions (paper 7). Similarly, the same pool was analysed based on constructions of identity (paper 3) and women's lives and relationships (paper 8). As analysis involved different aims, all studies were included but with careful consideration not to overemphasise (i.e., double count) the data within the synthesis.

Methods of data collection consisted of individual interviews (21), focus groups (10) and written accounts in response to open-ended questions (5). Sample sizes ranged from five to 500. Few studies reported on response rate or reasons for not participating.

## Demographics

Eighteen papers focused on endometriosis. The others included adenomyosis (1), dysmenorrhea (2), dyspareunia (2), vulvodynia (2), vestibulodynia (2), interstitial cystitis/painful bladder syndrome (IC/PBS) (5) and a combination of CPPS subtypes (4). Participants were recruited predominantly via hospital settings or online forums and support organisations. Participant ages ranged from 17-77 years, with twelve studies reporting participant ethnicity (33%).

## Quality Assessment

All studies were assessed to be of medium (N=22, 61%) or high quality (N =14, 39%). Noted areas of strengths included papers having a clear statement of aims, appropriately using qualitative methodology, and consideration of ethical issues. Providing a clear statement of findings and discussion about the value of the research with regards to the evidence base and new areas for research was a strength for all studies.

All the papers described how participants were selected but there was often limited discussion around other areas of recruitment such as why certain participants were selected, or why people chose not to participate. Other methodological limitations included limited justifications regarding research designs, data collection and synthesis.

Whilst many studies provided sufficient descriptions of their analysis process, they rarely included an examination of the researcher's role during analysis and selection of data. There was also very little transparency regarding the relationship between the researcher and participants in formulating the research question and data collection.

**Table 1**

*Characteristics of included studies*

| **Paper** | **Reference** | **Country** | **Sample size** | **Diagnoses** | **Age range (/mean if not given)** | **Race /ethnicity (reported verbatim)** | **Data collection method** | **Quality grading**<br>* medium quality<br>** high quality |
|---|---|---|---|---|---|---|---|---|
| 1 | (Chen et al., 2018) | USA | 225 | Dysmenorrhea | 18-57 | Hispanic Ethnicity (11.6%)<br>Race: Asian/Pacific Islander (5.3%), Black/African American (12.9%), White/Caucasian | Questionnaire | 12* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | (73.8%), Native American (3.1%) | | |
| 2 | (Chen et al., 2020) | Taiwan | 22 | IC/PBS | - | - | Individual interviews | 12* |
| 3[a] | (Cole et al., 2021) | UK | 34 | Endometriosis | 22-56 | White: British or other European (88%), Multiple Ethnic Group (one White and Black Caribbean and one Asian) (6%), Persian (2%), Black/Black British: African (2%) | Questionnaire | 19** |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 4 | (Ekholm et al., 2022) | Sweden | 5 | Dyspareunia | 27-36 | - | Individual interviews | 16** |
| 5 | (Facchin et al., 2018) | Italy | 74 | Endometriosis | 24-50 | Caucasian (100%) | Individual interviews | 16** |
| 6[b] | (Fernández-Martínez, Abreu-Sánchez, Pérez-Corrales, et al., 2020) | Spain | 33 | Primary dysmenorrhea | 22.72 | - | Focus groups | 18** |
| 7[b] | (Fernández-Martínez, Abreu-Sánchez, | Spain | 33 | Primary dysmenorrhea | 22.72 | - | Focus groups | 18** |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Velarde-García, et al., 2020) | | | | | | | |
| 8[a] | (Grogan et al., 2018) | UK | 34 | Endometriosis | 22-56 | White (88%), Multiple Ethnic Group White and Black Caribbean (2%), Persian (2%), Asian (2%), Black British (2%) | Questionnaire | 18** |
| 9 | (Groven et al., 2016) | Norway | 8 | Vestibulodynia | 23-32 | - | Individual interviews | 14* |
| 10 | (Hållstam et al., 2018) | Sweden | 13 | Endometriosis | 24-48 | - | Individual interviews | 16** |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 11 | (Happel-Parkins et al., 2020) | USA | 8 | Dyspareunia | 21-34 | Caucasian (100%) | Individual interviews | 18** |
| 12 | (Hawkey et al., 2022) | Australia | 17 | CPPS and endometriosis | 32 | - | Focus groups | 15* |
| 13 | (Hintz, 2019) | USA | 26 | Vulvodynia | 20-52 | Caucasian (84.6%), Multiracial (7.7%), African American (3.8%), Hispanic (3.8%) | Individual interviews | 15* |
| 14 | (Huang et al., 2022) | China | 18 | Adenomyosis | 27-50 | - | Individual interviews | 12* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 15 | (Hudson et al., 2016) | UK | 22 | Endometriosis | 25–50 | Caucasian (63.6%), South Asian (27.2%), Other ethnic backgrounds (9%) | Individual interviews | 14* |
| 16 | (Jaeger et al., 2022) | Austria | 10 | Endometriosis | 22–51 | - | Individual interviews | 12* |
| 17 | (Kanter et al., 2017) | USA | 15 | IC/PBS | 52.6 | American Indian/Alaskan Native (13.3%), Non-Hispanic Caucasian (40.0%), Hispanic (26.7%), Other (20.0%) | Focus groups | 13* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 18 | (Kirkham & Swainston, 2021) | UK | 20 | IC/PBS | 21–69 | - | Questionnaire | 18** |
| 19 | (LePage & Selk, 2016) | Canada | 8 | Vulvodynia | - | - | Individual interviews | 14* |
| 20 | (Mellado et al., 2016) | Brazil | 29 | Endometriosis | 21-49 | - | Focus groups | 11* |
| 21 | (Mellado et al., 2020) | Brazil | 58 | CPPS | 22-57 | - | Individual interviews | 13* |
| 22 | (Márki et al., 2022) | Hungary | 21 | Endometriosis | 31.57 | | Focus groups | 15* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 23 | (Matías-González et al., 2021) | Puerto Rico | 50 | Endometriosis | - | - | Focus groups | 16** |
| 24 | (McKernan et al., 2020) | USA | 27 | IC/PBS | 45 | White (88.89%), Black (7.47%), Multiracial (3.7%) | Focus groups | 14* |
| 25 | (Moradi et al., 2014) | Australia | 35 | Endometriosis | 17- 53 | - | Focus groups | 17** |
| 26 | (Namazi et al., 2021) | Iran | 20 | Endometriosis | 23–43 | - | Individual interviews | 17** |
| 27 | (Rea et al., 2020) | Italy | 25 | Endometriosis | 18- 54 | - | Individual interviews | 17** |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 28 | (Roomaney & Kagee, 2016) | South Africa | 16 | Endometriosis | 23- 42 | - | Individual interviews | 15* |
| 29 | (Roomaney & Kagee, 2018) | South Africa | 25 | Endometriosis | 25-42 | - | Individual interviews | 14* |
| 30 | (Rush & Misajon, 2018) | Australia | 500 | Endometriosis | 18-63 | - | Questionnaire | 12* |
| 31 | (Schneider et al., 2022) | Norway | 9 | Vestibulodynia | 24-37 | - | Individual interviews | 15* |
| 32 | (Sutcliffe et al., 2015) | USA | 57 | IC/PBS | 19–77 | Caucasian (91.2%) | Focus groups | 15* |
| 33 | (Wahl et al., 2021) | Canada | 17 | Endometriosis & dyspareunia | 23-50 | White (82%), Asian (12%), Other (6%) | Individual interviews | 15* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 34 | (Yoon et al., 2021) | South Korea | 14 | Endometriosis | 37.7 | | Individual interviews | 17** |
| 35 | (Zale et al., 2020) | USA | 12 | Endometriosis | 20-43 | Caucasian (90%), Hispanic (10%) | Individual interviews | 12* |
| 36 | (Zarbo et al., 2019) | Italy | 6 | Endometriosis | - | - | Individual interviews | 11* |
| [a] [b] sharing a superscript denotes having the same dataset | | | | | | | | |

**Table 2**

*Papers and associated themes and subthemes*

| | | 1. Dominance of CPPS | | | 2. Lack of understanding | | 3. Isolation | | 4. Negative sense of self | | 5. Psychosocial strategies | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 1a | 1b | 1c | 2a | 2b | 3a | 3b | 4a | 4b | 5a | 5b |
| **Reference** | | **Impacting multiple aspects of life** | **Disrupting life trajectories** | **Unpredictability of symptoms** | **Lack of CPPS awareness** | **Stigma** | **Reduced social life** | **Impact on sexual and intimate relationships** | **Lost identity** | **Self-blame** | **Unhelpful strategies** | **Helpful strategies** |
| **1** | (Chen et al., 2018) | x | | | x | | | | | | | |
| **2** | (Chen et al., 2020) | x | | | | | x | x | | | | x |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **3** | (Cole et al., 2021) | | x | | x | x | x | x | x | x | x | x |
| **4** | (Ekholm et al., 2022) | | | | | | | x | x | x | x | x |
| **5** | (Facchin et al., 2018) | x | x | | x | | | x | x | x | | |
| **6** | (Fernández-Martínez et al., 2020) | x | | x | | x | | | x | | x | x |
| **7** | (Fernández-Martínez et al., 2020) | x | | x | | | x | x | | | | |
| **8** | (Grogan et al., 2018) | x | | | x | | x | x | | | x | |
| **9** | (Groven et al., 2016) | | | | | | | x | x | | | |
| **10** | (Hållstam et al., 2018) | x | x | | | | x | x | x | x | x | x |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **11** | (Happel-Parkins et al., 2020) | | | | x | x | | x | | | x | |
| **12** | (Hawkey et al., 2022) | x | | | x | x | | x | x | x | x | x |
| **13** | (Hintz, 2019) | | | | x | x | | x | | | x | x |
| **14** | (Huang et al., 2022) | x | | | x | x | x | | x | x | | x |
| **15** | (Hudson et al., 2016) | x | x | | | x | x | x | x | x | | |
| **16** | (Jaeger et al., 2022) | | | | x | | x | | | | x | x |
| **17** | (Kanter et al., 2017) | x | x | x | x | | x | x | | | | |
| **18** | (Kirkham & Swainston, 2021) | x | x | | x | | x | x | x | | | x |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **19** | (LePage & Selk, 2016) | x | | | x | | x | x | | | | x |
| **20** | (Mellado et al., 2016) | | x | | x | | x | x | | | | |
| **21** | (Mellado et al., 2020) | x | | | | | x | x | | | | x |
| **22** | (Márki et al., 2022) | x | x | | x | | x | x | x | x | | x |
| **23** | (Matías-González et al., 2021) | | | | x | x | | | | | | |
| **24** | (McKernan et al., 2020) | x | | | x | | x | x | | | x | x |
| **25** | (Moradi et al., 2014) | x | x | x | x | | x | x | x | x | | |
| **26** | (Namazi et al., 2021) | x | | | x | | x | x | x | x | | x |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **27** | (Rea et al., 2020) | x | x | | x | | | x | | | | |
| **28** | (Roomaney & Kagee, 2016) | | | | | | | | | | x | x |
| **29** | (Roomaney & Kagee, 2018) | x | | | x | x | x | x | x | x | x | x |
| **30** | (Rush & Misajon, 2018) | x | x | x | x | | x | x | x | x | | |
| **31** | (Schneider et al., 2022) | | | | | | | x | x | | x | x |
| **32** | (Sutcliffe et al., 2015) | x | x | x | | | x | x | | x | | x |
| **33** | (Wahl et al., 2021) | | | | | | | x | | x | | |
| **34** | (Yoon et al., 2021) | x | x | x | x | | | | | | x | x |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **35** | (Zale et al., 2020) | x | x | | x | x | x | | x | | | |
| **36** | (Zarbo et al., 2019) | x | | x | x | | | | | x | x | |

## Meta-Synthesis

From the meta-synthesis, five themes were identified (see Table 2 for thematic loading). The first theme describes the dominance CPPS can have on an individual's life, with subthemes including its impact on multiple life domains, life trajectories and unpredictability of symptoms. The second theme describes a lack of understanding (individual and societal) and stigma. Themes three and four describe feeling isolated (due to a reduced social life and impact on sexual and intimate relationships) and a negative sense of self (lost identity and self-blame). A fifth theme describes psychosocial strategies with subthemes regarding their perceived utility.

Overall, there were relatively consistent reports relating to the dominance, impact of CPPS and strategies across the different CPPS subtypes. Initial insights around differing experiences depending on age, sexuality and culture are noted.

### *Theme 1 – Dominance of CPPS*

**Impacting multiple aspects of life.** A consistent theme was the dominance of CPPS. Some individuals felt that it "consumed them" and had "become my life". This included individuals' ability to move, eat, sleep, concentrate, care for themselves and complete basic tasks. Some women were concerned about having attacks of pain in public or leaking due to heavy bleeding. Often this led to carefully selecting their clothing, reduced spontaneity and feeling increasingly confined to their homes. This could have detrimental consequences on their education, occupation, relationships, hobbies, socialising, and mental health. The financial impact of CPPS was pronounced, due to a reduced ability or inability to work alongside the cost of investigations and procedures, especially when healthcare required self-funding.

**Disrupting life trajectories.** The chronic, incurable nature of CPPS also led to descriptions of a "ruined" life and CPPS as a "life sentence". This described how there was

no foreseeable end to symptoms, with resignation and helplessness about the impact of CPPS on life opportunities. This included establishing a career, forming a relationship, and having a family. For some individuals, actual and anticipated infertility disrupted many presumed narratives about having children and their future role in life. This could entail the emotional consequences of mourning the loss of a normal or anticipated life.

**Unpredictability of symptoms**. Another notable aspect was the unpredictability of symptoms and associated powerlessness. Not knowing when symptoms could flare up and varied pain intensity could feel "overwhelming" and "chaotic" and lead to "uncontrollable anxiety". Due to this uncertainty and lack of control, individuals often felt reluctant to undertake commitments or make plans. Even when symptoms remitted, fear and helplessness regarding the recurrence of symptoms could pervade individuals' lives. It was described how following a period of stability with their CPPS, experiencing a flare-up could lead to significant emotional setbacks by becoming "demoralized" and returning to "fear mode".

### *Theme 2 – Lack of understanding*

**Lack of CPPS awareness.** A lack of awareness around CPPS was commonly reported. Many individuals had not heard of their condition prior to diagnosis and had viewed symptoms as "part of life" rather than a legitimate health issue. Some individuals reported lacking information even following a diagnosis, with uncertainty around the prognosis making them feel particularly vulnerable. Consequently, many sought out information online but were concerned about its reliability. Indeed, some individuals lack understanding and hold misconceptions about the origin and course of their CPPS (Mellado et al., 2016).

A lack of awareness and empathy from partners, friends, family, employers, and healthcare professionals was reported. It was described how society can normalise

menstrual and sexual pain, resulting in scepticism or disbelief over the magnitude of symptoms and their impact. Some individuals reported being accused of being 'over-the-top' or exaggerating symptoms for gain (e.g., an excuse not to work). Some individuals felt let down especially by health professionals who had not taken their symptoms seriously and spent years being ignored and invalidated with labels such as 'hypochondriac'. It was felt that many professionals lacked the knowledge and skills to help them manage their CPPS, so they had to become their own expert and advocate.

**Stigma.** Many individuals reported difficulties discussing their condition. This appeared to link to wider discourses around 'taboo' topics involving the pelvis, sex, and menstruation. Stigma was linked to infertility and perceived weakness or hypochondria around menstruating and may be particularly pronounced regarding pain in the genital area and sexual dysfunction. Latina women described being labelled as "changueria" (an excessive whiner or complainer without reason) within family, social and healthcare interactions (Matías-González et al., 2021). Cultural and religious notions regarding 'normal' or 'appropriate' sex and gender roles may affect stigma and disclosure with religious messaging increasing fear and shame in discussing sexuality for Christian women (Happel-Parkins et al., 2020). There were also indications that South Asian women received especially strong narratives about social events being mandatory and the worthlessness of an infertile wife (Hudson et al., 2016).

### *Theme 3 – Isolation*

**Reduced social life.** Individuals frequently reported attending fewer social events due to their CPPS leading to restricted lifestyles and reduced social circles. Withdrawal from social engagements could be due to fatigue, pain, nausea, and discomfort. Some women reported not making plans in case they coincided with a flare-up, or as a deliberate strategy to conserve energy and reduce stress (which may cause pain). Some participants

described waiting for the pain to ease before re-engaging with activities but for others this motivation reduced over time with a resignation to CPPS taking over their life.

The perceived inability of others to understand the condition also led to social withdrawal. Some felt they had lost friends and were no longer invited to events due to repeatedly cancelling or changing plans. Even when social activities were attended despite being in pain, it was felt to impact their ability to interact with others. Some individuals also felt that their social engagement was negatively affected by feeling different from others. Jealousy was also a reported barrier including difficulties being around people with children when experiencing fertility difficulties. Not knowing anyone else with CPPS was common and increased feelings of isolation. There was evidence that younger individuals particularly struggle with the impact of CPPS on their social life (Moradi et al., 2014) and not being able to join activities to "fit in" with peers (Rush & Misajon, 2018).

**Impact on sexual and intimate relationships**. Experiencing dyspareunia was a significant source of distress. There were descriptions of negative concepts and fear of sex. Sexual activity was often reported to be reduced or avoided and for some, intimacy was also avoided. This was attributed to reduced libido due to treatments and stress (e.g., when trying to get pregnant) and feeling unattractive. Stress, anger, and mood swings were reported to affect relationships, especially when CPPS was not discussed or understood by their partner. Many reported difficulties concerning being open about their pain with their partner. Hintz (2019) describes this dilemma of women often wanting to talk to their partner but not feeling able. This was due to fearing others would not understand (especially if their partner has different anatomical parts) or feeling incapable of effectively communicating their experiences (vocabulary to relay pain experiences and feeling inhibited due to stigma). Indeed, one paper suggests anatomic similarities and previous experiences of breaking social norms help queer women to communicate their sexual needs (Ekholm et al., 2022).

Another dilemma involved feeling caught between valuing honesty within a relationship whilst fearing this could jeopardize it. Younger individuals (under 25) may be particularly worried about finding a partner who would accept dyspareunia and potential infertility (Rush & Misajon, 2018). In all ages, the inability to fulfil normative sexual expectations could cause anxiety about their relationship, including the fear that their partner would cheat or leave. It could cause frustration, guilt, and self-blame and result in individuals engaging in sexual intercourse despite significant pain. This could entail psychological trauma (Happel-Parkins et al., 2020) and the physiological maintenance of pain as fear around intercourse could result in more pain and fear (Basson, 2012). Whilst most reports were negative, in a minority of papers, some individuals appeared to navigate difficulties and reported that CPPS led to deepened relations and increased connectedness. This was through accepting difficulties without ruminating on limitations and reframing CPPS as something affecting and managed by both partners. There were initial insights that queer relationships without heteronormative scripts may buffer against difficulties, with greater flexibility and sexual exploration helping to nurture desire (Ekholm et al., 2022).

### *Theme 4 – Negative sense of self*

**Lost identity.** Some women reported that CPPS disrupted their sense of identity and femininity by "not feeling like myself anymore" and feeling "unattractive and unfeminine". For some, this linked to dissatisfaction with their body image due to feeling bloated, weight gain and scarring. Some reported having to select their clothes carefully and the significant impact on their mood and self-esteem. Feeling less feminine also linked to a felt failure to uphold social roles and gender scripts around being a "true woman". Some individuals stated, "I am not a woman" or "only half a woman". This linked to an ability to have 'normal' sex, feeling 'different' from other women, and not understanding their own body. It also linked to motherhood, including anticipated or actual infertility, a

reduced ability to care for children or inability to be the mother they had imagined. As such, lost identity seemed to be associated with deviance from an individual's norms and ideals. One paper exploring the experiences of queer women suggests that CPPS may be less likely to threaten their femininity but challenge other identities including being queer and feminist if these are the cultural norms CPPS separates them from.

**Self-blame.** Many women were aware of the impact upon partners and family members and felt guilty and ashamed of being a perceived burden. For some, this could be due to the emotional consequences of CPPS, including irritability, anxiety, distress, sadness, frustration, and embarrassment. Feeling bad about the impact of their mood swings could become an additional source of distress. Some women reported feeling helpless and burdensome, for example, in needing to be dependent on others for help. Guilt and self-blame were also felt due to the loss of sex and intimacy, not being able to attend events, infertility, and reduced ability to parent. In a minority of papers, some women suggested their partners should have sex with other women or leave them in case they could not have children.

### *Theme 5 –Psychosocial strategies*

**Unhelpful strategies.** An inability to prevent symptoms resulted in feeling helpless and the need to gain a sense of control. The cognitive impact of CPPS included catastrophising, preoccupation with the body and symptoms and hypervigilance for anything that may trigger a flare. Some individuals tried to exert control by always carrying medication, excessively planning their daily life, and attempting to control negative thoughts. These could be ineffective and exacerbate feelings of powerlessness if they still experienced difficult thoughts or unexpected pain, bleeding, or fatigue. Some individuals avoided taking painkillers to retain alertness whereas others reported relying on them. Some individuals reported taking more analgesics than recommended and using alcohol, tobacco, or illicit drugs to cope with CPPS-associated pain and feelings.

Many individuals felt unable to disclose their CPPS as they were unsure whether others would understand. Minimising or concealing symptoms and distress were felt to help avoid potential judgements and maintain a sense of normality but could result in increased isolation. Not making plans to avoid having to explain absences or let people down were also strategies that could increase isolation long term. This could also lead to a vicious cycle of inactivity and reduced health.

**Helpful strategies.** Remaining socially active, utilising support (especially from like-minded individuals and supportive partners, if available), and finding safe, empathetic social circles were frequently cited as helpful. Support from partners was particularly valuable, although one paper found that only half of the women reported a supportive and/or understanding partner (Moradi et al., 2014). Peer support groups with like-minded individuals also appeared a particularly valuable place to have a voice, obtain information and emotional support, and an opportunity to help others. Pacing to conserve energy was described as a helpful way to gain some control whilst some women found scheduling activities around their menstrual cycle beneficial. For individuals experiencing less pain, continuing with regular activities could be a good distraction from their symptoms and was a preferred coping strategy.

There were mixed reports regarding the utility of distancing from partner intimacy and disclosing pain to partners. Sometimes this harmed relationships whereas for others it created opportunities for partnership and exploration of alternatives. Some individuals redefined the focus of their relationship, and the meaning and nature of intimacy, although this appeared rare and there was limited exploration of how it was achieved.

Increased knowledge of CPPS and self-acceptance (as someone with a chronic condition rather than ‘abnormal’) appeared important. There were varying views on maintaining a positive attitude but generally it was felt helpful to balance optimism with realism. Finding meaning and sources of growth, adopting a positive life orientation,

engaging with spirituality and religion, positive self-talk, relaxation techniques and maintaining a sense of humour were also listed. Some women reported benefiting from professional help by learning about managing the physiological and emotional components of CPPS.

## Discussion

This review synthesised 36 qualitative studies published since 2014 exploring the experiences of women with CPPS. All studies were of medium-high quality. Results support previous research regarding the significant impact of CPPS. CPPS affects numerous life domains and is compounded by a lack of understanding and misunderstanding by individuals, their system and society. Feeling isolated and a negative sense of self were commonly reported.

### Interpretation of the Results

The invisibility of CPPS was felt to raise questions of credibility and legitimacy as seen in other chronic conditions such as fibromyalgia (Sim & Madden, 2008). CPPS impacted negatively on working life, activities, relationships, and emotional wellbeing. This is consistent with experiences of living with IBS (Shorey et al., 2020). The results also highlight the impact on an individual's sense of self in line with other chronic conditions including chronic fatigue syndrome, arthritis, fibromyalgia and depression (Larun & Malterud, 2007). It supports research regarding the similar experiences of chronic pain across a range of conditions and the utility of transdiagnostic pain management strategies (Crowe et al., 2017).

This review also builds upon the endometriosis-related stigma findings described in a recent review by Sims et al. (2021) to the detrimental effect more broadly within CPPS. Stigma was experienced within intimate, family, occupational and healthcare settings. This

is common throughout many conditions including IBS (Shorey et al., 2020), bipolar disorder (Hawke et al., 2013), epilepsy (de Boer, 2010), and type 2 diabetes (Olesen et al., 2020). Public health programs targeting stigma show mixed results and may be less effective at targeting self-stigma (Griffiths et al., 2014). Developing scales and assessments to understand the role of stigma in CPPS and how it may present in different sociocultural settings requires consideration prior to developing interventions.

### Limitations of the Evidence Included in the Review

Despite medium-high methodological quality, a notable weakness was a lack of transparency regarding the researchers' critical examination of their own roles. This is important, as qualitative analysis is a product of the interaction between the participants and researchers. This makes it harder to establish whether there were specific lenses or biases, for instance, towards exploring and reporting the negative consequences of CPPS. Generally, most of the experiences reported were negative but it is difficult to accurately assess if this is representative of most individuals.

Another limitation was a lack of demographic reporting, especially concerning ethnicity, which limits knowledge about the representativeness of participants. It is likely that ethnic and cultural differences were not able to be fully explored due to a limited evidence base. Similarly, this review could not synthesise male experiences of CPPS. Males may experience different sources of distress and stigma given that some difficulties appeared specific (e.g., heavy bleeding and motherhood). Similarly, there was an absence of LGBTQ+ individuals, which is problematic given that they already experience increased barriers and stigma (Bachmann & Gooch, 2018). Only one paper actively explored queer experiences with a sample size of five (Ekholm et al., 2022). Further research is required to understand the experiences of homosexual women, for example, around identity and potential societal assumptions about sexual and fertility needs. Research is also required to

understand the experience of individuals who do not identify as women, especially as CPPS healthcare often includes gendered language and clinical pathways.

Whilst the detrimental impact of pain and bleeding was reported, there was limited description of bladder and bowel dysfunction. This is despite evidence for the high prevalence of incontinence amongst nulliparous adolescents and middle-aged women (Almousa & van Loon, 2018). This may be even more prevalent within CPPS given that pelvic pain and reduced activity worsens pelvic floor functioning. It is unclear whether this is not relevant to those interviewed or if the research approach did not invite or report such accounts. In some cases, bowel and bladder issues were listed under symptoms without exploration of their impact on daily life (e.g. reluctance to engage in hobbies or sexual activity). It is possible that stigma around incontinence may contribute to non-disclosure, so developing sensitive prompts may help to explore this area further.

**Limitations of the Review Processes**

Using quality appraisal tools can include dilemmas as to whether appraisals are made on the quality of research or on reporting methods (Dixon-Woods et al., 2007; Goldsmith et al., 2007). As described by Majid and Vanstone (2018), research ethics approval does not guarantee ethical conduct. Yet inclusion of certain terminology may be sufficient to meet thresholds without deeper methodological rigour or self-reflexivity. Indeed, many studies reported conducting thematic analysis informed by Braun and Clarke, yet this can be misused and misinterpreted (Braun et al., 2019).

Regarding the CASP, subjectivity in applying scoring criteria remains a limitation including the threshold for meeting the ‘hints’ or what constitutes meeting sufficient hints. For instance, when evaluating whether data analysis is ‘sufficiently rigorous’, some studies included a very detailed description of the analysis process but no information on the

researcher's examination of their own role. In this instance, studies were rated as 'partial'. However, this could be misleading by implying mediocre rather than inconstant rigour.

It is acknowledged that strategies are recorded as 'helpful' and 'unhelpful' based on subjective reports. The utility of different strategies is likely to depend on individual and systemic contexts and how flexibly they are applied. For instance, engaging in hobbies during a flare-up may only be helpful for some individuals at certain times. The aim of the review was to capture these experiences to support further empirical testing examining their benefits.

The review is limited by excluding studies not written in English. Studies may be missed, and diversity reduced.

**Implications of the Results for Clinical Practice and Research**

Individuals described needing more reliable information about CPPS. Promoting understanding through gynaecologist-led educational seminars has shown a positive impact on psychological symptoms and sexual functioning for vestibulodynia (Brotto et al., 2010). Infertility and dyspareunia could be prominent sources of shame and guilt yet they are often not acknowledged in pain management programs. Further, they are not purely individual issues and must be considered within a wider context. As such, incorporating partners and family members within consultations, psychoeducation sessions and support groups should be considered. This could increase understanding and open dialogues to help reduce invalidation and interpersonal conflict. It may empower women to discuss and explore alternative ways to enjoy intimacy rather than either avoiding all intimacy or enduring painful sexual experiences. Isolation may also be reduced by promoting support groups, which appeared to be a valuable source of information and support.

Health professionals can be a valuable resource for raising awareness and signposting further support, for example, resources regarding healthcare costs. Support

could also include communication with workplaces to ensure CPPS is included in occupational health policies. It also raises the possible benefits of occupational therapy input into pain management programs to support holistic wellbeing. This could include education about the intermittent and unpredictable nature of CPPS and promote suitable task modifications and environmental adaptations such as home working and flexible hours.

Promoting greater societal understanding also requires consideration of perceived and actual stigma. This appeared prevalent due to the 'taboo' nature of pain associated with genitalia, sex, infertility, and menstruation. Further research is required around the potential stigma of difficulties with incontinence and toileting in CPPS. Health policies to support awareness campaigns and strengthen support groups and networks are required. School curricula should aim to promote open discourses, help-seeking, and awareness of 'typical' menstruation and CPPS symptoms. Adult student nurses with CPPS discussed the impact on their academic performance, including reduced concentration, learning and attendance (Fernández-Martínez et al., 2020). Further research is needed to understand the impact of CPPS during adolescence and associated difficulties with school and peer relationships. Longitudinal studies exploring age of CPPS onset and duration may reveal barriers and facilitators to coping.

Whilst this review did not aim to examine specific healthcare experiences, a lack of understanding and support appeared a considerable source of distress. Within healthcare settings, clear working arrangements between disciplines or access to specialist multidisciplinary services appear necessary to address complex needs (Edwards et al., 2015). This includes access to physiotherapists, occupational therapists, sex therapists and psychologists. Non-pharmacological interventions should be offered alongside pharmacological interventions to provide holistic care. Psychological interventions can facilitate coping strategies for the emotional and cognitive consequences of CPPS as in

other chronic pain conditions (Hann & McCracken, 2014; Morley et al., 1999). Strategies to help individuals tolerate uncertainty, promote acceptance and psychological flexibility may be especially helpful (Hughes et al., 2017). Indeed, the application of mindfulness-based stress reduction shows promising initial results in empowering individuals to cope with CPPS (Kanter et al., 2016).

A lack of predictability and control can be distressing as in many chronic pain conditions (Eccleston et al., 2021). Given the high comorbidity of depression in CPPS, it is important to consider the role of learned helplessness (Maier & Seligman, 1976). Feeling helpless is a significant predictor on pain level, disability and depression in chronic pain patients (Craner et al., 2016; Samwel et al., 2006). Treatments to help control symptoms, for instance hormone therapy for dysmenorrhea, could be considered to reduce unpredictability. Long-term management plans could help individuals to feel more supported when facing ongoing and recurring symptoms (Opoku-Anane et al., 2020).

Exploring cultural expectations can provide a platform for discussing topics that might be most distressing for an individual but feel too difficult to disclose. In particular, this review highlights the significant impact of dyspareunia, described as a 'neglected aspect' of endometriosis (Vercellini et al., 2011). Training is required for professionals to broach this topic sensitively as empathy and warm communication styles can improve outcomes in chronic conditions (Lo et al., 2016; Verheul et al., 2010). Further research into factors that facilitate safe disclosure of 'embarrassing' symptoms and ways to reduce self-stigmatisation is required.

Overall, this review synthesised qualitative studies exploring the experiences of women with CPPS. As with other chronic pain conditions, CPPS can disrupt all areas of life and lead to isolation and a negative sense of self. Further research is needed to understand the likelihood of these consequences as well as barriers and facilitators to disclosing and coping. This paper highlighted the significant psychosocial impact of CPPS

and the need for greater awareness and support to enable women to manage the multifaceted complexities of CPPS.

## References


Ahangari, A. (2014). Prevalence of chronic pelvic pain among women: an updated review. *Pain Physician, 17*(2), E141-E147.

Alappattu, M. J., & Bishop, M. D. (2011). Psychological factors in chronic pelvic pain in women: relevance and application of the fear-avoidance model of pain. *Physical therapy, 91*(10), 1542-1550.

Almousa, S., & van Loon, A. B. (2018). The prevalence of urinary incontinence in nulliparous adolescent and middle-aged women and the associated risk factors: a systematic review. *Maturitas, 107*, 78-83.

As-Sanie, S., Black, R., Giudice, L. C., Valbrun, T. G., Gupta, J., Jones, B., Laufer, M. R., Milspaw, A. T., Missmer, S. A., & Norman, A. (2019). Assessing research gaps and unmet needs in endometriosis. *American Journal of Obstetrics & Gynecology, 221*(2), 86-94.

Ayorinde, A. A., Bhattacharya, S., Druce, K. L., Jones, G. T., & Macfarlane, G. J. (2017). Chronic pelvic pain in women of reproductive and post-reproductive age: a population-based study. *European Journal of Pain, 21*(3), 445-455.

Bachmann, C. L., & Gooch, B. (2018). LGBT in Britain: Trans report. *London: Stonewall*.

Basson, R. (2012). The recurrent pain and sexual sequelae of provoked vestibulodynia: a perpetuating cycle. *The journal of sexual medicine, 9*(8), 2077-2092.

Beck, A. T., & Haigh, E. A. (2014). Advances in cognitive theory and therapy: The generic cognitive model. *Annual review of clinical psychology, 10*, 1-24.

Bergeron, S., Likes, W. M., & Steben, M. (2014). Psychosexual aspects of vulvovaginal pain. *Best Practice & Research Clinical Obstetrics & Gynaecology, 28*(7), 991-999.

Braun, V., Clarke, V., & Hayfield, N. (2019). ‘A starting point for your journey, not a map’: Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology,* 1-22.

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European Journal of Pain, 10*(4), 287-333.

Brotto, L. A., Sadownik, L., & Thomson, S. (2010). Impact of educational seminars on women with provoked vestibulodynia. *Journal of Obstetrics and Gynaecology Canada, 32*(2), 132-138.

Chen, C. X., Draucker, C. B., & Carpenter, J. S. (2018). What women say about their dysmenorrhea: a qualitative thematic analysis. *BMC Women's Health, 18*(1), 1-8.

Chen, H. C., Liu, C. Y., Liao, C. H., & Tsao, L. I. (2020). Self-perception of symptoms, medical help seeking, and self-help strategies of women with interstitial cystitis/painful bladder syndrome. *LUTS: Lower Urinary Tract Symptoms, 12*(3), 183-189.

Chen, L.-C., Hsu, J.-W., Huang, K.-L., Bai, Y.-M., Su, T.-P., Li, C.-T., Yang, A. C., Chang, W.-H., Chen, T.-J., & Tsai, S.-J. (2016). Risk of developing major depression and anxiety disorders among women with endometriosis: a longitudinal follow-up study. *Journal of affective disorders, 190*, 282-285.

Chung, S.-D., & Lin, H.-C. (2013). Association between chronic prostatitis/chronic pelvic pain syndrome and anxiety disorder: a population-based study. *PLoS ONE, 8*(5), e64630.

Cole, J. M., Grogan, S., & Turley, E. (2021). “The most lonely condition I can imagine”: Psychosocial impacts of endometriosis on women’s identity. *Feminism & Psychology, 31*(2), 171-191.

Craner, J. R., Gilliam, W. P., & Sperry, J. A. (2016). Rumination, magnification, and helplessness. *The Clinical Journal of Pain, 32*(12), 1028-1035.

Crowe, M., Whitehead, L., Seaton, P., Jordan, J., Mccall, C., Maskill, V., & Trip, H. (2017). Qualitative meta-synthesis: the experience of chronic pain across conditions. *Journal of advanced nursing, 73*(5), 1004-1016.

de Boer, H. M. (2010). Epilepsy stigma: moving from a global problem to global solutions. *Seizure, 19*(10), 630-636.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of health services research & policy, 10*(1), 45-53.

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A., & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of health services research & policy, 12*(1), 42-47.

Drabble, S. J. L., J.: Alele, B.: O'Cathain, A. (2020). Constellations of pain: a qualitative study of the complexity of women's endometriosis-related pain [Article]. *British Journal of Pain*. https://doi.org/10.1177/2049463720961413

Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of psychological distress. *Mental illnesses-understanding, prediction and control, 69*(2), 105-106.

European Association of Urology Guidelines. (2022) *Edn. presented at the EAU Annual Congress Amsterdam 2022*. ISBN 978-94-92671-16-5. https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Chronic-Pelvic-Pain-2022_2022-03-29-084111_kpbq.pdf

Eccleston, C., Fisher, E., Howard, R. F., Slater, R., Forgeron, P., Palermo, T. M., Birnie, K. A., Anderson, B. J., Chambers, C. T., & Crombez, G. (2021). Delivering transformative action in paediatric pain: a Lancet Child & Adolescent Health Commission. *The Lancet Child & Adolescent Health, 5*(1), 47-87.

Edwards, S. K., Bates, C. M., Lewis, F., Sethi, G., & Grover, D. (2015). 2014 UK national guideline on the management of vulval conditions. *International journal of STD & AIDS, 26*(9), 611-624.

Ekholm, E., Lundberg, T., Carlsson, J., Norberg, J., Linton, S. J., & Flink, I. K. (2022). ” A lot to fall back on”: experiences of dyspareunia among queer women. *Psychology & Sexuality*, 1-14.

Facchin, F., Barbara, G., Dridi, D., Alberico, D., Buggio, L., Somigliana, E., Saita, E., & Vercellini, P. (2017). Mental health in women with endometriosis: searching for predictors of psychological distress. *Human Reproduction, 32*(9), 1855-1861.

Facchin, F., Saita, E., Barbara, G., Dridi, D., & Vercellini, P. (2018). “Free butterflies will come out of these deep wounds”: A grounded theory of how endometriosis affects women’s psychological health. *Journal of Health Psychology, 23*(4), 538-549.

Fernández-Martínez, E., Abreu-Sánchez, A., Pérez-Corrales, J., Ruiz-Castillo, J., Velarde-García, J. F., & Palacios-Ceña, D. (2020). Living with pain and looking for a safe environment: A qualitative study among nursing students with dysmenorrhea. *International Journal of Environmental Research and Public Health, 17*(18), 6670.

Fernández-Martínez, E., Abreu-Sánchez, A., Velarde-García, J. F., Iglesias-López, M. T., Pérez-Corrales, J., & Palacios-Ceña, D. (2020). Living with Restrictions. The Perspective of Nursing Students with Primary Dysmenorrhea. *International Journal of Environmental Research and Public Health, 17*(22), 8527.

Gambadauro, P., Carli, V., & Hadlaczky, G. (2019). Depressive symptoms among women with endometriosis: a systematic review and meta-analysis. *American Journal of Obstetrics and Gynecology, 220*(3), 230-241.

Garner, P., Hopewell, S., Chandler, J., MacLehose, H., Akl, E. A., Beyene, J., Chang, S., Churchill, R., Dearness, K., & Guyatt, G. (2016). When and how to update systematic reviews: consensus and checklist. *bmj, 354*.

Goldsmith, M. R., Bankhead, C. R., & Austoker, J. (2007). Synthesising quantitative and qualitative research in evidence-based patient information. *Journal of Epidemiology & Community Health, 61*(3), 262-270.

Griffiths, K. M., Carron-Arthur, B., Parsons, A., & Reid, R. (2014). Effectiveness of programs for reducing the stigma associated with mental disorders. A meta-analysis of randomized controlled trials. *World psychiatry, 13*(2), 161-175.

Grogan, S., Turley, E., & Cole, J. (2018). 'So many women suffer in silence': a thematic analysis of women's written accounts of coping with endometriosis. *Psychology & Health, 33*(11), 1364-1378.

Groven, K. S., Råheim, M., Håkonsen, E., & Haugstad, G. K. (2016). "Will I ever be a true woman?" An exploration of the experiences of women with vestibulodynia. *Health Care for Women International, 37*(8), 818-835.

Hållstam, A., Stålnacke, B.-M., Svensén, C., & Löfgren, M. (2018). Living with painful endometriosis–A struggle for coherence. A qualitative study. *Sexual & Reproductive HealthCare, 17*, 97-102.

Hann, K. E., & McCracken, L. M. (2014). A systematic review of randomized controlled trials of Acceptance and Commitment Therapy for adults with chronic pain: Outcome domains, design quality, and efficacy. *Journal of contextual behavioral science, 3*(4), 217-227.

Happel-Parkins, A., Azim, K. A., & Moses, A. (2020). “I Just Beared Through It”: Southern US Christian Women's Experiences of Chronic Dyspareunia. *Journal of Women’s Health Physical Therapy, 44*(2), 72-86.

Hawke, L. D., Parikh, S. V., & Michalak, E. E. (2013). Stigma and bipolar disorder: a review of the literature. *Journal of Affective Disorders, 150*(2), 181-191.

Hawkey, A., Chalmers, K. J., Micheal, S., Diezel, H., & Armour, M. (2022). “A day-to-day struggle”: A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain. *Feminism & Psychology*, 09593535221083846.

Hintz, E. A. (2019). The Vulvar Vernacular: Dilemmas Experienced and Strategies Recommended by Women with Chronic Genital Pain. *Health Communication, 34*(14), 1721-1730. https://doi.org/10.1080/10410236.2018.1517709

Huang, R., Li, X., Jiang, H., & Li, Q. (2022). Barriers to self-management of patients with adenomyosis: A qualitative study. *Nursing Open, 9*(2), 1086-1095.

Hudson, N., Culley, L., Law, C., Mitchell, H., Denny, E., & Raine-Fenning, N. (2016). ‘We needed to change the mission statement of the marriage’: biographical disruptions, appraisals and revisions among couples living with endometriosis. *Sociology of Health & Illness, 38*(5), 721-735.

Hughes, L. S., Clark, J., Colclough, J. A., Dale, E., & McMillan, D. (2017). Acceptance and commitment therapy (ACT) for chronic pain. *The Clinical journal of pain, 33*(6), 552-568.

Jaeger, M., Gstoettner, M., & Fleischanderl, I. (2022). “A little monster inside me that comes out now and again”: endometriosis and pain in Austria. *Cadernos de Saúde Pública, 38,* e00226320.

Kanter, G., Komesu, Y. M., Qaedan, F., Jeppson, P. C., Dunivan, G. C., Cichowski, S. B., & Rogers, R. G. (2016). Mindfulness-based stress reduction as a novel treatment for interstitial cystitis/bladder pain syndrome: a randomized controlled trial. *International Urogynecology Journal, 27*(11), 1705-1711.

Kanter, G., Volpe, K. A., Dunivan, G. C., Cichowski, S. B., Jeppson, P. C., Rogers, R. G., & Komesu, Y. M. (2017). Important role of physicians in addressing psychological aspects of interstitial cystitis/bladder pain syndrome (IC/BPS): a qualitative analysis. *International Urogynecology Journal, 28*(2), 249-256.

Kirkham, A., & Swainston, K. (2021). Women's Experiences of Interstitial Cystitis/Painful Bladder Syndrome. *Western Journal of Nursing Research*, 0193945921990730.

Krsmanovic, A., Tripp, D. A., Nickel, J. C., Shoskes, D. A., Pontari, M., Litwin, M. S., & McNaughton-Collins, M. F. (2014). Psychosocial mechanisms of the pain and quality of life relationship for chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS). *Canadian Urological Association Journal, 8*(11-12), 403.

Laganà, A. S., La Rosa, V. L., Rapisarda, A. M. C., Valenti, G., Sapia, F., Chiofalo, B., Rossetti, D., Frangež, H. B., Bokal, E. V., & Vitale, S. G. (2017). Anxiety and depression in patients with endometriosis: impact and management challenges. *International journal of women's health, 9*, 323.

Larun, L., & Malterud, K. (2007). Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient Education and Counseling, 69*(1-3), 20-28.

LePage, K., & Selk, A. (2016). What do patients want? A needs assessment of vulvodynia patients attending a vulvar diseases clinic. *Sexual Medicine, 4*(4), e242-e248.

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet, 367*(9509), 528-529.

Lo, G. H.-W., Balasubramanyam, A. S., Barbo, A., Street Jr, R. L., & Suarez-Almazor, M. E. (2016). Mediated by self-efficacy status, positive clinician conveyed expectations of treatment effect reduces pain in knee osteoarthritis. *Arthritis care & research, 68*(7), 952.

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1), 31-42.

Maier, S. F., & Seligman, M. E. (1976). Learned helplessness: theory and evidence. *Journal of experimental psychology: general, 105*(1), 3.

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: a compendium of quality appraisal tools. *Qualitative Health Research, 28*(13), 2115-2131.

Márki, G., Vásárhelyi, D., Rigó, A., Kaló, Z., Ács, N., & Bokor, A. (2022). Challenges of and possible solutions for living with endometriosis: a qualitative study. *BMC Women's Health, 22*(1), 1-11.

Matías-González, Y., Sánchez-Galarza, A. N., Flores-Caldera, I., & Rivera-Segarra, E. (2021). "Es que tú eres una changa": stigma experiences among Latina women living with endometriosis. *Journal of Psychosomatic Obstetrics & Gynecology, 42*(1), 67-74.

McKernan, L. C., Bonnet, K. R., Finn, M. T., Williams, D. A., Bruehl, S., Reynolds, W. S., Clauw, D., Dmochowski, R. R., Schlundt, D. G., & Crofford, L. J. (2020). Qualitative analysis of treatment needs in interstitial cystitis/bladder pain syndrome: Implications for intervention. *Canadian Journal of Pain, 4*(1), 181-198.

Mellado, B. H., Falcone, A. C., Poli-Neto, O. B., e Silva, J. C. R., Nogueira, A. A., & Candido-dos-Reis, F. J. (2016). Social isolation in women with endometriosis and

chronic pelvic pain. *International Journal of Gynecology & Obstetrics, 133*(2), 199-201.

Mellado, B. H., Pilger, T. L., Neto, O. B. P., e Silva, J. C. R., Nogueira, A. A., do Vale Brandão, C., & Dos Reis, F. J. C. (2020). Daily life attitudes of women with moderate or severe chronic pelvic pain. A qualitative study. *European Journal of Obstetrics & Gynecology and Reproductive Biology, 254*, 109-113.

Mellado, B. H., Pilger, T. L., Poli-Neto, O. B., e Silva, J. C. R., Nogueira, A. A., & Dos Reis, F. J. C. (2019). Current usage of qualitative research in female pelvic pain: a systematic review. *Archives of Gynecology and Obstetrics, 300*(3), 495-501.

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women's lives: a qualitative study. *BMC Women's Health, 14*(1), 1-12.

Morley, S., Eccleston, C., & Williams, A. (1999). Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain, 80*(1-2), 1-13.

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. M. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry, 180*(5), 461-464.

Namazi, M., Behboodi Moghadam, Z., Zareiyan, A., & Jafarabadi, M. (2021). Exploring the impact of endometriosis on women's lives: A qualitative study in Iran. *Nursing Open, 8*(3), 1275-1282.

Naushad, N., Dunn, L. B., Muñoz, R. F., & Leykin, Y. (2018). Depression increases subjective stigma of chronic pain. *Journal of Affective Disorders, 229*, 456-462.

Olesen, K., Cleal, B., & Willaing, I. (2020). Discrimination and stigma among people with type 2 diabetes in the workplace: prejudice against illness or obesity? *Public health, 180*, 100-101.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *bmj, 372*.

Programme, C. A. S. (2018). CASP Qualitative Checklist: Critical Appraisal Skills Programme.

Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil, J. S., Ringkamp, M., & Sluka, K. A. (2020). The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain, 161*(9), 1976-1982.

Rea, T., Giampaolino, P., Simeone, S., Pucciarelli, G., Alvaro, R., & Guillari, A. (2020). Living with endometriosis: a phenomenological study. *International journal of qualitative studies on health and well-being, 15*(1), 1822621.

Roomaney, R., & Kagee, A. (2016). Coping strategies employed by women with endometriosis in a public health-care setting. *Journal of Health Psychology*, *21*(10), 2259-2268.

Roomaney, R., & Kagee, A. (2018). Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study. *Journal of Health Psychology, 23*(7), 905-916.

Roth, R. S., Punch, M. R., & Bachman, J. E. (2011). Patient beliefs about pain diagnosis in chronic pelvic pain: relation to pain experience, mood and disability. *The Journal of reproductive medicine*, *56*(3-4), 123-129.

Rush, G., & Misajon, R. (2018). Examining subjective wellbeing and health-related quality of life in women with endometriosis. *Health Care for Women International, 39*(3), 303-321.

Samwel, H. J., Evers, A. W., Crul, B. J., & Kraaimaat, F. W. (2006). The role of helplessness, fear of pain, and passive pain-coping in chronic pain patients. *The Clinical Journal of Pain, 22*(3), 245-251.

Schneider, M., Tallaksen, D. W., Haukland, M., & Haugstad, G. K. (2022). If I stop, then what am I supposed to do? The experiences of sexual intimacy of women who live with provoked vestibulodynia. *Health Care for Women International, 43*(1-3), 176-193. https://doi.org/10.1080/07399332.2020.1868473

Sewell, M., Churilov, L., Mooney, S., Ma, T., Maher, P., & Grover, S. R. (2018). Chronic pelvic pain–pain catastrophizing, pelvic pain and quality of life. *Scandinavian Journal of Pain, 18*(3), 441-448.

Shorey, S., Demutska, A., Chan, V., & Siah, K. T. H. (2020). Adults living with irritable bowel syndrome (IBS): A qualitative systematic review. *Journal of Psychosomatic Research*, 110289.

Sim, J., & Madden, S. (2008). Illness experience in fibromyalgia syndrome: a metasynthesis of qualitative studies. *Social Science & Medicine, 67*(1), 57-67.

Sims, O. T., Gupta, J., Missmer, S. A., & Aninye, I. O. (2021). Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay. *International Journal of Environmental Research and Public Health, 18*(15), 8210.

Sutcliffe, S., Bradley, C. S., Clemens, J. Q., James, A. S., Konkle, K. S., Kreder, K. J., Lai, H. H. H., Mackey, S. C., Ashe-McNalley, C. P., & Rodriguez, L. V. (2015). Urological chronic pelvic pain syndrome flares and their impact: qualitative

analysis in the MAPP network. *International Urogynecology Journal, 26*(7), 1047-1060.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(1), 1-10.

Toye, F., Seers, K., & Barker, K. (2014). A meta-ethnography of patients' experiences of chronic pelvic pain: struggling to construct chronic pelvic pain as 'real'. *Journal of advanced nursing, 70*(12), 2713-2727.

Van der Kolk, B. (2014). *The body keeps the score: Mind, brain and body in the transformation of trauma*. Penguin UK.

Vercellini, P., Meana, M., Hummelshoj, L., Somigliana, E., Viganò, P., & Fedele, L. (2011). Priorities for endometriosis research: a proposed focus on deep dyspareunia. *Reproductive Sciences, 18*(2), 114-118.

Verheul, W., Sanders, A., & Bensing, J. (2010). The effects of physicians' affect-oriented communication style and raising expectations on analogue patients' anxiety, affect and expectancies. *Patient Education and Counseling, 80*(3), 300-306.

Wahl, K. J., Imtiaz, S., Lisonek, M., Joseph, K., Smith, K. B., Yong, P. J., & Cox, S. M. (2021). Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain. *Sexual Medicine, 9*(1), 100274.

Wood, N., Qureshi, A., & Mughal, F. (2017). Positioning, telling, and performing a male illness: Chronic prostatitis/chronic pelvic pain syndrome. *British Journal of Health Psychology, 22*(4), 904-919.

Wood, N. Q., Annum: Mughal, Fahim. (2017). Positioning, telling, and performing a male illness: Chronic prostatitis/chronic pelvic pain syndrome. *British Journal of Health Psychology, 22*(4), 904-919. https://doi.org/10.1111/bjhp.12261

World Health Organization. (2017). Depression and other common mental disorders: global health estimates. 2017. *Licence: CC BY-NC-SA, 3*.

Yoon, Y., Park, M. A., & Park, S. (2021). Seeking adaptation from uncertainty: Coping strategies of South Korean women with endometriosis. *Research in Nursing & Health, 44*(6), 970-978.

Zale, M., Lambert, E., LaNoue, M. D., & Leader, A. E. (2020). Shedding light on endometriosis: Patient and provider perspectives on a challenging disease. *Journal of Endometriosis and Pelvic Pain Disorders, 12*(2), 69-76.

Zarbo, C., Brugnera, A., Dessì, V., Barbetta, P., Candeloro, I., Secomandi, R., Betto, E., Malandrino, C., Bellia, A., & Trezzi, G. (2019). Cognitive and Personality Factors Implicated in Pain Experience in Women With Endometriosis: A Mixed-Method Study. *The Clinical Journal of Pain, 35*(12), 948-957.

**Service Improvement Project**

# Title: How to Improve the Quality of Care to Women with Chronic Pelvic Pain Syndrome Admitted to the Gynaecology Department, John Radcliffe Hospital

Victoria Edwards

victoria.edwards@hmc.ox.uk

Department of Psychology, University of Oxford, Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

**Word count:** 4,996

**Date:** May 2022

**Internal Supervisor:** Dr Sarah Lack

Clinical Psychologist, Oxford Institute for Clinical Psychology Research and Training

**External supervisor:** Dr Emma Evans

Clinical Psychologist, Oxford University Hospitals NHS Foundation Trust

**Intended journal and rationale:** British Journal of Pain.

The British Journal of Pain is a peer-reviewed journal that publishes research on all major aspects of pain and pain management. The journal is suitable as it has a broad scope in publishing primary research including improvement projects and aims to be suitable for a multidisciplinary readership.

## Abstract

**Background:** Chronic pelvic pain syndrome (CPPS) can reduce quality of life and increase healthcare utilisation. The John Radcliffe Hospital Gynaecology Department can find supporting CPPS patients particularly challenging due to prolonged and repeated admissions and limited treatment options. Patients have made formal complaints when discharged without medical treatments and staff can be unsure how to best provide care. This project aimed to gain a greater understanding of these challenges and generate user-informed service recommendations.

**Method**: Two staff focus groups were conducted using opportune sampling. Patients were interviewed individually if they were 18 years and above, had been an inpatient within the past three years, remained under the department and were able to provide informed consent. Exclusion criteria included pregnancy, upcoming or ongoing surgery or safeguarding concerns. Staff and patient data were gathered using semi-structured interviews and analysed separately using inductive thematic analysis.

**Results:** Eleven nurses formed the staff focus groups. Themes included a) difficulties understanding chronic pain, b) working with a condition with no clear fix and c) what helps the service respond well. Nineteen patients were sent information packs with eight interviewed (42% response rate). Themes included a) never knowing what is going to happen, b) feeling medically safe, and c) being sent home unequipped.

**Conclusions:** Staff and patients described uncertainties about how to understand and manage pain and the nature and purpose of admissions. Some differences in how staff and patients conceptualised admissions are noted. This study supports and builds upon research into invalidating discourses around ‘women’s problems’ and ‘hidden’ chronic pain conditions and highlights the need for collaborative, multidisciplinary approaches. Key recommendations include staff training about CPPS, facilitating conversations with

patients to provide holistic care, reducing uncertainties, and re-framing admissions as support through a crisis rather than a ‘fix’.

***Keywords*:** Chronic pelvic pain syndrome; thematic analysis; support; service improvement

# Introduction

## Brief outline

The Gynaecology Department at the John Radcliffe Hospital (JR) is a large department offering a range of women's health services. Patients arrive for planned admissions (normally to receive surgery e.g., a hysterectomy) or as an acute (emergency) admission. For this latter group, surgery is rarely indicated, so the focus is pain management through medication and reassurance. The service can find knowing how to support these patients challenging and would value input on how to optimise support. This project aims to gain an understanding of patients and staff experiences and provide recommendations on how the service can best meet patients' needs.

## Literature review

The European Association of Urology (EAU) 2022 guidelines define chronic pelvic pain (CPP) as chronic or persistent pain (≥6 months) in structures related to the pelvis. It is often associated with symptoms suggestive of urinary tract, sexual, bowel, pelvic floor or gynaecological dysfunction and negative psychological, cognitive, behavioural, sexual and emotional consequences. The most recent definition of pain incorporates biopsychosocial complexities and self-report by defining pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020).

CPP is divided into a) specific disease-associated pelvic pain (with well-defined pathology e.g., infection or cancer) b) chronic pelvic pain syndrome (CPPS; without known pathology). CPPS has a prevalence of 14.8% in UK women over 25 years (Ayorinde et al., 2017). Despite a high burden of disease, including reduced quality of life (QoL), decreased work productivity, and increased healthcare utilisation, CPPS has limited research, healthcare planning and resource allocation (Latthe et al., 2006).

Ayorinde et al. (2017) identified two CPPS clusters: a) little/ no psychosocial distress; b) high psychosocial distress. This latter group (approximately 9%) included women with depression, fatigue, multiple somatic symptoms, sleep disturbance and lower QoL. CPPS can increase the likelihood of developing depression and anxiety disorders (Chen et al., 2016), whilst psychosocial factors may influence pain onset, pain severity and persistence of CPPS (Chung & Lin, 2013; Laganà et al., 2017). Associated psychological variables include fear and avoidance of pain, catastrophising pain implications (e.g., signs of serious undiagnosed conditions), helplessness and unhelpful coping strategies (e.g., social withdrawal) (Alappattu & Bishop, 2011; Borg et al., 2012; Mercado et al., 2005; Samwel et al., 2006).

The focus of CPPS admissions is usually pain medication. Whilst opioids may provide some benefits for chronic pain, there is less evidence regarding CPPS (Baranowski et al., 2014; Steele, 2014). Potential side-effects of chronic opioid use include: adverse events in multiple organ systems, sleep-disordered breathing, overdose and constipation (particularly problematic for exacerbating pelvic pain) (Baldini et al., 2012). Opioids may even increase pain sensitivity (Lee et al., 2011). Steele (2014) recommends avoiding pain medication (including opioids and other reclassified medications e.g., Gabapentin and Pregabalin) for CPPS, even within emergency department settings.

Clinical guidelines may differ from patients' expectations and requests for pain medication. As an alternative, patients may utilise psychological interventions to increase confidence to cope with symptoms and manage pain (e.g., self-soothing strategies) or reduce opioid intake. Despite the benefits of psychological interventions for chronic pain (Hann & McCracken, 2014; Morley et al., 1999) there is limited evidence for CPPS (Champaneria et al., 2012; Cheong et al., 2014). One meta-analysis regarding vaginal pain showed equivalent effects for psychological and medical treatments regardless of pain aetiology (Flanagan et al., 2015). The authors state that as psychological interventions are

less intrusive, they should be the first line approach, but qualitative studies are needed to explore patients' preferences.

As psychological factors play an important role in determining symptom severity and treatment efficacy in CPPS, a multidisciplinary approach is recommended for providing effective support (Laganà et al., 2017). In developing their CPP centre, Opoku-Anane et al. (2020) emphasise the need for clinical collaboration, integration of medicine and psychosocial interventions and training to healthcare providers and the community. One multidisciplinary intervention showing benefits for males with CPP utilised a clinical nurse specialist (CNS) in maintaining a structured relationship with patients, providing pain education and supporting psychology and physiotherapy interventions (Baranowski et al., 2013). It also demonstrated the benefits of connecting groups of patients to reduce isolation.

Service improvement projects that gather in-depth accounts of patients' experiences can drive user-led changes and shape services to be more patient-centred (Outlaw et al., 2018). Outlaw et al. (2018) used patients' accounts to generate recommendations (e.g., developing information leaflets to ease anxiety) and reported that including staff in projects helps recommendations to be actioned. Recommendations can also guide staff training needs, for example, training in applied relaxation techniques can improve nurses' knowledge of pain management and attitudes (Abdalrahim et al., 2011; Lin et al., 2008). Depending on identified needs, educational programs may be provided to patients. This can reduce post-operative pain and medication side-effects, increase non-pharmacologic pain management methods and increase return to daily activities in chronic pain patients (O'donnell, 2015).

**Rationale for project**

The service identified the following challenges to drive this project:

I. Formal complaints from patients discharged without medical treatments (i.e., no change in pain medication) who feel 'let down' and 'abandoned' by the service.
II. Significant service demands from CPPS patients, including prolonged admissions, multiple investigations (e.g., CT scans) and emergency surgery often with negative operative findings as evidenced by a JR gynaecology audit (Stratta et al., 2016).
III. Reports from staff of feeling uncertain about how best to care for CPPS patients.

The service was keen to widen support in response to these challenges but was unsure what form this would take. Therefore, qualitative interviews were conducted as they enable detailed insights into the experiences and perspectives of patients and healthcare professionals (Braun & Clarke, 2014). Staff and patient data was analysed separately, and similarities and contrasts in themes were discussed.

**Aims**

I. Understand staff's experiences of supporting CPPS patients and ideas for service improvements.
II. Understand patients' experiences of admissions and how to increase support.
III. Explore whether patients and staff have similar perceptions of challenges and potential solutions.
IV. Produce service recommendations.

## Method

The scope for the project was set out through collaboration with the gynaecology staff, including the clinical psychologist (CP) and ward sister (WS). The service anticipated that detailed exploration of the challenges experienced by staff and patients would result in greater understanding of needs and lead to user-informed service improvements. It was hoped this would reduce patient distress (and associated formal

complaints) and in the long term may reduce repeat admissions. Through discussion with the WS and nurses, it was felt that staff would feel safe to share within a group setting so this would be an effective method for exploring experiences and generating recommendations.

A patient representative (PR) was involved from the start to ensure their ideas and feedback was integrated throughout the project. This included the development of patient-facing documents, interview schedules and discussion of results. The PR advised that due to the sensitive nature of CPPS and the potential for reports of difficult experiences, the patient interviews should be conducted individually.

Prior to commencing the study, a bracketing interview (Appendix G) was conducted and recorded. This process involved increasing awareness of assumptions that may influence the project (e.g., how psychologically-minded staff may be, the emotional impact of CPPS and benefits of psychological interventions) and holding these in mind throughout the project.

## Participants

### Staff eligibility criteria

Any members of staff who have worked with CPPS patients within the Gynaecology Department. Opportune sampling was used, with the WS helping to identify available staff on each day.

### Patient eligibility criteria

Inclusion criteria were informed by the 2016 ward audit (Stratta et al., 2016) and discussion with the clinical team and PR. Potential participants were screened against the following criteria:

*Inclusion criteria*

I. ≥18 years old

II. At least one inpatient admission in the past 3 years

III. Still under the care of the department

IV. Capacity to provide informed consent

*Exclusion criteria*

I. Pregnancy

II. Currently undergoing or preparing for surgery within the next month

III. Current safeguarding concerns

## Study design

### Staff focus groups

Two staff focus groups were conducted in person on separate days. Interview schedule Appendix K.

### Patient interviews

Potential participants were sent information packs (Appendix H) detailing how to contact the researcher if they were interested in participating. Verbal consent was taken prior to the interview and a debrief sheet (Appendix I) provided post-interview. Nineteen patients were sent information packs and ten stated an interest in participating. Two individuals dropped out, so eight semi-structured interviews were conducted (42% response rate) via telephone due to social distancing constraints during the COVID-19 pandemic (interview schedule Appendix L).

## Data collection, analysis, and management

To minimize prior assumptions and increase validity, open questions concerning broad themes were established, with additional prompts to provide follow-up questions or clarifications. Interviews were transcribed verbatim and analysis facilitated by NVivo12

software. Data analysis began on completion of the first interview and proceeded iteratively, allowing the interview schedule to be modified to explore early insights in later interviews.

Since there is limited research in this area, an inductive thematic analysis (TA) approach was applied using a realist methodology (Braun & Clarke, 2006, 2013, 2019). This data-driven approach allows identification, analysis and reporting of themes from the data rather than driven by pre-existing concepts (Braun & Clarke, 2006, 2012, 2013, 2014). Although the active role of the researcher in identifying themes is acknowledged and the influence of their theoretical positions and values in the decisions made (Braun & Clarke, 2006). TA can generate unanticipated insights and highlight similarities and differences across data (Braun & Clarke, 2006). It is a versatile technique that can be used to analyse data obtained under a number of theoretical qualitative frameworks, including grounded theory (Patton, 1990). TA allows for robust analyses that can be presented in accessible forms and can be particularly useful in applied research such as health settings (Braun & Clarke, 2014).

Key words or phrases were highlighted and used to develop initial codes. Codes were then compared and organised into themes and subthemes that characterised participants' experiences. Once key themes were established, discussions with two clinical psychologists allowed consideration of how the data was being coded (including reflecting on researchers' own lenses and role) and refining of themes.

Interviews were audio-recorded on a password-protected, encrypted Oxford Health NHS Foundation Trust iPad. They were anonymised, transcribed and will be deleted after 5 years in accordance with NHS policy. A password-protected spreadsheet recording verbal consent and linking participants' names with participant identification number were securely stored on the Oxford Health OneDrive account.

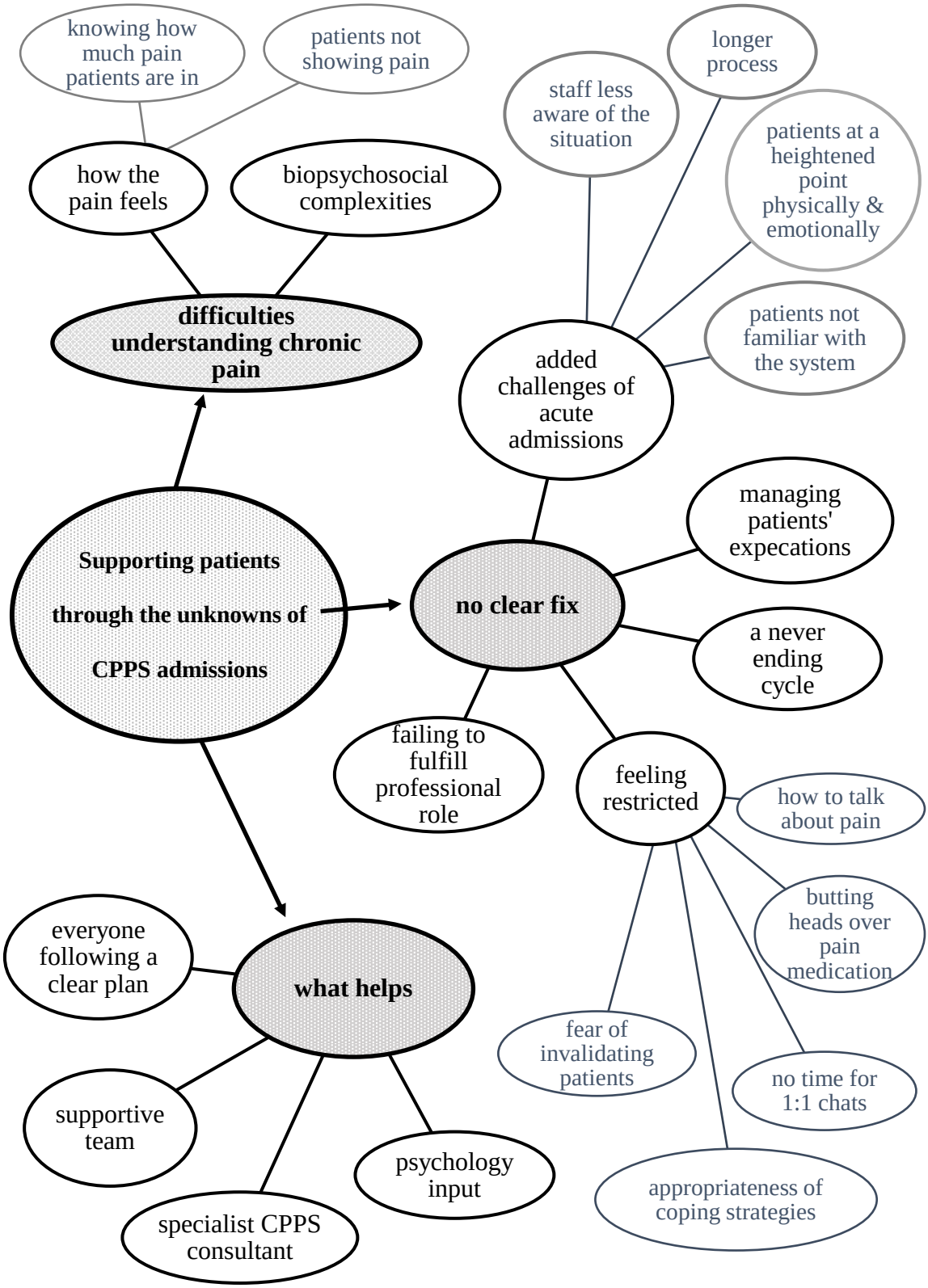
# Results

## Staff focus groups

The first group included 6 attendees (3 nurses, nursing assistant, student nurse and deputy WS). The second group included 5 attendees (5 nurses). All attendees were female and the majority White British. Both focus groups lasted approximately 40 minutes. The final coding scheme for the staff focus groups included three main themes (summary Figure 1 and further verbatim excerpts Appendix M).

**Figure 1**

*Results from Staff Focus Groups*



***Difficulties understanding chronic pain***

The first theme describes the staff' difficulties understanding chronic pain. This is due to its subjective nature, which makes it hard to conceptualise and empathise with: *'we don't know what they're feeling'.*

There are also inconsistencies in pain behaviour as, despite describing high levels of pain, patients appear *'absolutely fine'*.

Pain is also challenging as it can encompass multiple physical health needs, social and psychological factors: '*it's not just one thing, it can be multiple things and that just prolongs the experience'.*

***No clear fix***

A second theme portrays the difficulty of working with a condition with no clear 'fix': *'the most difficult thing is like managing expectations. Like I say, they come in and expect us to fix something or get rid of their pain'*.

Challenges are often intensified for acute admissions. There are more uncertainties (about causes of pain and how the system works) and heightened distress: '*it's a longer process, and their pain threshold is a lot lower so they get more frustrated'*.

For repeat admissions, the ward can be a *'safe place'* and '*each time they feel more comfortable with us'* so it becomes a *'never-ending cycle'*.

Staff can feel *'restricted'* in the support they can offer. This was due to lack of training and confidence talking to patients about pain and fears of appearing invalidating: *'you don't want to say the wrong thing to make them feel even worse'.*

Regarding medications, clinical guidelines can clash with patients' requests, leading to a *'butting of heads'*.

Offering coping strategies can be negatively received by patients and may be impractical on the ward: '*I'm not gonna look at them and say I'm not gonna give you any pain relief – breathe better – or something – like it's not really manageable'*.

Patients can seem *'lonely'* but chats with patients are viewed as a short-term solution and not always possible due to time constraints.

This can make staff feel like they are failing: '*it makes you feel like you can't... fulfil what they've come in for'.*

***What helps***

A third theme describes factors that help admissions to go more smoothly and reduce repeat admissions. This included a consistent staff response in upholding plans: *'making sure a plan's in place, we're all following them'*.

Input from different professionals was highly valued to *'cover the gaps of the care'* and to create *'more of a team feeling'*.

The specialist consultant was reported to be pivotal in *'trying to reassure them and think of other strategies'* and that they *'review them straight away and that helps clarify the plan'.*

The CP can support the consultant and provide supervision to help nurses learn about CPPS. This was highly valued: '*I'm really happy we've started it because there was nothing on before'.*

Informal team support was also valued in being able to *'talk things over'* and that for particularly challenging cases the team will often *'share it out'*.

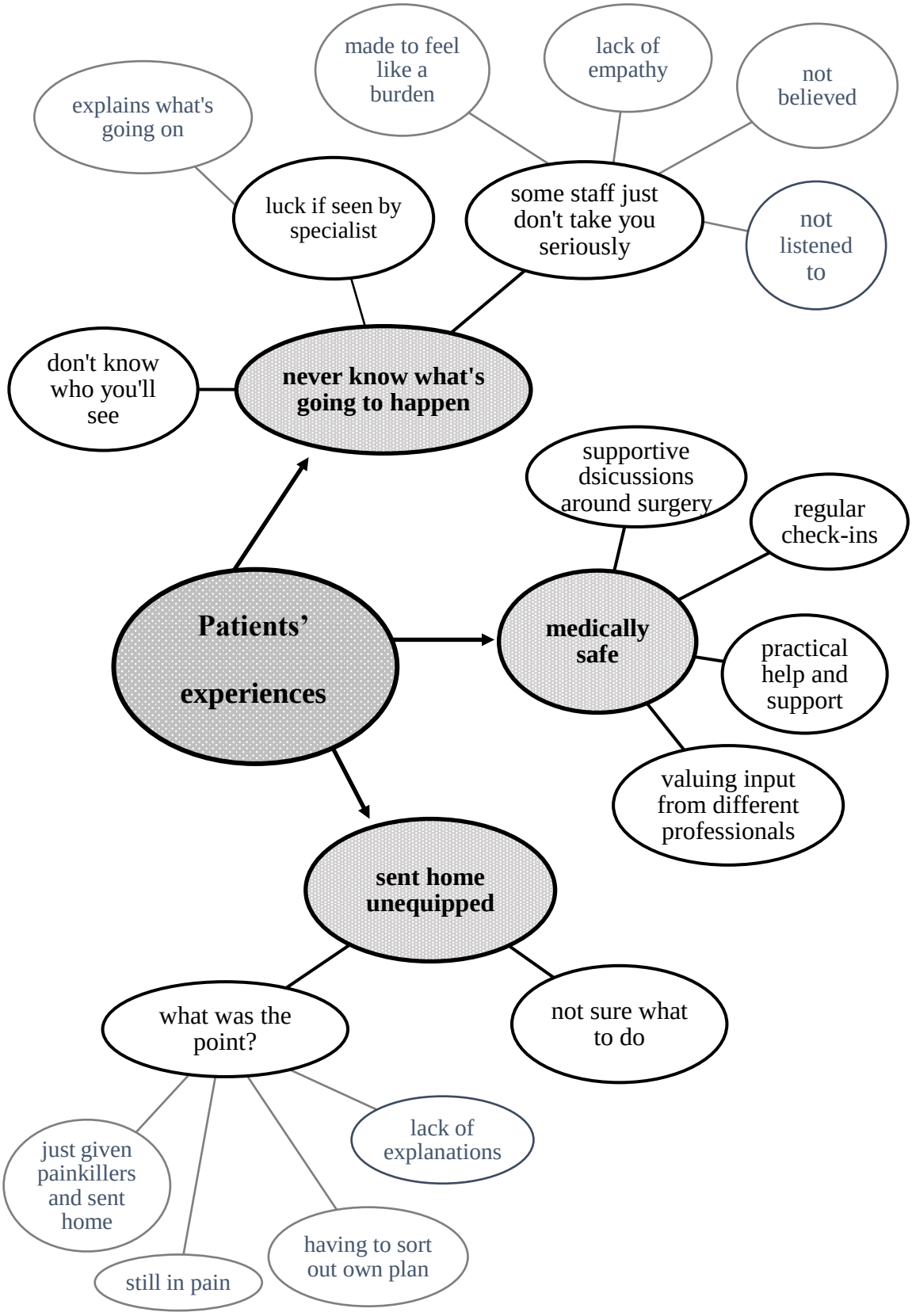
**Patient interviews**

Eight patients were interviewed. This represents 20% of the patients seen by the service annually. Interviews lasted 13-49 minutes (mean = 28). Participants' ages ranged

from 20-43 years (mean = 33). The number of admissions ranged from 1-16 (mean = 7.4). CPPS duration ranged from 3.5-28 years (mean = 13.2). Appendix J displays further demographic details. Figure 2 displays a summary of results and Appendix N provides further verbatim excerpts.

**Figure 2**

*Results from Patient Interviews*



***Never know what's going to happen***

This theme represented the uncertainty patients described around admissions. Patients are unsure which members of staff they will meet: *'It is not clear who you'll be seen by and you might not see the same doctor more than once.'*

Patients also described uncertainties around how staff would treat them, with some staff not taking them seriously. This was to the extent that they avoided admissions:

*'I just sat in the emergency room talking to a doctor and they didn't believe me… And that is disheartening for the patient. You think, why did I bother?'*

Patients felt there could be a *'tick box'* of whom staff felt deserved to be on the ward and as their pain is *'hidden'*, they can be made to feel like a *'burden'* or *'inconvenience'*. Patients felt that their pain could be *'disregarded'*, with staff lacking understanding and empathy. Further, despite patients stating their pain *'wasn't normal'* or informing staff which medications work for them, that sometimes they felt that *'you just don't feel listened to at all'.*

Unlike other staff members, the consultant *'explains everything'* and forms a *'plan of action'* but it can be *'luck'* if and how quickly patients are seen: '*very safe and supported but it was the consultant who very much took me under her wing but… that was 2 days in and just pure luck and coincidence'.*

***Medically safe***

This theme characterised patients feeling safe and supported regarding their medical needs. One way this was achieved was regular check-ins: '*they were constantly coming up asking if I needed anything'.*

Also through staff providing practical help and support: '*they would like hold my hand and assist me… just things like that was really, really nice'.*

Discussions around surgery felt supportive, with treatment rationales clearly communicated: '*when I had my surgery as well I was fully informed the whole time… I felt a lot calmer and more reassured'.*

Access to different professionals (including physiotherapists, psychologists and counsellors) with more awareness helped patients to feel supported: '*one of the physios she said no, it is a chronic condition you have, it is a very painful condition, and you shouldn't feel bad for having that pain'.*

***Sent home unequipped***

The final theme portrays how patients felt that they were sent home unequipped to manage their CPPS. This included what to look out for and whom to contact with concerns: '*I got given a phone number for the ward and I did phone them once but they didn't seem to really know anything about what was going on… I wasn't really sure where to go from there'.*

Patients advocated for greater guidance such as written information and follow-up calls: *'I think it would be good to be able to have, even if it's just a leaflet, sort of thing, with different strategies to help you'.*

Some patients questioned the point of admissions as they were discharged still in pain and without an explanation or a plan: '*every single time I've gone there, I've just been told that, basically just been given painkillers and just been sent home'.*

**Presentation of results to the service**

A joint meeting was held with the service to discuss key findings and recommendations (agenda Appendix O). The service was receptive to results and stated themes were consistent with clinical experiences, especially regarding difficulties of admissions when there is no 'fix'. Staff stated that the results provided important insights

to respond to and build upon. In particular, the consultant voiced concerns around patients feeling it was 'luck' if they were seen and developing more explicit pathways. In the light of results, the team will shape the role of a newly appointed CNS, especially around pain education, reassurance and supporting multidisciplinary professionals. The WS asked for the results to be presented to the wider gynaecology team during their next away day to increase awareness and emphasise the importance of future training.

## Discussion

### Summary of main findings

This study aimed to increase understanding of staff and patients' experiences of inpatient admissions. Staff and patients described uncertainties around CPPS: how to understand pain, ways to manage pain, and the exact nature and purpose of admissions. Staff and patients described how individuals with CPPS can feel unheard and invalidated, supporting research regarding unhelpful discourses about 'women's problem's' and how their pain can be disregarded by healthcare professionals (Toye et al., 2014). There were also differences between how staff and patients conceptualised admissions. Staff felt repeat patients found a 'home from home' on the ward and more comfortable with each admission. In contrast, patients described trying to avoid admissions, as they are not taken seriously. Staff described patients as 'lonely' and whilst recognising the benefits of one-to-one chats, viewed them as a short-term solution and not often feasible on a busy ward. Yet for patients, not having these conversations often meant they did not feel listened to and epitomised a lack of empathy.

### Main implications

A key service implication is to improve staff understanding of CPPS. Staff and patients felt the 'hidden', subjective nature of pain makes it hard to understand, so staff can view CPPS admissions as less legitimate. The complexities of pain were also highlighted

in line with the biopsychosocial model of chronic pain (Gatchel et al., 2007). Services should therefore integrate a mind and body approach to provide holistic care (Toye et al., 2014). Eccleston et al. (2021) state that clinical priorities for pain management should include making pain understood (including its subjective nature and biopsychosocial aspects) and making pain visible (asking about the effect of pain in daily life and developing pain measures using a person-centred approach). Patients also felt that staff needed training to facilitate empathy and provide explanations to them. Educational programs can improve staff attitudes and knowledge of pain management and provide better outcomes for chronic pain patients (Abdalrahim et al., 2011; Lin et al., 2008; O'donnell, 2015). Whilst the specialist consultant effectively provided explanations and coping strategies, nurses did not feel equipped. This is acknowledged by the service and the CP had started clinical supervision sessions with nurses (although stopped during the pandemic). These sessions were highly valued, and it is recommended that they are prioritised and expanded to all staff.

Patient interviews allowed a greater understanding of causes of distress. The impetus for this project was formal complaints from patients feeling 'let down' by the service. The service believed this was because patients had not received the expected changes to their pain medication. Indeed, staff reported that medication was a source of friction that led to patients feeling invalidated. Although some patients reported feeling unheard regarding medication, this was only one aspect of a wider challenge of feeling unheard. In fact, some patients reported staff being forthcoming with medication. Therefore, grievances may link to how the rationale is communicated or how quickly doctors approve alternatives. Further, patients felt frustrated that they had *'just being given painkillers and sent home',* acknowledging the limitations of medication and need for alternative support.

Another service expectation for the project involved patients having firm ideas about requiring investigations and surgery. Staff reported that managing expectations (about what the service would offer and not going home pain-free) was particularly challenging. Patients reported frustrations that nothing had been offered and they were discharged still in pain. However, whilst pain severity is a predictor for undergoing surgery, it does not predict endometriosis severity or diagnosis (Conroy et al., 2021). Therefore, information about what pain means (or does not mean) may be an important way for the service to reduce patients' anxiety. Reframing the nature of admissions may also help manage expectations. Patients and staff reported frustrations around a 'never-ending cycle' of repeat admissions. This seemed to symbolise a failure of staff (to support patients) or patients (to manage their condition). Although staff felt that chats with patients were only a short-term fix and could not be prioritised for every patient, they are an opportunity to provide support through crises and pain education. This may allow patients to see a 'point' in their admission, even if they are not discharged pain-free.

There are also implications for how the service supports discharges. Patients reported many uncertainties which may link to difficulties understanding whether pain is normal (Toye et al., 2014). Patients advocated for written information, and information leaflets can reduce anxiety for chronic pain patients (Outlaw et al., 2018). The pre-operative period may be a 'teachable moment' (Wynter-Blyth & Moorthy, 2017) and pre-operative pain education has shown benefits for chronic pain patients (O'donnell, 2015). Services should also acknowledge that pain and uncertainty can be inherent within chronic pain conditions (Eccleston et al., 2021) so interventions may need to focus on helping patients tolerate uncertainty, pain acceptance and psychological flexibility (Hughes et al., 2017). Investing in the development of written materials and psychological interventions may help alleviate distress and potentially reduce repeated admissions, so further research should examine the cost-effectiveness of preventative measures.

Acknowledging the different experiences between surgical and acute admissions may allow the service to support staff with the additional challenges of acute admissions. Patients who felt like a 'burden' and not taken seriously were acute admissions. In contrast, patients with surgical-based admissions emphasised feeling supported through regular check-ins, practical assistance, clear communication and treatment plans. This may demonstrate how staff are currently better equipped to manage the physical side of admissions than the psychological needs of CPPS patients. Nursing staff may need to learn how to talk about pain in a way that feels empathetic and validating (whilst upholding clinical guidelines). Explaining the rationale for not having surgery may be as important in containing patients' distress as providing information pre-operatively. Clinical oversight also varies as surgical patients meet the consultant, yet acute patients may not have done. Staff and patients highlighted how the consultant allows patients to feel in 'safe hands' by providing explanations and clear plans. The situation can feel 'muddled' in the absence of the consultant, and patients may receive contradictory information from different doctors. Therefore, training ward doctors to create clear care plans and emphasising the importance of upholding them is recommended.

Both staff and patients value input from different professionals, supporting research on the importance of multidisciplinary working for CPPS (Baranowski et al., 2013; Laganà et al., 2017; Opoku-Anane et al., 2020). Interestingly, only nurses attended the focus groups (doctors and healthcare assistants were invited). Doctors were reportedly unable to attend due to time-constraints which may encapsulate the difficulties of consistent, team working within a busy service. It may also speak to how CPPS patients, a minority group on the ward, may be less prioritised. The service acknowledges varying staff knowledge about CPPS and the CP will resume clinical supervision sessions to support this need.

**Recommendations**

1. **Staff training to increase knowledge of the following**:

1.1. The subjective nature of pain and how patients may present.

1.2. The biopsychosocial complexities of pain.

1.3. The validity of CPPS inpatient admissions (although the ward wants to minimise admissions, they may be required during crises).

1.4. How to talk about pain and pain management in ways that feel validating to patients and uphold clinical guidelines.

1.5. Training doctors to create and uphold care plans for CPPS patients.

2. **Facilitating conversations with patients to provide holistic care**:

2.1. The service should view spending time providing reassurance and explaining treatments (or lack of) as a legitimate use of staff time.

2.2. One-to-one support may be facilitated on a busy ward by identifying times when conversations are more feasible or by forming job roles.

3. **Reducing uncertainties for patients**:

3.1. Provide opportunities for patients to learn about CPPS and pain management.

3.2. Provide resources (e.g., leaflets and medication timetables) for staff to discuss with patients.

3.3. Offer all patients (not just surgical) a follow-up call following discharge.

3.4. Consider running groups for CPPS to provide pain education, normalise and validate challenges and facilitate peer support.

4. **Re-framing admissions:**

4.1. Viewing admissions as support through a crisis rather than a ‘fix’.

4.2. Acknowledging that despite being discharged without medical changes, continued recovery and adjustments are required.

## Limitations

This project is service specific, therefore not generalisable to other services. The focus of interviews regarded experiences within the JR rather than broader healthcare experiences or attitudes around CPPS. The project coincided with the COVID-19 pandemic. Although interviews included exploration of how this may have affected experiences, and most had experienced the ward pre-pandemic, it may have impacted reporting.

Sample sizes were small, so future research would benefit from larger sample sizes to increase validity and gain a broader representation of ethnicities. Further research could explore group differences between individuals with planned versus acute admissions. This study relied on patients coming forwards to express their views, so it may not be fully representative and include a greater chance of polarised feedback. The staff focus groups were dependent on availability and only nurses were represented. Feedback from other staff members would provide broader experiences and may uncover further barriers and facilitators to providing support. Gathering anonymous staff feedback would aid validity.

## Future work

Due to the novel and exploratory nature of this project, the emphasis was gaining an understanding of experiences to direct resources and future research. This should include:

I. Patient surveys: supplementing the generic survey given at discharge with additional questions for CPPS patients to explore a greater breadth of experiences. Differentiating types of support (feeling understood and medically safe) and how these may correlate with demographic factors could help tailor support.

II. Investigating outcomes for the recommendations listed above, for instance, if facilitating groups help to contain patients' uncertainties and reduce repeat admissions or unnecessary investigative procedures.

III. Staff wellbeing survey: whilst there are positive reports of informal team support, there is currently no official support. A staff survey would provide greater understanding of staff wellbeing in the context of reported challenges, and if required, advocate for space to reflect and debrief.

## References


Abdalrahim, M. S., Majali, S. A., Stomberg, M. W., & Bergbom, I. (2011). The effect of postoperative pain management program on improving nurses' knowledge and attitudes toward pain. *Nurse education in practice, 11*(4), 250-255.

Ahangari, A. (2014). Prevalence of chronic pelvic pain among women: an updated review. *Pain Physician, 17*(2), E141-E147.

Alappattu, M. J., & Bishop, M. D. (2011). Psychological factors in chronic pelvic pain in women: relevance and application of the fear-avoidance model of pain. *Physical therapy, 91*(10), 1542-1550.

Almousa, S., & van Loon, A. B. (2018). The prevalence of urinary incontinence in nulliparous adolescent and middle-aged women and the associated risk factors: a systematic review. *Maturitas, 107*, 78-83.

As-Sanie, S., Black, R., Giudice, L. C., Valbrun, T. G., Gupta, J., Jones, B., Laufer, M. R., Milspaw, A. T., Missmer, S. A., & Norman, A. (2019). Assessing research gaps and unmet needs in endometriosis. *American Journal of Obstetrics & Gynecology, 221*(2), 86-94.

Ayorinde, A. A., Bhattacharya, S., Druce, K. L., Jones, G. T., & Macfarlane, G. J. (2017). Chronic pelvic pain in women of reproductive and post-reproductive age: a population-based study. *European Journal of Pain, 21*(3), 445-455.

Bachmann, C. L., & Gooch, B. (2018). LGBT in Britain: Trans report. *London: Stonewall*.

Baldini, A., Von Korff, M., & Lin, E. H. (2012). A review of potential adverse effects of long-term opioid therapy: a practitioner's guide. *The primary care companion to CNS disorders, 14*(3).

Baranowski, A., Lee, J., Price, C., & Hughes, J. (2014). Pelvic pain: a pathway for care developed for both men and women by the British Pain Society. *British journal of anaesthesia*, *112*(3), 452-459.

Baranowski, A. P., Mandeville, A. L., Edwards, S., Brook, S., Cambitzi, J., & Cohen, M. (2013). Male chronic pelvic pain syndrome and the role of interdisciplinary pain management. *World journal of urology*, *31*(4), 779-784.

Basson, R. (2012). The recurrent pain and sexual sequelae of provoked vestibulodynia: a perpetuating cycle. *The journal of sexual medicine*, *9*(8), 2077-2092.

Beck, A. T., & Haigh, E. A. (2014). Advances in cognitive theory and therapy: The generic cognitive model. *Annual review of clinical psychology*, *10*, 1-24.

Bergeron, S., Likes, W. M., & Steben, M. (2014). Psychosexual aspects of vulvovaginal pain. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *28*(7), 991-999.

Borg, C., Peters, M. L., Schultz, W. W., & de Jong, P. J. (2012). Vaginismus: Heightened harm avoidance and pain catastrophizing cognitions. *The journal of sexual medicine*, *9*(2), 558-567.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., Clarke, V., & Hayfield, N. (2019). 'A starting point for your journey, not a map': Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology*, 1-22.

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European Journal of Pain*, *10*(4), 287-333.

Brotto, L. A., Sadownik, L., & Thomson, S. (2010). Impact of educational seminars on women with provoked vestibulodynia. *Journal of Obstetrics and Gynaecology Canada, 32*(2), 132-138.

Champaneria, R., Daniels, J. P., Raza, A., Pattison, H. M., & Khan, K. S. (2012). Psychological therapies for chronic pelvic pain: systematic review of randomized controlled trials. *Acta obstetricia et gynecologica Scandinavica, 91*(3), 281-286.

Chen, C. X., Draucker, C. B., & Carpenter, J. S. (2018). What women say about their dysmenorrhea: a qualitative thematic analysis. *BMC Women's Health, 18*(1), 1-8.

Chen, H. C., Liu, C. Y., Liao, C. H., & Tsao, L. I. (2020). Self-perception of symptoms, medical help seeking, and self-help strategies of women with interstitial cystitis/painful bladder syndrome. *LUTS: Lower Urinary Tract Symptoms, 12*(3), 183-189.

Chen, L.-C., Hsu, J.-W., Huang, K.-L., Bai, Y.-M., Su, T.-P., Li, C.-T., Yang, A. C., Chang, W.-H., Chen, T.-J., & Tsai, S.-J. (2016). Risk of developing major depression and anxiety disorders among women with endometriosis: a longitudinal follow-up study. *Journal of affective disorders, 190*, 282-285.

Cheong, Y. C., Smotra, G., & de C Williams, A. C. (2014). Non-surgical interventions for the management of chronic pelvic pain. *Cochrane Database of Systematic Reviews*(3).

Chung, S.-D., & Lin, H.-C. (2013). Association between chronic prostatitis/chronic pelvic pain syndrome and anxiety disorder: a population-based study. *PLoS ONE, 8*(5), e64630.

Cole, J. M., Grogan, S., & Turley, E. (2021). “The most lonely condition I can imagine”: Psychosocial impacts of endometriosis on women’s identity. *Feminism & Psychology, 31*(2), 171-191.

Conroy, I. C., Mooney, S. S., Kavanagh, S., Duff, M., Jakab, I., Robertson, K., Fitzgerald, A., McCutchan, A., Madden, S., & Maxwell, S. (2021). Pelvic Pain: what are the symptoms and predictors for surgery, endometriosis and endometriosis severity? *medRxiv*.

Craner, J. R., Gilliam, W. P., & Sperry, J. A. (2016). Rumination, magnification, and helplessness. *The Clinical Journal of Pain*, *32*(12), 1028-1035.

Crowe, M., Whitehead, L., Seaton, P., Jordan, J., Mccall, C., Maskill, V., & Trip, H. (2017). Qualitative meta-synthesis: the experience of chronic pain across conditions. *Journal of advanced nursing*, *73*(5), 1004-1016.

de Boer, H. M. (2010). Epilepsy stigma: moving from a global problem to global solutions. *Seizure*, *19*(10), 630-636.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of health services research & policy*, *10*(1), 45-53.

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A., & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of health services research & policy*, *12*(1), 42-47.

Drabble, S. J. L., J.: Alele, B.: O'Cathain, A. (2020). Constellations of pain: a qualitative study of the complexity of women's endometriosis-related pain [Article]. *British Journal of Pain*. https://doi.org/10.1177/2049463720961413

Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of psychological distress. *Mental illnesses-understanding, prediction and control*, *69*(2), 105-106.

European Association of Urology Guidelines. (2022) *Edn. presented at the EAU Annual Congress Amsterdam 2022*. ISBN 978-94-92671-16-5. https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Chronic-Pelvic-Pain-2022_2022-03-29-084111_kpbq.pdf

Eccleston, C., Fisher, E., Howard, R. F., Slater, R., Forgeron, P., Palermo, T. M., Birnie, K. A., Anderson, B. J., Chambers, C. T., & Crombez, G. (2021). Delivering transformative action in paediatric pain: a Lancet Child & Adolescent Health Commission. *The Lancet Child & Adolescent Health, 5*(1), 47-87.

Edwards, S. K., Bates, C. M., Lewis, F., Sethi, G., & Grover, D. (2015). 2014 UK national guideline on the management of vulval conditions. *International journal of STD & AIDS, 26*(9), 611-624.

Ekholm, E., Lundberg, T., Carlsson, J., Norberg, J., Linton, S. J., & Flink, I. K. (2022). ” A lot to fall back on”: experiences of dyspareunia among queer women. *Psychology & Sexuality*, 1-14.

Facchin, F., Barbara, G., Dridi, D., Alberico, D., Buggio, L., Somigliana, E., Saita, E., & Vercellini, P. (2017). Mental health in women with endometriosis: searching for predictors of psychological distress. *Human Reproduction, 32*(9), 1855-1861.

Facchin, F., Saita, E., Barbara, G., Dridi, D., & Vercellini, P. (2018). “Free butterflies will come out of these deep wounds”: A grounded theory of how endometriosis affects women’s psychological health. *Journal of Health Psychology, 23*(4), 538-549.

Fernández-Martínez, E., Abreu-Sánchez, A., Pérez-Corrales, J., Ruiz-Castillo, J., Velarde-García, J. F., & Palacios-Ceña, D. (2020). Living with pain and looking for a safe environment: A qualitative study among nursing students with dysmenorrhea. *International Journal of Environmental Research and Public Health, 17*(18), 6670.

Fernández-Martínez, E., Abreu-Sánchez, A., Velarde-García, J. F., Iglesias-López, M. T., Pérez-Corrales, J., & Palacios-Ceña, D. (2020). Living with Restrictions. The Perspective of Nursing Students with Primary Dysmenorrhea. *International Journal of Environmental Research and Public Health, 17*(22), 8527.

Flanagan, E., Herron, K. A., O'Driscoll, C., & Williams, A. C. d. C. (2015). psychological treatment for vaginal pain: does etiology matter? A systematic review and meta-analysis. *The journal of sexual medicine, 12*(1), 3-16.

Gambadauro, P., Carli, V., & Hadlaczky, G. (2019). Depressive symptoms among women with endometriosis: a systematic review and meta-analysis. *American Journal of Obstetrics and Gynecology, 220*(3), 230-241.

Garner, P., Hopewell, S., Chandler, J., MacLehose, H., Akl, E. A., Beyene, J., Chang, S., Churchill, R., Dearness, K., & Guyatt, G. (2016). When and how to update systematic reviews: consensus and checklist. *bmj, 354*.

Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychological bulletin, 133*(4), 581.

Goldsmith, M. R., Bankhead, C. R., & Austoker, J. (2007). Synthesising quantitative and qualitative research in evidence-based patient information. *Journal of Epidemiology & Community Health, 61*(3), 262-270.

Griffiths, K. M., Carron-Arthur, B., Parsons, A., & Reid, R. (2014). Effectiveness of programs for reducing the stigma associated with mental disorders. A meta-analysis of randomized controlled trials. *World psychiatry, 13*(2), 161-175.

Grogan, S., Turley, E., & Cole, J. (2018). 'So many women suffer in silence': a thematic analysis of women's written accounts of coping with endometriosis. *Psychology & Health, 33*(11), 1364-1378.

Groven, K. S., Råheim, M., Håkonsen, E., & Haugstad, G. K. (2016). "Will I ever be a true woman?" An exploration of the experiences of women with vestibulodynia. *Health Care for Women International, 37*(8), 818-835.

Hållstam, A., Stålnacke, B.-M., Svensén, C., & Löfgren, M. (2018). Living with painful endometriosis–A struggle for coherence. A qualitative study. *Sexual & Reproductive HealthCare, 17*, 97-102.

Hann, K. E., & McCracken, L. M. (2014). A systematic review of randomized controlled trials of Acceptance and Commitment Therapy for adults with chronic pain: Outcome domains, design quality, and efficacy. *Journal of contextual behavioral science, 3*(4), 217-227.

Happel-Parkins, A., Azim, K. A., & Moses, A. (2020). "I Just Beared Through It": Southern US Christian Women's Experiences of Chronic Dyspareunia. *Journal of Women's Health Physical Therapy, 44*(2), 72-86.

Hawke, L. D., Parikh, S. V., & Michalak, E. E. (2013). Stigma and bipolar disorder: a review of the literature. *Journal of Affective Disorders, 150*(2), 181-191.

Hawkey, A., Chalmers, K. J., Micheal, S., Diezel, H., & Armour, M. (2022). "A day-to-day struggle": A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain. *Feminism & Psychology*, 09593535221083846.

Hintz, E. A. (2019). The Vulvar Vernacular: Dilemmas Experienced and Strategies Recommended by Women with Chronic Genital Pain. *Health Communication, 34*(14), 1721-1730. https://doi.org/10.1080/10410236.2018.1517709

Huang, R., Li, X., Jiang, H., & Li, Q. (2022). Barriers to self-management of patients with adenomyosis: A qualitative study. *Nursing Open, 9*(2), 1086-1095.

Hudson, N., Culley, L., Law, C., Mitchell, H., Denny, E., & Raine-Fenning, N. (2016). 'We needed to change the mission statement of the marriage': biographical disruptions, appraisals and revisions among couples living with endometriosis. *Sociology of Health & Illness, 38*(5), 721-735.

Hughes, L. S., Clark, J., Colclough, J. A., Dale, E., & McMillan, D. (2017). Acceptance and commitment therapy (ACT) for chronic pain. *The Clinical journal of pain, 33*(6), 552-568.

Jaeger, M., Gstoettner, M., & Fleischanderl, I. (2022). "A little monster inside me that comes out now and again": endometriosis and pain in Austria. *Cadernos de Saúde Pública, 38*, e00226320.

Kanter, G., Komesu, Y. M., Qaedan, F., Jeppson, P. C., Dunivan, G. C., Cichowski, S. B., & Rogers, R. G. (2016). Mindfulness-based stress reduction as a novel treatment for interstitial cystitis/bladder pain syndrome: a randomized controlled trial. *International Urogynecology Journal, 27*(11), 1705-1711.

Kanter, G., Volpe, K. A., Dunivan, G. C., Cichowski, S. B., Jeppson, P. C., Rogers, R. G., & Komesu, Y. M. (2017). Important role of physicians in addressing psychological aspects of interstitial cystitis/bladder pain syndrome (IC/BPS): a qualitative analysis. *International Urogynecology Journal, 28*(2), 249-256.

Kirkham, A., & Swainston, K. (2021). Women's Experiences of Interstitial Cystitis/Painful Bladder Syndrome. *Western Journal of Nursing Research*, 0193945921990730.

Krsmanovic, A., Tripp, D. A., Nickel, J. C., Shoskes, D. A., Pontari, M., Litwin, M. S., & McNaughton-Collins, M. F. (2014). Psychosocial mechanisms of the pain and quality of life relationship for chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS). *Canadian Urological Association Journal, 8*(11-12), 403.

Laganà, A. S., La Rosa, V. L., Rapisarda, A. M. C., Valenti, G., Sapia, F., Chiofalo, B., Rossetti, D., Frangež, H. B., Bokal, E. V., & Vitale, S. G. (2017). Anxiety and depression in patients with endometriosis: impact and management challenges. *International journal of women's health, 9*, 323.

Larun, L., & Malterud, K. (2007). Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient Education and Counseling, 69*(1-3), 20-28.

Latthe, P., Latthe, M., Say, L., Gülmezoglu, M., & Khan, K. S. (2006). WHO systematic review of prevalence of chronic pelvic pain: a neglected reproductive health morbidity. *BMC public health, 6*(1), 1-7.

Lee, M., Silverman, M., Hansen, M., Patel, M., & Manchikanti, M. (2011). A comprehensive review of opioid-induced hyperalgesia. *Pain physician, 14*, 145-161.

LePage, K., & Selk, A. (2016). What do patients want? A needs assessment of vulvodynia patients attending a vulvar diseases clinic. *Sexual Medicine, 4*(4), e242-e248.

Lin, P. C., Chiang, H. W., Chiang, T. T., & Chen, C. S. (2008). Pain management: evaluating the effectiveness of an educational programme for surgical nursing staff. *Journal of Clinical Nursing, 17*(15), 2032-2041.

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet, 367*(9509), 528-529.

Lo, G. H.-W., Balasubramanyam, A. S., Barbo, A., Street Jr, R. L., & Suarez-Almazor, M. E. (2016). Mediated by self-efficacy status, positive clinician conveyed expectations of treatment effect reduces pain in knee osteoarthritis. *Arthritis care & research, 68*(7), 952.

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1), 31-42.

Maier, S. F., & Seligman, M. E. (1976). Learned helplessness: theory and evidence. *Journal of experimental psychology: general, 105*(1), 3.

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: a compendium of quality appraisal tools. *Qualitative Health Research, 28*(13), 2115-2131.

Márki, G., Vásárhelyi, D., Rigó, A., Kaló, Z., Ács, N., & Bokor, A. (2022). Challenges of and possible solutions for living with endometriosis: a qualitative study. *BMC Women's Health, 22*(1), 1-11.

Matías-González, Y., Sánchez-Galarza, A. N., Flores-Caldera, I., & Rivera-Segarra, E. (2021). "Es que tú eres una changa": stigma experiences among Latina women living with endometriosis. *Journal of Psychosomatic Obstetrics & Gynecology, 42*(1), 67-74.

McKernan, L. C., Bonnet, K. R., Finn, M. T., Williams, D. A., Bruehl, S., Reynolds, W. S., Clauw, D., Dmochowski, R. R., Schlundt, D. G., & Crofford, L. J. (2020). Qualitative analysis of treatment needs in interstitial cystitis/bladder pain syndrome: Implications for intervention. *Canadian Journal of Pain, 4*(1), 181-198.

Mellado, B. H., Falcone, A. C., Poli-Neto, O. B., e Silva, J. C. R., Nogueira, A. A., & Candido-dos-Reis, F. J. (2016). Social isolation in women with endometriosis and chronic pelvic pain. *International Journal of Gynecology & Obstetrics, 133*(2), 199-201.

Mellado, B. H., Pilger, T. L., Neto, O. B. P., e Silva, J. C. R., Nogueira, A. A., do Vale Brandão, C., & Dos Reis, F. J. C. (2020). Daily life attitudes of women with

moderate or severe chronic pelvic pain. A qualitative study. *European Journal of Obstetrics & Gynecology and Reproductive Biology, 254*, 109-113.

Mellado, B. H., Pilger, T. L., Poli-Neto, O. B., e Silva, J. C. R., Nogueira, A. A., & Dos Reis, F. J. C. (2019). Current usage of qualitative research in female pelvic pain: a systematic review. *Archives of Gynecology and Obstetrics, 300*(3), 495-501.

Mercado, A. C., Carroll, L. J., Cassidy, J. D., & Côté, P. (2005). Passive coping is a risk factor for disabling neck or low back pain. *Pain, 117*(1-2), 51-57.

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women's lives: a qualitative study. *BMC Women's Health, 14*(1), 1-12.

Morley, S., Eccleston, C., & Williams, A. (1999). Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain, 80*(1-2), 1-13.

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. M. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry, 180*(5), 461-464.

Namazi, M., Behboodi Moghadam, Z., Zareiyan, A., & Jafarabadi, M. (2021). Exploring the impact of endometriosis on women's lives: A qualitative study in Iran. *Nursing Open, 8*(3), 1275-1282.

Naushad, N., Dunn, L. B., Muñoz, R. F., & Leykin, Y. (2018). Depression increases subjective stigma of chronic pain. *Journal of Affective Disorders, 229*, 456-462.

O'donnell, K. F. (2015). Preoperative pain management education: A quality improvement project. *Journal of PeriAnesthesia Nursing, 30*(3), 221-227.

Olesen, K., Cleal, B., & Willaing, I. (2020). Discrimination and stigma among people with type 2 diabetes in the workplace: prejudice against illness or obesity? *Public health, 180*, 100-101.

Outlaw, P., Tripathi, S., & Baldwin, J. (2018). Using patient experiences to develop services for chronic pain. *British journal of pain, 12*(2), 122-131.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *bmj, 372*.

Programme, C. A. S. (2018). CASP Qualitative Checklist: Critical Appraisal Skills Programme.

Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil, J. S., Ringkamp, M., & Sluka, K. A. (2020). The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain, 161*(9), 1976-1982.

Rea, T., Giampaolino, P., Simeone, S., Pucciarelli, G., Alvaro, R., & Guillari, A. (2020). Living with endometriosis: a phenomenological study. *International journal of qualitative studies on health and well-being, 15*(1), 1822621.

Roomaney, R., & Kagee, A. (2016). Coping strategies employed by women with endometriosis in a public health-care setting. *Journal of Health Psychology, 21*(10), 2259-2268.

Roomaney, R., & Kagee, A. (2018). Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study. *Journal of Health Psychology, 23*(7), 905-916.

Roth, R. S., Punch, M. R., & Bachman, J. E. (2011). Patient beliefs about pain diagnosis in chronic pelvic pain: relation to pain experience, mood and disability. *The Journal of reproductive medicine*, *56*(3-4), 123-129.

Rush, G., & Misajon, R. (2018). Examining subjective wellbeing and health-related quality of life in women with endometriosis. *Health Care for Women International, 39*(3), 303-321.

Samwel, H. J., Evers, A. W., Crul, B. J., & Kraaimaat, F. W. (2006). The role of helplessness, fear of pain, and passive pain-coping in chronic pain patients. *The Clinical Journal of Pain, 22*(3), 245-251.

Schneider, M., Tallaksen, D. W., Haukland, M., & Haugstad, G. K. (2022). If I stop, then what am I supposed to do? The experiences of sexual intimacy of women who live with provoked vestibulodynia. *Health Care for Women International, 43*(1-3), 176-193. https://doi.org/10.1080/07399332.2020.1868473

Sewell, M., Churilov, L., Mooney, S., Ma, T., Maher, P., & Grover, S. R. (2018). Chronic pelvic pain–pain catastrophizing, pelvic pain and quality of life. *Scandinavian Journal of Pain, 18*(3), 441-448.

Shorey, S., Demutska, A., Chan, V., & Siah, K. T. H. (2020). Adults living with irritable bowel syndrome (IBS): A qualitative systematic review. *Journal of Psychosomatic Research*, 110289.

Sim, J., & Madden, S. (2008). Illness experience in fibromyalgia syndrome: a metasynthesis of qualitative studies. *Social Science & Medicine, 67*(1), 57-67.

Sims, O. T., Gupta, J., Missmer, S. A., & Aninye, I. O. (2021). Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay. *International Journal of Environmental Research and Public Health, 18*(15), 8210.

Steele, A. (2014). Opioid use and depression in chronic pelvic pain. *Obstetrics and Gynecology Clinics, 41*(3), 491-501.

Sutcliffe, S., Bradley, C. S., Clemens, J. Q., James, A. S., Konkle, K. S., Kreder, K. J., Lai, H. H. H., Mackey, S. C., Ashe-McNalley, C. P., & Rodriguez, L. V. (2015). Urological chronic pelvic pain syndrome flares and their impact: qualitative analysis in the MAPP network. *International Urogynecology Journal, 26*(7), 1047-1060.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(1), 1-10.

Toye, F., Seers, K., & Barker, K. (2014). A meta-ethnography of patients' experiences of chronic pelvic pain: struggling to construct chronic pelvic pain as 'real'. *Journal of advanced nursing, 70*(12), 2713-2727.

Van der Kolk, B. (2014). *The body keeps the score: Mind, brain and body in the transformation of trauma*. Penguin UK.

Vercellini, P., Meana, M., Hummelshoj, L., Somigliana, E., Viganò, P., & Fedele, L. (2011). Priorities for endometriosis research: a proposed focus on deep dyspareunia. *Reproductive Sciences, 18*(2), 114-118.

Verheul, W., Sanders, A., & Bensing, J. (2010). The effects of physicians' affect-oriented communication style and raising expectations on analogue patients' anxiety, affect and expectancies. *Patient Education and Counseling, 80*(3), 300-306.

Wahl, K. J., Imtiaz, S., Lisonek, M., Joseph, K., Smith, K. B., Yong, P. J., & Cox, S. M. (2021). Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain. *Sexual Medicine, 9*(1), 100274.

Wood, N., Qureshi, A., & Mughal, F. (2017). Positioning, telling, and performing a male illness: Chronic prostatitis/chronic pelvic pain syndrome. *British Journal of Health Psychology, 22*(4), 904-919.

Wood, N. Q., Annum: Mughal, Fahim. (2017). Positioning, telling, and performing a male illness: Chronic prostatitis/chronic pelvic pain syndrome. *British Journal of Health Psychology, 22*(4), 904-919. https://doi.org/10.1111/bjhp.12261

World Health Organization. (2017). Depression and other common mental disorders: global health estimates. 2017. *Licence: CC BY-NC-SA, 3*.

Wynter-Blyth, V., & Moorthy, K. (2017). Prehabilitation: preparing patients for surgery. *BMJ: British Medical Journal (Online), 358*.

Yoon, Y., Park, M. A., & Park, S. (2021). Seeking adaptation from uncertainty: Coping strategies of South Korean women with endometriosis. *Research in Nursing & Health, 44*(6), 970-978.

Zale, M., Lambert, E., LaNoue, M. D., & Leader, A. E. (2020). Shedding light on endometriosis: Patient and provider perspectives on a challenging disease. *Journal of Endometriosis and Pelvic Pain Disorders, 12*(2), 69-76.

Zarbo, C., Brugnera, A., Dessì, V., Barbetta, P., Candeloro, I., Secomandi, R., Betto, E., Malandrino, C., Bellia, A., & Trezzi, G. (2019). Cognitive and Personality Factors Implicated in Pain Experience in Women With Endometriosis: A Mixed-Method Study. *The Clinical Journal of Pain, 35*(12), 948-957.

**Theoretically Driven Research Project**

# Title: The Role of Social Support in Over-Acquiring and Keeping Possessions: A Cross-Sectional Study

Victoria Edwards

victoria.edwards@hmc.ox.uk

Department of Psychology, University of Oxford, Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

**Word Count:** 4,999

**Date:** June 2022

**Internal Supervisors:**

Professor Paul Salkovskis

Director for the Oxford Institute for Clinical Psychology Training and Research and the Oxford Cognitive Therapy Centre

Dr Victoria Bream

Oxford Cognitive Therapy Centre

**Intended journal and rationale:** The British Journal of Clinical Psychology. This journal is suitable since it publishes original research within clinical psychology that has implications for clinical theory and practice.

## Abstract

**Background:** Unmet interpersonal needs may play a role in excessive emotional attachments to objects for people with hoarding difficulties (HD). Evidence of attachment difficulties stemming from childhood have been noted in HD and may be reflected in the extent of social networks. Previous research indicates that attachment difficulties may not be specific to HD but there are preliminary indications that the extent of social support may be specific.

**Aims**: To evaluate social networks and support in HD relative to clinical controls with obsessive compulsive disorder (OCD) and healthy controls (HC). The secondary aim was to explore the extent of loneliness and thwarted belongingness. Potential mechanisms for deficits in social support were also examined.

**Method:** A cross-sectional between-groups design was used to compare scores on measures in those with HD ($n$ = 37); OCD ($n$ = 31); and HCs ($n$ = 45).

**Results:** Whilst individuals with HD and OCD both report smaller social networks than HC, lower levels of social support appear to be specific to HD. The HD group also showed higher levels of loneliness and thwarted belonging compared to OCD and HC. No differences were found between groups for perceived criticism or trauma.

**Conclusions:** These results support the previous finding of lower levels of self-reported social support within HD. Loneliness and thwarted belongingness also appear significantly elevated within HD compared with OCD and HC. Further research is required to explore the nature of felt support and belonging, direction of effect and to identify potential mechanisms. Clinical implications include the importance of advocating and promoting support systems for individuals with HD and consideration of the role of personal supporters and professionals with healthcare, social care, and charitable sectors.



***Keywords:*** *Hoarding, OCD, social support, loneliness, thwarted belongingness*

## Introduction

Hoarding disorder (HD) is a condition defined by a persistent difficulty with over-acquiring and failure to discard possessions, typically due to a strong perceived need to save items and/or distress associated with discarding (American Psychiatric Association, 2013). It is estimated that HD affects 2.5% of the population in developed countries (Postlethwaite et al., 2019). Symptoms of HD typically develop before the age of 20 (Tolin et al., 2010). Difficulties commonly increase in severity over time, with clinically significant levels most likely to manifest in middle to late adulthood (Dozier et al., 2016) and with clinical presentation often occurring in later life (Thew & Salkovskis, 2016). Whilst previously categorised under the umbrella of obsessive-compulsive disorder (OCD) or obsessive-compulsive personality disorder (OCPD), HD is now classified as a distinct psychiatric diagnosis (American Psychiatric Association, 2013).

For individuals with HD, the most evident difficulties focus on the accumulation of belongings in ways that result in severe clutter and the obstruction of living areas to the point of being unusable. The extent of hoarding is linked to levels of distress and impairment (Timpano et al., 2013). Extreme clutter can lead to a range of related problems including unsanitary living conditions, high rates of evictions and fire hazards (Frost et al., 2008). It can adversely impact and threaten the health and safety of the individual, those around them and surrounding community (Frost et al., 2008; Frost et al., 2000). Compared to community controls, individuals with HD are more likely to have a physical health condition or comorbid mental health disorder and less likely to be married (Nordsletten et al., 2013). Greater clutter and hoarding symptomatology is also associated with a lower frequency of friends and family visiting the home (Davidson et al., 2020), possibly indicating links between HD and levels of social support.

Social support is broadly defined as the assistance and protection given to individuals and may refer to tangible help (e.g., financial aid) and intangible help (e.g.,

emotional assistance) (Langford et al., 1997). Social support can play a substantial role in the maintenance of mental wellbeing and in the prevention of and recovery from mental health difficulties (Mezzina et al., 2006; Wang et al., 2018). Langford et al. (1997) describe three antecedents to social support: a social network (a structure of people around the individual), social embeddedness (the connectedness to those in their network) and social climate (whether there is an atmosphere of helpfulness and protection). It is possible that individuals may have large networks but do not feel connected to or helped by them. Individuals may experience social isolation (an objective lack of interactions with others or the wider community) and loneliness (a subjective feeling of the absence of a social network or a companion), both of which are associated with poorer mental health outcomes (Leigh-Hunt et al., 2017). Further, Joiner's interpersonal theory of suicide states that the presence of two interpersonal constructs, thwarted belongingness (TB) ('I am alone') and perceived burdensomeness (PB) ('I am a burden') increases suicide risk (Van Orden et al., 2010).

According to cognitive-behavioural models of HD, abnormal object attachment may be an attempt to compensate for unmet interpersonal needs and/or attachment difficulties (Frost & Hartl, 1996). It may be that those with HD develop abnormal attachments to possessions as a compensatory source of connectedness, with inanimate objects being experienced as more reliably providing comfort and safety (Yap & Grisham, 2019). However, a recent systematic review found that whilst interpersonal attachment and negative early family environment (e.g., parental warmth) showed some association with greater HD symptomatology, this was associated with broader clinical symptomatology rather than specific to HD (Chia et al., 2021). Indeed, Barton et al. (2021) found that individuals with HD did not differ from OCD controls in terms of impaired parental bonding, attachment insecurity and loneliness; both groups were impaired relative to community controls. However, these authors found that whilst individuals with HD and

OCD had comparably lower numbers of close relationships than community controls, individuals with HD reported feeling significantly less supported.

Chen et al. (2022) found in a community sample recruited online that HD symptoms were correlated with decreased social support and reduced social motivation, even after controlling for depressive symptoms. Another community sample found that loneliness and object attachment were positively associated with HD symptoms (Yap & Grisham, 2019). Poor social support may also form a barrier to recovery as it was associated with increased likelihood of dropping out of treatment in older adults with HD (Weiss et al., 2020).

Reduced social support may be particularly apparent in HD due to the nature of extreme clutter and associated health and safety risks. Interpersonal conflict with family, neighbours and housing providers is common, with stigma surrounding poor housekeeping potentially contributing to defensiveness and conflict (Bratiotis et al., 2019). Reduced support may be associated with alienation from family members who, typically out of concern, try clear the homes of individuals with HD (Kim et al., 2001; Tolin et al., 2008). Yet individuals with HD report that the clearing of clutter can lead to feelings such as loss and violation so may damage relationships (Taylor et al., 2019). There may also be a negative feedback loop between reduced social support and increased clutter as described by the compensatory model of HD (Yap & Grisham, 2019). This suggests that possessions are an attempt to compensate for interpersonal needs such as loneliness, but this may unintentionally perpetuate interpersonal problems and further increase isolation, object attachment and possessions.

It is possible that family environments may be a mechanism for differences in support. Expressed emotion (EE) refers to the quality of a family context and caregiving relationship (Kuipers, 1979). High EE is linked to poorer outcomes in mental health conditions including OCD, depression, and schizophrenia (Bebbington & Kuipers, 1994;

Chambless & Steketee, 1999; Hooley & Teasdale, 1989). Indeed, family members of individuals with HD often report high levels of frustration, conflict, hostility, relationship impact (including rejection and breakdown) and loss of 'normal' family life (Büscher et al., 2014; Park et al., 2014; Tolin et al., 2008; Wilbram et al., 2008). Family conflict and low family competence (defined as poor cohesion, communication and co-operative problem-solving) is associated with increased object attachment and HD symptoms (Davidson et al., 2020).

This may also link to wider social discourses and stigma, as HD was associated with a more negative public perception than conditions such as OCD (Chasson et al., 2018). Individuals with HD were assigned more blame for their condition compared to those with severe mental illness and OCD. Further, participants who had a friend or loved one with HD reported greater disdain and blame towards individuals with HD. Self-criticism and shame have been positively associated with HD symptoms (Chou et al., 2018) suggesting that perceived criticism (PC) may feature in HD.

It is also possible that individuals with HD utilise less social support as they experience relationships as more threatening. Individuals with HD symptoms often report increased rates of physical assault and sexual trauma (Przeworski et al., 2014; Shaw et al., 2016) and interpersonal difficulties and violence has been associated with symptom onset or exacerbation (Tolin et al., 2010). Individuals with HD report greater exposure to a range of traumatic and stressful life events compared with individuals with OCD (without HD) and non-clinical controls (Landau et al., 2011).

As social support, loneliness, and TB represent related but distinct constructs (Berkman et al., 2000; Van Orden et al., 2012) their role within clinical populations including HD should be investigated. As there is evidence for greater levels of criticism and trauma amongst individuals with HD, these could be potential mechanisms.

## Aims and hypotheses

In previous work, individuals with HD reported a comparably reduced quantity of social support as individuals with OCD, and there was an indication that in HD only there was also a reduction in the perceived quality of support (Barton et al., 2021). This current study aimed to replicate and extend that finding, seeking to understand the role of present-day relationships. This study will include a more comprehensive assessment of available support, including the extent of social networks (size of network, length known and frequency of contact) and support (emotional support and aid). Measures of loneliness and TB were added to evaluate the extended impact of feeling unsupported, and two potential mechanisms were considered (perceived criticism and self-reported trauma).

I. *Primary hypothesis: Those in HD and OCD groups will both have smaller social networks relative to HC, however, HD will report lower levels of perceived support compared to OCD and HC.*
II. *Secondary hypothesis: Individuals with HD will report greater loneliness and thwarted belongingness than those with OCD and HC.*
III. *Exploratory variables (possible mechanisms) were PC and trauma*

# Method

## Design

The study had a cross-sectional, between-group design (HD, OCD and HC). Data collection took place from August 2021-April 2022. Ethical approval was obtained from the University of Oxford Central University Research Ethics Committee (R74797/RE001; Appendix Q).

## Sample size

Power analysis was conducted using G*Power (Faul et al., 2007) to determine sample size. For a three-group independent measures ANOVA (with 80% power, $\alpha$=0.05), 111 participants (37 per group) were required to detect a medium effect size of 0.4. This was informed by previous findings (Barton et al., 2021).

## Participants

Participants were recruited from the general population. Inclusion criteria included adults (≥18 years with no upper limit) based in the United Kingdom. Participants were excluded if they were unable to speak English or provide informed consent. Participants in the HC group were excluded if they meet criteria for obsessive, compulsive, or hoarding difficulties (assessed through SCID and measures).

## Procedure

### *Service user involvement*

Key study documentation and measures were piloted with individuals representing each of the three groups to consider clarity, ease of understanding and participant burden. Overall, feedback indicated that the survey was clear and accessible. Following feedback clarifying points were made, for example, specifying if participants were being asked how much they felt supported in general or regarding specific difficulties. Given feedback around the length of the questionnaires and ease of use, the 2-item PCM and OCI-short form were selected.

### *Recruitment and procedure*

Participants were recruited through voluntary organisations (e.g., Hoarding Disorders UK and OCD UK) and through social media (e.g., Twitter). The HC group were recruited by social media and snowball sampling via individuals in the clinical groups to

help recruit participants with similar demographics. Individuals who had previously participated in research at the University of Oxford and who had consented to be contacted about future studies that might be of interest, were emailed study details.

Participation included a telephone call and a battery of self-report demographic and psychometric measures taking approximately 30-40 minutes (further procedural details Appendix R). Key study documentation including information sheet, consent form and debrief sheet are available in Appendix S.

### *Measures*

Standardised measures are outlined in Table 1. Sociodemographic characteristics are shown in Appendix T.

**Table 3**

*Measures and their Psychometric Properties*

| Domain | Measure |
|---|---|
| Diagnostic screening | **Structured Clinical Interview for DSM-5 (SCID)** (First et al., 2015): A semi-structured interview for making major DSM-5 Axis I diagnoses. It provides criteria to allow judgements on whether participants met the criteria for HD and OCD subsections. |
| Psychopathology | **The Patient Health Questionnaire-9 (PHQ-9)** ***(Kroenke et al., 2001)***: A widely used 9-item questionnaire is a reliable and valid measure to screen for depression. The PHQ9 shows excellent internal reliability (Cronbach's $\alpha = 0.92$) and test-retest reliability (Kroenke et al., 2001). Within this study, the PHQ-9 also showed excellent internal reliability (Cronbach's $\alpha = 0.92$). |
| | **Generalized Anxiety Disorder-7 (GAD-7)** ***(Spitzer et al., 2006):*** A widely used 7-item questionnaire is a measure using a four-point scale of the severity of anxiety symptoms over the past two weeks. The GAD-7 demonstrates excellent internal consistency (Cronbach's $\alpha = 0.94$) and good test-retest reliability (interclass correlation = 0.83) (Spitzer et al., 2006). Within this study the GAD-7 showed high internal reliability (Cronbach's $\alpha = 0.91$). |
| | **Work and Social Adjustment Scale (WSAS)** ***(Mundt et al., 2002):*** A 5-item measure of an individual's ability to carry out day-to-day tasks on an 8-point scale. It is a simple, reliable, and valid |

| | |
|---|---|
| | way of measuring impaired functioning. The WSAS demonstrates good-excellent internal consistency (Cronbach's α = 0.70-0.94) and acceptable test-retest reliability (interclass correlation = 0.73) (Mundt et al., 2002). Within this study the WSAS showed good internal reliability (Cronbach's α = 0.84). |
| | **Savings-Inventory Revised (SIR)** ***(Frost et al., 2004):*** A 23-item measure of HD with three subscales: Difficulty Discarding, Clutter and Acquisition. The SI-R demonstrates excellent internal consistency (Cronbach's α = 0.94) and good test-retest reliability (*r* = 0.86) (Frost et al., 2004). Within this study the SIR showed excellent internal reliability (Cronbach's α = .98). |
| | **Obsessive Compulsive Inventory -Revised (OCI-R)** (Foa et al., 2002): A short version of the Obsessive Compulsive Inventory (Foa et al., 1998) containing 18 items and 6 subscales. Test-retest reliability has been demonstrated for OCD patients (*r*= 0.74–0.91) and non-anxious controls (*r* = 0.58–0.87). It has good diagnostic ability for OCD (Abramowitz & Deacon, 2006). The OCI-R total demonstrates excellent internal consistency (Cronbach's α = 0.90) (Foa et al., 2002). In the current study, OCI-R total demonstrated excellent internal reliability (Cronbach's α = 0.92). |
| | **Beliefs About Hoarding Questionnaire Revised (BAH)** (Gordon et al., 2013): A 28-item measure to assess beliefs and experiences characteristic of HD. It includes subscales for HD motivated by harm avoidance, material deprivation, and attachment disturbance. |

| | |
|---|---|
| | The BAH demonstrates excellent internal consistency (Cronbach's α = 0.96) and good test-retest reliability for individuals with HD (r = 0.83) (Gordon et al., 2013). In the current study, BAH demonstrated excellent internal reliability (Cronbach's α = 0.97). |
| Social support | **Revised Norbeck Social Support Questionnaire (NSSQ-R)** (Norbeck et al., 1981): Participants are asked to write a list of significant people in their life and rate them on various categories. Total network includes a) number of supporters, b) duration of relationship and c) frequency of contact. Total support comprises a) affect (how much they feel liked/loved and respected/admired), b) affirmation (how much they feel agreed with and can confide in supporters), and c) aid (immediate and longer-term help). It shows excellent test-retest reliability over one-week period (*r* = 0.86-0.92) (Norbeck et al., 1981). As recommended, averaged scores using the NSSQ-R with the use of n/a response options were used (Gigliotti & Samuels, 2020). In the current study, NSSQ-R network subscale demonstrated excellent internal reliability (Cronbach's α = 0.97) as did the support subscale (Cronbach's α = 0.98). |
| | **Medical Outcomes Study Social Support Survey (MOS-SSS)** (Sherbourne & Stewart, 1996) A 20-item measure of social support. Items are divided into four subscales: perceived adequacy of tangible, emotional and affectionate support as well as positive social interaction. Each item is rated on a 5-point Likert scale to indicate how often the respondent receives support. One additional question ascertains the respondents' number of close relatives and |

| | |
|---|---|
| | friends. The MOS-SSS demonstrates good internal consistency (α = 0.97), and good test-retest reliability over a one-year period (*r* = 0.78). In the current study, the MOSS-SSS demonstrated excellent internal reliability (Cronbach's α = 0.97) (Sherbourne & Stewart, 1996). |
| Loneliness | **UCLA Loneliness Scale** (Russell et al., 1980): A 20-item measure related to experiences of loneliness where participants rate their feelings using a 4-point Likert scale. It has a good internal reliability and convergent validity with other measures of loneliness. It demonstrates good internal consistency (α = 0.89-0.94) and test-retest reliability over a one-year period (*r* = 0.73) (Russell et al., 1980). In the current study, the scale demonstrated excellent internal reliability (Cronbach's α = 0.96). |
| Thwarted belongingness and perceived burdensomeness | **Interpersonal Needs Questionnaire-Revised (INQ-R)** (Van Orden et al., 2012): A 15-item measures of the extent to which individuals believe their need to belong is met (i.e., thwarted belongingness; INQ-R-TB) and the extent to which they perceive themselves to be a burden on others (i.e., perceived burdensomeness; INQ-R-PB). Good internal reliability has been established for TB items (Cronbach's α = 0.85) and PB items (Cronbach's α = 0.89) (Van Orden et al., 2008). The current study demonstrated excellent internal reliability for TB items (Cronbach's α = 0.94) and PB items (Cronbach's α = 0.91). |

| | |
|---|---|
| Perceived criticism (PC) | **The Perceived Criticism Measure (PCM)** (Hooley & Teasdale, 1989; Masland & Hooley, 2015): Participants rate each important person to them on a scale from 1 (not at all critical) to 10 (very critical) and the extent they get upset when the important person criticises them from 1 (not at all) to 10 (extremely). PC has been identified as the most important element of EE (Hooley & Parker, 2006). The PCM is a straightforward measure to administer with good concurrent and predicative validity (Masland & Hooley, 2015).The test–retest reliability for the criticism portion of the PCM was shown to be moderately high ($r$ = .75) over approximately five months (Hooley & Teasdale, 1989). In the current study, the scale demonstrated excellent internal reliability for PC (Cronbach's α = .97) and for perceived upset (Cronbach's α = .98). |
| Trauma | **Life Events Checklist for DSM-5 (LEC-5)** (Weathers et al., 2013): A self-report measure of traumatic events. It assesses exposure to 16 events known to potentially result in PTSD or distress with an additional item assessing any other extraordinarily stressful event not captured by the previous items. The scale demonstrates good test-retest reliability over a one-week period ($r$ = 0.82). For the purposes of this study, LEC-5 total will refer to the total of the following subscales: happened to me, witnessed it, learnt about it happening to close family member or friend, part of my job. |

### *Data analysis*

Statistical analyses were performed using IBM SPSS (version 28) and interpreted with reference to 0.05 significance levels. There were no missing data; most participants (118; 98%) completed the questionnaires online, which required all items to be completed. Measures of psychopathology were examined to ensure that individuals were appropriately assigned to diagnostic groups by looking at the spread of scores between and within groups. Data was screened for deviations from normality. Chi-square analysis was used to determine differences between the groups on categorical demographic variables. Continuous data were assessed for assumptions of normality. Analysis of Variance (ANOVA) were employed to compare means across the three groups. Where repeated measures ANOVA showed evidence of intercorrelation, this was adjusted using a Greenhouse-Geisser (G-G) correction. Where indicated, multiple comparisons used the LSD test; where the Levene test indicated problems with homogeneity of variance, Dunnets T3 was used instead.

## Results

### Sample characteristics

A total of 132 individuals completed the telephone screening interview and 120 completed questionnaires. Seven individuals met criteria for both OCD and HD. As this was insufficient for a fourth comparison group, their data was excluded from analyses. One individual initially assigned to the OCD group was excluded from analysis due to a low OCI-R score (scoring 11). Therefore, data analysis was on 113 participants: HD=37, OCD=31 and HC=45.

**Demographic and descriptive variables**

All participants were aged between 23-84 years (*M=50.38, SD=16.54*). Participants were predominantly female (79.6%), identified as Caucasian (89.4%) with secondary school education or higher (100%). Fifty-five participants were married or living as a couple (48.7%) and fifty-six were employed (49.6%). Supplementary information Appendix T.

There was a significant main effect of group on age ($F_{(2, 110)}$=15.53, $p$<.001). Multiple comparisons indicated that the OCD group was significantly younger than HD and HC (which did not significantly differ). A Chi-Square test was performed to assess the association between group and gender. No significant association was observed ($\chi^2_{(4)}$=.018, $p$>.05). There was no association between group and employment ($\chi^2_{(2)}$=4.82, $p$>.05) or being married/ living as a couple ($\chi^2_{(4)}$=2.94, $p$>.05). There was a significant association between the group and education ($\chi^2_{(4)}$=17.90, $p$ =.001). Individuals in OCD and HC groups generally had higher education. There were group differences in past and current mental health support (see Table 2).

**Table 4**

*Characteristics by Group*

| | **HD (n=37)** | | **OCD (n=31)** | | **HC (n=45)** | | **Main effect** |
|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | |
| **Age** | 58.76[a] | 10.19 | 38.87[b] | 11.05 | 51.42[a] | 19.37 | $F_{(2, 110)}$=15.53, $p$<.001 |
| | | | | | | | |
| | N | % | N | % | N | % | |
| **Gender** | | | | | | | $\chi^2_{(4)}$=.018, $p$=.991 |
| Female | 30 | 81.1 | 24 | 77.4 | 36 | 80.0 | |
| Male | 7 | 18.9 | 6 | 19.4 | 9 | 20.0 | |
| Other | 0 | 0 | 0 | 0 | 1† | 0.9 | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Ethnicity** | | | | | | | ‡ |
| Caucasian | 33 | 89.2 | 28 | 90.3 | 40 | 88.9 | |
| Other | 4 | 10.8 | 3 | 9.7 | 5 | 11.1 | |
| **Education** | | | | | | | $\chi^2_{(4)}$=17.90 *p*=.001 |
| Secondary school | 17 | 45.9 | 8 | 25.8 | 5 | 11.1 | |
| University degree | 15 | 40.5 | 10 | 32.3 | 17 | 37.8 | |
| Postgraduate degree | 5 | 13.5 | 13 | 41.9 | 23 | 51.1 | |
| **Occupational status** | | | | | | | $\chi^2_{(2)}$=4.82, *p*=.090 |
| Employed | 14 | 37.8 | 20 | 64.5 | 22 | 48.9 | |
| Other | 23 | 51.1 | 11 | 35.5 | 23 | 62.2 | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Civic status** | | | | | | | $\chi^2_{(4)}=2.94$, $p=.237$ |
| Married /living as a couple | 14 | 37.8 | 18 | 58.1 | 23 | 51.1 | |
| Other | 23 | 62.2 | 13 | 41.9 | 22 | 48.9 | |
| **Past mental health support** | | | | | | | ‡ |
| Yes | 33 | 89.2 | 29 | 93.5 | 25 | 55.6 | |
| No | 4 | 10.8 | 2 | 6.5 | 20 | 44.4 | |
| **Currently receiving professional mental health support** | | | | | | | $\chi^2_{(2)}=16.82$, $p<.001$ |
| Yes | 13 | 35.1 | 18 | 58.1 | 6 | 13.3 | |
| No | 24 | 64.9 | 13 | 41.9 | 39 | 86.7 | |
| **Currently receiving talking therapy** | | | | | | | $\chi^2_{(2)}=18.10$, $p<.001$ |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Yes | 8 | 21.6 | 15 | 48.39 | 3 | 6.6 | |
| No | 29 | 78.37 | 16 | 51.6 | 42 | 93.3 | |
| **Currently taking medication for mental health** | | | | | | | $\chi^2_{(2)}$=16.10 $p$<.001 |
| Yes | 20 | 54.1 | 16 | 51.6 | 7 | 15.6 | |
| No | 17 | 45.9 | 15 | 48.4 | 38 | 84.4 | |

†item excluded to complete chi-square analysis

‡cell count too small to complete chi-squared analysis

**Table 5**

*Measures of Psychopathology (with Multiple Comparisons Used)*

| | **HD (n=37)** | | **OCD (n=31)** | | **HC (n=45)** | | |
|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | Main effect of group |
| **PHQ-9** | 10.76[a] | 6.36 | 10.03[a] | 8.09 | 3.44[b] | 4.07 | $F_{(2, 110)}$=17.63, $p$<.001 |
| **GAD-7** | 7.76[a] | 5.11 | 10.58[a] | 6.11 | 3.22[b] | 3.69 | $F_{(2, 110)}$=21.76, $p$<.001 |
| **WSAS** | 21.24[a] | 10.05 | 18.29[a] | 10.96 | 5.00[b] | 6.64 | $F_{(2, 110)}$=36.92 $p$<.001 |
| **OCI-R total (-hoarding)** | 21.38[a] | 9.42 | 31.74[b] | 14.25 | 6.64[c] | 6.76 | $F_{(2, 110)}$=58.72, $p$<.001 |
| OCI-R: washing | 1.16[a] | 1.84 | 5.58[b] | 4.80 | .47[a] | 1.04 | $F_{(2, 110)}$=33.63, $p$<.001 |
| OCI-R: checking | 2.84[a] | 2.57 | 5.25[b] | 3.75 | 1.07[c] | 1.67 | $F_{(2, 110)}$=22.69, $p$<.001 |
| OCI-R: ordering | 4.16[a] | 2.90 | 5.65[a] | 4.27 | 1.80[b] | 2.61 | $F_{(2, 110)}$=13.74, $p$<.001 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| OCI-R: obsessing | 3.81[a] | 2.91 | 8.74[b] | 2.61 | 1.5[c] | 1.93 | $F_{(2, 110)}$=78.43, $p$<.001 |
| OCI-R: neutralising | .97[a] | 1.44 | 3.35[b] | 3.70 | .49[a] | 1.39 | $F_{(2, 110)}$=15.70, $p$<.001 |
| OCI-R: hoarding | 8.43[a] | 2.51 | 3.16[b] | 3.25 | 1.27[c] | 1.64 | $F_{(2, 110)}$=89.96, $p$<.001 |
| **SIR total** | 60.92[a] | 15.60 | 23.81[b] | 19.47 | 12.31[c] | 10.70 | $F_{(2, 110)}$=110.15, G-G $p$<.001 |
| SIR: clutter | 24.70[b] | 8.10 | 7.42[a] | 7.81 | 4.47[a] | 6.39 | $F_{(2, 110)}$=84.22, G-G $p$<.001 |
| SIR: DD | 20.24[a] | 8.10 | 9.06[b] | 7.51 | 4.18[c] | 4.58 | $F_{(2, 110)}$=81.46, G-G $p$<.001 |
| SIR: EA | 15.97[a] | 5.63 | 7.32[b] | 6.30 | 3.67[c] | 3.278 | $F_{(2, 110)}$=61.91, G-G $p$<.001 |
| **BAH - HA** | 3.28[a] | 3.28 | 3.28[a] | 3.12 | 1.41[b] | .74 | $F_{(2, 110)}$=13.48, $p$<.001 |
| **BAH - MD** | 5.62[a] | 2.26 | 3.19[b] | 2.70 | 1.67[c] | .99 | $F_{(2, 110)}$=39.23, $p$<.001 |
| **BAH - AD** | 5.21[a] | 2.51 | 3.57[b] | 2.62 | 1.98[c] | 2.51 | $F_{(2, 110)}$=23.24, $p$<.001 |

†Figures that share superscript are not significantly different on multiple comparisons, those that do not share a subscript are statistically different.

SIR-DD= difficulty discarding; SIR-EA= excessive acquisition. BAH-HA = harm avoidance subscale; BAH-MD = material deprivation; BAH-AD = attachment disturbance.

GG=Greenhouse Geisser adjustment applied.

As shown in Table 3, there were group differences on measures of depression, anxiety, and general functioning (WSAS). Clinical groups did not differ and scored significantly higher than HC.

As the OCI-R contained a hoarding subscale, a mixed-model ANOVA for the other five subscales was conducted: 3 (diagnostic group) x5 (subscale). There was a significant main effect of diagnostic group ($F_{(1,110)}$=345.24, $p$<.001). There was a significant main effect of subscale ($F_{(4, 440)}$=30.81, $p$<.001). These effects were modified by a significant group x subscale interaction ($F_{(8,440)}$=6.30, $p$<.001). A follow-up simple main effects analysis was carried out on each scale. A one-way ANOVA between groups on the OCI-R hoarding subscale indicated that HD showed highest levels followed by OCD then HC.

A mixed-model ANOVA for the SIR subscales was carried out: 3 (diagnostic group) x3 (subscale). There was a significant main effect of diagnostic group *(*$F_{(1,110)}$=504.69, $p$<.001) and subscale ($F_{(1.70, 186.4)}$=16.19, G-G $p$<.001). These effects were modified by a group x subscale interaction ($F_{(3.4, 186.4)}$=12.13, G-G $p$<.001). Simple main effects analysis indicated that HD had significantly higher clutter compared to OCD and HC (with no significant difference between OCD and HC). There were significant differences between groups for difficulty discarding and excessive acquisition, with HD reporting the greatest difficulties followed by OCD then HC.

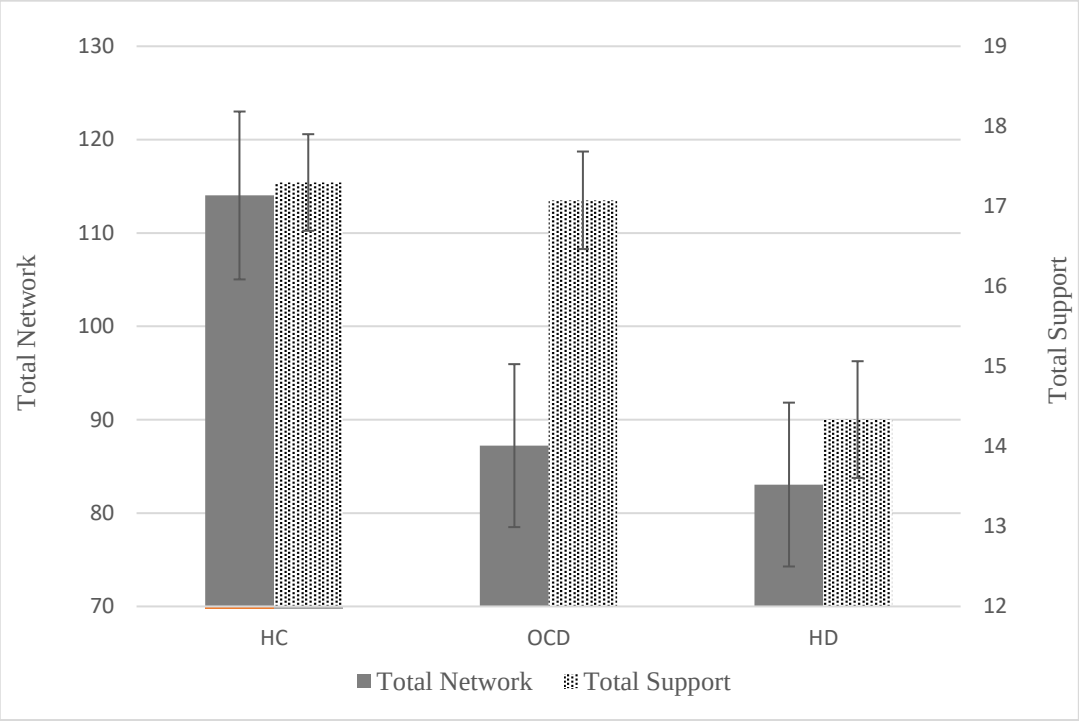
A mixed-model ANOVA for the BAH subscales was carried out: 3 (diagnostic group) x3 (subscale). There was a significant main effect of diagnostic group ($F_{(2,110)}$=28.58, $p$<.001) and subscale ($F_{(1, 110)}$=39.50, $p$<.001). These effects were modified by a group x subscale interaction ($F_{(2, 110)}$=11.49, $p$<.001). A follow-up simple main effects analysis was carried out on each scale. HD and OCD showed

equal and significantly higher levels of harm avoidance than HC. There was a significant difference between all groups on material deprivation and attachment disturbance, with HD reporting the greatest difficulties followed by OCD then HC.

**Primary outcome**

**Figure 2**

*Social Network and Social Support by Group as Measured by the NSSQ-R*




*Note:* Error bars represent standard errors

*Social network:*

A one-way ANOVA was conducted to see if there was a difference in size of social network between each group. There was a significant main effect of group ($F_{(2,110)}$=6.39, $p$=.002). Planned comparisons revealed that, as predicted, HD and OCD had significantly similar and smaller social networks than HC (Table 4). Analysis of subscales revealed that HD and OCD both had similar and reduced numbers of

supporters and had known them less time than HC. HD had significantly less contact with supporters than the HC group (with no significant difference between OCD and HD or HC).

*Perceived social support:*

A one-way ANOVA was conducted to see if there was a difference in degree of perceived social support between each group. This showed a main effect of group on perceived support ($F_{(2, 110)}$=6.39, $p$=.002). Planned comparisons showed that HD reported less support than OCD and HC (which showed no significant difference from each other). Analysis of subscales showed a significant difference in emotional support between HD and HC groups (with no significant difference between OCD and HD or HC). HD reported receiving significantly less aid than OCD and HC (which showed no significant difference from each other).

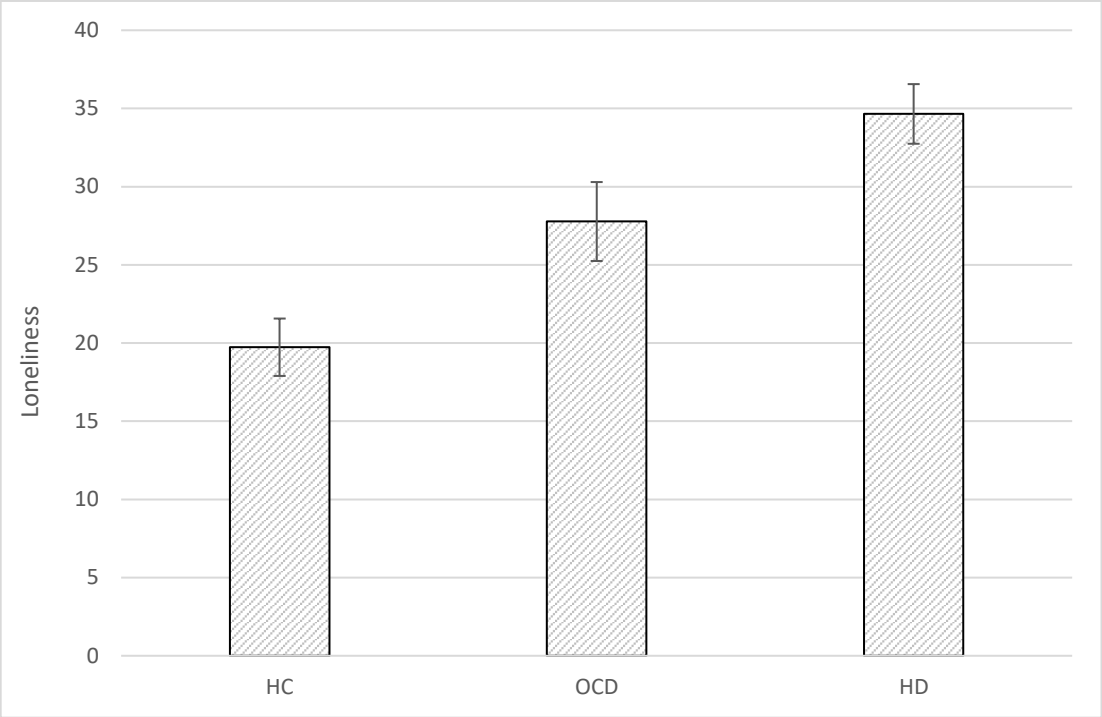
As this study aimed to replicate findings by (Barton et al., 2021) which utilised the MOSS-SSS, this was also analysed here. There was a significant main effect of group ($F_{(2, 110)}$=9.62, G-G $p$<.001). Planned comparisons showed that HD and OCD reported statistically similar and fewer close friends and relatives than HC. A one-way ANOVA showed a significant difference in support between groups ($F_{(2, 110)}$=10.91, $p$<.001). Planned comparisons revealed that HD reported significantly less support than OCD and HC groups (which did not significantly differ from each other). This finding was consistent for all subscales.

**Secondary outcomes**

*Loneliness*

**Figure 3**

*Reported Loneliness by Group as Measured by the UCLA*




*Note:* Error bars represent standard errors

A one-way ANOVA was conducted to investigate whether there was a difference in loneliness between groups. This showed a significant main effect of group ($F_{(2,110)}$=14.37, $p$<.001). Planned comparisons revealed statistically significant differences between all groups. As predicted, HD individuals were the loneliest, followed by OCD then HC.

*Thwarted Belongingness*

A one-way ANOVA was conducted to see if there was a difference in thwarted belonging between groups. There was a significant main effect on group ($F_{(2, 110)}$=12.50, $p$<.001). Post-hoc analysis showed a statistically significant difference in TB. HD reported greatest TB, followed by OCD, then HC.

As PB was measured as part of the INQ-R this was also analysed. A one-way ANOVA was also conducted to see if there was a difference in PB between group. There was a significant main effect of group ($F_{(2, 110)}$=13.90, $p$<.001). Post-hoc analysis showed that HD and OCD had statistically similar and higher PB than HC.

**Exploratory analyses**

*PC*

A one-way ANOVA was conducted to see if there was a difference in PC between groups. There was no significant main effect of PC ($p$=.281). The measures also included a separate question asking how upset individuals felt when criticised. There was a significant main effect of upset on group ($F_{(2,109)}$=4.95, $p$=.009). Post-hoc analysis showed that the OCD group reported significantly greater upset when criticised compared with HD and HC (with no significant difference between HD and HC).

*Trauma*

A one-way ANOVA was conducted to see if there was a difference in trauma between each group. There was no significant main effect on total trauma ($p$=.060) or 'happened to me' subscale between groups ($p$=.052). Therefore, no further analyses were conducted.

*Correlations*

As there were significant between group differences, correlations between age, social support, loneliness and TB were conducted (within and across groups). Only one correlation was significant: TB and age across groups ($r_{(111)}$=.203, $p$=.031). This correlation was not significant within groups. No other correlations with age were significant ($p$>.05).

Another difference between groups was education and a partial eta squared was conducted for social support ($\eta_p^2$= 0.16; 2.56% of the variance), loneliness ($\eta_p^2$= 0.261; 13.03% of the variance) and TB ($\eta_p^2$= 0.376; 14.12% of the variance).

**Table 6**

*Outcome Measures*

| | HD (n=37) | | OCD (n=31) | | HC (n=45) | | |
|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | Main effect of group |
| **NSSQ-R- network** | 83.05[a] | 53.38 | 87.23[a] | 48.60 | 114.02[b] | 60.31 | $F_{(2, 110)}$=3.82, $p$ =.025 |
| - no. supporters | 8.97[a] | 5.94 | 9.16[a] | 5.25 | 12.09 [b] | 6.67 | $F_{(2, 110)}$=3.38, $p$ =.038 |
| - length known | 41.03[a] | 27.20 | 41.68[a] | 24.78 | 57.29 [b] | 30.84 | $F_{(2, 110)}$=4.38, $p$ =.015 |
| -freq. of contact | 33.05[a] | 20.87 | 36.39[ab] | 19.03 | 44.64[b] | 23.35 | $F_{(2, 110)}$=3.9, $p$ =.045 |
| **NSSQ-R- support** | 14.34[a] | 4.44 | 17.08[b] | 3.40 | 17.30[b] | 4.05 | $F_{(2, 110)}$=6.39, $p$=.002 |
| - emotional | 10.60[a] | 3.04 | 11.76 [ab] | 2.59 | 12.29[b] | 2.68 | $F_{(2, 110)}$=3.82, $p$=.025 |
| - aid | 3.73[a] | 1.86 | 5.31[b] | 1.53 | 5.01[b] | 1.73 | $F_{(2, 110)}$=6.39, $p$<.001 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **MOSS-SSS - supporters** | 4.32[a] | 3.20 | 5.97[a] | 4.45 | 8.80 [b] | 5.79 | $F_{(2, 110)}$=9.62, $p$<.001 |
| **MOSS-SSS – total support** | 37.73[a] | 16.47 | 54.03[b] | 18.70 | 54.84[b] | 18.56 | $F_{(2, 110)}$=10.91, G-G $p$<.001 |
| - emotional | 17.24[a] | 7.77 | 23.10[b] | 8.42 | 23.91[b] | 7.37 | $F_{(2, 110)}$=8.32, G-G $p$<.001 |
| - tangible | 6.68[a] | 5.03 | 11.16[b] | 4.71 | 10.44[b] | 5.33 | $F_{(2, 110)}$=8.16, G-G $p$<.001 |
| - affection | 5.78[a] | 3.64 | 8.87[b] | 3.19 | 9.00[b] | 3.86 | $F_{(2, 110)}$=9.54, G-G $p$<.001 |
| - positive | 6.19[a] | 2.95 | 8.19[b] | 3.49 | 8.69[b] | 3.25 | $F_{(2, 110)}$=6.54, G-G $p$=.002 |
| **UCLA** | 34.65[a] | 11.60 | 27.77[b] | 14.05 | 19.73c | 12.31 | $F_{(2,110)}$=4.37, $p$<.001 |
| **PC–criticism** | 2.41[a] | 2.48 | 1.74[a] | 2.49 | 1.56[a] | 2.42 | $F_{(2,110)}$=1.28, $p$=.281 |
| **PC–upset** | 2.74[ab] | 1.75 | 3.42[b] | 1.70 | 2.17[a] | 1.68 | $F_{(2, 109)}$=4.95, $p$=.009 |
| **INQ-R-PB** | 8.70[a] | 7.87 | 7.13[a] | 8.58 | 1.33[b] | 3.29 | $F_{(2, 110)}$=13.90, $p$<.001 |
| **INQ-R-TB** | 29.22[a] | 13.06 | 20.68[b] | 13.38 | 14.04[c] | 12.61 | $F_{(2, 110)}$=12.50, $p$<.001 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **LEC – happened to me** | 1.59[a] | 1.36 | 1.10[a] | 1.22 | 1.59[a] | 1.36 | $F_{(2, 110)}$=3.03, $p$=.052 |
| †Figures that share superscript are not significantly different on multiple comparisons; those that do not share a subscript are statistically different. | | | | | | | |

## Discussion

This study investigated the role of social support in HD relative to OCD as a clinical control group and healthy controls. We sought to replicate previous findings that individuals with HD experience reduced social support (Barton et al., 2021). These findings were replicated; those with HD and OCD both had smaller social networks than HC, but reduced support was specific to HD. This included significant differences in reported emotional support and aid. The HD group reported significantly higher loneliness and thwarted belongingness relative to both OCD and HC. There was no significant difference in PC or trauma between groups.

The replication of Barton et al. (2021) was observed using the NSSQ-R which is a more comprehensive evaluation, as well as the original MOSS-SSS. Whilst Barton et al. (2021) found that OCD and HD experienced reduced (but comparable) loneliness, the present study found HD to have significantly greater loneliness. It is possible that completing the NSSQ-R induced greater feelings of loneliness. The present study occurred during the COVID-19 pandemic, and it is possible that lockdowns had a particularly exacerbating effect on individuals with HD.

The results are consistent with previous findings from community samples that HD symptoms are correlated with reduced social support (Chen et al., 2022) and increased loneliness (Yap & Grisham, 2019). It builds upon studies showing associations between HD and poorer social functioning that used demographic variables as a proxy for social support (Archer et al., 2019).

Previous research has found differences in relationship status between HD and OCD and HC (e.g., Barton et al., 2021). In this study HD did not differ significantly in terms of being married/living as a couple. However, in both the current study and Barton et

al., (2021) HD report reduced social support compared to OCD and HC, so partnership appears unlikely to account for reduced social support in HD.

Previous studies suggest increased trauma within HD which was not found in this study. Studies typically report correlations between increased trauma and increased hoarding symptoms (e.g., Przeworski et al., 2014; Shaw et al., 2016) rather than between group comparisons established by a SCID as in this study. Trauma may increase certain HD symptoms but may not be specific to HD. It is also possible our sample is not representative (e.g., individuals with a trauma history may be less likely to participate in studies with a telephone interview, or as the sample had higher partnership rates this may correspond to reduced adverse relationships). It could also be that the LEC did not capture HD-related trauma (e.g., sudden material deprivation) so future research should consider alternative measures.

**Strengths and limitations**

This study utilised the SCID to increase validity in assigning individuals to diagnostic groups and included a comparison of HD with comparably impaired clinical controls as well as HCs. It included a comprehensive measure of social support which includes consideration and rating of all listed individuals.

The recruitment method (samples of convenience from social media and personal contacts including other trainee research) may have impacted the representativeness of the groups. Whilst paper questionnaires were available to those without internet access, most of the recruitment was online (especially as support groups were no longer face-to-face due to COVID-19). The use of the SCID means validity of groupings was strong but the recruitment strategy likely impacted who was aware of the study and volunteered. However, this would be expected to be comparable across groups so is unlikely to account for group differences.

The sample predominantly consisted of well-educated Caucasian females limiting generalisability; exploring how support and belonging may vary between cultures is required. The sample was also self-selected, with some clinical participants recruited via support groups. Individuals attending support groups may do so as they have smaller social networks and support. However, it is also possible that these individuals are more open to support. Future research should record whether individuals belong to support groups and experience professional contacts as supportive.

There were differences between groups which may have influenced the dependent variables. Follow-up correlational analyses indicated that age had little impact on key dependent variables. Whilst the OCD group was younger, this had a minor role on HD having comparatively reduced social support and increased loneliness and TB.

Education also had little impact on social support. Interestingly, education accounted for high rates of variance for loneliness and TB. This might strengthen the notion that these are separate constructs, as education may influence the experience of loneliness and thwarted belongingness (but not receiving support). The samples were highly educated, particularly the OCD and HC groups. Future research with similar level of education between groups (and greater spread of education throughout groups) would help to understand the role of education.

**Theoretical implications**

This study highlights features apparent in both clinical groups (e.g. smaller network size) and those in HD only (e.g., low perceived support, high loneliness and thwarted belongingness). Salkovskis and Forrester (2002) differentiate between disorder-specific and disorder-relevant constructs. Characteristics *specific* to HD would occur more in HD compared to individuals with other disorders but may not be unique to HD. As well as being specific, they need to be relevant to the formation or maintenance of difficulties. To

consider whether variables are specific and relevant, Salkovskis and Forrester (2002) promote a theory-driven approach. Therefore, given that differences in perceived support were found to be specific, and fit with the compensatory model of HD (Yap & Grisham, 2019), experimental studies are required to assess whether this is a maintaining factor in HD.

Social support, loneliness, and TB represented related but distinct constructs (Berkman et al., 2000; Van Orden et al., 2012). In their model, Berkman et al. (2000) describe how social networks provide opportunities for social support and social engagement which influence inner needs or states such as TB. The model also describes other inner states such as self-efficacy and self-esteem. In their qualitative study, Taylor et al. (2019) found that barriers to engaging with social support included negative feelings about the self, particularly shame and guilt around clutter. Whilst PC was not significantly different between groups in this study, stigma and shame in HD are likely to be important factors. Berkman et al. (2000) describe broader social-cultural influences on social networks, and more negative public perception has been shown towards HD than conditions such as OCD (Chasson et al., 2018); participants who knew someone with HD reported greater disdain and blame. It is of note that measures in this study focused on listing individuals who provide support but there may be other people, not listed, who are unsupportive or critical.

As reduced social support is as a reliable predictor of suicidal ideation, attempts, and completion (Van Orden et al., 2010), individuals with HD may have a heightened risk given the significantly higher rates of PB and TB. High rates of suicidality were found in treatment-seeking individuals with HD who were less likely to be married or have children and more likely to live alone (Archer et al., 2019). Further, recent meta-analyses demonstrate a high prevalence of lifetime suicidal ideation and lifetime suicide attempts in OCD and HD (13.5% and 24.1% respectively for suicide attempts) (Pellegrini et al., 2021;

Pellegrini et al., 2020). In a population sample, HD severity was significantly associated with PB after controlling for negative affect, but there was no association with TB (Raines et al., 2016). The authors hypothesised that this may be explained by the negating effect of increased object attachment in providing a sense of belonging. In contrast, this study highlights the significance of TB in clinical samples and suggests that object attachment does not prevent loneliness.

**Research implications**

The key question is whether feeling less social support is a cause or a consequence of HD. Qualitative studies could help to explore social identity within HD and to understand how individuals feel (or do not feel) connected with and supported by others. Barriers to receiving help could be explored including whether individuals are not offered, do not ask for, or accept support, and the extent to which help refers to or is restricted by clutter. Exploration of the support felt from different multi-agency professionals could have clinical implications for staff training and co-production.

As social interactions are two-way, qualitative interviews with supporters of individuals with HD could help explore social support, connectedness, and other interpersonal factors such as blame and conflict. Exploring the role of stigma (public stigma, stigma within personal and professional networks and self-stigma) could be valuable.

There is also scope for experimental-based designs in furthering understanding of social support. This could include utilising induction procedures involving support on ratings of ability to discard items.

**Clinical implications**

Whether or not the results indicate that feeling unsupported and lonely is a cause or a consequence of HD, professionals should consider enabling individuals to access

opportunities for support and connection, including but not confined to HD based support groups. It would be important to establish if improving support and belonging leads to less reliance on objects and changes to acquiring and/or discarding. The results also have implications for helping supporters to provide and maintain support. This may involve psychoeducation, facilitating discussions around support, strengthening connectedness and if applicable promoting reconciliation. This may be especially important where individuals do not recognise difficulties with hoarding. If these individuals lose support and connectedness this may reduce wellbeing and motivation to change. As such, promoting understanding and support for individuals with HD as well as their social networks is required.

## Conclusion

This study found that individuals with HD and OCD have reduced social networks and that reduced social support, loneliness and thwarted belonging were specific to HD relative to OCD and HC. Further research is required to explore the nature of felt support, whether it forms a maintenance factor and identification of potential mechanisms. The findings have important implications for advocating and promoting individual and systemic support for HD.

## References


Abramowitz, J. S., & Deacon, B. J. (2006). Psychometric properties and construct validity of the Obsessive–Compulsive Inventory—Revised: Replication and extension with a clinical sample. *Journal of Anxiety Disorders, 20*(8), 1016-1035.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5). American psychiatric association Washington, DC.

Archer, C. A., Moran, K., Garza, K., Zakrzewski, J. J., Martin, A., Chou, C.-Y., Uhm, S. Y., Chan, J., Gause, M., & Salazar, M. (2019). Relationship between symptom severity, psychiatric comorbidity, social/occupational impairment, and suicidality in hoarding disorder. *Journal of Obsessive-Compulsive and Related Disorders, 21*, 158-164.

Barton, J. A., Salkovskis, P., & Walters, S. (2021). Investigating the diagnostic specificity of attachment and relational needs in hoarding disorder. *Journal of Obsessive-Compulsive and Related Disorders, 30,* 100659.

Bebbington, P., & Kuipers, L. (1994). The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. *Psychological medicine, 24*(3), 707-718.

Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social science & medicine, 51*(6), 843-857.

Bratiotis, C., Woody, S., & Lauster, N. (2019). Coordinated community-based hoarding interventions: evidence of case management practices. *Families in Society, 100*(1), 93-105.

Büscher, T., Dyson, J., & Cowdell, F. (2014). The effects of hoarding disorder on families: an integrative review. *Journal of Psychiatric and Mental Health Nursing, 21*(6), 491-498.

Chambless, D. L., & Steketee, G. (1999). Expressed emotion and behavior therapy outcome: A prospective study with obsessive–compulsive and agoraphobic outpatients. *Journal of consulting and clinical psychology, 67*(5), 658.

Chasson, G. S., Guy, A. A., Bates, S., & Corrigan, P. W. (2018). They aren't like me, they are bad, and they are to blame: A theoretically-informed study of stigma of hoarding disorder and obsessive-compulsive disorder. *Journal of Obsessive-Compulsive and Related Disorders, 16,* 56-65.

Chen, W., McDonald, S., Wearne, T., & Grisham, J. R. (2022). Interpersonal functioning in hoarding: An investigation of the link between hoarding symptoms and social support, social anhedonia, and social rewards. *Journal of Affective Disorders Reports, 8,* 100313.

Chia, K., Pasalich, D. S., Fassnacht, D. B., Ali, K., Kyrios, M., Maclean, B., & Grisham, J. R. (2021). Interpersonal attachment, early family environment, and trauma in hoarding: A systematic review. *Clinical psychology review, 90,* 102096.

Chou, C.-Y., Tsoh, J., Vigil, O., Bain, D., Uhm, S. Y., Howell, G., Chan, J., Eckfield, M., Plumadore, J., & Chan, E. (2018). Contributions of self-criticism and shame to hoarding. *Psychiatry Research, 262*, 488-493.

Davidson, E. J., Dozier, M. E., Mayes, T. L., Baer, K. A., & Ayers, C. R. (2020). Family and social functioning in adults with hoarding disorder. *Children Australia, 45*(3), 159-163.

Dozier, M. E., Porter, B., & Ayers, C. R. (2016). Age of onset and progression of hoarding symptoms in older adults with hoarding disorder. *Aging & mental health, 20*(7), 736-742.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods, 39*(2), 175-191.

First, M. B., Williams, J. B., Karg, R. S., & Spitzer, R. L. (2015). Structured clinical interview for DSM-5—Research version (SCID-5 for DSM-5, research version; SCID-5-RV). *Arlington, VA: American Psychiatric Association*(1–94).

Foa, E. B., Huppert, J. D., Leiberg, S., Langner, R., Kichic, R., Hajcak, G., & Salkovskis, P. M. (2002). The Obsessive-Compulsive Inventory: development and validation of a short version. *Psychological assessment, 14*(4), 485.

Foa, E. B., Kozak, M. J., Salkovskis, P. M., Coles, M. E., & Amir, N. (1998). The validation of a new obsessive–compulsive disorder scale: The Obsessive–Compulsive Inventory. *Psychological assessment, 10*(3), 206.

Frost, R. O., & Hartl, T. L. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour research and therapy, 34*(4), 341-350.

Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: saving inventory-revised. *Behaviour research and therapy, 42*(10), 1163-1182.

Frost, R. O., Steketee, G., Tolin, D. F., & Renaud, S. (2008). Development and validation of the clutter image rating. *Journal of Psychopathology and Behavioral Assessment, 30*(3), 193-203.

Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: a community health problem. *Health & social care in the community, 8*(4), 229-234.

Gigliotti, E., & Samuels, W. E. (2020). Tests of Revisions to the Norbeck Social Support Questionnaire. *SAGE Open Medicine, 8*, 2050312120911293.

Gordon, O. M., Salkovskis, P. M., & Oldfield, V. B. (2013). Beliefs and experiences in hoarding. *Journal of Anxiety Disorders, 27*(3), 328-339.

Hooley, J. M., & Parker, H. A. (2006). Measuring expressed emotion: an evaluation of the shortcuts. *Journal of Family Psychology, 20*(3), 386.

Hooley, J. M., & Teasdale, J. D. (1989). Predictors of relapse in unipolar depressives: expressed emotion, marital distress, and perceived criticism. *Journal of abnormal psychology, 98*(3), 229.

Kim, H.-J., Steketee, G., & Frost, R. O. (2001). Hoarding by elderly people. *Health & Social Work, 26*(3), 176-184.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine, 16*(9), 606-613.

Kuipers, L. (1979). Expressed emotion: a review. *British Journal of Social and Clinical Psychology, 18*(2), 237-243.

Landau, D., Iervolino, A. C., Pertusa, A., Santo, S., Singh, S., & Mataix-Cols, D. (2011). Stressful life events and material deprivation in hoarding disorder. *Journal of Anxiety Disorders, 25*(2), 192-202.

Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: a conceptual analysis. *Journal of advanced nursing, 25*(1), 95-100.

Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public health, 152*, 157-171.

Masland, S. R., & Hooley, J. M. (2015). Perceived criticism: A research update for clinical practitioners. *Clinical Psychology: Science and Practice, 22*(3), 211.

Mezzina, R., Davidson, L., Borg, M., Marin, I., Topor, A., & Sells, D. (2006). The social nature of recovery: Discussion and implications for practice. *Archives of Andrology, 9*(1), 63-80.

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. M. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry, 180*(5), 461-464.

Norbeck, J. S., Lindsey, A. M., & Carrieri, V. L. (1981). The development of an instrument to measure social support. *Nursing research*.

Nordsletten, A. E., Reichenberg, A., Hatch, S. L., de la Cruz, L. F., Pertusa, A., Hotopf, M., & Mataix-Cols, D. (2013). Epidemiology of hoarding disorder. *The British Journal of Psychiatry*, *203*(6), 445-452.

Park, J. M., Lewin, A. B., & Storch, E. A. (2014). Adult offspring perspectives on parental hoarding behaviors. *Psychiatry Research, 220*(1-2), 328-334.

Pellegrini, L., Maietti, E., Rucci, P., Burato, S., Menchetti, M., Berardi, D., Maina, G., Fineberg, N. A., & Albert, U. (2021). Suicidality in patients with obsessive-compulsive and related disorders (OCRDs): A meta-analysis. *Comprehensive psychiatry, 108*, 152246.

Pellegrini, L., Maietti, E., Rucci, P., Casadei, G., Maina, G., Fineberg, N. A., & Albert, U. (2020). Suicide attempts and suicidal ideation in patients with obsessive-compulsive disorder: a systematic review and meta-analysis. *Journal of affective disorders, 276*, 1001-1021.

Postlethwaite, A., Kellett, S., & Mataix-Cols, D. (2019). Prevalence of hoarding disorder: a systematic review and meta-analysis. *Journal of affective disorders, 256*, 309-316.

Przeworski, A., Cain, N., & Dunbeck, K. (2014). Traumatic life events in individuals with hoarding symptoms, obsessive-compulsive symptoms, and comorbid obsessive-compulsive and hoarding symptoms. *Journal of Obsessive-Compulsive and Related Disorders, 3*(1), 52-59.

Raines, A. M., Short, N. A., Fuller, K. L., Allan, N. P., Oglesby, M. E., & Schmidt, N. B. (2016). Hoarding and depression: The mediating role of perceived burdensomeness. *Journal of psychiatric research, 83*, 24-28.

Russell, D., Peplau, L. A., & Cutrona, C. E. (1980). The revised UCLA Loneliness Scale: concurrent and discriminant validity evidence. *Journal of personality and social psychology, 39*(3), 472.

Salkovskis, P. M., & Forrester, E. (2002). Responsibility. In *Cognitive approaches to obsessions and compulsions* (pp. 45-61). Elsevier.

Shaw, A. M., Witcraft, S. M., & Timpano, K. R. (2016). The relationship between traumatic life events and hoarding symptoms: a multi-method approach. *Cognitive Behaviour Therapy, 45*(1), 49-59.

Sherbourne, C. D., & Stewart, A. L. (1996). Medical Outcomes Study (MOS) Social Support Survey 1991.

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine, 166*(10), 1092-1097.

Taylor, J. K., Theiler, S., Nedeljkovic, M., & Moulding, R. (2019). A qualitative analysis of emotion and emotion regulation in hoarding disorder. *Journal of clinical psychology, 75*(3), 520-545.

Thew, G. R., & Salkovskis, P. M. (2016). Hoarding among older people: an evaluative review. *The Cognitive Behaviour Therapist, 9*.

Timpano, K. R., Broman-Fulks, J. J., Glaesmer, H., Exner, C., Rief, W., Olatunji, B. O., Keough, M. E., Riccardi, C. J., Brähler, E., & Wilhelm, S. (2013). A taxometric exploration of the latent structure of hoarding. *Psychological assessment, 25*(1), 194.

Tolin, D. F., Frost, R. O., Steketee, G., & Fitch, K. E. (2008). Family burden of compulsive hoarding: results of an internet survey. *Behaviour research and therapy, 46*(3), 334-344.

Tolin, D. F., Meunier, S. A., Frost, R. O., & Steketee, G. (2010). Course of compulsive hoarding and its relationship to life events. *Depression and anxiety, 27*(9), 829-838.

Van Orden, K. A., Cukrowicz, K. C., Witte, T. K., & Joiner Jr, T. E. (2012). Thwarted belongingness and perceived burdensomeness: construct validity and psychometric properties of the Interpersonal Needs Questionnaire. *Psychological assessment, 24*(1), 197.

Van Orden, K. A., Witte, T. K., Cukrowicz, K. C., Braithwaite, S. R., Selby, E. A., & Joiner Jr, T. E. (2010). The interpersonal theory of suicide. *Psychological review, 117*(2), 575.

Van Orden, K. A., Witte, T. K., Gordon, K. H., Bender, T. W., & Joiner Jr, T. E. (2008). Suicidal desire and the capability for suicide: tests of the interpersonal-psychological theory of suicidal behavior among adults. *Journal of consulting and clinical psychology*, *76*(1), 72.

Wang, J., Mann, F., Lloyd-Evans, B., Ma, R., & Johnson, S. (2018). Associations between loneliness and perceived social support and outcomes of mental health problems: a systematic review. *BMC psychiatry, 18*(1), 1-16.

Weathers, F., Blake, D., Schnurr, P., Kaloupek, D., Marx, B., & Keane, T. (2013). The life events checklist for DSM-5 (LEC-5).

Weiss, E. R., Landers, A., Todman, M., & Roane, D. M. (2020). Treatment outcomes in older adults with hoarding disorder: The impact of self-control, boredom and social support. *Australasian Journal on Ageing, 39*(4), 375-380.

Wilbram, M., Kellett, S., & Beail, N. (2008). Compulsive hoarding: A qualitative investigation of partner and carer perspectives. *British Journal of Clinical Psychology, 47*(1), 59-73.

Yap, K., & Grisham, J. R. (2019). Unpacking the construct of emotional attachment to objects and its association with hoarding symptoms. *Journal of behavioral addictions, 8*(2), 249-258.

## Executive Summary

### Background

Hoarding disorder (HD) is a mental health condition defined by a persistent difficulty with over acquiring and discarding possessions due to a strong perceived need to save items and/or distress associated with getting rid of items. These difficulties mean that belongings can accumulate and result in severe clutter within living areas to the point where they are unusable and potentially unsafe. It has been suggested that increased attachment to objects in HD may be linked to decreased attachment with people. A recent study (Barton et al., 2021) found that individuals with HD were similarly impaired to those with obsessive compulsive disorder (OCD) in terms of recalled childhood attachments. However, an unanticipated finding was that whilst individuals with HD and OCD both reported having fewer people to support them compared to healthy controls (HC), what seemed to be unique to HD was that they felt significantly less supported by the people in their network.

Therefore, this study developed and extended this finding. Firstly, through using a more comprehensive assessment of social support to see if there were differences between HD, OCD and HC groups. The measure asked about an individual's social network (how many people are available to provide support, length known and frequency of contact) and perceived social support (including emotional support and aid). This study also examined whether there were differences in the experience of loneliness and social belonging between groups. Other measures included looking at how criticised individuals felt by people in their network and experiences of trauma.

### Method

Participants with OCD and HD were recruited as well as healthy controls (individuals without HD or OCD). Participants completed questionnaires taking

approximately 30-40 minutes. Measures included demographic questions, as well as questionnaires about mental health difficulties and social support.

**Results**

Data was obtained from a total of 113 participants: 37 individuals with HD, 31 with OCD, and 45 HC. All participants were aged between 23 and 84 (*M=50.38, SD=16.54*). Participants were predominantly female (79.6%) and identified as Caucasian (89.4%).

Statistical analysis indicated that HD and OCD groups had similarly reduced social networks which included significantly less people than HC. However, individuals with HD reported that they felt less supported than both OCD and HC. Individuals with HD also reported experiencing greater loneliness, with HD individuals being most lonely followed by OCD then HC. It was also found that HD had greater thwarted belongingness than both OCD and HC, meaning that individuals with HD experience reduced belonging and a greater sense of being alone in the world. There were no differences between groups on levels of perceived criticism or trauma.

**Research implications**

Further research is required to understand whether these findings relate to the causes of difficulties with hoarding, or whether they are an effect of this problem. That is, does having hoarding difficulties result in that person feeling unsupported, or does feeling unsupported result in hoarding behaviour as a compensatory strategy. Similarly, questions remain about the direction of effect for loneliness and thwarted belonging in their association with hoarding difficulties. Experimental studies and qualitative studies with individuals and their support networks may be particularly helpful in exploring and understanding these differences. Trialling specifically targeted support to see if it helps with distress and/or hoarding behaviours would also be informative.

**Clinical implications**

The results have important implications for strengthening support and belonging for individuals with HD. Professionals from multiple agencies should help enable individuals to consider opportunities for support and connection, such as support groups. The results also have implications for helping supporters to provide and maintain support. As such, efforts to understand the potential role of stigma, and promote better understanding and support for individuals with HD as well as their social networks is required. Multi-agency professionals in healthcare, social care and charitable services should also evaluate how their support is received. This could have important implications for advocating and promoting individual and systemic support for HD.

## Connecting/ Reflective Narrative

Whilst considering the design of my three projects, I wanted to utilise the opportunity to develop a breadth of experiences and skillsets. As I was using quantitative data for my TDRP, I was keen to explore qualitative methodology for my SIP and CRL. I also wanted to conduct research in different clinical areas. My SIP and CRL apply psychological theory and research within physical health which gave me the opportunity to work with a multidisciplinary team and build upon my interest in societal narratives around the mind and body. Meanwhile my TDRP, which included structured clinical interviews, strengthened my assessment and evaluation of mental health difficulties within a research framework.

A common thread throughout all three projects is giving a voice to those who have conditions that may by particularly stigmatised and isolating. I am pleased to contribute to these relatively under-researched fields. Below is a discussion on the process of conducting each of the projects including reflections, challenges and learning points.

### Critical Review of the Literature

During initial discussions, my external supervisor mentioned that as many women in the UK have endometriosis as they do diabetes. I felt that I was broadly aware when people I know have diabetes but the same could not be said for endometriosis. Further, I began to discover that endometriosis was by far the most spoken about chronic pelvic pain both within societal discourse and research. Discussions with my external supervisor and service user representative emphasised how exclusionary this was, especially when individuals often have multiple, overlapping, or undefined symptoms and I became increasingly curious and motivated to ‘give voice’ to the impact of these symptoms on all these people I did not know about.

I found my CRL the most demanding project to complete, largely due to its labour intensive and time-consuming nature. It felt that it took a long time to get to the actual synthesis but, on reflection, I learnt a lot along the way. Each step involved careful consideration and justifications of my steps whether that was in defining search terms or in rating the quality of papers. As a result, this project has provided a lot of learning and increased my confidence to critically appraise and synthesise large amounts of papers and their data.

Service Improvement Project

The idea for the SIP was presented by my external supervisor who stated that there were patients who could not be offered anything by the service and were making formal complaints as they felt 'abandoned'. I was very struck by this term and the service's openness about these complaints and willingness for this to be explored. It allowed for a very collaborative experience; from the start, at which I was helped to identify potential patient representatives to when I fed back results at the end of the project. One of the challenges was recruitment, which the service found surprising given that many patients had previously been very vocal about raising complaints. However, this project coincided with the lockdowns associated with the COVID-19 pandemic and many of the potential participants were likely to be juggling working from home and home-schooling children. It was also interesting to consider how much the pandemic impacted the staff focus group attendance, particularly in terms of not having a wider representation of disciplines, or whether this represents more ingrained team and systemic dynamics. If it had been possible, it would have been valuable to have spent time on the ward getting to know different team members and patients to help to promote the study. Yet given the limitations, I was very touched by the honesty of participants and the richness of quotes. I am optimistic that these will lead to increased awareness and clinical changes that will benefit service users. Through completing this project, I have become more curious and

attuned within clinical placements regarding what the service is fundamentally hoping to provide and whether this is being met. I hope to continue to pursue further SIP opportunities within qualified roles.

Theoretically Driven Research Project

I became particularly interested in hoarding when I was working as an assistant psychologist and my role involved a lot of home visits. Whilst I was aware of how much shame could be associated with hoarding, I was surprised how little understanding and compassion there could be compared to other mental health conditions.

As with the SIP, COVID-19 introduced additional recruitment challenges, particularly as many of the support groups were not running or were operating a reduced, remote version. An unexpected challenge was the large number of friends and relatives of people with hoarding difficulties who got in touch desperate to share their experiences of trying to provide support when this was outside the remit of the study. They would commonly share that the individual they knew would not participate, as they did not recognise the problem or want support. During the project I became increasingly interested about when and how individuals were able to express the need for support, join support groups and how the type of support asked for may differ from what is offered. It has felt particularly topical to research social support and loneliness throughout lockdowns, and I hope that this allows people to connect with its importance.

Conclusions

This thesis includes studies with populations where there is dearth of research and draws on fundamental needs such as feeling supported and not alone. These themes have been particularly recognised as key components of life during the pandemic and associated lockdowns. As such, I hope that the contributions from these studies are timely. I look

forward to disseminating the results and continuing to contribute actively to the evidence base once qualified.

## Acknowledgments

I would like to acknowledge and thank everyone who took the time to consult on and participate in my research. It would not have been possible without you, and I hope that this helps contribute to service improvements and the knowledge base.

I am very grateful to my research supervisors, Dr Matthew Knight, Dr Emma Evans, Dr Sarah Lack, and Professor Salkovskis for all your advice, support, and encouragement. I would also like to thank all my clinical supervisors who have supported and shaped me as a psychologist. Thank you also to my course tutor, Dr Susannah Jenner, for being so approachable and supportive.

I would like to thank my DClinPsy cohort for all the understanding, encouragement, help and friendships over the past three years.

I would also like to extend my thanks to my family and friends. A special thanks to my parents who are always there to support me. Also, to Anna BH, for always being there and getting it.

Finally, to Luke, for your help, patience and unwavering energy and commitment to supporting me every step of the way.

# Appendices

## Appendix A: CRL – Approvals

The project proposal was approved by the Project Approval Panel, Oxford Clinical Psychology Doctoral Training Programme, on 29/05/20. It was registered with the PROSPERO International prospective register of systematic reviews on 06/11/20.

## Appendix B: CRL – Supplementary information on bracketing interview

A bracketing interview was conducted between with the main reviewer and an independent researcher prior to conducting the literature searches. This process aims to enhance reflexivity by increasing the researcher's awareness of assumptions and biases that may influence the project.

The main researcher does not have personal experience of CPPS but consulted a service user representative and Clinical Psychologist working within a CPPS setting in developing the research project. It was acknowledged that the service user representative and reviewers had a particular interest in psychosocial factors and that there were assumptions about chronic conditions entailing a (negative) psychosocial impact. Yet it was discussed how even if no psychosocial implications were evident or particularly pronounced, this would be equally interesting.

The lead researcher identifies as female and worked closely with another female clinician based at a Women's centre in the development of this research question. Gender was therefore acknowledged as CPPS affects males and individuals who do not identify as women. Broader issues relating to diversity (or lack of) were also closely held in mind as CPPS literature often focuses on heterosexual, cisgender, white women with endometriosis. The researcher was keen to explore diverse experiences without being tokenistic or over-emphasising the weighted distribution of studies.

**Appendix C: CRL – Search strategy**

Below is a demonstration of the search strategy used for the Web of Science electronic database. A similar strategy was used for each database.

"Chronic Pelvic Pain" OR "Chronic Pelvic Pain Syndrome" OR "Pelvic pain" OR "Pelvic pain syndrome" OR "Pelvis pain" OR "Pelvis pain syndrome" OR "Gynaecological" OR "Gynecological" OR "Urological" OR "Endometriosis" OR "Bladder pain syndrome" OR "Interstitial cystitis" OR "Vulvodynia" OR "Vulvar pain" OR "Vestibulodynia" OR "Clitoral pain" OR "Dysmenorrhoea" OR "Dysmenorrhea" OR "Vulvar vestibulitis" OR "Vulvitis" OR "Dyspareunia" OR "Adenomyosis" OR "Pelvic inflammatory disease"

AND

"Qualitative research" OR "Qualitative" OR "Qualitative analysis" OR "Unstructured interview" OR "semi-structured interview" OR "structured interview" OR "Focus group" OR "Focus groups" OR "Grounded Theory" OR "Grounded analysis" OR "Thematic analysis" OR "Content analysis" OR "Narrative analysis" OR "Interpretative phenomenological analysis" OR "Phenomenological analysis"

Limits:

1. Year = 2014- current
2. English language

## Appendix D: CRL – Supplementary information on CASP

The methodological quality of studies was assessed using the CASP Qualitative Studies Checklist (CASP Qualitative Checklist, 2018). This is a commonly used appraisal tool for evaluating qualitative research (Majid & Vanstone, 2018). The CASP provides a guide for appraising the strengths and limitations of qualitative studies including upholding of ethical standards and evaluating validity and utility of results. Items are rated on a 3-point scale (no/ partial/yes). There are 10 items on the CASP which include 'hints' by which to judge criteria. To increase transparency and objectivity, this was supplemented by the authors to detail how many hints would characterise each rating. The scale was also supplemented by utilising a scoring system (no = 0, partial = 1, yes =2) to provide a more tangible overview of the quality of studies.

## Appendix E: CRL – Supplementary information on exclusion rationale

Through the searches, only one paper concerning males with CPPS was identified (Wood et al., 2017). Additional searches within all the electronic databases using specific terms relating to male CPPS subtypes including "prostatitis" and "epididymitis" did not identify any further papers. As such, the accounts of 12 males from one study did not appear a significantly robust evidence base with which to represent experiences and draw cross-cutting themes about gender. Therefore, this paper was not included in the synthesis as with the previous CPPS review (Toye et al., 2014). For completeness, information regarding this paper is displayed below.

| Reference | Country | Sample size | Diagnoses | Age range (/mean if range not provided) | Race /ethnicity (reported verbatim) | Data collection method | Quality grading *medium **high |
|---|---|---|---|---|---|---|---|
| **(Wood, 2017)** | UK | 12 | Chronic prostatitis | 34-42 | - | Individual interviews and written responses | 18** |

## Appendix F: SIP – Approvals

The project proposal was approved by the Project Approval Panel, Oxford Clinical Psychology Doctoral Training Programme, on 20/03/2020. Oxford University Hospitals (OUH) Research & Development committee classified the project as a service evaluation on 13/08/2020 and the OUH clinical audit team gave their approval on 14/09/2020.

## Appendix G: SIP – Supplementary information on bracketing interview

**Bracketing interview semi-structured script**

**Guidance:** The interviewer uses curiosity and reflexivity to spot any assumptions they might be making, using prompts to further explore assumptions (e.g. "so it sounds like you might think...?" > "how might thinking that influence how you approach this research?")

**Questions to aid discussion:**

- What areas do you think are important for me to ask about? (then make a list and ask about each one)
- Tell me about your views on /experiences with chronic pelvic pain syndrome/ chronic pain. Where does that come from?
- When you've been doing reading around this, what theories or ideas are you drawn to? Why is that?
- What sorts of things do you expect to hear/do you expect people to say?
- How do you think your views/beliefs about chronic pelvic pain might influence your research?
- What made you choose this particular topic?
- In what way do you think your previous experience might have influenced your research at the moment or going forward with the interviews?
- What themes are you expecting to come out? What do you suspect might come out of the interviews? Where are those ideas coming from?
- Do you feel invested in particular research outcomes?
- What do you feel you should look out for in terms of how you demographically relate (or differ) to the participant sample?
- Why would someone sign up for your study and agree to do it?
- What would it be like to be asked by someone you don't know about your topic?
- What do you want from the study?

## Appendix H: SIP – Information pack







Oxford University Hospitals
NHS Foundation Trust

Pelvic Pain Service,
Gynaecology department,
John Radcliffe Hospital
Headley Way
Headington
Oxford
OX3 9DU
Tel: 01865 231405

**Private & Confidential**

**Re: Invitation to participate in a service improvement project**

**Improving the service provided to women with chronic pelvic pain admitted to the inpatient Gynaecology Department, John Radcliffe Hospital**

We would like to invite you to take part in a project to understand the levels of satisfaction with the treatment and support received within the inpatient gynaecology department and your suggestions for improving the service.

If you choose to take part in this project, I will arrange a time to talk with you (either over the phone or using video conferencing in light of COVID-19) to discuss the project and to answer any queries you may have. An information sheet is attached and if you are happy to take part following our discussion, you will be asked to give verbal consent. We will then discuss your opinions and feedback on the service, which may last approximately 30-45 minutes.

It is completely up to you whether you take part and your decision and feedback will not affect your healthcare in any way. All accounts will be anonymous. This project is being conducted in line with the educational requirements of my doctoral thesis. The results will be used to generate ideas on how best to support patients in the service.

You will find enclosed an information sheet. If you would like to find out more information, please feel free to contact me on the email address below.

Yours Sincerely

Victoria Edwards

Trainee Clinical Psychologist

Oxford Institute of Clinical Psychology Training
Email: victoria.edwards@oxfordhealth.nhs.uk

UNIVERSITY OF OXFORD

NHS
Oxford University Hospitals
NHS Foundation Trust

## Information Sheet

**Service improvement project: Improving the service provided to women with chronic pelvic pain admitted to the inpatient gynaecology department, John Radcliffe Hospital**

We would like to invite you to take part in a project to understand the levels of satisfaction and areas for improvement regarding the service provided to women who have been an inpatient within the gynaecology department.

**Why are we doing this project?**
The aim of this project is to understand the experiences of women who have been an inpatient in the gynaecology department. We are interested in the levels of satisfaction with the treatment and support received and any suggestions for improving the service. This project is being undertaken by a University student and will contribute to the fulfilment of an educational requirement (a doctoral thesis).

**Why have I been invited?**
You have been invited to help us with this project because you have been an inpatient within the past 18 months.

**Do I have to take part?**
No, this is entirely optional. Whatever you decide will not affect your healthcare at the hospital.

**What will happen if I take part?**
If you choose to take part in this project, I will arrange a time to talk with you (either over the phone or using video conferencing in light of COVID-19) to discuss the project and to answer any queries you may have. A consent form is attached and if you are happy to take part following our discussion, you will be asked to give verbal consent. We will then discuss your opinions and feedback regarding the service which should last approximately 30-45minutes.

The interview will be audio recorded, transcribed and then deleted. All feedback will remain completely anonymous. You will not have to answer any questions that you do not want to. You can take a break during the interview if you would like, and can end the interview at any time.

**What are the possible benefits of taking part?**
We hope that by taking part in this study, you will be helping us learn more about the service and improvements that can be made. Unfortunately we cannot offer reimbursement for your time.

**What are the possible disadvantages or risks of taking part?**
Is possible that thinking about your experiences as an inpatient may be difficult to think about. You will be able to take a break at any time, or withdraw at any point. If the researcher has any concerns around your safety we may need to inform your GP or other health professionals but we would always do our best to talk to you about this first. At the end of the study, everyone will be provided with contact details of support services.

**What if there is a problem?**
If you have a concern about the project, you should contact us on the details below. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. If you wish to contact the PALS team, please contact 01865 221473 or PALS@ouh.nhs.uk.

**What will happen with the results of the project?**
The results of the project will be used to help generate ideas on how best to support patients during their inpatient admissions. The project will contribute to the fulfilment of a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible. Additionally, a report may be written for publication in an academic journal. Quotes from interviews may be used in the report however these will be anonymous.

**What do I do next?**
If having read this information sheet you are happy to participate, please contact me using the email address below. I will answer any questions you have and if you wish to take part, organise a time for the discussion.

**Contact details:**
Victoria Edwards
Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training
Email: victoria.edwards@oxfordhealth.nhs.uk

Victoria Edwards
Email: victoria.edwards@oxfordhealth.nhs.uk

## Consent form for providing verbal consent

**Service improvement project: Improving the service provided to women with chronic pelvic pain admitted to the inpatient gynaecology department, John Radcliffe Hospital**

1. I confirm that I have read and understand the information sheet dated 05.02.2021 (version 1.2) for the above project. I have had the opportunity to think about the information, ask questions and have had these answered satisfactorily.

2. I understand that I do not have to take part in this project if I do not want to. If I chose not to take part, it will not affect my medical care.

3. I know that I can stop the discussion at any time without providing a reason.

4. I agree to the discussion being audio recorded and for anonymised quotes and any demographic information provided to be used in research reports and publications.

5. I understand that if the researcher is concerned about my safety, they will need to inform other healthcare professionals e.g. my GP.

6. I agree to take part in the project.

I confirm that (insert unique project identification code) _____ has agreed that they have had the opportunity to read the information provided, ask questions and given verbal consent to all of the statements above: YES / NO

Name of person taking consent:

Date consent taken:

## Appendix I: SIP – Debrief sheet







Oxford University Hospitals
NHS Foundation Trust

### Debrief Sheet

**Title of Project: Improving the service provided to women with chronic pelvic pain admitted to the inpatient Gynaecology Department, John Radcliffe Hospital**

Thank you for participating in this project! Your participation will help us think about how best to support women with chronic pain admitted as inpatients to the gynaecology department.

We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be difficult or you would like further NHS support, please see the following sources of support:

**Sources of advice and support**

1. Your General Practitioner
2. NHS 111
3. The Samaritans 116 123

If you have any questions about any aspect of this project, please speak to the researcher [redacted] or their supervisor [redacted] who will do their best to answer your query. Please find their contact details below.

**Contact details:**

[redacted]
Email: [redacted]

[redacted]
Principal Clinical Psychologist Pelvic Pain
Email: [redacted]
Tel: [redacted]

**Appendix J: SIP – Participant demographic and descriptive information**

| | **Total (n= 8)** |
|---|---|
| **Type of admission** | |
| Planned | 3 |
| Unplanned / emergency admission | 5 |
| **Year of latest inpatient admission** | |
| 2018 | 1 |
| 2019 | 0 |
| 2020 | 6 |
| 2021 | 1 |
| **Number of nights on most recent inpatient admission** *(mean = 3)* | |
| 1 | 2 |
| 2 | 1 |
| 3 | 2 |
| 4 | 1 |
| 5 | 2 |
| **Number of inpatient admissions at the JR** *(mean = 7.4)* | |
| 1-5 | 1-5 |
| 6-10 | 6-10 |
| >10 | >10 |
| **Number of years under the care of JR for CPPS** *(mean = 5.6)* | |
| 0-5 | 4 |
| 6-10 | 3 |
| >10 | 1 |
| **Admissions to any other hospitals due to CPPS** | |
| Yes | 3 |
| No | 5 |
| **Duration of CPPS (years)** *(mean = 13.2)* | |
| 0-5 | 1 |
| 6-10 | 3 |
| 11-15 | 2 |
| 16-20 | 1 |
| 21+ | 1 |
| **Any other medical conditions?** | |

| | |
|---|---|
| Yes | 3 |
| No | 5 |
| **Any past/ present mental health difficulties** | |
| Yes | 5 |
| No | 3 |
| **Age (years)** *(mean = 32.3)* | |
| 18-29 | 3 |
| 30-39 | 3 |
| 40-49 | 2 |
| **Ethnicity** | |
| British white | 8 |
| **Work status whilst an inpatient** | |
| Unemployed | 2 |
| Employed | 5 |
| Student | 1 |
| **Living arrangements whilst an inpatient** | |
| Single occupancy | 1 |
| Single parent with children | 1 |
| Partner | 2 |
| Partner and children | 3 |
| Parents | 1 |
| **Living arrangement whilst an inpatient** | |
| Married/living as couple | 5 |
| Divorced or separated | 1 |
| Single | 1 |
| Missing | 1 |

## Appendix K: SIP – Staff focus group interview schedule

1. **What do you think patients need from the inpatient service?**
    - Do patients appear to have clear ideas about what they need from the service?
    - What do patients in the inpatient ward focus on? (e.g. medication / pain relief, surgery, reassurance or support?)
    - What do you think these treatment expectations based on? (online, other services)
    - Are there different emphasis / challenges in planned vs unplanned admissions?

2. **What are the challenges of working with this population?**
    - Do you think patients' expectations / beliefs about what they need from the service are appropriate/ able to be met?
    - Do treatment plans feel clear to the whole team?
    - How does it feel communicating treatment decisions?
    - What is the impact when it is not possible to provide treatments (e.g. not increasing pain medication) on patients and staff?
    - Impact of patients' emotional distress / frustrations etc on staff
        - Do you feel you have skills / resources to support patients?
        - Do you feel supported yourself?

3. **Are there wider service issues/ challenges?**
    - Communication between colleagues
    - Are there challenges joining up different elements of patients care?
    - How joined up to other services/ departments?

4. **Has anything been implemented to overcome any of these challenges?**
    - If yes, how were these received? What worked/ didn't work so well?
    - If no, what are the barriers?

5. **Areas and ideas for improvements**
    - What could help with the challenges identified?
    - What would need to be different to make changes / challenges to feel less overwhelming?
    - How could you feel supported to make changes?

**Appendix L: SIP – Patient semi-structured interview schedule**

1. **Did you have expectations around your inpatient admission? Was it a planned or unplanned admission?**
    - Did you have a clear idea about what you wanted / needed from the service?
        - Prompt: medication / pain relief, surgery, support
    - What were treatment expectations based on?
        - Prompt: past admissions, internet forums

2. **As an inpatient did you feel supported (day-to-day)?**
    - Did you feel listened to?
    - Were your concerns understood?
    - Were you treated holistically/ as an individual?

3. **Were there any challenges during your inpatient admission?**
    - Environmental factors
    - Other patients
    - Staff interactions
    - Have you had any previous admissions to the gynaecology ward where this was also a challenge?
    - To what extent do you think this might have been covid-related?

4. **Were you satisfied with the treatment you received?**
    - Did you understand why you were/were not offered X?
    - Was the treatment rationale clear? / Do you think there was sufficient explanation of the factors that had been weighed up in making the decision?
    - Did the factors match your experience/ priorities?
    - Were your own knowledge / preferences acknowledged?
    - How was this communicated to you?
    - Did you have access to other professionals?
        - Prompt: physio / counselling / chaplaincy

5. **Did the service provide sufficient explanation for what you were experiencing and plan going forwards?**
    - Were causes (or lack of identifiable causes) explained to you clearly?
    - Were any implications of this explained?
    - How appropriate / helpful was the way in which it was explained?
    - Did you feel there was a plan in place going forwards?
    - Did you feel you have more understanding / better able to manage your pain going forwards?

6. **Do you have any further ideas/ recommendations for how the service could improve?**
    - How to make your admission more supported/ safe/ comfortable?
    - During treatment / post-treatment?
    - Any other ideas to increase support?
        - Prompt: clearer communication / resources / coping strategies?

**Appendix M: SIP – Representative quotes from staff focus groups**

| **Difficulties understanding chronic pain** |
| --- |
| How the pain feels<br><br>• "We don't know what they're feeling - everyone has pain in a different way"<br>• "It's difficult when someone's saying they're in pain we can't really monitor their pain or say they're not in as much pain or whatever"<br>• "I try to understand because sometimes they can appear that they're absolutely fine like sitting upright and they're saying they are in pain and it's trying to figure they are in pain it's just not, they're just so used to it it's not showing any signs or things like that"<br>• "They'll say it's really bad its 10/10 and 5 minutes later you're up wondering around, going outside or whatever"<br>• "Most of the time there's very little understanding as to why things are, why they're in pain" |
| Biopsychosocial complexities<br><br>• "When they're like trying to get a diagnosis it's not just one thing, it can be multiple things and that just prolongs the experience"<br>• "Also, they have problems with other things in that area like appendix and different stuff like that"<br>• "They feel lonely… because when I was looking after those patients, when I sit down with them, they start talking … they completely forget about the pain… so they wanted all the time for someone to be there for them" |

- "A lot of anger comes with it doesn't it… Because their life's changed…Like they really wanted to have children or things like that. That's quite upsetting for them, knowing that that's probably not going to happen"
- "Sometimes get people that are like you know it's they're like difficult patients, they've got, it's all like in their head and it's like no if you were in pain every day of your life wouldn't you be a bit depressed or whatever as well like cos there are so many things that makes it a bit more complex"

**No clear fix**

Managing patients' expectations

- "That's the most difficult thing is like managing expectations. Like I say they come in and expect us to fix something or get rid of their pain and then for a lot of these chronic pelvic pain patient…they're not going to go home pain free"
- "I think they're hoping to fix it of sort, I don't know, when they come in they need pain relief but we don't do it any different to how they do it, so I think they think maybe someone's got a different opinion or someone might do a different test or MRI or scans things like that, or sometimes surgery. But it isn't necessarily the way out of it"
- "If there is a different on call consultant, they'll see someone different who's not the pelvic pain consultant. And then the next day comes round and someone will go 'oh we won't do that' and they'll go 'but yesterday I could have an MRI'"

Added challenges of acute admissions

- "If they were having surgery we'd have a clear plan…with an acute exacerbation sometimes we're already busy and not aware of the situation as much"

- "They come in and start to have scans and everything and their pain, it's a longer process, and their pain threshold is a lot lower so they get more frustrated whereas if we have reoccurring like chronic pain that like know the system and know how it works, we know them, like we have a relationship with them"
- "When they come in with acute exacerbation or something they're normally at a more heightened like kind of point physically and emotionally like people get you know they can get really worked up and get in a more negative space"
- "When it's acute because you're not always expecting it as well you know if your more complex patient coming in for a hysterectomy say we'll kind of brief the team that this is happening, it's going to be rough but we can like sort it out and stuff. But when it's acute and they're coming in it's a bit more up in the air"

A never-ending cycle

- "We don't have the time to sit down with them… but even then like, even if you did, even if you were like 1:1 if you sat down and had a chat with them whilst they were here and they unloaded, they felt better, you know they're going to go home and then in a few weeks it'll be the same"
- "Thing is when they have come in so many times, each time they feel more comfortable with us"
- "If you've got a psychological problem alongside it a gynaecological problem its just a never-ending cycle"
- "It's nice that they come for that safety but that have to eventually they'll have to do it on their own themselves. And yeah, you can tell when they're going to phone. If it's been a few months without a visit, you're usually due one"

Feeling restricted

- "They know themselves and their condition and they feel with like pain relief as well we're restricted. You have to go up paracetamol then codeine and go up to morphine and they're like 'none of that stuff works for me only this works got me, I only want this' and that's not how it works here… sometimes it's just a bit of a butting of heads"
- "A lot of the time these women have gone through you know like years of pain, like if there isn't anything on a scan people say there's no reason for it, and it all makes it like, build up I think. The last thing you want them to do is to come into hospital and then be like, 'oh we're not going to give you this pain relief'"
- "It can be quite tricky. Because they always complain and then they always feel like we don't believe them as well. And we try to; well I always go along with what they say"
- "In a key flare up, I'm not gonna look at them and say I'm not gonna give you any pain relief – breathe better – or something – like it's not really manageable – you can't really facilitate it in this kind of setting"
- "They come here wanting help, wanting us to kind of, just to chat, but if you kind of, if you don't know what you're talking about, it kind of doesn't put any faith in us"
- "You don't want to say the wrong thing to make them feel even worse"
- "Even if there's just some staff on the ward that even just a little bit of training in it then they can just like go and in the interim [before seeing the consultant] go and have a chat"

Unable to fulfil professional role

- "As a nurse it's awful. This feeling of being helpless and not being able to do anything to help"

- "It makes you feel like can't... fulfil what they've come in for"
- "People get angry and upset and frustrated and the last thing as a nurse, healthcare assistant, anything, you wanna do is leave your patient in pain but when there's physically nothing else you can give them it is difficult"
- "It's quite hard work, especially if they're in for a while, so seeing the same person over and over with no change"
- "It can be quite frustrating for staff as well sometimes because, you think, what am I doing here, that they couldn't do themselves at home?"

**What helps**

Everyone following a clear plan

- "It's just sticking to a firm plan between the consultants, especially the pelvic pain team. So that the consultants don't start offering things they don't need. Having a very strict plan of what they need and then getting them back out again to the clinics"
- "You have the chronic pelvic pain team so they do obviously all the chronic pelvic pain but then there's ones who just do the gynae stuff so it's a case of making sure pelvic pain plan is followed. Making sure a plans in place, we're all following them"
- "I just think it's much better management at the moment. And [patients are] being seen to, so we don't see, not too many [repeat admissions]"

Psychology input

- "I think clinical supervision is useful which we've started doing. And I'm really happy we've started it because there was nothing on before"

- "[The Clinical Psychologist] was coming round, taking us through what chronic pelvic pain is, and treatments and how it affects women and stuff so yeah I think it's great… I think staff will feel more supported now"
- "We're talking about loads of different conditions, like it's endometriosis, it's vulvodynia it's loads of different things that are not necessarily any of us really know a lot about. Especially when they're conditions that you can't necessarily see the physical side"
- "It's more of a team feeling you can do something cos sometimes before that we're nurses right, we're more than happy to try and cover and support our women, it's a holistic matter isn't it, nursing is holistic, there are lots of different aspects that build the nursing profession, so you try… but you're not a psychologist"
- "We can communicate easily to [the Clinical Psychologists] and they come and see the patients and I think it's a great support for [Consultants] and staff because before that they had all of this on their shoulders and it's just too much. Because it's clinic or wards, you can't cover everything. You can't just telephone them on their day off, it's not fair, it's not good. But if you've got more professionals around, they can cover the gaps of the care"

Specialist CPP consultant

- "[The CPP consultant] is very good at seeing patients, trying to reassure them and think of other strategies rather than getting them onto the ward"
- "I think the lead consultant is very good at calling them back. Getting plans done pretty fast. But she helps a lot"
- "When we've got this kind of patient regarding medication we always say okay we're going to email or give her a ring to come and talk to them"

| |
|---|
| • "She's really good and if she's around she'll review them straight away and that helps clarify the plan. But when there's different doctors there that aren't specialist in that topic, yeah, it does sometimes get a little muddled and it's not as straight forwards" |
| Supportive team<br>• "People talk amongst themselves and if they've got a problem or within the team I feel people are able to talk things over I think so it's kind of clinical supervision unofficially"<br>• "If you're in the next day someone will be like 'have a break' you know? I'll take them. And we kind of like share it out" |

**Appendix N: SIP – Representative quotes from patient interviews**

| **Never know what's going to happen** |
|---|
| Don't know who you'll see<br>• "I think it's just the uncertainty of what's going on, who you'll see, the consultant /doctors or anything like that, and if you'll actually see somebody, what's going to happen whilst you're there"<br>• "I think the doctors fall short, it's I don't think I've ever seen the same doctor, I've been up there quite a few times admitted and I don't think I've seen the same doctor more than once"<br>• "I just don't know what to expect, and to be honest its quite scary to not know what's going on" |
| Luck if seen by specialist |

- “Very safe and supported but I it was the consultant who very much took me under her wing but it was you know that was 2 days in and just pure luck and coincidence that she happened to pop her head around the curtain”
- “There wasn’t any consultant that had any speciality in endometriosis. Which I find absolutely crazy on a gynaecology ward in somewhere that is an endometriosis centre you know so at first I was being told I wasn’t going to see anyone who’d understand my condition, so we’d just wait for them”
- “I was very lucky to actually see the clinical lead for the pelvic pain clinic and subsequently the plan of action was planned”
- “I couldn’t ask for a better consultant… She explains everything to me, I never feel like I’m a burden”
- “If I see my consultant… then she explains everything, but if she’s not in, like she’s on holiday or something and I see somebody else then it’s not explained to me”

Some staff just don't take you seriously

- “I just sat in the emergency room talking to a doctor and they didn’t believe me. They didn’t believe me. And that is disheartening for the patient. You think, why did I bother?”
- “I would just like them to believe that you’re in pain and that you are hurting and that it’s genuine, it’s just its hidden”
- “Most of the time I feel listened to, but sometimes when you’re there you just don’t feel listened to at all. Not just from the nursing staff but some of the doctors as well… you just don’t feel like you’re being listened to, that’s what the problem is”

- "I knew the pain I was going through wasn't normal. It wasn't normal for my body. And I think no matter how many times you go into hospital it shouldn't, it shouldn't feel like you're being a – what's the word- a nuisance?"
- "I felt that me being in pain was really – not by all members of staff, some members of staff were absolutely lovely –but there were a couple that really disregarded like the amount of pain I was actually in"
- "A lot of nurses that were there helping me don't understand it. To them it's not an emergency"
- "A huge part of people's recovery in illness is psychological and emotional particularly in a women's ward and with that missing, you know, it does make everything so much harder"
- "As a patient when you're in that pain and you go somewhere for some help, and that's the reason we all go to hospital, go to the doctors because we need help one way or the other and to feel that you're a burden… that's frustrating. And you're a bit of a pest, for want of a better word"
- "One of the consultants I've seen before, I don't and interestingly others have said the same thing of late, don't find [them] to be empathetic or sympathetic to women's situations in general"

**Medically safe**

Regular check-ins

- "I had my own room but I felt that they came and checked on me quite a lot, I don't feel that I was left for a very long period of time"
- "I can't fault them. And everything that everyone's going through at the moment um they did everything, they constantly coming up asking if I needed anything"

- "I've had nothing but amazing support when I've been in, every single time. Some of the nurses recognise me from being in there before. I always felt well looked after"
- "I felt they looked after me really quite well. I don't really have any complaints in terms of that. You know I wasn't in active pain, they came and regularly topped up my painkillers"
- "They were understaffed unfortunately but they kept, kept me up to date all the way through"

Practical help and support

- "I couldn't move around at all after my surgery and took me a while to recover but every time I needed the toilet they would come and help me out of bed, they would like hold my hand and assist me… just things like that was really really nice"
- "The sister on the ward was absolutely amazing she said let's get you out of this pain, and let's get you to having a wee and she fitted me with a catheter, she explained everything as she was going, and she was very it was all done and dusted"
- "I didn't like the first pill I tried I wanted to change to a different one, they were very happy to just change that and listen to what I wanted and they've I've never felt like they've forced their opinion or what they think is best for me, they let me decide what I want to take myself"
- "The biggest compliment I suppose is when I've been up there and been in pain and asked for my medication um they're pretty forthcoming, and it's pretty quickly done and they've given it to me. Um there has been the odd occasion where I wasn't allowed it because it was too soon and the timings wasn't right. So

| |
|---|
| then they've gone back to the doctor and found me something else I can have instead" |
| Supportive discussions around surgery<br>• "I had a discussion with my consultant before the surgery about what the plan was and what the outcome of you know why I was having the surgery and you know what we were hoping for and then she obviously spoke to me about the risks and you know, it might not work, I might end up worse but you know we kinda weighed up"<br>• "They've always discussed like, why I need to stay in hospital. Because obviously I've been in for like a week loads of times I've been in not just like overnight, and they've obviously explained why I need to be there to control my pain and my bleeding, they've always kept me informed of everything which is really really helpful"<br>• "When I had my surgery as well I was fully informed the whole time… I felt a lot calmer and more reassured and it did help because I do suffer with anxiety. I feel like they took that on board and knew that I suffered and really made me feel reassured" |
| Valuing input from different professionals<br>• "I was really struggling to understand why, because I was in such a depressed state at the time, my whole thought process just wasn't right like, why am I in pain, I hate my body, like I wish my body was different, why me - things like that, but obviously, I was in a very bad place and that's all I was thinking. Whereas now, like speaking to the therapist and counsellor, my gynaecologist and my physio, actually I do have a chronic condition, I know what causes it, I take the pill to help control it, I've gone to physio to help control it" |

- "I remember one of the physios she said no, it is a chronic condition you have, it is a very painful condition, and you shouldn't feel bad for having that pain. And it's really like stuck in my mind, I'm not just not tolerating pain, I do have severe pain and I do put up with a lot of pain day-to-day and when I do come to hospital for pain I shouldn't feel stupid"
- "… is a physio at the gynaecology department so she understands it slightly more because she has the training. She has you know she gets it"
- "The consultant and the other specialists that you see sort of thing like yourself like if you see psychologist or physio whilst you're actually in they give you support"

**Sent home unequipped**

What was the point?

- "You're in that pain and you're left… And you're lucky if you see a doctor. What's the point of it? And then you're sent home after 4 or 5 days in hospital, with medicine you've taken in hospital"
- "You go to hospital in pain to try and sort it but you're sent home with exactly the same pain and with no difference. It's just disbelief"
- "To get that explained to me, why it was happening wasn't forthcoming, it wasn't easy to get that thing and I still haven't had it explained"
- "There wasn't actually a plan that came into place. I actually sought private care… so my route forwards was to try to find somebody that could treat me"
- "It's a general not understanding from doctors but also patients we don't necessarily get told what it is, you have to research it yourself, and that's not a good thing to do because you know what the internet is like!"

- "Every single time I've gone there I've just been told that, basically just been given painkillers and just been sent home"
- "Just to have a bit more like, a plan. Just that I'm ready to go home but look we're gonna book you in an appointment for I don't know, to see gynaecologist here in the day…but none of that was done"

Not sure what to do

- "I got given a phone number for the ward and I did phone them once but they didn't seem to really know anything about what was going on they were just like I'm not really sure what to do about that, you know, and then I wasn't really sure where to go from there"
- "I wasn't really told what to look for to be worried or to receive more help you know? I mean I was told like you know if you get a lot of bleeding or whatever then let us know but I wasn't given a clear list of what would've been worrying that I would need to contact someone about… I don't know maybe just like a leaflet like what this is, what to look out for, you know, that you need to keep medical attention on"
- "I think it would be good to be able to have, even if it's just a leaflet, sort of thing, with different strategies to help you with, like a generalised sort of thing. I think that would actually be quite a helpful thing to have"
- "I loose track of my pain relief so I have to physically write it down. It's hard because I will worry I will take an overdose.. it'd be good like if, rather than just given the medication, actually given like a timetable and also when you leave hospital to say what time you last took medication"
- "It would be good to have something where like one of the nursing staff or a NA contacts you like a week later to like discuss like how you're getting on or if

there's anything they could do to help. That sort of thing would actually be quite good. Because you don't get that support after, once you've left, that's it"

## Appendix O: SIP – Agenda for service feedback




NHS
Oxford University Hospitals
NHS Foundation Trust

Service improvement project: Improving the service provided to women with chronic pelvic pain admitted to the inpatient gynaecology department, John Radcliffe Hospital

**Feedback and discussion of key results and recommendations**

Date: [redacted]
Time: [redacted]
via Microsoft Teams

Attendees:
[redacted] (trainee clinical psychologist)
(clinical psychologist)
(ward sister for the gynaecology ward)
(consultant gynaecologist)
(service user representative)

Agenda:
1. Presentation of key themes from staff focus groups and patient interviews
2. Service recommendations
3. Response from service and discussion

## Appendix P: SIP – Lay summary

The John Radcliffe Hospital Gynaecology Department is a large department based in the Women's Centre that offers a wide range of women's health services. This includes

supporting patients with chronic pelvic pain syndrome (CPPS). Individuals with CPPS may experience gynaecological, urinary, sexual, bowel and pelvic floor difficulties. Chronic pain has a significant impact in many different areas of life including sleep disturbance, worries around fertility implications and maintaining relationships, inability to work, anxiety and depression. Unfortunately, treatment options such as surgery or pain medication often have limited or no benefit. This raises particular challenges for this group of patients and the staff who support them. This project aimed to understand these challenges through interviews with patients and staff. Based on the experiences and feedback provided, a list of service recommendations was developed to improve quality of care. This included staff training, how to make patients feel more heard, and how to support patients to understand their condition and manage their CPPS.

**Appendix Q: MRP – Approvals**

The project proposal was approved by the Project Approval Panel, Oxford Clinical Psychology Doctoral Training Programme, on 04/08/2020. Ethical approval for the study was granted by the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford (Ethics Approval Reference: R74797/RE001) on 23/04/2021.

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

**CONFIDENTIAL**

Victoria Edwards
Oxford Institute for Clinical Psychology Training
(OxICPT)
Isis Education Centre
Warneford Hospital
Oxford

23 April 2021

Dear Victoria,

**Research Ethics Approval - CUREC 1**

**Ethics Approval Reference: R74797/RE001**

**Study title: The role of social support and perceived criticism in over acquiring and keeping possessions: A cross-sectional study**

**Short title: An investigation into Social Support, Possessions & Obsessions**

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

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on **23rd April 2021**.

Approval is **subject to:**

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

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

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

Yours Sincerely

H. Barnby-Porritt

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

**Appendix R: MRP – Supplementary information on recruitment and procedure**

Individuals interested in participating were called (over telephone or Microsoft Teams as requested) to explain the study, answer questions and compete the HD and OCD subsections of the Structured Clinical Interview for DSM-5 Research Version (First et al., 2015). Individuals provided oral consent to the interview with the additional option of consenting for this to be recorded. This was for training and supervision purposes. Following the interview, it was checked whether individuals were happy to proceed with the next part of the study. All participants were happy to proceed. Individuals were then assigned a participant identification number and either emailed a link to the questionnaire (on Qualtrics software) or sent a paper copy by post (as requested).

The questionnaire pack included a battery of self-report demographic and psychometric measures taking approximately 30-40 minutes. Participants completed a consent form at the start of the questionnaire pack which included confirmation that they had read and understood the participant information sheet. A debrief page was provided at the end of the questionnaire. A pop-up message with support services appeared if online responses indicated any risk (see below).

*Online 'pop-up' message:*

Thank you for sharing your thoughts so honestly. We noticed you indicated having suicidal thoughts. We would suggest that you take this up with your General Practitioner (GP). GPs can support people by making referrals to talking therapies in your area and/or may consider other interventions if you would like support. In addition, you are also able to call Samaritans on 116 123. If you should feel in immediate risk of harming yourself or someone else, we strongly recommend you visit your local A&E. We would also recommend you visit the following webpage:

https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/where-to-get-urgent-help-for-mental-health/

## Appendix S: MRP – Study documentation

Oxford Institute for Clinical Psychology Training (OxICPT)
Isis Education Centre
Warneford Hospital, Oxford
OX3 7JX

Victoria Edwards
victoria.edwards@hmc.ox.ac.uk
Oxford Institute of Clinical Psychology Training
Oxford University telephone number: +44 (0) 1865 226431

### An Investigation into Social Support, Possessions & Obsessions

### PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee (CUREC) Approval Reference: R74797/RE001

My name is Victoria Edwards and I am a Trainee Clinical Psychologist at the University of Oxford, working with Paul Salkovskis and team. This is an invitation to take part in our research study.

Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve. Please take time to read this Information Sheet, and discuss it with others if you wish. *If there is anything that is not clear, or if you would like more information, please email* victoria.edwards@hmc.ox.ac.uk

#### 1. *Why is this research being conducted?*

The amount of social support people receive (or don't receive) can have a big impact on their thoughts and experiences. We are interested in the amount and type of social support experienced by people who have difficulties with a) over acquiring and keeping possessions, b) obsessional and compulsive problems, and c) those without problems with either. From this research, we hope to develop a greater understanding of factors that may make someone more vulnerable to difficulties with obsessions and compulsions or hoarding belongings, with the hope of tailoring and improving treatments.

We are keen to hear from a range of people including those who have no current mental health problems, those with have obsessional problems and those who have hoarding difficulties.

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

You are very kindly interested in helping with our research. We are happy to hear from anyone who has heard about the study and is interested in finding out more information about participation. In some instances, you may have been asked to participate, as we are keen to gather the thoughts of people 18 years and above, from these 3 groups:

1. Consider themselves to have a significant problem with over acquiring and keeping possessions

2. Consider themselves to have Obsessive Compulsive Disorder
3. Have no current experience of mental health difficulties

### 3. *Do I have to take part?*

No. You can ask questions about the research before deciding whether or not you wish to continue and take part. If you do agree to take part, you may withdraw yourself from the study, without giving a reason, and without negative consequences by advising me of this decision. As the data collected is anonymous we will be unable to withdraw your data once you complete the study.

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

The study will involve two parts:

1. A discussion over the telephone or on video conferencing using Microsoft Teams,
2. Filling out a series of questionnaires online (or a paper copy as requested)

The telephone session will take approximately 15 minutes and will be arranged for a time convenient for you. The researcher will talk you through the study procedures and give you the chance to ask any questions. If you are still happy to take part, you will be asked to give oral consent. You will then be asked a series of questions to determine if you meet diagnostic criteria for "Hoarding Disorder", Obsessive Compulsive Disorder, or to confirm you are not currently experiencing mental health problems. This semi-structured interview is used widely across the globe in psychological research and in clinical practice. You can ask to pause or stop the interview at any time. With your consent, I would like to take notes and audio record the conversation so that my supervisor can listen to a sample to ensure diagnostic criteria are being accurately recorded. Once this is checked the audio recordings will be deleted.

Following the telephone interview, you will be emailed a link to complete an online questionnaire along with your unique anonymised Personal Identification Number (PIN). Alternatively, you can request a paper copy of the questionnaires to be sent by post. You will be reminded of the details of the study and asked to provide your consent to take part in this second part of the study. The questionnaire will include questions about your mental health, your levels of social support and sense of belonging as well as any significant life events. This portion of the study may take approximately 30 minutes although for some people it may take longer. You can log in and log out of the program at your convenience using your allocated PIN, if you would like to take a break from the questionnaires. We would appreciate if you could complete the questionnaires within a week.

You will also be asked whether you consent for your details to be retained within a secure research database by the Clinical Research Group, which constitutes Trainee Clinical Psychologists and Research Staff from the Oxford Institute for Clinical Psychology Training. If you give your permission, your contact details and information from your screening telephone call will be retained so that you can be contacted with information about similar research studies that you may wish to participate in. This is optional and does not affect your ability to participate in the current study. You can also ask, at any stage, for your name to be removed from the group.

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

Taking part could take up to approximately 45-60 minutes of your time in total.

All questionnaires are standardised measures and have been included with feedback from people with lived experience of having problems with their personal possessions in order to minimise the potential for distress. However, some of the content may feel difficult to think about and it is possible you might find answering the questions upsetting. You can take a break from the study and return to it later or withdraw from the study at any point. At the end of the study, or if you withdraw at any point, you will provided with contact details of services and third-party organisations that will be able to offer support and guidance.

To ensure confidentiality, you will be provided with a unique personal identification number with which to fill out the questionnaires. In order to link telephone and questionnaire data, a password-protected database on an encrypted, password-protected device will store the data (details below).

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

We hope that your participation in this will help us understand people who are experiencing difficulties and distress related to their possessions. This may contribute to the development of treatments. However, there will be no direct or personal benefit to you from taking part in this research.

### 7. *What happens to the data provided?*

Data protection regulation requires that we state 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.

The information you provide during the study is the research data. Any research data from which you can be identified (i.e., name, email address, telephone number and home address, should you request the questionnaires by post) are known as personal data. Personal data will be stored on a password-protected, encrypted Oxford Health NHS Foundation trust iPad. Personal data will be stored for 3 months after the study has concluded itself and then permanently deleted.

Other research data (including consent forms and sensitive data obtained from questionnaires such as your racial or ethnic origin or information regarding your mental health) will be stored for at least 3 years after publication or public release of the work of the research. This information will then be shredded or permanently deleted and destroyed.

The research team involved in this study will have access to the research data. Responsible members of University of Oxford may be given access to data for monitoring and/or audit of the research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public. Using the research data, we hope to report our findings in academic journals and present them to relevant charities, and to health professionals at conferences. The findings will also contribute to a research thesis. You will not be identified in any reports or publications arising from the study.

### 8. *Will the research be published?*

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

The research will be written up as part of Victoria Edwards' Doctorate in Clinical Psychology. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible. The research is likely to be written up for publication in a peer-reviewed scientific journal.

The research team also aims to disseminate findings to Hoarding UK and OCD UK charities.

### 9. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R74797/RE001).

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

Every care has been taken to ensure your safety during the course of the study. If you have a concern about any aspect of this study, please contact Victoria Edwards (victoria.edwards@hmc.ox.ac.uk, 01865 226431) or Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk, 01865 226431) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with.

If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

### 11. *Data Protection*

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

### 12. *Further Information and Contact Details*

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

Victoria Edwards
Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Headington, Oxford
OX3 7JX
Oxford University telephone number: +44 (0) 1865 226431
victoria.edwards@hmc.ox.ac.uk

You can also speak to the supervisors of the project about any questions or concerns using the details below:

Professor Paul Salkovskis (University of Oxford) paul.salkovskis@hmc.ox.ac.uk
Dr Victoria Bream, Clinical Psychologist University of Oxford)
victoria.bream@hmc.ox.ac.uk

**I'm Interested! What's Next?**

If you would like to participate, please email Victoria Edwards to set up a telephone interview: victoria.edwards@hmc.ox.ac.uk

**Thank you for taking the time to read this information sheet and for your interest in the project.**

Oxford Institute for Clinical Psychology Training (OxICPT)
Isis Education Centre
Warneford Hospital, Oxford
OX3 7JX

Victoria Edwards
victoria.edwards@hmc.ox.ac.uk
Oxford Institute of Clinical Psychology Training
Oxford University telephone number: +44 (0) 1865 226431
PI: Paul Salkovskis

**PARTICIPANT ONLINE CONSENT FORM**

Central University Research Ethics Committee (CUREC) Approval Reference: R74797/RE001

**An Investigation into Social Support, Possessions & Obsessions**

Thank you for your continued interest in our study. To remind you, the broad aim of our study is to understand the role of social support in how people relate to possessions.

You will have completed the telephone portion of the study- thank you! You will now be invited to the main part of our research, involving several different questionnaires. We would like to know more about the role of social support in obsessions and compulsions as well as over acquiring and keeping possessions. Some of the questionnaires will ask you about your mental health generally, some will ask you about your social support, feelings of belonging and life events. The questionnaires may take around 30 minutes to complete.
/
Please read through the statements below and tick the box on the right of the screen to give your consent to participate.

| | | *Please tick each box* |
|---|---|---|
| 1 | I confirm that I have read and understand the information sheet Version 1.0 dated 07.12.2020 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | ☐ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty. | ☐ |
| 3 | I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my data. | ☐ |
| 4 | I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. | ☐ |
| 5 | I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project. | ☐ |

| | | |
|---|---|---|
| 6 | I understand that this research will be written up and published. | ☐ |
| 7 | I understand how to raise a concern or make a complaint. | ☐ |
| 8 | I agree to take part in the study | ☐ |

*The next statement is optional and does not affect your ability to consent to this particular study. If you would like to participate in future studies and, therefore, for researchers to keep your personal contact details you are welcome to tick the following box. If in the future you wish for your name to be removed then please direct your enquires to Professor Paul Salkovskis paul.salkovskis@hmc.ox.ac.uk*

| | | |
|---|---|---|
| **Optional** | I agree that my personal contact details can be retained in a secure database so that the researchers can contact me about future studies. | ☐ |

Oxford Institute for Clinical Psychology Training (OxICPT)
Isis Education Centre
Warneford Hospital, Oxford
OX3 7JX

Victoria Edwards
victoria.edwards@hmc.ox.ac.uk
Oxford Institute of Clinical Psychology Training
Oxford University telephone number: +44 (0) 1865 226431
PI: Paul Salkovskis

**PARTICIPANT WRITTEN CONSENT FORM**

Central University Research Ethics Committee (CUREC) Approval Reference: R74797/RE001

## An Investigation into Social Support, Possessions & Obsessions

Thank you for your continued interest in our study. To remind you, the broad aim of our study is to understand the role of social support in how people relate to possessions.

You will have completed the telephone portion of the study- thank you! You will now be invited to the main part of our research, involving several different questionnaires. We would like to know more about the role of social support in obsessions and compulsions as well as over acquiring and keeping possessions. Some of the questionnaires will ask you about your mental health generally, some will ask you about your social support, feelings of belonging and life events. The questionnaires may take around 30 minutes to complete.

Please read through the statements below and initial the box on the right of the statements to give your consent to participate.

| | | *Please initial each box* |
|---|---|---|
| 1 | I confirm that I have read and understand the information sheet Version 1.0 dated 07.12.2020 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | ☐ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty. | ☐ |
| 3 | I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my data. | ☐ |
| 4 | I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. | ☐ |
| 5 | I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project. | ☐ |

| | | |
|---|---|---|
| 6 | I understand that this research will be written up and published. | ☐ |
| 7 | I understand how to raise a concern or make a complaint. | ☐ |
| 8 | I agree to take part in the study | ☐ |

The next statement is optional and does not affect your ability to consent to this particular study. If you would like to participate in future studies and, therefore, for researchers to keep your personal contact details you are welcome to tick the following box. *If in the future you wish for your name to be removed then please direct your enquires to Professor Paul Salkovskis paul.salkovskis@hmc.ox.ac.uk*

**Optional:** I agree that my personal contact details can be retained in a secure database so that the researchers can contact me about future studies.

| | | |
|---|---|---|
| Name of participant | Date (DD/MM/YYYY) | Signature |
| Name of researcher taking consent | Date (DD/MM/YYYY) | Signature |

Oxford Institute for Clinical Psychology Training (OxICPT)
Isis Education Centre
Warneford Hospital, Oxford
OX3 7JX

UNIVERSITY OF OXFORD

**PARTICIPANT DEBRIEF SHEET**

## An Investigation into Social Support, Possessions & Obsessions

Thank you for taking part in this study, we really appreciate your help!

We understand that some of the questions may be difficult to think about so we really appreciate your time in contributing to our understanding of the role of social support in relation to over acquiring and keeping possessions and obsessional thoughts. We hope that through this work we are better able to tailor the interventions and support that are offered.

To remind you, all of your data is anonymous and confidential. We store the results on a password-protected computer, which can only be accessed by the research team. Personally identifiable information, such as telephone numbers or email addresses supplied to us to take part in this study will be destroyed as soon as the study comes to a close.

**Further advice and support**
The NHS can help if you are experiencing difficulties with your mental health. There are also many charities who can provide advice, emotional and practical support. If you are concerned about your mental health, we encourage you to speak to your GP who can then refer you for further specialist help.

**Sources of advice and support**
1. Your General Practitioner
2. NHS 111
3. Helplines:
   a. The Samaritans 116 123
   b. SANE 0300 304 7000 or http://www.sane.org.uk/

**Further questions**
If you have any more questions about any aspect of this project, please speak to the researcher Victoria Edwards (victoria.edwards@hmc.ox.ac.uk) or their supervisor Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk), who will do their best to answer your query.

If you have any concerns, or wish to make a formal complaint, please contact the relevant Chair of the Research Ethics Committee at the University of Oxford: Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

If you know anyone who may like to participate in this study, you are welcome to provide them with the details of our website here: https://oxicptr.web.ox.ac.uk/help-our-research#collapse3087036

**Appendix T: MRP – Additional descriptive information**

| | | Frequency, (%) | % |
|---|---|---|---|
| **Gender** | Female | 90 | 76.9 |
| | Male | 22 | 19.5 |
| | Other | 1 | 0.9 |
| **Ethnicity** | Ashkenazi | 1 | 0.9 |
| | Asian (other) | 1 | 0.9 |
| | Bangladeshi | 1 | 0.9 |
| | Black British / Caribbean | 1 | 0.9 |
| | Black Pakistani | 1 | 0.9 |
| | Caucasian | 101 | 84.9 |
| | Chinese | 1 | 0.9 |
| | Indian | 1 | 0.9 |
| | Mixed | 2 | 1.8 |
| | Mixed – White and Asian | 1 | 0.9 |
| | Mixed – North African and English | 1 | 0.9 |
| | Prefer not to say | 1 | 0.9 |

| | | | |
|---|---|---|---|
| **Highest level of education completed** | Secondary school | 30 | 26.5 |
| | University degree | 42 | 37.2 |
| | Postgraduate degree | 41 | 36.3 |
| **Employment status** | Unemployed | 4 | 3.5 |
| | Employed | 56 | 49.6 |
| | Retired | 29 | 25.7 |
| | Homemaker | 4 | 3.5 |
| | Student | 5 | 4.4 |
| | Non-paid or voluntary work | 1 | .9 |
| | Carer | 2 | 1.8 |
| | Other | 12 | 10.6 |
| **Civic status** | Married | 43 | 38.1 |
| | Living as couple | 12 | 10.6 |
| | Divorced or separated | 21 | 18.6 |
| | Single | 30 | 26.5 |
| | Widowed | 6 | 5.3 |
| | Prefer not to say | 1 | 0.9 |

**Appendix U: MRP – Measures pack**

Demographic Information

Q3.1 What is your gender?

- Male
- Female
- Other
- Prefer not to say

Q3.2 How old are you? (years)

_____

Q3.3 How would you describe your ethnicity?

_____

Q3.4 What is the highest level of education you have completed?

- No formal schooling
- Less than primary school
- Primary school completed
- Secondary or high school completed
- University degree completed
- Post graduate degree completed

Q3.5 Which of the following best describes your main work status over the past 12 months?

- Unemployed
- Employed
- Retired
- Homemaker
- Student
- Non-paid or voluntary work
- Carer
- Other

Q3.6 What is your civic status?

- Married
- Living as couple
- Divorced or separated
- Single
- Widowed
- Other
- Prefer not to say

Q3.7 Have you, in the past, received professional support for your mental health?

- Yes
- No

Q3.8 Do you currently receive professional support for your mental health?

- Yes
- No

Q3.9 If yes, does this include talking therapy? (e.g. cognitive behavioural therapy, counselling)

- Yes
- No

Q3.10 Are you currently taking medication for your mental health?

- Yes
- No

Q3.11 Approximately how old were you when your particular mental health difficulties started? (please write NA if this does not apply to you)

_____

Q4.1 Patient Health Questionnaire (PHQ9)

Over the last TWO WEEKS, how often have you been bothered by any of the following problems?

| | 0 – Not at all | 1 - Several days | 2 -More than half the days | 3 - Nearly every day |
|---|---|---|---|---|
| 1. Little interest or pleasure in doing things | ○ | ○ | ○ | ○ |
| 2. Feeling down, depressed, or hopeless | ○ | ○ | ○ | ○ |
| 3. Trouble falling or staying asleep, or sleeping too much | ○ | ○ | ○ | ○ |
| 4. Feeling tired or having little energy | ○ | ○ | ○ | ○ |
| 5. Poor appetite or overeating | ○ | ○ | ○ | ○ |
| 6. Feeling bad about yourself or that you are a failure or have let yourself or your family down | ○ | ○ | ○ | ○ |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | ○ | ○ | ○ | ○ |
| 8. Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot more than usual | ○ | ○ | ○ | ○ |

| | | | | |
|---|---|---|---|---|
| 9. Thoughts that you would be better off dead, or of hurting yourself | ○ | ○ | ○ | ○ |

Q5.1 Generalised Anxiety Disorder Assessment (GAD7)

Over the last TWO WEEKS, how often have you been bothered by the following problems?

| | 0 - Not at all | 1 - Several days | 2 -More than half the days | 3 - Nearly every day |
|---|---|---|---|---|
| 1. Feeling nervous, anxious, or on edge | ○ | ○ | ○ | ○ |
| 2. Not being able to sleep or control worrying | ○ | ○ | ○ | ○ |
| 3. Worrying too much about different things | ○ | ○ | ○ | ○ |
| 4. Trouble relaxing | ○ | ○ | ○ | ○ |
| 5. Being so restless that it is hard to sit still | ○ | ○ | ○ | ○ |
| 6. Becoming easily annoyed or irritable | ○ | ○ | ○ | ○ |
| 7. Feeling afraid, as if something awful might happen | ○ | ○ | ○ | ○ |

Q6.1 Work and Social Adjustment Scale

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity.

Please select the most appropriate answer

| | 0 (not at all) | 1 | 2 (slightly) | 3 | 4 (definitely) | 5 | 6 (markedly) | 7 | 8 (very severely) | N/A |
|---|---|---|---|---|---|---|---|---|---|---|
| 1) WORK - if you are retired or choose not to have a job for reasons unrelated to your problem, please tick N/A (not applicable) | ○ | | | ○ | ○ | | ○ | ○ | ○ | ○ |
| 2) HOME MANAGEMENT - Cleaning, tidying, shopping, cooking, looking after home/children, paying bills etc | ○ | | | ○ | ○ | | ○ | ○ | ○ | ○ |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 3) SOCIAL LEISURE ACTIVITIES - With other people, e.g. parties, pubs, outings, entertaining etc | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4) PRIVATE LEISURE ACTIVITIES - Done alone, e.g. reading, gardening, sewing, hobbies, walking etc. | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5) FAMILY AND RELATIONSHIPS - Form and maintain close relationships with others including the people that I live with | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Q7.1 Revised NSSQ (Norbeck Social support questionnaire)

Please list each significant person in your life on the first column. Consider all the people who provide personal support for you or who are important to you. Use only first names or initials, then indicate the relationship, as in the following example:

1. Mary T. friend
2. Bob. brother
3. MT. mother
4. Sam friend
5. Mrs R neighbour

Use the following list to help you think of the people important to you. List as many people as apply in your case.

- spouse or partner
- significant other
- family member or relative
- neighbour
- friend
- work associate
- healthcare provider
- counsellor or therapist
- minister / priest / rabbi
- other / please specify

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life

| | First name or initials | Relationship |
|---|---|---|
| 1 | | |
| 2 | | |
| 3 | | |
| 4 | | |
| 5 | | |
| 6 | | |
| 7 | | |
| 8 | | |
| 9 | | |
| 10 | | |
| 11 | | |
| 12 | | |
| 13 | | |
| 14 | | |
| 15 | | |
| 16 | | |
| 17 | | |
| 18 | | |
| 19 | | |
| 20 | | |
| 21 | | |
| 22 | | |
| 23 | | |
| 24 | | |

*Note to readers: Those listed under 'first name or initials' would automatically show on all subsequent tables (i.e., in place of 'Person 1')*

For each person you listed, please answer the following questions by filling in the appropriate response from the following scale:

Q8.1 How much does this person make you feel liked or loved?

| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
|---|---|---|---|---|---|---|
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.2 How much does this person make you feel respected or admired? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.3 How much can you confide in this person? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.4 How much does this person agree with or support your actions or thoughts (other than matters regarding over acquiring and keeping possessions and/or obsessional and compulsive problems)? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.4.b If relevant, how much does this person agree with or support your actions or thoughts regarding your over acquiring and keeping possessions and/or obsessional and compulsive problems? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.5 If you needed immediate help, how much could this person usually help? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

| Q8.6 If you needed help for several weeks, how much could this person help you? | | | | | | |
|---|---|---|---|---|---|---|
| | 0 = not at all | 1 = a little | 2 = moderately | 3 = quite a bit | 4 = a great deal | NA |
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ |

Q8.7 How long have you known this person?

| | less than 6 months | 6 to 12 months | 1 to 2 years | 2 to 5 years | 5 years or more |
|---|---|---|---|---|---|
| *Person 1* | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ |

8.8 How frequently do you usually have contact with this person?

(Phone calls, visits, texts, email, letters)

| | daily | weekly | monthly | a few times a year | once a year or less |
|---|---|---|---|---|---|
| *Person 1* | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ |

Q8.9 How critical do you think this person is of you?

On a scale from 1 (not at all) to 10 (very critical).

| | 1 - not at all critical | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 -very critical |
|---|---|---|---|---|---|---|---|---|---|---|
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Q8.10 When this person criticises you, how upset do you get? On a scale from 1 (not at all) to 10 (very upset).

| | 1 - not at all upset | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 - very upset |
|---|---|---|---|---|---|---|---|---|---|---|
| *Person 1* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 2* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 3* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 4* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 5* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 6* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 7* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 8* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 9* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 10* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 11* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 12* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 13* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 14* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 15* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 16* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 17* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 18* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 19* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 20* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 21* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 22* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| *Person 23* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| *Person 24* | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Q8.11 During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

- ○ Yes
- ○ No

Q8.12 Please indicate the number of persons from each category who are no longer available to you

| | Please indicate the number of persons from each category who are no longer available to you |
|---|---|
| spouse or partner | |
| significant other | |
| family member or relatives | |
| neighbours | |
| friends | |
| work associates | |
| health care providers | |
| counsellor or therapist | |
| minister / priest / rabbi | |
| other (please specify) | |

Q8.13 Overall, how much of your support was provided by these people who are no longer available to you?

- 0 - none at all
- 1 - a little
- 2 - a moderate amount
- 3 - quite a bit
- 4 - a great deal

Q9.1. MOSSS-SSS. Next are some questions about the support that is available to you. About how many close friends and relatives do you have (people you feel at ease with and can talk to about what is on your mind)? Write in number of close friends and close relatives:

---

Q9.2 People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Choose one number from each line.

| | 1- None of the time | 2 - A little of the time | 3 - Some of the time | 4 - Most of the time | 5 - All of the time |
|---|---|---|---|---|---|
| 1. Someone to help you if you were confined to bed | ○ | ○ | ○ | ○ | ○ |
| 2. Someone you can count on to listen to you when you need to talk | ○ | ○ | ○ | ○ | ○ |
| 3. Someone to give you good advice about a crisis | ○ | ○ | ○ | ○ | ○ |
| 4. Someone to take you to the doctor if you needed it | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 5. Someone who shows you love and affection | ○ | ○ | ○ | ○ | ○ |
| 6. Someone to have a good time with | ○ | ○ | ○ | ○ | ○ |
| 7. Someone to give you information to help you understand a situation | ○ | ○ | ○ | ○ | ○ |
| 8. Someone to confide in or talk to about yourself or your problems | ○ | ○ | ○ | ○ | ○ |
| 9. Someone who hugs you | ○ | ○ | ○ | ○ | ○ |
| 10. Someone to get together with for relaxation | ○ | ○ | ○ | ○ | ○ |
| 11. Someone to prepare your meals if you were unable to do it yourself | ○ | ○ | ○ | ○ | ○ |
| 12. Someone whose advice you really want | ○ | ○ | ○ | ○ | ○ |
| 13. Someone to do things with to help you get your mind off things | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 14. Someone to help with daily chores if you were sick | ○ | ○ | ○ | ○ | ○ |
| 15. Someone to share your most private worries and fears with | ○ | ○ | ○ | ○ | ○ |
| 16. Someone to turn to for suggestions about how to deal with a personal problem | ○ | ○ | ○ | ○ | ○ |
| 17. Someone to do something enjoyable with | ○ | ○ | ○ | ○ | ○ |
| 18. Someone who understands your problems | ○ | ○ | ○ | ○ | ○ |
| 19. Someone to love and make you feel wanted | ○ | ○ | ○ | ○ | ○ |

Q10.1 UCLA Loneliness Scale

Indicate how often each of the statements below is descriptive of you.

| | 1- Never | 2 - Rarely | 3 - Sometimes | 4 - Often |
|---|---|---|---|---|
| 1. How often do you feel that you are "in tune" with the people around you? | ○ | ○ | ○ | ○ |
| 2. How often do you feel that you lack companionship? | ○ | ○ | ○ | ○ |
| 3. How often do you feel that there is no one you can turn to? | ○ | ○ | ○ | ○ |
| 4 How often do you feel alone? | ○ | ○ | ○ | ○ |
| 5. How often do you feel part of a group of friends? | ○ | ○ | ○ | ○ |
| 6. How often do you feel that you have a lot in common with the people around you? | ○ | ○ | ○ | ○ |
| 7. How often do you feel that you are no longer close to anyone? | ○ | ○ | ○ | ○ |
| 8. How often do you feel that your interests and ideas are not shared by those around you? | ○ | ○ | ○ | ○ |
| 9. How often do you feel outgoing and friendly? | ○ | ○ | ○ | ○ |

| | | | | |
|---|---|---|---|---|
| 10. How often do you feel close to people? | ○ | ○ | ○ | ○ |
| 11. How often do you feel left out? | ○ | ○ | ○ | ○ |
| 12. How often do you feel that your relationships with others are not meaningful? | ○ | ○ | ○ | ○ |
| 13. How often do you feel that no one really knows you well? | ○ | ○ | ○ | ○ |
| 14. How often do you feel isolated from others? | ○ | ○ | ○ | ○ |
| 15. How often do you feel you can find companionship when you want it? | ○ | ○ | ○ | ○ |
| 16. How often do you feel that there are people who really understand you? | ○ | ○ | ○ | ○ |
| 17, How often do you feel shy? | ○ | ○ | ○ | ○ |
| 18. How often do you feel that people are around you but not with you? | ○ | ○ | ○ | ○ |
| 19. How often do you feel that there are people you can talk to? | ○ | ○ | ○ | ○ |
| 20. How often do you feel that there are people you can turn to? | ○ | ○ | ○ | ○ |

Q11.1 Interpersonal Needs Questionnaire – Revised (INQ-R)

The following questions ask you to think about yourself and other people. Please respond to each question by using your own current beliefs and experiences, NOT what you think is true in general, or what might be true for other people. Please base your responses on how you've been feeling recently. Use the rating scale to find the number that best matches how you feel and circle that number. There are no right or wrong answers: we are interested in what you think and feel.

| | 1 - not at all true for me | 2 | 3 | 4 - Somewhat true for me | 5 | 6 | 7 - very true for me |
|---|---|---|---|---|---|---|---|
| 1.These days the people in my life would be better off if I were gone | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2. These days the people in my life would be happier without me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3.These days I think I am a burden on society | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4. These days I think my death would be a relief to the people in my life | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5. These days I think the people in my life wish they could be rid of me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 6.These days I think I make things worse for the people in my life | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 7. These days, other people care about me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 8. These days, I feel like I belong | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 9.These days, I rarely interact with people who care about me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 10.These days, I am fortunate to have many caring and supportive friends | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 11.These days, I feel disconnected from other people | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 12.These days, I often feel like an outsider in social gatherings | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 13.These days, I feel that there are people I can turn to in times of need | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 14.These days, I am close to other people | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 15. These days, I have at least one satisfying interaction every day | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Q12.1 Life Events Checklist (LEC-5)

Instructions: Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it happened to you personally; (b) you witnessed it happen to someone else; (c) you learned about it happening to a close family member or close friend; (d) you were exposed to it as part of your job (for example, paramedic, police, military, or other first responder); (e) you're not sure if it fits; or (f) it doesn't apply to you.

Be sure to consider your entire life (growing up as well as adulthood) as you go through the list of events.

| | Happened to me | Witnessed it | Learned about it | Part of my job | not sure | Doesn't apply |
|---|---|---|---|---|---|---|
| 1. Natural disaster (for example, flood, hurricane, tornado, earthquake) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. Fire or explosion | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. Serious accident at work, home, or during recreational activity | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. Exposure to toxic substance (for | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | | |
|---|---|---|---|---|---|---|
| example, dangerous chemicals, radiation) | | | | | | |
| 6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 9. Other unwanted or uncomfortable sexual experience | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. Combat or exposure to a war-zone (in the military or as a civilian) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | | |
|---|---|---|---|---|---|---|
| 12. Life-threatening illness or injury | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. Severe human suffering | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14. Sudden violent death (for example, homicide, suicide) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15. Sudden accidental death | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16. Serious injury, harm, or death you caused to someone else | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| 17. Any other very stressful event or experience | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Q13.1 Savings Inventory Revised (SIR)

For each question below, circle the number that corresponds most closely to your experience  DURING THE PAST WEEK.

| | 0 - none | 1 - a little | 2- A moderate amount | 3 - most / much | 4 Almost All/ Complete |
|---|---|---|---|---|---|
| 1. How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms). | ○ | ○ | ○ | ○ | ○ |
| 2. How much control do you have over your urges to acquire possessions? | ○ | ○ | ○ | ○ | ○ |
| 3. How much of your home does clutter prevent you from using? | ○ | ○ | ○ | ○ | ○ |
| 4. How much control do you have over your urges to save possessions? | ○ | ○ | ○ | ○ | ○ |
| 5. How much of your home is difficult to walk through because of clutter? | ○ | ○ | ○ | ○ | ○ |

Q13.2 For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

| | 0 - not at all | 1 - mild | 2 - moderate | 3 - considerable / severe | 4- extreme |
|---|---|---|---|---|---|
| 6. To what extent do you have difficulty throwing things away? | ○ | ○ | ○ | ○ | ○ |
| 7. How distressing do you find the task of throwing things away | ○ | ○ | ○ | ○ | ○ |
| 8. To what extent do you have so many things that your room(s) are cluttered? | ○ | ○ | ○ | ○ | ○ |
| 9. How distressed or uncomfortable would you feel if you could not acquire something you wanted? | ○ | ○ | ○ | ○ | ○ |
| 10. How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter. | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 11. How strong is your urge to buy or acquire free things for which you have no immediate use? | ○ | ○ | ○ | ○ | ○ |
| 12. To what extent does clutter in your home cause you distress? | ○ | ○ | ○ | ○ | ○ |
| 13. How strong is your urge to save something you know you may never use? | ○ | ○ | ○ | ○ | ○ |
| 14. How upset or distressed do you feel about your acquiring habits? (how much you buy/ collect / save) | ○ | ○ | ○ | ○ | ○ |
| 15. To what extent do you feel unable to control the clutter in your home? | ○ | ○ | ○ | ○ | ○ |
| 16. To what extent has your saving or compulsive buying resulted in financial difficulties for you? | ○ | ○ | ○ | ○ | ○ |

Q13.3 For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK

| | 0 - never | 1- rarely | 2 - sometimes / occasionally | 3- frequently / often | 4 - very often |
|---|---|---|---|---|---|
| 17. How often do you avoid trying to discard possessions because it is too stressful or time consuming? | ○ | ○ | ○ | ○ | ○ |
| 18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things? | ○ | ○ | ○ | ○ | ○ |
| 19. How often do you decide to keep things you do not need and have little space for? | ○ | ○ | ○ | ○ | ○ |
| 20. How frequently does clutter in your home prevent you from inviting people to visit? | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need? | ○ | ○ | ○ | ○ | ○ |
| 22. To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc. | ○ | ○ | ○ | ○ | ○ |
| 23. How often are you unable to discard a possession you would like to get rid of? | ○ | ○ | ○ | ○ | ○ |

Q14.1 OCI-R

The following statements refer to experiences that many people have in their everyday lives. Select the answer that best describes how much that experience has distressed or bothered you during the past month.

| | 0- not at all | 1 - a little | 2 - moderately | 3- a lot | 4 - extremely |
|---|---|---|---|---|---|
| 1. I have saved up so many things that they get in the way. | ○ | ○ | ○ | ○ | ○ |
| 2. I check things more often than necessary. | ○ | ○ | ○ | ○ | ○ |
| 3. I get upset if objects are not arranged properly. | ○ | ○ | ○ | ○ | ○ |
| 4. I feel compelled to count while I am doing things. | ○ | ○ | ○ | ○ | ○ |
| 5. I find it difficult to touch an object when I know it has been touched by strangers or certain people. | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 6. I find it difficult to control my own thoughts. | ○ | ○ | ○ | ○ | ○ |
| 7. I collect things I don’t need. | ○ | ○ | ○ | ○ | ○ |
| 8. I repeatedly check doors, windows, drawers, etc. | ○ | ○ | ○ | ○ | ○ |
| 9. I get upset if others change the way I have arranged things. | ○ | ○ | ○ | ○ | ○ |
| 10. I feel I have to repeat certain numbers. | ○ | ○ | ○ | ○ | ○ |
| 11. I sometimes have to wash or clean myself simply because I feel contaminated. | ○ | ○ | ○ | ○ | ○ |
| 12. I am upset by unpleasant thoughts that come into my mind against my will. | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| 13. I avoid throwing things away because I am afraid I might need them later. | ○ | ○ | ○ | ○ | ○ |
| 14. I repeatedly check gas and water taps and light switches after turning them off. | ○ | ○ | ○ | ○ | ○ |
| 15. I need things to be arranged in a particular way. | ○ | ○ | ○ | ○ | ○ |
| 16. I feel that there are good and bad numbers. | ○ | ○ | ○ | ○ | ○ |
| 17. I wash my hands more often and longer than necessary. | ○ | ○ | ○ | ○ | ○ |
| 18. I frequently get nasty thoughts and have difficulty in getting rid of them. | ○ | ○ | ○ | ○ | ○ |

Q15.1 Beliefs About Hoarding Questionnaire

The following list includes various beliefs which people sometimes hold about their possessions. Over the last two weeks, when you were thinking about your ordinary possessions or items, how much did you believe each of the ideas below to be true? Please read each statement and rate how much you believed these ideas at the time you were thinking about your possessions by placing a circle around the number on the line that most accurately applies to your belief. Do this by thinking of where it might lie between the ends of the scale shown below, from “I did not believe this idea at all” at one end through to “I was completely convinced this idea was true”.

Over the past two weeks when I was thinking about my ordinary possessions:

| | 0 - I did not believe this idea at all | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 - I was completely convinced this idea was true |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. I have to have this if there is even a very slight chance I will need it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 2. It would be disloyal to this item if I don't take care of it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3. Many of my possessions are linked to someone I care about, so it would be very distressing to lose them | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4. If I throw this away, it would be like losing part of myself | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5. If I throw this away, I'm throwing away an opportunity which could change my life | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 6. It is important to keep this to make sure that nothing bad happens | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 7. If something is free then it would be very upsetting not to have it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 8. This reminds me of someone I know so I can't let it come to harm | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 9. It feels exhilarating and very exciting to get new items to add to my things | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 10. I am responsible for finding a use for this item | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 11. To throw this away would be cruel to the object | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 12. This will cause someone harm unless I keep it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 13. If I throw this out, I might be crippled by regret if I ever need it in the future | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 14. This possession is my friend so I must keep it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 15. I have to have this item because I would have been grateful for it in the past | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 16. I see an importance in my possessions that others can’t see | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 17. If I throw this possession away, it will be upsetting because it's like throwing away a memory of my past | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 18. I would feel terrible if I got rid of this item because it would be wasteful to do so | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 19. If I get rid of this item it is like abandoning someone I love | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 20. I can see how valuable my possessions are although others can’t | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 21. If harm comes to this possession, that means that harm will come to the person connected to it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 22. I will be rejecting someone connected to this possession if I don’t look after it properly | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 23. I would be very upset if I didn’t keep something which might come in handy someday | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 24. I will throw this item out only when it feels completely right to throw it out | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 25. I cannot stand the idea that I would be blamed for not having something important even if it seemed ordinary at the time I got rid of it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 26. This possession will be hurt if I don’t take care of it | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 27. It will be upsetting if I throw this item out without | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| being sure it will be put to good use | | | | | | | | | | | |
| 28. I can't throw things like this away because it might cause harm to come to someone I care for | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |