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Keywords: emotionally unstable personality disorder, borderline personality disorder, caregiver, qualitative research.

Service Improvement Project

Background: Sexual intimacy difficulties are common in women with chronic gynaecological conditions (CGCs). Despite this, guidance on how to address sexual intimacy difficulties in this group is limited. Evidence suggests psychosexual interventions improve sexual function in those with CGCs and sexual intimacy difficulties. However, little is known about the views of women with CGCs on psychosexual support and how it can be improved. The main aim of this study was to understand patient views on how psychosexual support offered at a gynaecology department can be improved. **Methods:** A mixed-methods design was used for this service improvement project, which took place in an NHS acute hospital in the south of England. Twenty-four women aged 20-57 with CGCs and sexual intimacy difficulties completed an online survey; Eight participated in semi-structured interviews. Descriptive statistics were used to analyse quantitative data; Qualitative data were analysed using thematic analysis. **Results:** Ninety-two percent of participants said they would engage in psychosexual support. One-to-one support was ranked as most helpful. Qualitative accounts revealed five themes: ‘increase awareness’, ‘improve access’’, ‘one size doesn’t fit all’, ‘talking to others can feel unsafe’, and ‘let’s be in it together’. **Conclusions:** This study provides important insights into how psychosexual support for women with CGCs and sexual intimacy difficulties can be improved. The recommendations may be applied to similar settings to inform service improvement.

Keywords: sexual dissatisfaction, female sexual dysfunction, gynaecological condition, women’s health.

Theory Driven Research Project

Background: Hearing voices is widely stigmatised by society, which can affect one's readiness to identify as a voice-hearer. Research shows social identity has an important role in health outcomes in clinical populations. Specifically, integrating multiple distinct social identities into a coherent sense of self has been linked to improved psychological wellbeing in voice-hearers. Theory and research suggest internalised stigma might inhibit the integration process, whereas empathy from others may facilitate this process. **Objectives:** This study aims to explore the role of these factors in the social identity integration process for people who self-identify as voice-hearers. **Design:** A cross-sectional design was used, and three analyses were conducted. **Methods:** Seventy-six voice-hearers completed an online questionnaire assessing internalised stigma, social identity integration, perceptions of empathy from non-voice-hearers, paranoia, voice severity and depression. **Results:** An ANCOVA showed no significant difference in the degree of social identity integration between voice-hearers with high versus low levels of internalised stigma. A regression revealed perceptions of empathy from non-voice-hearers were significantly and positively associated with social identity integration. A hierarchical regression showed the overall model was significant, with covariates accounting for a significant amount of variance in social identity integration. Internalised stigma and perceptions of non-voice-hearer each contributed small amounts of variance, though these changes were not significant. **Conclusion:** These results extend beyond previous research and offer some preliminary support for the cognitive-developmental theory underpinning social identity integration processes. Further research is needed to enhance understanding.

Keywords: voice-hearer, social identity, internalised stigma.

Systematic Review of the Literature

Informal Caregiving Experiences of Family and Friends of People with Emotionally Unstable Personality Disorder: A Qualitative Systematic Review

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Proposed journal: This project is intended for submission to Personality and Mental Health and has been formatted in accordance with the guidelines (Appendix A1). This journal has been selected due to its focus on research related to personality disorders and its status as a peer-reviewed, open access publication.

Conflict of interest: No conflict of interests declared.

Abstract

Living with Emotionally Unstable Personality Disorder (EUPD) can impact on the life of the individual and those around them. Family and friends of people with EUPD often adopt an informal caregiver role. Research shows that informal caregivers of people with EUPD can themselves experience mental health difficulties and high burden. Cross-cultural studies highlight differences in informal caregiving experiences for other carer groups, but cultural differences have not yet been considered in this population. This review aimed to synthesise what is known about experiences of informal caregiving by family and friends of people with EUPD, including a consideration of potential cultural variation. PsycINFO, CINAHL, MEDLINE and EMBASE databases were searched in March 2025. Qualitative, peer-reviewed studies that explored informal caregiving experiences of family and friends of people with EUPD were included. The CASP Qualitative Studies Checklist was used to assess methodological quality. Data was analysed using thematic synthesis. Nine studies published since 2008 from across six countries were retrieved. All were rated as medium-to-high quality. Thematic synthesis resulted in five themes: ‘relentless roles and responsibilities’, ‘the all-encompassing impact of caregiving’, ‘facing stigma, blame and misunderstanding’, ‘drawing on self and others to cope’, and ‘navigating the healthcare system’. This review highlights the challenges faced by informal caregivers of people with EUPD. Implications for research and clinical practice are discussed, particularly in the currently under-explored area of cultural differences in caregiving experiences.

Keywords: emotionally unstable personality disorder, borderline personality disorder, caregiver, qualitative research.

Introduction

Emotionally Unstable Personality Disorder (EUPD or Borderline Personality Disorder) is characterised by difficulties managing affect, identity and interpersonal relationships alongside patterns of reckless, impulsive and/or harmful behaviours (Leichsenring et al., 2023). EUPD has a lifetime prevalence of 0.7-2.7%, increasing to up to 22% in inpatient psychiatric services (Leichsenring et al., 2024). Comorbid presentations are common, including mood disorders (Fornaro et al., 2016), eating disorders (Sansone et al., 2004) and substance use (Trull et al., 2018). Therefore, living with EUPD can have a significant impact across different life domains for the individual.

Research shows that family members living with a relative with EUPD also experience significant emotional strain and conflict within family relationships (Guillén et al., 2021; Lawn & McMahon, 2015). They are also known to experience blame, discrimination and/or social stigma from others due to their loved one's behaviours (Meshkinyazd et al., 2021). Family interactions have been noted to have a central role in the development and maintenance of EUPD (Crowell, 2016; Crowell et al., 2009; Fitzpatrick et al., 2023; Fonagy & Bateman, 2008; Fonagy et al., 2000). Specifically, disrupted attachment relationships and invalidating family environments in childhood are thought to contribute to the development of EUPD, and high levels of expressed emotion and poor mentalising abilities in others can exacerbate interpersonal conflict and emotional reactivity in people with EUPD (Crowell, 2016; Crowell et al., 2009; Fitzpatrick et al., 2023; Fonagy & Bateman, 2008; Fonagy et al., 2000).

Informal Caregivers

Due to the significant impact of living with EUPD, family members and friends of people with EUPD often find themselves in an informal caregiver role. The Department of Health and Social Care has defined an informal carer as “someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction” (The United Kingdom’s Government, 2018). The responsibilities of informal caregivers vary widely, though typically include personal care, and/or social, emotional, financial, spiritual or practical support (Carers Week, 2023).

Research shows that many people in informal caregiving roles do not self-identify as a caregiver (Carers Week, 2023). Several reasons for this have been identified, including cultural values, the depersonalisation of the relationship between the caregiver and their loved one, the view that caregiving responsibilities are part of their role as a family member or friend, and/or the amount or type of care provided is seen by the caregiver as insufficient (Carers Week, 2023; Eifert et al., 2015). As such, there are likely many ‘hidden caregivers’ who are at risk of going undetected by services and unaware and/or unable to access the practical and financial support they are entitled to that can help reduce the known mental, physical and financial impacts of informal caregiving (Smith et al., 2014).

Research shows that informal caregivers of people with EUPD report high levels of carer burden, grief and mental health difficulties (Bailey & Grenyer, 2015; Fonseca-Baeza et al., 2023), with some studies finding that these levels are significantly higher in this group when compared with other carer groups (Bailey & Grenyer, 2014; Seigerman et al., 2020). “Caregiver burden” in the literature

describes “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time” (Liu et al., 2020). Less research has identified the positive aspects of caregiving experienced by informal caregivers of people with EUPD. However, reported benefits for caregivers include motivation to be self-determined, reconnect with their loved one and provide empowered care (Kay et al., 2018).

Cultural Considerations

Importantly, studies on informal caregiving consistently report differences in the experience of caregiving and associated level of burden across cultures (Calderón & Tennstedt, 1998; Knight et al., 2000; Pharr et al., 2014). A recent meta-ethnographic review involving informal caregivers from a range of ethnocultural backgrounds identified key themes in informal caregiving motivations, including family roles and duty, social expectations, reciprocity and spirituality (Zarzycki et al., 2022). Specifically, the results highlighted that these themes were rooted in and strongly influenced by caregivers’ cultural self-identity, which shaped their perceptions of responsibility and caregiving practices. Additionally, cultural factors have also been found to influence caregiver’s help-seeking behaviours and engagement with professional support (Knipping et al., 2023; Mohamad et al., 2013; Nguyen et al., 2022). Understanding this is important, particularly in western contexts where culturally diverse informal caregivers have been found to encounter unique systemic barriers in relation to accessing support for either themselves or on behalf of their loved one (Knipping et al., 2023). Whilst there is a lack of research explicitly investigating cultural variation in the experience of informal caregiving in EUPD, insights from the broader literature highlight the importance of considering

the influence and emergence of cultural factors in understanding caregiving experiences within this population.

Caregiver Stress Theory

Lazarus and Folkman (1984) “stress-appraisal-coping” model is often applied to investigate caregiver stress and burden (Bora et al., 2017; Wei et al., 2022). Szmukler et al. (1996) adapted the model to provide a “stress-coping” model of caregiving for caregivers of people with mental health conditions (Appendix A2). Szmukler et al. (1996) suggests the caregiver experience will ultimately be determined by how a caregiver appraises their caregiving situation. Stressors (e.g. caregiving demands) are appraised by the caregiver, which is influenced by a range of mediating factors (e.g. social support, financial resources). Outcomes related to a caregiver’s health, wellbeing and functioning are the result of an interaction between the appraisal and the caregiver’s coping strategies. Whilst these models are typically used to investigate caregiver burden and stress, the model accounts for individual differences in caregiving experiences.

Socio-cultural stress coping models of caregiving (Knight & Sayegh, 2009; Knight et al., 2000) adapted from the original model (Lazarus & Folkman, 1984) propose that this is due to the influence of cultural values on caregivers appraisals and coping styles and/or resources. For example, non-western cultures that emphasise familism over individualism might perceive informal caregiving as less burdensome due to beliefs about family roles and the importance of interdependence and have access to more social support, both of which would influence the experience and outcomes for the caregiver (Aranda & Knight, 1997).

Related Reviews

Bailey and Grenyer (2013) systematically reviewed the experience of caregivers of people with EUPD and found reports of significant caregiver burden, reduced quality of life and need for support. Since then, a range of family and caregiver interventions have been developed and tested (Bateman & Fonagy, 2019; Guillén et al., 2024; Pearce et al., 2017). Several reviews have investigated the effects of such interventions on patient, family and/or caregiver related outcomes (Fitzpatrick et al., 2019; Fossati & Somma, 2018; Guillén et al., 2021; Sutherland et al., 2020), showing improved patient engagement and family function and reduced caregiver burden and distress.

Whilst these reviews offer some helpful insights into the needs of informal caregivers of people with EUPD and useful interventions, they focus on quantitative outcomes and intervention studies only. As such, qualitative studies that explore detailed accounts of informal caregiving experiences are missed, thereby limiting the depth of understanding. Other reviews have explored qualitative experiences of those close to people with EUPD, though this has been limited to broader experiences of romantic partners (Greer & Cohen, 2018) or focused on family and caregiver experience of services or crisis care, specifically (Acres et al., 2019; Lamont & Dickens, 2021). Therefore, the proposed review will address the identified gap and add to understanding by synthesising qualitative data on the informal caregiving experiences of family and friends of people with EUPD across different cultures.

The current study is a systematic review of the qualitative literature exploring informal caregiving experiences of family and friends of people with EUPD. The review aims to answer the following questions:

1. What is known about experiences of informal caregiving by family and friends of people with EUPD?
2. How is informal caregiving experienced by family and friends of people with EUPD across different cultures, and are there any differences?

Methods

The qualitative review was pre-registered on Prospero (registration number: CRD42024554194) and adhered to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ; Tong et al., 2012) guidelines.

Study Eligibility

The SPIDER tool was used to determine study eligibility (Cooke et al., 2012). The eligibility criteria applied are outlined below:

Inclusion

- Studies where participants were family members or friends of a person with an EUPD diagnosis, and who met The Department of Health and Social Care definition of an informal caregiver (see above).
- Studies where participants were from all cultural, racial and social class backgrounds.
- Qualitative or mixed methods studies that explored experiences of informal caregiving and/or related caregiving themes (based on the Szmukler et al. (1996) and Knight and Sayegh (2009) models of caregiving).
- Full text available in English.

- Article published in a peer-reviewed journal.

Exclusion

- Studies where participants were paid/professional caregivers.
- Studies where the participants and/or the care recipient was aged 18 years and under.
- Studies investigating the experience of living with or having a relative or friend with EUPD where the experience of informal caregiving was not explored.
- Quantitative only studies, protocols, case studies and other reviews.
- Intervention studies, where the experience of receiving an intervention is the focus (i.e. caregiver experience of a carer intervention, or their perspectives on their loved one's experience of an intervention).
- Grey literature.

Search Strategy

A pre-planned comprehensive search strategy was designed to seek all available studies related to the topic. Search terms were developed by reviewing the titles of published qualitative research and similar systematic reviews on the topic. The final search strategy included variations of terms related to EUPD, caregivers and qualitative methodology and were combined using Boolean operators:

1. ("borderline personality disorder" OR BPD OR "emotionally unstable personality disorder" OR EUPD)

2. (family OR families OR relative* OR husband OR wife OR partner* OR spouse OR brother OR sister OR sibling* OR mother OR father OR parent* OR grandparent* OR uncle OR aunt* OR carer* OR caregiver* OR caregiving)
3. (qualitative OR interview* OR phenomenological OR narrative OR focus group)
4. 1 AND 2 AND 3

The first reviewer carried out searches across PsychINFO, CINAHL, MEDLINE and EMBASE in March 2025. No exclusion fields were applied. After the final list of included studies were identified, the first reviewer carried out forward and backward citations searching to identify potentially eligible studies not captured in the database searches. No further eligible studies were identified.

Screening

The combined database searches retrieved 2241 records. After 1086 duplicates and 23 non-English records were removed, 1132 studies remained. Titles and abstracts of 25% of studies were independently screened by two reviewers (AB and AL). Inter-rater agreement was excellent (Cohen's kappa 0.85). Disagreements were resolved through discussion, and the first reviewer completed this stage. Thirty percent of the selected full texts were independently screened by the same reviewers. Inter-rater agreement was perfect (Cohen's kappa 1). The first reviewer completed full text screening for the remaining studies.

Quality Assessment

The Critical Appraisal Skills Programme (CASP, 2018) Qualitative Studies Checklist tool was applied to all studies included in the review to assess quality. This tool was selected due to its suitability and flexible applicability across different qualitative methodologies. Studies were given a score to denote their methodological strength. A grading system adapted from Babb et al. (2022) was used to determine ‘high’, ‘medium’ and ‘low’ quality studies. Studies were not excluded based on their quality, however, the appraisal process provided detail on the methodological strengths and limitations of each study which were considered when findings were synthesised. Thirty percent of the selected studies were independently appraised by two reviewers (AB and AL). Inter-rater agreement was excellent (Cohen’s kappa .86). Disagreements were resolved through discussion. The first reviewer completed this stage for the remaining studies.

Data Extraction

Two reviewers (AB and AL) independently extracted study characteristics from 50% of the included studies using Microsoft Excel. Inter-rater agreement was near perfect (Cohen’s kappa 0.97). Discrepancies were resolved through discussion between reviewers. The first reviewer (AB) extracted study characteristics from the remaining studies and all research findings. This included key themes, participant quotes and author interpretations in the results that related to the experience of caregiving, according to the Szmukler et al. (1996) and Knight and Sayegh (2009) models of caregiving. A second reviewer (AL) independently checked the extracted findings for accuracy and completeness for 50% of the studies. No discrepancies were found.

Data Synthesis

Thomas and Harden's (2008) thematic synthesis approach was used to synthesise the findings. This methodology was chosen as it is a commonly used in healthcare reviews that address people's perspectives and experiences, and it enables higher order analytical insights to be developed to contribute new understandings (Thomas & Harden, 2008). The first reviewer imported extracted findings into NVivo (version 14) for inductive line-by-line coding. Next, concepts were translated from one study to another by reviewing the similarities and differences between codes across studies. Codes were organised into a hierarchical tree structure to create descriptive themes. Descriptive themes were then organised into higher-order analytical themes, which were identified based on perceived salience to the research aims. To enhance credibility and reduce bias, a second reviewer (EK) reviewed a subset of the transcripts and was involved in the refinement of codes and theme development.

Reflexivity Statement

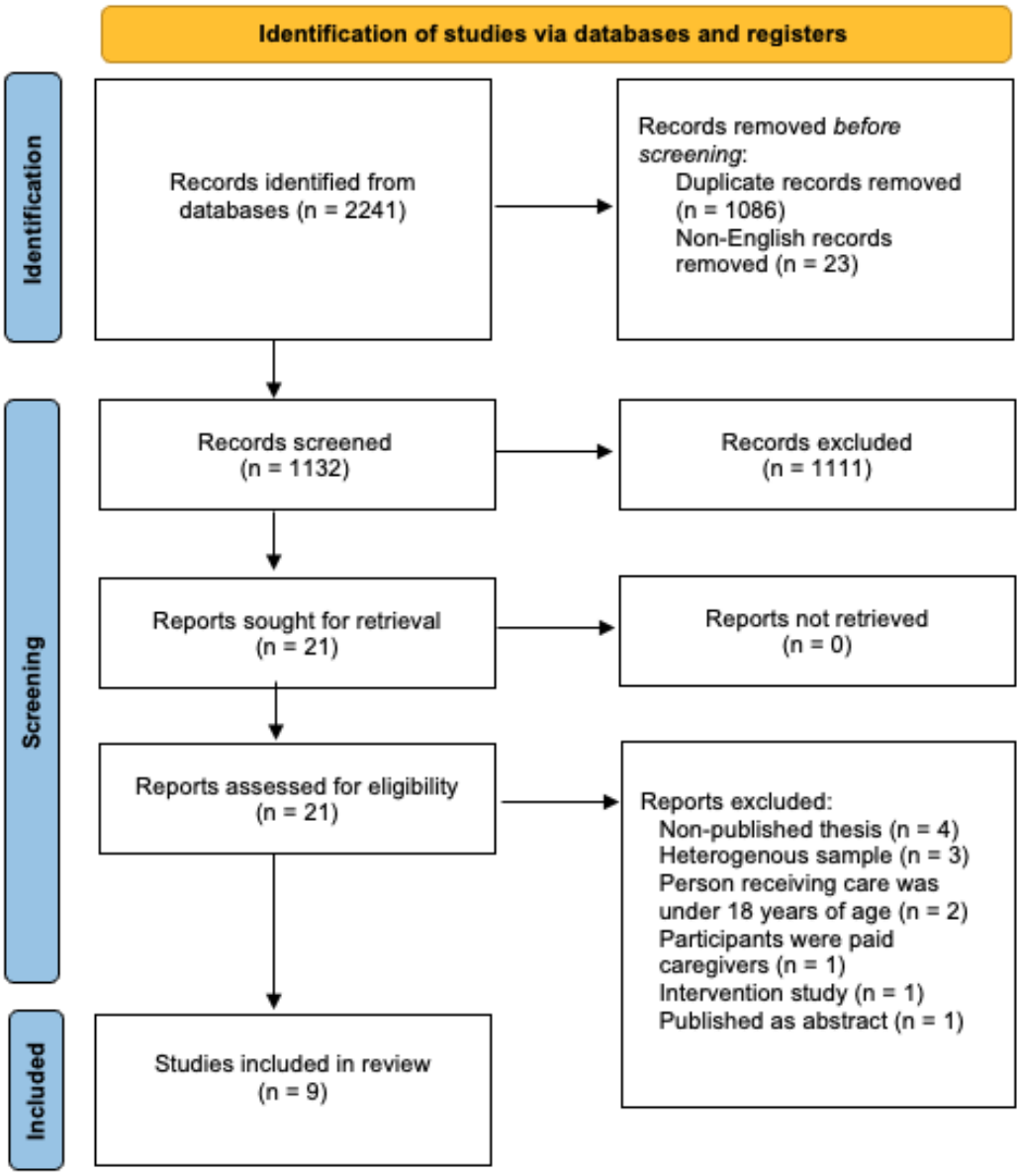
The lead researcher (AB) has previous personal caregiving experience for family members with physical health conditions, and professional experience of supporting family members caring for a loved one with a diagnosed mental health condition. EK does not have personal caregiving experience, but has previously worked with the parents of young people with significant mental health challenges.

Results

Nine eligible studies reporting on eight datasets were identified for the review (see Figure 1). In line with ENTREQ guidelines, The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Page et al., 2021) has been used to outline the selection process for transparency.

Figure 1

The PRISMA Flow Diagram for Study Selection



Study Characteristics

The extracted characteristics for the selected studies are presented in Table 1**.**

Table 1

Characteristics and Quality Appraisal of Included Studies

Authors and date	Location (country, context, study setting)	Aim and research question/s	Sample (N, age (range and mean), gender, ethnicity, relationship, recruitment method)	Method and design (methodology, method, analysis)	Author reflexivity	CASP score
Buteau, Dawkins & Hoffman (2008)	USA Non-healthcare service	To learn directly from family members what their experiences have been in four key areas: knowledge about BPD, BPD treatments, coping with BPD, reasons for hope. Research question/s not specified	12 participants Age not reported 2 males 10 females Ethnicity not reported 9 parents 1 legal guardian 1 spouse 1 sibling Recruitment method not specified	Qualitative, cross-sectional Methodology not specified Individual semi-structured interviews (60 minutes) Approach to analysis not specified	Role and potential bias not considered	5.5/10 medium
Caluza, Poggenpoel, Myburgh & Ntshingila (2023)	South Africa Johannesburg Inpatient service	To understand the lived experiences of family members who have a sibling with BPD to make recommendations for promoting family members' mental health. Research question/s not	7 participants Range: 22-49 years Mean: 30 years 4 males 3 females Ethnicity not reported	Qualitative, cross-sectional Phenomenological Individual semi-structured interviews (37.9-55 minutes) Observations Field notes Colaizzi's	Role given but potential bias not considered	9.5/10 high

		specified	4 brothers 3 sisters Purposive sampling	descriptive phenomenological method of analysis		
Dunne & Rogers (2013)	England Rural East of England Community service	To explore carers' experiences of the caring role, mental health and community services. Research question/s not specified	8 participants Age not reported 5 males 3 females Ethnicity not reported 4 partners 3 parents 1 sibling Recruitment method not specified	Qualitative, cross-sectional Phenomenological Two focus groups Braun and Clarke's thematic analysis	Role and potential bias considered	7.5/10 medium
Ekdahl, Idvall, Samuelsson & Perseius (2011)	Sweden Non-healthcare service	Explore how significant others experience what it is like to live close to a person with BPD and how the significant others experience their encounter with health care in general and psychiatric care in particular. Research question/s not specified	19 participants Range: 43-75 years Mean: not reported 5 males 14 females Ethnicity not reported 17 parents 1 spouse 1 adult child Purposive sampling	Qualitative, cross-sectional Narrative Questionnaires Group semi-structured interviews (100-120 minutes) Burnard's content analysis	Role and potential bias considered	9/10 high
Giffin (2008)	Australia Victoria Inpatient service	To hear the voice of a small sample of family members who have an adult daughter or sister receiving treatment in Victorian mental health services for severe personality	4 participants Age not reported 1 male 3 females Ethnicity not reported	Qualitative, cross-sectional Grounded theory Individual interviews Glaser and Strauss' grounded theory	Role given but potential bias not considered	6/10 medium

		disorder featuring a chronic pattern of self-harm and suicidality. Research question/s not specified	3 mothers 1 father Recruitment method not specified			
Hultsjö, Appelfeldt, Wärdig & Cederqvist (2022)	Sweden Southern Sweden Inpatient service	To highlight experiences of being a family member of a person suffering from BPD and self-harming behaviour with access to brief-admission. Research question/s not specified	12 participants Range: 22-75 years Mean: 46 years 8 females 4 males Ethnicity not reported 5 mothers 3 sisters 3 husbands 1 close friend Purposive sampling	Qualitative, cross-sectional Phenomenological Individual interviews (30-75 minutes) Observation Dahlberg et al's descriptive phenomenological approach	Role not given but potential bias considered	8/10 high
Kay, Poggenpoel, Myburgh & Downing (2018)	South Africa Gauteng Inpatient service	To explore and describe the experiences of family members who have a relative diagnosed with BPD. What was the experience of family members who have a relative diagnosed with BPD?	8 participants Range: 24-74 years Mean: 48 years 4 males 4 females Ethnicity not reported 3 mothers 2 husbands 1 father 1 daughter 1 uncle Purposive sampling	Qualitative, cross-sectional Phenomenological Individual interviews Field notes Tesch's descriptive analysis	Role given but potential bias not considered	7/10 medium
Meshkinyazd, Bordbar & Heydari (2021)	Iran Mashad Inpatient service	To determine the lived experiences of family caregivers of patients with BPD of social	10 participants Range: 25-55 years Mean: not	Qualitative, cross-sectional Phenomenological	Role not given but potential bias considered	9/10 high

		stigma. Research question/s not specified	reported 4 males 6 females Ethnicity not reported Relationship to care recipient not reported Purposive and snowball sampling	Individual semi-structured interviews (40-80 minutes) Diekelmann, Allen and Tanner's interpretative method		
Meshkinyazd, Heydari & Bordbar (2020)	Iran Mashad Inpatient service	To explore the experiences of caregivers of patients with BPD by using an interpretive phenomenological approach. Research question/s not specified	10 participants Range: not reported Mean: 38.7 years 4 males 6 females Ethnicity not reported Purposive sampling	Qualitative, cross-sectional Phenomenological Individual semi-structured interviews (60-100 minutes) Diekelmann, Allen and Tanner's interpretative method	Role and potential bias not considered	8/10 high

Note. BPD = Borderline Personality Disorder

The studies were published between 2008 and 2023 across six different countries: USA (n = 1), England (n = 1), Australia (n = 1), South Africa (n = 2), Sweden (n = 2) and Iran (n = 2). See Table 1 for specific references. Two studies reported data from the same set of interviews but had different aims: Meshkinyazd et al. (2020) aimed to explore experiences of caregivers more broadly, whilst Meshkinyazd et al. (2021) aimed to examine caregivers' experiences of social stigma, specifically.

Six studies used a phenomenological methodology, one study used a narrative approach, and one used a grounded theory approach. One study did not

specify a specific qualitative methodology. Eight studies collected data from interviews. Of these, one study also used a questionnaire; another study also used observations. One study collected data from two focus groups. See Table 1 for specific references.

The total number of participants across the 9 studies was 90, ranging from 4 to 19. Participants' age ranged from 22 – 75 years and 63.3% (n = 57) of participants were female. The type of relationship between each participant and recipient of care was not detailed for two studies (Meshkinyazd et al., 2021; Meshkinyazd et al., 2020). Across the seven studies that reported this information, there were: 42 parents, 11 partners or spouses, 12 siblings, two adult children and one legal guardian, one uncle and one close friend. Only two studies reported demographic information of the care recipient, though detail was limited (Giffin, 2008; Kay et al., 2018).

Methodological Quality

Overall, 5 studies were rated as 'high' quality (CASP score ≥ 8) and 4 were rated as 'medium' quality (CASP scores 4.5-7.5). See Table 1 for each study's score. No studies were assed as being 'low' quality (CASP scores ≤ 4).

Notable areas of strengths included studies having a clear statement of aims, appropriate use of qualitative methodology and design and consideration of ethical issues, though some studies lacked sufficient detail to fully assess whether ethical standards were maintained. Further, studies offered a clear statement of findings and discussion about the value of the research regarding contribution to practice, however, areas for new research and transferability of results were not always considered.

Whilst most studies outlined the sampling approach used, three did not, and authors offered limited discussion around recruitment. Similarly, the data collection setting and method was named across studies but occasionally studies lacked depth in their descriptions and justification of decisions made. Many studies provided descriptions of their analysis process, though authors rarely critically examined their role and the potential for bias during the analysis and interpretation of results, and there was a lack of transparency and detail regarding the relationship between the researchers and participants throughout the research process.

Analytical Themes

Five inter-connected themes relating to the experience of caregiving were identified: ‘relentless roles and responsibilities’, ‘the all-encompassing impact of caregiving’, ‘facing stigma, blame and misunderstanding’, ‘drawing on self and others to cope’ and ‘navigating the healthcare system’. Each theme is described in more detail below. Across the included studies, there was a lack of data explicitly related to cultural influences or differences in caregiving, or that could be implicitly identified.

Theme One: Relentless Roles and Responsibilities

This theme captures what caregivers perceived as the non-stop nature of informal caregiving that is characterised by their descriptions of needing to be constantly vigilant to respond to the many unyielding duties and demands of caregiving. Caregivers appeared to switch between many unofficial roles (e.g. crisis responder, financial supporter, advocate) whilst seemingly trying to assimilate their

caregiving role into the role they had in their original relationship with their loved one.

Across studies, caregivers experienced the caregiving role as having no clear boundaries which they felt was accompanied by a sense of obligation to constantly be on hand to respond and support their loved one (*"It's us that have to deal with it 7 days a week"* (Dunne & Rogers, 2013)). Caregivers outlined a range of emotional, social and practical support they provide their loved one whilst appearing to navigate their volatile emotions and life-threatening or reckless behaviours *("My experience started when my wife was scratching (self-mutilating) and later cut her wrist. She was overwhelmed by stress. She had relapses and tried to overdose on medication"* (Kay et al., 2018)). Caregivers often described needing to take a considered or cautious approach in their interactions with their loved one so to avoid triggering conflict or distress *("We therefore need to have a strategy around how we approach her"* (Caluza et al., 2023)).

In addition to supporting their loved one's emotional needs, caregivers appeared to take on various practical responsibilities as part of caregiving, including being a healthcare advocate, sourcing suitable accommodation and providing financial support *("…You get a name [of a therapist/treatment facility] and call them. And they say, well, why don't you call this place? And we call them, and they say call this other place"* (Buteau et al., 2008)). Whilst taking on to the many caregiving demands and responsibilities, caregivers described a process of adjustment that involved integrating their caregiving role into their pre-existing relationship with the person they care for, which appears to influence how they appraise their caregiving role. For example, partners view caregiving as an extension of their role as a partner, whereas parents view their support as going above and beyond what is

typically expected of them (*"I've chosen that person and that's what comes with the baggage if you like"*, *"I'm doing a lot more than a mum would do probably for another nineteen-year-old"* (Dunne & Rogers, 2013)).

Theme Two: The All-Encompassing Impact of Caregiving

This theme reflects participants' perceptions of the many ways in which caregiving appeared to impact on their lives. Caregivers across studies described how caregiving directly impacts on the way they live their lives, their emotional and physical wellbeing, and their social connections and financial sustainability.

Caregivers appeared to feel as though being a caregiver had inherently changed them as an individual and affected the way they were able to live their lives (*"I don't think you're the same person in many ways that you were before"* (Dunne & Rogers, 2013)). Caregivers described experiencing difficulties with being able to manage other aspects of their lives and carry out non-caregiving related activities (*"It is difficult to make everyday life go together with children, job, finances"* (Hultsjo et al., 2023)) and many felt that their relationships with others were often deprioritised and neglected (*"I can't do my maternal and spouse duties well. I get caught by this patient*" (Meshkinyazd et al., 2020)).

Beyond this, caregivers seemed to experience a significant emotional burden of caregiving and described feeling trapped and weighed down (*"I just feel like I'm drowning, and there's not a ship or a life preserver or anything in sight."* (Buteau et al., 2008)). Feelings of powerlessness and helplessness appeared to permeate caregivers' experiences of supporting their loved one, and they often expressed

feelings of worthlessness and underappreciation ("*I've come to a place where I feel absolutely worthless*" (Kay et al., 2018)).

Caregivers also reported feelings of uncertainty, worry and fear which they attributed to the unpredictable and extreme nature of their loved ones struggles ("*… you wonder what in the hell you're going to find in the morning when you wake up*" (Giffin, 2008)). Some caregivers described how responding to their loved one's crises appeared to have ongoing and lasting effects on their psychological wellbeing ("*She's cut herself to ribbons, strangled herself. I've had to go in there and mop the blood up. I can still see it, blood everywhere, all over the place and the smell of it. I cannot get the smell out of my nose*" (Giffin, 2008).

Overall, participants expressed the emotional toll left them feeling drained, exhausted and at breaking point *("But I'm so weary; I don't want to cope any more"* (Buteau et al., 2008)) and some described being unable to take interest or experience joy in their lives *("I have no interest in life anymore. I think I'm so involved in the problems that I am not happy about anything"* (Meshkinyazd et al., 2020)). In addition to this, some participants reported physical symptoms that they believed were due to the emotional strain of caregiving (*"For about the last three months I have felt so nauseated, I just think it's emotional ..."* (Giffin, 2008)).

In addition to the emotional and physical burden, caregivers also described a financial impact of caregiving (*"We are not in a good, i.e. economical situation in our lives; we have problems with our normal living expenses"* (Meshkinyazd et al., 2020)). Further, caregivers appeared to experience difficulties with taking on paid work due to the demands of caregiving, which they felt contributed to financial strain (*"We've got less money coming in as I don't work…"* (Dunne & Rogers, 2013)).

Theme Three: Facing Stigma, Blame and Misunderstanding

This theme reflects caregivers' perceptions of negative responses they experienced from those around them (including friends, family and healthcare professionals) which they felt were related to their loved one's diagnosis of EUPD. Across studies, caregivers shared their experiences of being judged, criticised, blamed and misunderstood by others and described their difficulties with this.

Participants sometimes expressed finding it difficult to talk to family and friends about their experiences of caregiving, due to a perceived lack of awareness and understanding of EUPD (*"So often family can't understand so even if you're close to your own family, it's very difficult''* (Dunne & Rogers, 2013)). Further, caregivers appeared to experience others as holding stigmatising views towards their loved one (*"My relatives and acquaintances in any place saying that, this person is crazy"* (Meshkinyazd et al., 2021)) and described their experience of social rejection which they appeared to believe were linked to these views (*"…but since my son has been ill, my relatives are no longer the same as before. They no longer care about us, and they don't even invite us to parties"* (Meshkinyazd et al., 2020)).

Caregivers also talk about their experiences and perceptions of stigma from staff within healthcare services *("There's been a lot of stigma and a lot of unhelpful comments about 'it's just behaviour"* (Dunne & Rogers, 2013)). Specifically, parents in the caregiver role appear to experience criticism and blame from healthcare professionals which they attribute to being seen as responsible for their child's difficulties or for "mishandling" situations (*"The first thing they said to me was that they viewed it as, you know, because of non-maternal bonding"* (Buteau et al., 2008), *"You haven't succeed as a mother since your daughter is here [a treatment facility]"* (Ekdahl et al., 2011)).

The social interactions involving stigma and judgement from others appeared to not only be perceived negatively by caregivers but were also described as contributing a significant emotional strain (*"When I heard these words, I was overwhelmed. They humiliated me. In that situation, my face was flashed, and my blood pressure was going up. I was getting angry"* (Meshkinyazd et al., 2021)), which likely adds to the emotional burden caregivers experience in their role.

Theme Four: Drawing on Self and Others to Cope

This theme captures the many ways caregivers appear to cope with the demands and impact of caregiving, by seemingly drawing on a range of internal and external resources.

Caregivers describe relying on their own resilience, determination and mental strength to cope with their situation, and express feeling like they have no other choice but to cope (*"Well, there's that saying–that which doesn't kill you makes you stronger. And I do think I'm a pretty strong person, because I've had to be"* (Buteau et al., 2008)). Caregivers also appear to suppress their own thoughts and feelings to try and cope with their situation (*"I always had to put my decisions and my feelings aside because hers are more important…"* (Caluza et al., 2023)) and seem set boundaries for self-preservation (*"I need help to set limits and cope with her needs"* (Kay et al., 2018)).

Specifically, when faced with judgement and stigma from others, caregivers described using avoidant coping strategies (*"… when my husband was in a mental hospital, I didn't tell anyone"* (Meshkinyazd et al., 2020)). Whilst these strategies might be experienced by some caregivers as adaptive and helpful in the short term, over time they may contribute to a sense of social isolation and increased caregiver

burden and can therefore become unhelpful strategies if maintained in the long-term. Conversely, when caregivers do not experience stigma from those around them, they seem to find it useful to turn to family and friends for emotional and practical support which appears to help them feel less alone in their struggles *("We call each other in the family; not everyone feels as bad all the time. An older sister can say that she is so angry with her right now, why can't they just lock her up what is she doing, what has she done to herself, I am going insane! Then I can calm her down; next time it may be me who is angry…"* (Hultsjo et al., 2023)).

Caregivers also found that accessing support from professionals and peers helped them cope. Specifically, caregivers expressed interest in engaging in caregiver support as they seemed to want to develop their knowledge and skills in their role as a caregiver and connect with others in similar situations (*"I would like to complete the parenting programme, to show me how to help her"* (Kay et al., 2018), *"… just having the support is such a weight lifted off when you know you're not dealing with it completely alone…"* (Buteau et al., 2008)). Caregivers also appear to access professional support to cope with the effect caregiving has on their own wellbeing (*"Every two weeks I see a nurse at the psychiatric clinic, just to cope…"* (Hultsjo et al., 2023)). Further, caregivers also reported that the professional support offered to their loved one seems to help them cope, as they found it helped alleviated some of the pressure they face and provided them respite from the day-to-day duties and stressors of caregiving (*"I think that this tool, BA [brief admission], could help make everyday life work instead of the horrible existence that it sometimes is"* (Hultsjo et al., 2023)).

Theme Five: Navigating the Healthcare System

This theme reflects caregivers' experiences of the healthcare system and professionals within it. Caregivers describe their perceptions of their loved one's care and discuss their experience of involvement, as well as their impression of professionals failing to recognise their needs as caregivers.

Caregivers expressed a sense of hope and security which they attributed to the availability of suitable treatment and professional support ("*It is a security with BA for me as a relative"* (Hultsjo et al., 2023)). However, caregivers often appeared to hold negative perceptions of the support their loved one receives ("*I think the care is fragmented when someone is inpatient"* (Buteau et al., 2008)) and they described their struggle to seemingly trust healthcare professionals to adequately care for their loved one and keep them safe ("*My God, she is hospitalized because she has tried to kill herself and then they give her leave and what does she do [new suicide attempt at leave] and when can I relax then, I feel?"* (Ekdahl et al., 2011)).

Across studies, caregivers expressed feeling unrecognised, uninvolved and dismissed by healthcare professionals ("*I find the system also has no idea what a carer is…"* (Dunne & Rogers, 2013), "*One out of fifty [professionals] has seen me, I believe…"* (Ekdahl et al., 2011)). When caregivers were involved in their loved one's care, they described feeling unheard and ignored "*I also feel that quite often CPA's are merely tick boxes … they're not really listening to carers' views"* (Dunne & Rogers, 2013)).

Caregivers expressed a desire for more recognition and involvement in their loved one's care *("Call rather one time to much then one too less, we want to help, we exist!"* (Ekdahl et al., 2011)) and appeared to want more guidance, support and information from healthcare professionals to feel empowered and supported in their

role (*"… as far as what I've come across, there is not much information about what to do to help"* (Buteau et al., 2008)).

Discussion

This qualitative review aimed to explore what is known about experiences of informal caregiving by family and friends of people with EUPD and investigate whether there are any differences across cultures. The review synthesised nine qualitative studies across six countries published since 2008. All studies were of medium-high quality. Despite the cross-cultural scope of this review, the qualitative data from the original studies did not explicitly address cultural factors and it was not felt possible to infer implicit cultural differences as part of the analysis. Therefore, we were unable to directly address the second aim of this review. The limitations of this and inferences about the potential role of cultural context in relation to the experience of informal caregiving are discussed below, as part of the broader discussion of the review's findings and limitations.

Interpretation of Results

This review emphasises caregivers' experience of the complex, multifaceted nature of providing care to a loved one with EUPD and highlights the ways in which caregiving appeared to impact across various domains of their lives. The theme 'Relentless Roles and Responsibilities' captures caregivers' perceptions of the non-stop and extensive responsibilities they appear to take on by switching between many unofficial roles, whilst seemingly attempting to integrate their caregiver role into their pre-existing relationship. These findings add important nuance to our

understanding of the adjustments and transitions informal caregivers appear to experience whilst meeting their caregiving demands, and is consistent with findings from a recent qualitative study on paid and unpaid family/friend caregivers of people with EUPD (Murray et al., 2025).

As captured by the theme ‘All-Encompassing Impact of Caregiving’, caregiving appeared to influence caregivers’ sense of identity, which is perhaps partly due to the sacrifices made in other areas of their lives, and caregivers reported experiencing a direct negative impact on their emotional, psychological, physical, social and financial wellbeing. These findings extend previous quantitative studies by providing a deeper insight into the caregiver experience of the seemingly multifaceted impact of caregiving for this group, and complements studies that show caregivers of people with EUPD experience higher levels of burden compared to other carer groups (Bailey & Grenyer, 2014; Seigerman et al., 2020). Caregivers’ experience of negative responses from others, captured by the theme ‘Facing Stigma, Blame and Misunderstanding’, most likely contribute to the level of burden experienced by this carer group. Specifically, parent caregivers in this review reported experiences of blame and criticism for their role in their loved one’s struggles. This finding is consistent with other research (Klein et al., 2022) and might be a product of societal stigma and reductionist views held about the aetiological understanding of EUPD (Ociskova et al., 2023). Therefore, this could be a unique experience for this carer group, though more research is needed.

The theme ‘Drawing on Self and Others to Cope’ highlights the many internal and external strategies and resources caregivers report using to try and cope with their demands. This aligns with established caregiver coping-stress models, which suggest caregivers use both various emotion-focused and problem-focused

strategies (Lazarus & Folkman, 1984; Szmukler et al., 1996). Importantly, one way caregivers appear to cope is by accessing support, guidance and information from professionals in the healthcare system. However, caregivers' reported experiences of stigma within services and the theme 'Navigating the Healthcare System' captured caregivers' experiences of feeling overlooked and undervalued by staff. These findings are consistent with previous research (Bauer et al., 2012; Klein et al., 2022; Murray et al., 2025) and are important barriers to be addressed. The ways this could be done are considered in discussion of the clinical implications below.

Whilst cultural factors were not directly addressed in the findings of the primary studies, the existing literature and socio-cultural stress coping models of caregiving (Knight & Sayegh, 2009; Knight et al., 2000) provide a basis for drawing tentative inferences about the potential influence of culture on caregivers' experiences. For example, previous research has shown that caregivers' perceptions of their personal responsibility and obligation to provide care is influenced by cultural and societal norms, with some evidence suggesting that caregivers from more collectivist cultures report stronger familial obligations compared to those in more individualist cultures (Zarzycki et al., 2022; Zarzycki et al., 2024). In terms of the impact of caregiving, psychological related outcomes in caregivers are known to vary across countries and are thought to be influenced by a range of factors including access to formal support and the subjective meaning caregivers ascribe to their caregiving role, which is influenced by cultural values and norms (Zarzycki et al., 2024).

Additionally, research shows that caregiver coping styles tend to vary between cultures, with social-focused coping thought to be influenced by socio-cultural context (Rexhaj et al., 2016). For example, research suggests experiences

of stigma and/or fear of discrimination from others can influence help-seeking behaviours (Knipping et al., 2023; Mohamad et al., 2013). Given that attitudes towards people with mental health conditions are known to vary significantly across cultures (Ahad et al., 2023; Krendl & Pescosolido, 2020), experiences of stigma, judgement and social rejection might have been more pronounced for caregivers from cultures where mental illness is more stigmatised. Whilst experiences of stigma were reported in studies across different cultures, only one study directly explored experiences of stigma in depth (Meshkinyazd et al., 2021), and so cultural differences in the experience of stigma were not identified in the analysis. Finally, caregivers' experiences of professional support and barriers encountered are likely influenced both by differences in healthcare systems and service provision across countries, and variation in cultural perspectives and beliefs about illness and trust in services (Knipping et al., 2023; Nguyen et al., 2022).

Limitations

One noted limitation of the evidence included is the lack of consideration given to cultural context. This limits our understanding of how cultural factors might have influenced informal caregiving experiences and potential differences between cultures. Limitations of the review process may have contributed to this issue. Specifically, culturally specific terms were not included in the search strategy. Whilst this decision was made based on preliminary scoping searches that indicated such terms significantly reduced the number of studies retrieved and did not contribute additional relevant literature, this approach might have limited the systematic identification of studies that explicitly explored the influence of cultural on the caregiving experience. Further, the inclusion of only peer reviewed studies written in

English might have limited the geographic and cultural diversity of included studies. Whilst these criteria were applied to ensure accessibility and to uphold the methodological rigor and quality of studies included in the review, experiences of caregivers from other cultures might be under-represented and underexplored.

Another limitation was the lack of demographic reporting in the original studies, especially concerning the age of caregivers and recipients of care. Whilst steps were taken to mitigate this limitation (i.e. authors were contacted, eligibility criteria were revised to exclude studies involving caregivers and/or care recipients under the age of 18 years), we were unable to apply age-based inclusion criteria to ensure the results of review reflect experiences of the intended population (adult caregivers of adults with EUPD).

Further, there was the lack of consistency across studies in relation to the level of transparency and critical reflection given by researchers regarding their own role, perspectives and potential biases, and how this could have influenced the research process. Comprehensive reflexivity is essential in qualitative research, given that the findings are influenced by the interactions and relationships between the participants and researchers, as well as a range of individual and contextual factors (Shaw, 2010). Therefore, this makes it more difficult to assess for potential biases in interpretations and therefore assess the credibility and validity of the some of the results. In relation to the review process itself, it is important to note the potential for reviewer bias and subjectivity throughout the review, despite the steps taken to enhance transparency, credibility and rigor at different stages of the review.

Implications for Research and Clinical Practice

The findings of this review highlight implications for future research. Firstly, whilst theory and research from broader caregiver populations show caregiver experiences vary across cultures, this has not yet been extended to caregivers of people with EUPD. Research should aim to explicitly consider socio-cultural influences on the experience of informal caregiving in this carer group and recruit participants from across diverse cultures, including under-representative groups, to support understanding of potential cross-cultural differences. Specifically, studies could explore the role of cultural self-identity in relation to forming a caregiver identity, and how cultural values and norms influence caregiving motivations and access to informal support, which have been studied in other carer groups (Knipping et al., 2023; Mohamad et al., 2013; Nguyen et al., 2022; Zarzycki et al., 2024). Further, improved demographic reporting is required to strengthen the validity of results and conclusions drawn in any future reviews.

In relation to clinical implications, the results from this review highlight a need for caregivers to have more information, guidance and support from healthcare professionals within the services involved in their loved one's care to feel empowered in their role. Specifically, the findings suggest that caregivers experience high levels of stress and anxiety towards managing their loved one's intense emotions and risky behaviours and the perceived unpredictable nature of these. Therefore, professionals should proactively support caregivers by helping them to identify initial, perhaps more subtle signs of emotional and/or behavioural escalation for their loved one and offer practical guidance on how to use de-escalation skills to cope with crises, as well as information on the crisis support available to them. Further, caregivers of people with EUPD report feeling like they needed to "tiptoe" around their loved one to reduce conflict or distress.

Professionals should therefore also support caregivers to develop effective communication skills to improve caregivers' confidence in navigating the interpersonal challenges they face. Such guidance can be offered to caregivers as part of an evidence-based group (e.g. 'Family Connections'; Guillén et al., 2024) which can also enable caregivers to connect with others who share similar experiences and support them to develop ways of managing their own emotional responses to challenging behaviours. This is particularly important given the high level of emotional burden experienced by caregivers of people with EUPD included in this review and reported elsewhere (Bailey & Grenyer, 2014, 2015; Fonseca-Baeza et al., 2023).

Whilst this review did not explicitly identify cultural differences in the experience of caregiving from which clinical implications can be drawn, previous research on other caregiver groups suggests caregiver socio-cultural values, norms, beliefs and expectations can influence caregiver experiences and engagement with formal support (Knipping et al., 2023; Mohamad et al., 2013; Nguyen et al., 2022; Zarzycki et al., 2024). As such, it may be beneficial for services to promote cultural competence through the adaptation of future caregiver interventions to enhance accessibility and effectiveness in culturally diverse caregivers. However, more research is needed to explore this specifically in caregivers of people with EUPD.

Further, this review identified potential barriers to caregivers of people with EUPD accessing support and being involved in their loved one's care, including a limited awareness and stigmatising attitudes amongst healthcare staff. These potential barriers highlight the need for professionals to be trained to identify those in informal caregiving roles and to enhance their understanding of the challenges faced by informal caregivers of people with EUPD and the importance of their role in

the treatment process. Previous research shows caregivers from different cultural backgrounds face additional unique barriers to accessing formal support, including language barriers, mistrust in the healthcare system and lack of perceived cultural sensitivity amongst professionals (Knipping et al., 2023). Therefore, it would be beneficial for staff to receive both stigma reduction training to address potential misconceptions about EUPD and the role of family members, and training in cultural competence, to promote empathic, non-stigmatising interactions between staff, patients and caregivers, and to be better equipped to support caregivers from a range of diverse cultural backgrounds. Finally, the development of public awareness campaigns would support a reduction in stigma amongst the general public towards those with EUPD and their loved ones.

Conclusion

Overall, this review synthesised qualitative studies that explore the experiences of informal caregiving by family and friends of people with EUPD. Findings emphasise the multiple emotional, psychological, relational, systemic and practical challenges faced by informal caregivers and the burden of these, as well as the different ways caregivers adapt and cope. Future research should address the gap in the literature by exploring the role of cultural factors in relation to informal caregiving in this group. This review highlights important clinical implications for healthcare providers regarding the involvement and support of informal caregivers of people with EUPD.

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Service Improvement Project

How can the Psychosexual Support for Women with Chronic Gynaecological Conditions and Sexual Intimacy Difficulties be Improved in a Gynaecology Department?

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Proposed journal: This project is intended for submission to BMC Women's Health and has been formatted in accordance with the guidelines (Appendix B1). This journal was selected as it has an established reputation in the field of women's health research and is an open-access publication, facilitating wide access and dissemination of findings.

Conflict of interest: No conflict of interests declared.

Abstract

Background: Sexual intimacy difficulties are common in women with chronic gynaecological conditions (CGCs). Despite this, guidance on how to address sexual intimacy difficulties in this group is limited. Evidence suggests psychosexual interventions improve sexual function in those with CGCs and sexual intimacy difficulties. However, little is known about the views of women with CGCs on psychosexual support and how it can be improved. The main aim of this study was to understand patient views on how psychosexual support offered at a gynaecology department can be improved. **Methods:** A mixed-methods design was used for this service improvement project, which took place in an NHS acute hospital in the south of England. Twenty-four women aged 20-57 with CGCs and sexual intimacy difficulties completed an online survey; Eight participated in semi-structured interviews. Descriptive statistics were used to analyse quantitative data; Qualitative data were analysed using thematic analysis. **Results:** Ninety-two percent of participants said they would engage in psychosexual support. One-to-one support was ranked as most helpful. Qualitative accounts revealed five themes: ‘increase awareness’, ‘improve access’, ‘one size doesn’t fit all’, ‘talking to others can feel unsafe’, and ‘let’s be in it together’. **Conclusions:** This study provides important insights into how psychosexual support for women with CGCs and sexual intimacy difficulties can be improved. The recommendations may be applied to similar settings to inform service improvement.

Keywords: sexual dissatisfaction, female sexual dysfunction, gynaecological condition, women’s health.

Background

Chronic gynaecological conditions (CGCs) is a term used to cover a range of conditions that affect the female reproductive system for at least three months (1). Examples include polycystic ovary syndrome, endometriosis and chronic pelvic pain. Prevalence rates vary across studies and conditions. For example, the prevalence of endometriosis varies between 1-8%, whereas prevalence for chronic pelvic pain varies between 6.4-25.4% (2, 3). Women with CGCs are at greater risk of experiencing sexual intimacy difficulties, which includes sexual dissatisfaction and female sexual dysfunction (FSD; 4, 5). Sexual dissatisfaction is defined as a negative experience of sexual intimacy, due to lack of sexual pleasure or absence of feelings of connection and safety with another (6). FSD is defined as difficulties encountered in the sexual response cycle that deviates from a woman's normal range of functioning (7), and can be due to a lack of sexual desire, impaired arousal, inability to orgasm or pain with sexual activity (8).

Sexual intimacy difficulties in CGCs are transdiagnostic and appear unrelated to physical disease burden (9). High prevalence rates of sexual intimacy difficulties are seen across CGCs, including endometriosis (10, 11) polycystic ovary syndrome (12) and urogynaecological conditions (13). A complex, bi-directional relationship exists between sexual intimacy difficulties and psychological wellbeing (14, 15). Such difficulties are associated with poorer mental health, and impact negatively on one's self-esteem, identity and body image (14, 16, 17, 18).

Theory

A biopsychosocial approach can be used to understand the needs of patients with CGCs and sexual intimacy difficulties (Appendix B2; 19), as it allows for the consideration of relevant interacting biological (e.g. hormonal), psychological (e.g. self-esteem) and social factors (e.g. sexual relationships) which contribute to the development and maintenance of sexual dysfunction (20, 21). Researchers have highlighted the direct and/or mediating effect of psychological factors in sexual intimacy difficulties for women, including those with vaginismus (22), sexual desire and orgasm disorders (23, 24) and sexual dissatisfaction (25).

Treatment

In line with the theories above, the national guidelines recommend a multidisciplinary and biopsychosocial approach for the treatment of CGCs (26, 27, 28, 29). However, despite the high prevalence of sexual intimacy difficulties in CGCs and the known influence of various psychological factors, there is no clear guidance on how to address these in women with CGCs.

Psychosexual support is one way a patients' psychosexual difficulties might be addressed. Psychosexual interventions target a variety of factors (e.g. thoughts, emotions, behaviours, couple interactions) that contribute to sexual intimacy difficulties, with an aim to increase adaptive coping, decrease pain intensity and ultimately improve the quality of patients' sexual functioning (30). Different approaches are used in psychosexual interventions, including cognitive behavioural therapy, systemic approaches with couples and, more recently, compassion-focussed or mindfulness-based therapies (31).

Psychosexual interventions have been found to effectively improve sexual function and sexual wellbeing outcomes for women with sexual intimacy difficulties

and CGCs (32, 33). Further research addressing the efficacy of psychosexual interventions for women with CGCs is required.

Studies exploring patient experiences and perspectives of gynaecological care highlight that patients often report feeling as though their difficulties were dismissed or minimised and simply seen as “part of being a woman” (34, 35). Whilst such findings are discouraging, recent studies have explored patient perspectives on how gynaecological care can be improved (36, 37, 38). However, there is a paucity of literature exploring the views and perspectives of women with CGCs and sexual intimacy difficulties on psychosexual support, specifically.

Current Study

This service improvement project took place at the John Radcliffe Hospital’s Women’s Centre in 2024, where a range of specialist women’s reproductive health services are offered. Examples of services provided include a Fertility Clinic, Endometriosis Care Centre and Pelvic Pain Service. Anecdotal feedback from healthcare professionals across the department suggests a large proportion of patients they support experience sexual intimacy difficulties in the context of a CGC. However, the provision of psychosexual support for women with CGCs and sexual intimacy difficulties varies between services, with many patients unable to access psychosexual support as an integrated part of their treatment, which highlights a potential unmet need across services.

Specifically, only those under the care of the Pelvic Pain Service can access psychosexual support if needed. This is primarily provided by two part-time psychologists who offer one-to-one support guided by Basson’s model of the sexual response cycle (39). A range of therapeutic approaches are used, including Sensate

Focus (a range of techniques used to improve sex and intimacy; 40) and traditional and third-wave cognitive behavioural therapy. In addition to this, a once-monthly psychosexual clinic is held by a dual trained doctor and accredited psychosexual therapist. Patients referred for this support can access a single session of one-to-one support, with the option for partner involvement if desired. This support typically involved offering initial suggestions to help patients with their sexual intimacy difficulties and included signposting patients to services for further support (e.g. local sexual heath clinics) and/or psychoeducational material (e.g. sensate focus techniques, educational resources and YouTube videos).

Whilst this support is a valuable resource, waitlists are currently long, and the scope and accessibility are limited. Therefore, psychologists working in the Pelvic Pain Service were keen to establish how to improve psychosexual support for women with CGCs and sexual intimacy difficulties across the department. This is in line with the Government's 'Women's Health Strategy for England' which commits to improved sexual and reproductive healthcare and outcomes for women across the United Kingdom (41).

Anticipated Service Impact

The results of this project will establish whether the current support provided is meeting patient needs. The findings will likely identify how psychosexual support for women with CGCs and sexual intimacy difficulties can be improved. A potential outcome will be implementation of improved psychosexual provision for women with CGCs and sexual intimacy difficulties across the department.

Methods

Aims

The aims of this project were to:

1. Understand patient views on how the psychosexual support for women with CGCs and sexual intimacy difficulties can be improved in the John Radcliffe Hospital's Women's Centre.
2. Explore patient perspectives on engaging in psychosexual support.
3. Gain insight into patient perspectives of the current psychosexual support available and any views on any unmet psychosexual patient needs.

Design

This study used a mixed methods approach and was made up of three phases: (1) staff consultations; (2) patient survey; (3) patient interviews.

Ethical Considerations

The project was classified as a service evaluation based on the Health Research Authority decision tool (Appendix B3), approved by the Trust's research governance team (Appendix B4) and registered on the Trust's governance system. Participants were provided an information sheet (Appendix B5) and gave verbal and written consent to participate in each stage of the study (Appendix B6). Participants were aware of their right to withdraw.

Phase One: Staff Consultations

Six staff members working in clinical roles within gynaecology services were consulted about their views on the current psychosexual support available and the needs of patients with CGCs and sexual intimacy difficulties. Information gathered at

phase one (see Appendix B7) was used to inform survey questions and interview schedule design and was not formally analysed.

Participant Recruitment

Participants were recruited once Phase One of the project was complete. Patients could participate if they were assigned female at birth, aged 18 years and over, had a CGC and experienced ongoing sexual intimacy difficulties, and were outpatients from selected gynaecology services at the John Radcliffe Women's Centre. Table 1 shows a list of included and excluded services. Patients accessing the excluded services were not included in the study as they require more specialised care for their condition which is thought to have a different impact on sexual intimacy.

Table 1

Included and Excluded Services

Included Services	Excluded Services
Endometriosis services	Gynae-oncology services
Polycystic ovarian syndrome services	Female genital mutilation or cutting services
Fertility services	
Menopause services	
Early pregnancy and pregnancy loss services	
Pelvic pain services	
Colposcopy services	
Urogynaecology services	

Two patients with lived experience of a CGC and sexual intimacy difficulties were consulted to share their views on the recruitment and study materials developed. Initially, participants were recruited via physical copies of study posters and leaflets displayed throughout the department and provided during outpatient

clinics, where the clinician deemed this appropriate. However, due to post-COVID-19 infection control measures resulting in the frequent removal of displayed leaflets and low response rates, the recruitment strategy was modified. Specifically, patients from the Pelvic Pain Service who had previously consented to being approached about research were invited to participate in the study via email and were provided with the study information and link to participate.

A minimum target of 25 survey participants was chosen, representing approximately 65% of the typical number of referrals received over a four-month period (the intended duration for recruitment). This number was considered sufficient to explore trends in a representative proportion of the population and provide meaningful descriptive analysis, whilst also being practically feasible. Further, a minimum target of six interview participants was chosen based on prior similar studies and was considered sufficient to capture a range of perspectives whilst remaining feasible within time constraints.

Phase Two: Online Survey

An anonymised online survey was designed for Phase Two (Appendix B8). The survey questions were informed by the project aims and research questions, information gathered at the first phase and feedback from two patients with lived experience of a CGC and sexual intimacy difficulties.

Phase Three: Semi-Structured Interviews

Participants who completed the survey could opt-in to take part in Phase Three of the project. A semi-structured interview schedule (Appendix B9) was developed. Questions were designed to allow for a more in-depth understanding of patient

views on the current psychosexual support available, facilitators and barriers to engagement, and their opinions on different types of psychosexual support.

Interviews were held online between April and June 2024 using Microsoft Teams video calls, were between 20 and 60 minutes and were audio recorded. Prompts were used when necessary to gain additional information or clarify understanding.

Analysis

Quantitative survey data was analysed using descriptive statistics. Qualitative survey and interview patient accounts were analysed separately, using Braun and Clarke's (42) reflexive thematic analysis (see Appendix B10 for the author's self-reflexivity statement). The lead researcher followed the six-step process: familiarisation, coding, construction of themes, reviewing themes, defining and naming themes, writing up the findings. An inductive approach was used, as coding and theme development were driven solely by the data content.

Results

Online Survey

Twenty-two participants aged 20-57 (*M* = 33.4) completed the survey between March and June 2024. Table 2 summarises relevant participant clinical characteristics. Participants reported a range of different CGCs. Most participants (86.4%) reported that they had a diagnosis of chronic pelvic pain. All but one participant (95.5%) stated they were receiving support from the Pelvic Pain Service

at the time of completing the study. Most participants (59.1%) stated they had previously engaged in psychosexual support.

Table 2

Participant Clinical Characteristics

Clinical Characteristics and Service Use	*n* (%)
Gynaecological Presentation	
Chronic Pelvic Pain	18 (81.2%)
Endometriosis	13 (59.1%)
Adenomyosis	11 (50.0%)
Urinary Incontinence	3 (13.6%)
Menopause	2 (9.1%)
Other	6 (27.3%)
Gynaecological Service	
Pelvic Pain Service	21 (95.5%)
Obstetrics and General Gynaecology	4 (18.2%)
Endometriosis Clinic	3 (13.7%)
Menopause Service	1 (4.5%)
Other	1 (4.5%)
Previous Psychosexual Support	
Yes	13 (59.1%)
No	9 (40.9%)

Quantitative data. Forty-one percent of participants were aware of the psychosexual support currently offered. Of these, 89% thought more psychosexual support should be provided. Participants' average level of confidence that the psychosexual support met their needs was slightly below neutral (M = 2.67, SD = 1.32, range = 1-5; Figure 1) and their satisfaction with the psychosexual support was slightly higher than neutral (M = 3.00, SD = 1.37, range = 1-5; Figure 2).

Figure 1

Participants' Ratings of their Confidence that the Current Psychosexual Support Meets their Needs

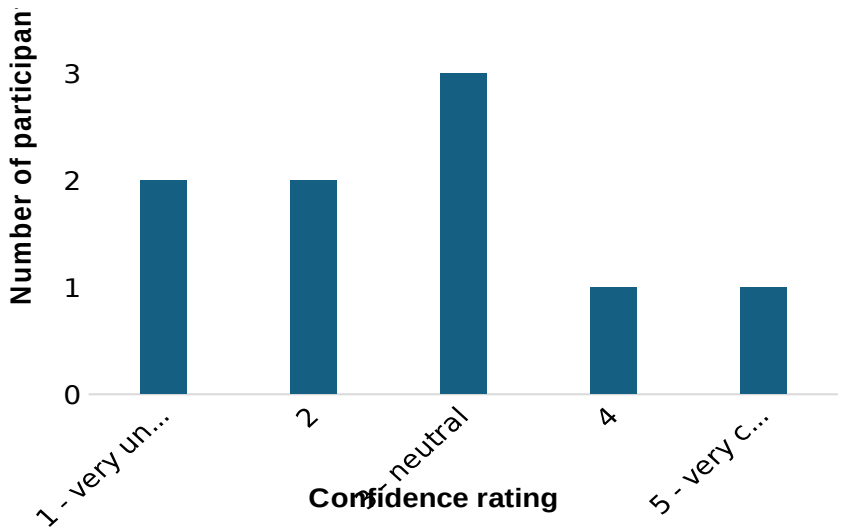
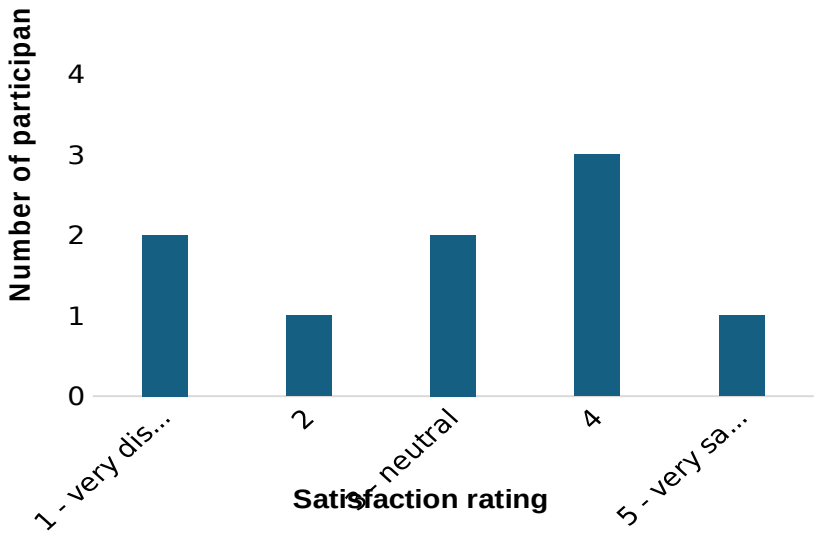


Figure 2

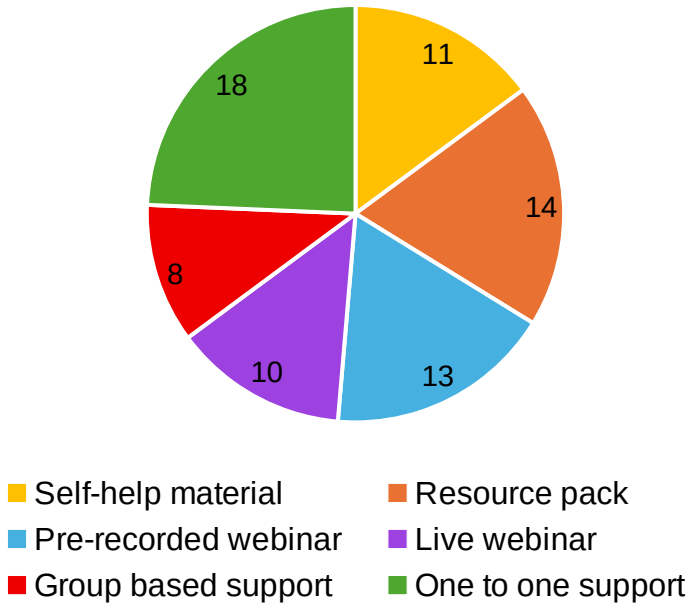
Participants' Ratings of their Satisfaction with the Current Psychosexual Support



Overall, 91% of participants stated they would be likely to engage in psychosexual support. Figure 3 shows the types of psychosexual support participants stated they would be likely to engage in.

Figure 3

Frequency Counts of Responses for Types of Psychosexual Support Participants are Likely to Engage In



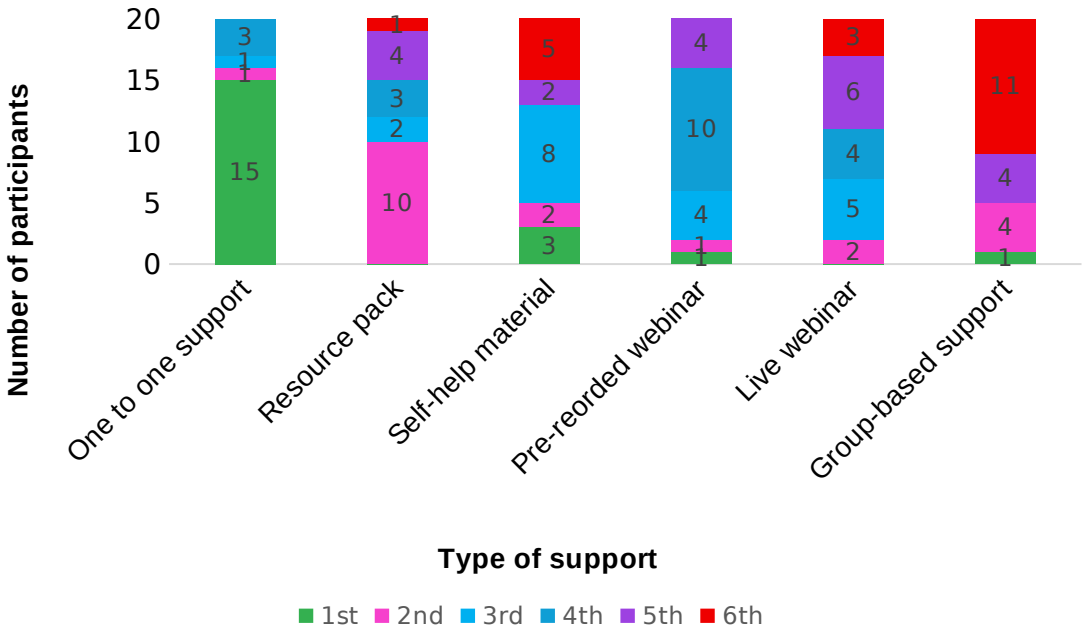
Participants were asked to rank different types of psychosexual support based on how helpful they think they would be, ranging from 1 (the most helpful) to 6 (the least helpful; Figure 4). Participants ranked the following types of support:

1. Self-help material. Contains worksheets and tools to help patients cope.
2. Resource pack: Offers information and educational material.
3. Pre-recorded webinar: Accessible at any time and provides some educational information delivered by a psychologist and a volunteer who shares their personal experience.
4. Live webinar: Similar to the pre-recorded webinar but is delivered live and would therefore offer patients the chance to ask questions.
5. Group based support: Weekly sessions with other patients who have similar difficulties.
6. One to one support: Weekly sessions with a psychologist.

Overall, one-to-one support was the type of support most participants (N=18) would be likely to engage in and was ranked as the most helpful form of support. Only one participant reported they would be unlikely to engage in one-to-one support. Group-based support was the type of support participants (N=8) would be least likely to engage in and was ranked as the least helpful form of support.

Figure 4

Participant Rankings of how Helpful Different Types of Psychosexual Support Would Be



Specifically, 15% of participants stated they would want their partner present if they were to engage in group-based support, 30% said that the sex/gender of the group facilitator would matter to them, and 40% stated aspects of their own identity would be relevant for staff to consider when offering psychosexual support.

Qualitative data. Open-ended questions were included in the online survey. Preliminary analysis revealed the same themes as those developed from the interview data (see below) and did not include any additional information (see Appendix B11). Therefore, the findings from the interview data are reported below, which offer a richer and more nuanced understanding.

Semi-Structured Interviews

Eight participants took part in a semi-structured interview with the lead researcher. See Table 3 for a summary of demographic information. Participants were aged between 23-56 (*M* = 34.75) and reported a range of CGCs, including (but not limited to) endometriosis, adenomyosis and pelvic floor dysfunction. All interview participants were patients under the Pelvic Pain Service with access to psychosexual support if needed. However, only two participants had accessed psychosexual support as part of their treatment, and so most participants were unable to share their views on the psychosexual support currently being offered.

Table 3

Demographics of Interview Participants

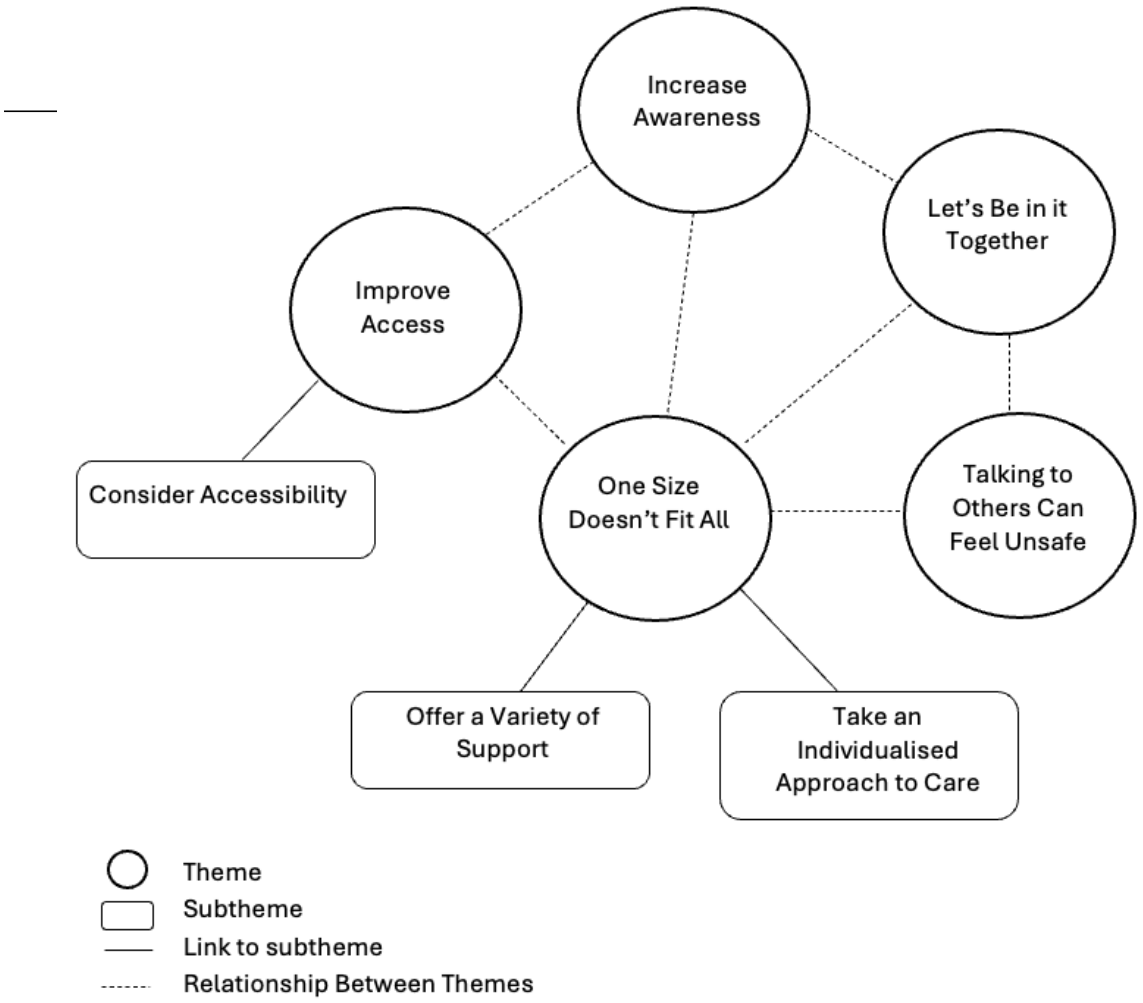
Participant	Age	Ethnicity	Gynaecological presentation
P1	41	White European	Endometriosis
P2	23	White British	Endometriosis, adenomyosis, chronic pelvic pain, pelvic floor dysfunction

P3	26	White British	Endometriosis, adenomyosis
P4	30	White British	Endometriosis, premenstrual dysphoric disorder
P5	29	White British	Endometriosis, adenomyosis, chronic pelvic pain
P6	56	White British	Endometriosis, adenomyosis
P7	37	White British	Chronic pelvic pain, adenomyosis
P8	36	White British	Vulvodynia and pelvic floor dysfunction

Interviews revealed five main themes: ‘increase awareness’, ‘improve access’, ‘one size doesn’t fit all’, ‘talking to others can feel unsafe’, and ‘let’s be in it together’ (Figure 5).

Figure 5

Thematic Map



on the importance of increasing patient awareness of the psychosexual support, including what it involves and how to access it. Despite all participants being under the care of the only service within the department to offer psychosexual support, many were unaware the support exists (P6: *"Up until you contacted me, I didn't even know about it",* P7: *"I wasn't made aware of this service…").* Participants highlighted the need for staff to take a proactive approach to increase awareness (P8: *"… promoting it and making people more aware, I think that's all you can do",* P5: *"I think that it probably should be… advertised more"*) and emphasised the value of patients being informed early in treatment (P6: *"… had I have known about it when I first started my journey, I think things would be a lot different").*

Theme Two: Improve Access. This theme explores the idea that access to psychosexual support should be improved. Offering patients useful resources whilst on the waitlist was identified as one way to improve access to psychosexual support (P3: *"it's better than not having anything cause you're just waiting not knowing what's happening otherwise").* Participants wanted more access to staff-led support (P4: *"… the six session thing I think if they went on longer, erm you probably could get to the bottom of it…")* but recognised a need for more resources and funding for this (P5: *"I think it's just increasing the capacity of the staff would be the thing I need*"). One subtheme 'consider accessibility' emerged. This subtheme explores participants views on the quality of how reachable psychosexual support is and factors that would be helpful to consider in relation to making support accessible (P6: *"… a lot of the groups are based in Oxford and it's a long way out depending on where you are";* P2: *"… if you wanted to schedule it for 10am on a Tuesday morning, a lot of people would be working…").* The interview data emphasises the need for timely access to psychosexual support, and the importance of being able to access this around other responsibilities in life.

Theme Three: One Size Doesn't Fit All. This theme explores the idea that patients have different preferences and needs to be met by psychosexual support. Two subthemes emerged. The first subtheme 'offer a variety of support' captures participants' views on how different patients find value in different types and formats of psychosexual support (P6: *"For each of the areas [types of support], somebody is going to find some value in that",* P4: *"… some people really prefer support in person, personally I don't find there to be any difference").* The second subtheme

‘take an individualised approach to care’ explores participants views on how psychosexual support should meet individual needs of patients (P7: *“So being a lesbian… I specifically asked “does it cover same sex relationships?” She didn't think it did.”).* Participants felt this was most achievable in one-to-one support (P1: *“So obviously everyone is different and everyone will have different views and different difficulties, so I think one-to-one sessions).* However, group support was still considered useful providing it was tailored to the needs of those attending (P4: *“I think group sessions for example, erm, if it's specific to a condition or specific to a topic then I think there's stuff you can do”).* The interviews emphasise having flexibility in the approach to offering support is necessary and individualised support tailored to the needs of the patient is most helpful.

Theme Four: Talking to Others Can Feel Unsafe. This theme captures the view that talking about sexual intimacy difficulties feels unsafe. Participants described increased anxiety when talking about their sexual intimacy difficulties (P1: *“… if you start talking your voice will go shaky and you think ‘oh my god’”)* and reasons why talking about this topic is difficult (P2: *“… it sort of is still like a taboo subject isn’t it”).* Several participants stated who they talk to about their sexual intimacy difficulties influences how safe they feel. Specifically, some participants stated being offered support with a male clinician would be a barrier to engagement (P7: *“I think if the clinician or practitioner was male… I think for me that would be a barrier”).* Several participants shared their view that group settings can feel particularly unsafe, especially if group members differed in their age or sexuality (P6: *“If the age range was too great and you've got a too big a mix of age groups, I think I might feel a bit inhibited to speak”,* P8: *“I guess maybe like their sexual*

orientation, maybe they won't want to talk about it"). Other participants expressed indifference about this and held the view that similarity in experiences of difficulties is more important to feel safe to talk openly with others (P7: *"Well, it's in my opinion that everybody is unique… I think the thing that would unite everybody is we do actually, despite whatever it is, all have that one thing in common").* Participants offered ideas about how this barrier to talking about sexual intimacy difficulties could be reduced (P2: *"… not everyone would want a group session, so the option to have more one-to-ones would be good",* P6: *"thinking about the group that you're putting together and possibly the differences and how those people would feel being put into a group with such individuals").* The interviews highlight that talking about sexual intimacy difficulties can feel unsafe and uncomfortable for many reasons and staff should consider ways to reduce this barrier.

Theme Five**:** Let's Be in it Together. This theme captures participants' desire for psychosexual support to involve a sense of connection to another. Participants described wanting to connect with staff (P5: *"I like to have that personal connection that you don't have with when you're in a group, and actually like with the therapist")* and their partners (P1: *"… it would be good if, the partners will be involved as well…").* Participants also highlighted the value of connecting with their peers via psychosexual support (P2: *"… hearing someone's personal experiences and how they've improved something would be helpful"),* though different views were held about discussing sexual intimacy difficulties amongst peers with different CGCs (P1: *"… despite different conditions I think it's very similar"*, P4: *"If I'm talking about the kind of sexual intimacy issues that come with PMDD that's really different and not relatable to someone with endometriosis…").* The interviews emphasised that

engaging in psychosexual support completely independently is not preferred nor sufficient and whilst group-based support might be challenging for some, it offers patients a chance to connect with peers over a shared experience which is valued.

Dissemination

The themes above are to be presented to the stakeholder service at a multi-disciplinary team meeting. Feedback from the service on the findings will be sought. Additionally, the findings were summarised and shared with staff members involved in the consultation phase of the project and participants (Appendix B12).

Discussion

The biopsychosocial approach is an evidence-based framework that is used to understand the needs of patients with CGCs and sexual intimacy difficulties. Gynaecology services are well set-up to address relevant biological factors for patients with CGCs and sexual intimacy difficulties, through use of medical, physical and/or surgical interventions. However, interventions that address important psychological and/or social factors are rare. This was reflected in feedback from healthcare professionals working in the John Radcliffe Hospital's Women's Centre, which highlighted many patients experiencing sexual intimacy difficulties had no access to "in house" psychosexual support.

Primary aim: Understand patient views on how the psychosexual support for women with CGCs and sexual intimacy difficulties can be improved in a gynaecology department.

Key areas for improvement identified from the findings include increasing awareness and improving access. Only 41% of participants stated they were aware of the psychosexual support currently offered. Research suggests being unaware of psychosexual support and how to access it can be a barrier as it leads patients to think the support is unreachable or difficult to access (43). Participants' varied levels of awareness of the psychosexual support currently offered likely led to different perspectives about areas for improvement. Importantly, many participants were unaware of the psychosexual support currently offered despite being receiving care from the only service within the department to offer this support. Therefore, if the recommended changes (see below) are made and psychosexual support is offered across the gynaecology department, increased awareness for both patients and healthcare professionals across services within the department is essential.

In relation to accessing psychosexual support, patients' views reflect broader perspectives held by women towards increasing access to women's sexual and reproductive healthcare (44). The findings in relation to the secondary and tertiary project aims discussed below should also be used to understand how to improve the psychosexual support available.

Secondary aim: Explore patient perspectives on engaging in psychosexual support.

Whilst 91% of participants stated they would engage in psychosexual support, they emphasised talking to others about sexual intimacy difficulties can feel unsafe. Group-based psychosexual support was perceived as particularly unsafe for some, which is perhaps unsurprising given that emotions such as shame are often experienced (45, 46). However, participants highlighted a degree of perceived

commonality or shared experiences (e.g. same condition) with others can increase feelings of safety, suggesting that social context is an important factor to consider.

Participants also emphasised that psychosexual support should meet different patient's preferences and needs. Most participants expressed their preference for individualised, one-to-one support, however, attitudes varied amongst patients, as seen elsewhere (47). Additionally, different types of support offer patients the opportunity for different types of connections, which was captured in a separate theme. One-to-one support allows for strong therapeutic relationships to be formed, which is thought to be important for improved psychosexual related outcomes (48). Some participants expressed a desire for more partner involvement in one-to-one support, which is thought be beneficial as it acknowledges the interpersonal nature and impact of sexual intimacy difficulties and allows for shared understanding and mutual support (49). However, only a minority of participants stated they would like their partner to be involved in a group.

Despite some reluctance from participants to engage in group-based support, a desire to connect with peers with similar experiences was captured. It is possible that peer-group support might be preferable for patients compared to group-based therapy. Research shows connecting with peers via groups can be informative for patients and a useful space to hear about other people's experiences (47). As some patients might still not want to engage in peer-group support due it feeling too unsafe, then offering patients alternative types of psychosexual support that involve interpersonal connections in other ways is necessary.

Tertiary aim: Gain insight into patient perspectives of the current psychosexual support available and any views on any unmet psychosexual patient needs.

Ninety percent of participants believe the current psychosexual support is not enough and think more support should be provided. One of the themes captures participant views on how patients' psychosexual needs are left unmet due to limited opportunities to access to psychosexual support. As only two interview participants accessed the psychosexual support currently offered, there was limited chance to gather data capturing participant views on whether this support sufficiently meets patient needs. Future projects could specifically explore the experiences and views of patients who have engaged in psychosexual support to understand this further.

Limitations and Future Research

One limitation is the under representativeness of the sample. Despite initially aiming to recruit participants with a range of CGCs and from across services within the department, over 80% of survey participants experienced pelvic pain and all but one participant were patients under the Pelvic Pain Service. As such, the results may be biased towards perspectives of pelvic pain patients and omit those of patients who do not access support for chronic pelvic pain, thereby limiting the generalisability of the results to the wider gynaecological population. This under-representation was likely influenced by a selection bias introduced by the modified recruitment strategy. Additionally, as participants were self-selecting, it is possible that patients who were highly motivated and felt strongly about the need for improvements to psychosexual support chose to participate. This could have biased the results, as it is possible that perspectives from patients who do not perceive a

need for improvement to psychosexual support were missing. Future research should address these issues by using a more systematic sampling method (e.g. stratified sampling) to increase the representativeness of the sample and generalisability of results, and reduce bias, though appropriateness and suitability of the chosen method should be considered given the sensitivity of the research topic. Further, the sample had limited ethnic and cultural diversity. As norms around sexual behaviours and views on talking about sex can differ greatly across cultures, future projects would benefit from a more culturally diverse sample.

Qualitative survey responses often lacked depth, and some were incomplete or left blank, though it was evident that responses were consistent with interview data. Further, the quality of some survey questions could be improved (e.g. fully labelled scales).

Recommendations

The following recommendations were made based on the findings:

- Make a business case to request more resources to increase access to a range of psychosexual support in the following ways:
    - Create psychosexual self-help material, a resource pack containing educational material or a pre-recorded webinar to offer waiting list support to patients.
    - Offer more one-to-one individualised psychosexual support, with the opportunity for patients to involve their partners should they wish.
    - If group-based therapeutic support is offered, hold initial one-to-one appointments with patients to discuss their readiness to engage, any

concerns and increase their sense of safety. When selecting group participants, consider the extent to which patients might be able to relate to others in the group. Topics should be specific in focus and relevant to patients attending.

    - Signpost patients to online forums and/or communities to allow them to connect to others with shared experiences.

- Take a flexible approach to offering psychosexual support and offer a mix of online and in-person options to meet different accessibility needs and personal preferences.
- Should the availability of psychosexual support expand across the gynaecology department, the following steps are recommended to increase staff awareness of support available:
    - Inform service leads in departmental meetings.
    - Develop an information leaflet summarising the available support.
    - Hold ‘drop-in’ sessions for staff to ask questions learn more.
    - Develop and clearly outline patient eligibility criteria and the referral process.
    - Encourage services to identify psychosexual support ‘champions’ who can be a point of contact regarding referrals.
- To support staff to increase patients’ awareness of the psychosexual support available, develop resources that can be used to either support these conversations (e.g. leaflets) or signpost patients to further information (e.g. a pre-recorded webinar and/or a video of a patient testimonial).

Conclusion

This study explored the views of women with CGCs and sexual intimacy difficulties on how to improve psychosexual support within a gynaecological department. Findings highlighted a need for improved awareness of and access to a range of individualised psychosexual support. Patients should be supported to feel safe to discuss their sexual intimacy difficulties with professionals and be offered the opportunity to involve partners or connect with peers if desired. Whilst the results highlight some improvements can be made by using relatively in-expensive means, more funding and resources are needed across women's sexual and reproductive healthcare to meet the psychosexual needs of patients. One limitation of this study is the under-representative sample, which may limit the generalisability of the results to individuals with other gynaecological conditions. These findings could be used to inform service-improvement in other services with similar contexts.

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Theory Driven Research Project

The Role of Internalised Stigma and Perceived Empathy in Social Identity Processes for People who Hear Voices

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Abstract

Background: Hearing voices is widely stigmatised by society, which can affect one's readiness to identify as a voice-hearer. Research shows social identity has an important role in health outcomes in clinical populations. Specifically, integrating multiple distinct social identities into a coherent sense of self has been linked to improved psychological wellbeing in voice-hearers. Theory and research suggest internalised stigma might inhibit the integration process, whereas empathy from others may facilitate this process. **Objectives:** This study aims to explore the role of these factors in the social identity integration process for people who self-identify as voice-hearers. **Design:** A cross-sectional design was used, and three analyses were conducted. **Methods:** Seventy-six voice-hearers completed an online questionnaire assessing internalised stigma, social identity integration, perceptions of empathy from non-voice-hearers, paranoia, voice severity and depression. **Results:** An ANCOVA showed no significant difference in the degree of social identity integration between voice-hearers with high versus low levels of internalised stigma. A regression revealed perceptions of empathy from non-voice-hearers were significantly and positively associated with social identity integration. A hierarchical regression showed the overall model was significant, with covariates accounting for a significant amount of variance in social identity integration. Internalised stigma and perceptions of non-voice-hearer each contributed small amounts of variance, though these changes were not significant. **Conclusion:** These results extend beyond previous research and offer some preliminary support for the cognitive-

developmental theory underpinning social identity integration processes. Further research is needed to enhance understanding.

Keywords: voice-hearer, social identity, internalised stigma.

Introduction

Voice-Hearers

Hearing a voice (or voices) that others do not hear when there is no speaker around to explain the experience is not uncommon, with a median lifetime prevalence of 13.2% in the general population (Beavan et al., 2011). The experience of hearing voices is often associated with a range of psychiatric diagnoses, however, many voice-hearers live well without ever getting a psychiatric diagnosis or accessing mental health services (Johns et al., 2014). Even though hearing voices is a common experience, public perceptions and portrayals of those who hear voices are mostly negative and stigmatising (Vilhauer, 2014, 2016).

The Social Identity Approach to Health

The social identity approach to health (SIAH; Haslam et al., 2009; Jetten et al., 2012) emphasises the importance of social identity in relation to health outcomes and suggests “because it is the basis for meaningful group life, social identity is central to both good and ill health” (Haslam et al., 2018, p17). Underpinning the SIAH, Tajfel and Turner’s (1979) social identity theory defines social identity as “that part of the individuals’ self-concept which derives from their knowledge of their membership of a social group (or groups)” (Tajfel, 1982). As such, a voice-hearer social identity can be part of an individual’s self-concept that is derived from their sense of belonging to the group of people who hear voices.

A growing body of literature has explored the role of social identity in relation to health and wellbeing in different clinical populations, including people recovering from eating disorders, substance misuse and acquired brain injuries (Dingle et al., 2019; McNamara & Parsons, 2016; Muldoon et al., 2019). Social identity is particularly important to investigate when one identifies with a publicly stigmatised group, as evidence suggests it can be either a “social curse” or a “social cure” (Kellezi & Reicher, 2012; Muldoon et al., 2019). For example, adopting a stigmatised “illness identity” has been linked to poorer recovery-related outcomes across populations with various mental health conditions, such as anxiety, mood and schizophrenia spectrum disorders (Dubreucq et al., 2021; Livingston & Boyd, 2010; Yanos et al., 2010). However, the SIAH suggests that identifying with a stigmatised group can be a “social cure” and can be psychologically protective if the identification is strong, perceived positively and supportive (Jetten et al., 2012). Research supports this and demonstrates that strongly identifying with and connecting to members of a stigmatised group can buffer against the negative effects of perceived discrimination on wellbeing (Branscombe et al., 1999; Molero et al., 2011) and can support improved outcomes through the development of recovery-orientated social identities (Dingle et al., 2019; McNamara & Parsons, 2016). Therefore, holding a stigmatised social identity can either facilitate or hinder wellbeing.

At any single point in time, an individual can hold multiple social identities. Whilst the SIAH suggests that holding multiple compatible social identities is conducive to psychological wellbeing, it does not postulate the mechanisms through which this occurs, nor does it address how one integrates their distinct identities resolves holding seemingly conflicting social identities. The Cognitive-

Developmental Model of Social Identity Integration (CDMSII; Amiot et al., 2007) is a four-stage theoretical model that outlines the sequential intraindividual processes that underlie the development and integration of multiple social identities. The stages are: (1) Anticipatory categorisation: when one anticipates becoming part of a new social group and projects self-characteristics onto the new group. (2) Categorisation: when differences among multiple social identities become salient and there is little or no overlap between old and new identities. (3) Compartmentalisation: when one identifies with both old and new social groups (context specific) but perceives their multiple social identities as mostly separate. (4) Integration: when one recognises the cohesion between their multiple and distinct social identities, which are encompassed within an over-arching, coherent identity.

The CDMSII proposes that identity integration leads to greater psychological wellbeing (Amiot et al., 2007). This is supported by both quantitative and qualitative studies (Amiot et al., 2015; Hogg et al., 2024; Yampolsky et al., 2013). In addition, Amiot et al. (2007) hypothesised inhibitory or facilitatory factors that might influence the integration process. For example, feelings of threat in the context of identity development are proposed to slow or inhibit the identity integration process, whereas coping and social support are thought to facilitate identity integration. Given the links between identity integration and psychological wellbeing, investigating this process and potential inhibitors and/or facilitators is of particular importance for clinical populations.

Internalised Stigma and Identity Integration

Corrigan and colleagues' (2011) outline a model in which experiences of stigma can become internalised (when one accepts and applies negative

stereotypes and attitudes to oneself; Corrigan & Watson, 2002; Link & Phelan, 2001). Internalised stigma (IS) is common and sometimes severe in voice-hearers. A large-scale study found 41.7% of mental health service users with a diagnosis of schizophrenia or other psychotic disorder reported high levels of IS (Brohan et al., 2010). Psychological harm is a widely accepted consequence of IS. Research shows IS negatively impacts on self-esteem, emotional distress and personal recovery in people who experience psychosis and can influence voice-hearing experiences (Burke et al., 2016; Vass et al., 2015; Vilhauer, 2016; Wood et al., 2017).

IS can be conceptualised as a source of internal threat that might slow or inhibit identity integration. In support of this, Hogg et al. (2024) found initial evidence that IS is associated with identity compartmentalisation in voice-hearers. This study aims to build on this further and directly investigates the relationship between IS and identity integration in this population.

Perceived Empathy and Felt Understanding

Recent attention has been given to the role of perceptions of empathy in others or “felt understanding” (a related concept) in relation to social identification processes and wellbeing (Du et al., 2024; Hogg et al., 2024; Hogg et al., 2022; Livingstone et al., 2020). Whilst difficult to define, according to most conceptualisations, empathy is thought to be a complex multidimensional construct that involves cognitively understanding another’s feelings alongside an affective component elicited by an emotional stimulus (Cuff et al., 2016). On the other hand, felt understanding is the belief that another understands and accepts one’s own perspectives, including their beliefs, values, experiences and self-identity

(Livingstone et al., 2020). Felt understanding has primarily been studied in inter-group relationships and has been identified as a key determinant of positive inter-group relations in various social contexts (Livingstone et al., 2020), and mediates the relationship between social identification and mental health outcomes (Du et al., 2024). Building on this, Hogg et al. (2024) explored the relationship between social identity processes and wellbeing in voice-hearers, and found that perceptions of empathy in others appeared to facilitate identity integration. Therefore, it seems that perceptions of out-group empathy, understanding and acceptance may serve an important protective function for individuals who hold a stigmatised identity and potentially facilitate social identity integration.

Aims

Given that research suggests that IS slows or inhibits social identity integration, which negatively affects psychological wellbeing in voice-hearers, investigating the relationship between these two variables in this population is important. Additionally, the extent to which IS and out-group empathy together account for variance in social identity integration is yet to be explored. Therefore, this study aims to (1) compare the degree of social identity integration between voice-hearers with high versus low levels of IS, and (2) explore whether IS and perceptions of out-group empathy explain variance in the degree of social identity integration in voice-hearers.

Possible covariates were identified based on clinical, theoretical and/or empirical relevance to account for factors that may influence the relationship between IS, perceptions of out-group empathy and identity integration. Time since onset of voice-hearing was included due to its likely influence on the social identity

integration process. Voice hearing severity, paranoia and depression were also included because of their influence on perceptions of the self, others and social interactions (Combs et al., 2013; Combs & Penn, 2004; Livingston & Boyd, 2010).

Research Questions and Hypotheses

1. Does the extent of identity integration differ between voice-hearers with high versus low levels of IS, after controlling for the effects of time since voices started, voice-hearer severity, paranoia and depression?

   Hypothesis 1: Voice-hearers with higher levels of IS will have significantly less social identity integration compared to voice-hearers with lower levels of IS, after controlling for the effects of time since voices started, severity of voices, paranoia and depression.

2. Are perceptions of out-group empathy positively associated with identity integration among voice-hearers?

   Hypothesis 2: Perceptions of out-group empathy will be significantly and positively associated with extent of identity integration.

3. Do levels of IS and perceptions of out-group empathy contribute to the variance in social identity integration, after controlling for time since voices started, severity of voices, paranoia, depression?

   Hypothesis 3 (exploratory): After statistically controlling for possible covariates of time since voices started, severity of voices, paranoia and depression, IS and perceptions of out-group empathy will be associated with

identity integration and will contribute a significant amount of additional variance beyond that accounted for by covariates.

Materials and Methods

Design

This study adopts a cross-sectional design. For our first hypothesis, a between-subjects approach was used. For our remaining hypotheses, associations between continuous variables were examined for the whole sample. The study received ethical approval from the Oxford University Medical Sciences Interdivisional Research Ethics Committee (ref: R92775/RE001; Appendix C2).

Participants

An a-priori power calculation was conducted using G*Power 3.1 for an ANCOVA. Using an effect size of $f = 0.343$ (based on previous research; Hogg et al., 2024) with an alpha level of 0.05 and power of 0.80, a minimum sample of n=69 is required to detect a medium-to-large effect size.

Seventy-six participants were recruited through adverts shared via social media (e.g. Facebook, Instagram), online forums (e.g. Reddit) and organisers of relevant organisations or groups (e.g. Hearing Voices Network). Inclusion criteria included being aged 18 years or above, living within the United Kingdom and self-identifying as someone who hears voices. Individuals were excluded if they were

unable to fluently speak, read or write English or provide informed consent, or if they experienced voices solely in the context of drug and/or alcohol use.

Procedure

Recruitment took place between May 2024 – March 2025. The recruitment advert provided a link for potential participants to access the information sheet (Appendix C3), check their eligibility to take part and provide informed consent (Appendix C4). Participants were reminded of their right to withdraw and were invited to complete the online survey anonymously using the platform Qualtrics, with the option to complete the study via the telephone upon request. Of the 76 participants, five completed the survey via the telephone. Participants provided demographic information and completed a series of questionnaires. Depending on whether participants completed the survey online or via telephone, participants were shown or read a debrief information sheet (Appendix C5), which included information about a range of supportive organisations they could access. No participants received incentives or rewards for their participation.

Measures

Demographics/Clinical Information

Participants were asked to self-report demographic characteristics and relevant clinical information, including how long they have experienced voices, whether they have received a mental health diagnosis in relation to hearing voices and whether they have accessed professional support for hearing voices.

Single Item Social Identification Measure (SISI; Postmes et al., 2013).

The SISI is a single item questionnaire that was adapted for use with voice-hearers (e.g. ‘I identify with people who hear voices’) to assess participants’ level of voice-hearer identification. This measure was used to contextualise and describe the sample. The item is scored on a 7-point Likert scale from 1 (strongly agree) to 7 (strongly disagree). The SISI measure has good convergent and divergent validity and test-retest reliability (Postmes et al., 2013) and evidence shows social identification to be a sufficiently homogenous construct to be adequately operationalised with a single item (Postmes et al., 2013).

Internalised Stigma of Mental Illness Scale (ISMI-9; Hammer & Toland, 2017).

The ISMI-9 is a measure of IS of mental illness (Hammer & Toland, 2017) and was adapted for use with a voice-hearer sample. The measure consists of 9 items (e.g. ‘stereotypes about voice-hearers apply to me’) which are scored on a 4-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). Higher scores indicate greater IS. Psychometric evaluation of the measure showed good internal consistency (α = .86; Hammer & Toland, 2017). In the current study, Cronbach’s alpha was good (α = .83).

The Perceived Empathy Scale (PES; Nambisan, 2011).

Perceptions of out-group empathy was measured using an adapted version of the PES (Appendix C6). The original PES measures participants’ perception of empathy from others (Nambisan, 2011). Hogg et al. (2024) adapted the scale to create in-group and out-group empathy subscales for use with a voice-hearer sample. The out-group empathy subscale of the adapted version was chosen for this study. The scale has 8 items. Participants rated how they have felt in their

interactions with people who do not hear voices themselves on a 7-point scale (e.g. 1 – “unsympathetic” to 7 – “sympathetic”). Higher scores indicate greater perceived out-group empathy. The original PES and adapted version of the scale had good (α = .85) to excellent (α = .95) internal consistency, respectively (Hogg et al., 2024; Nambisan, 2011). In the current study, Cronbach’s alpha was excellent (α = .93).

The Integration Subscale of the Multicultural Identity Integration Scale (MULTIIS; Yampolsky et al., 2016).

Identity integration was measured using the integration subscale of the MULTIIS, adapted for voice-hearers (Appendix C7; Hogg et al., 2024). The subscale is made up of 8 items (e.g. ‘my identity as a voice-hearer fits within a broader identity’) that are scored on a 7-point scale (1 – “not at all” to 7 – “exactly”). Higher scores indicate greater identity integration. Both the original subscale and adapted version had good internal consistency (α = .87; .86 respectively; Hogg et al., 2024; Yampolsky et al., 2016). In the current study, Cronbach’s alpha for this measure was excellent (α = .92).

Negative Voice Impact Subscale of the Hamilton Program for Schizophrenia Voices Questionnaire (HPSVQ; Van Lieshout & Goldberg, 2007).

Severity of voices was measured using an adapted version of the Negative Voice Impact Subscale of the HPSVQ (Appendix C8; Van Lieshout & Goldberg, 2007). Three items related specifically to the severity of voice hearing were selected (e.g. ‘how distressing are the voices that you hear?’) that are scored on a 5-point scale (0 – “least severe” to 4 – “most severe”). The full scale has good internal

consistency, concurrent validity and test-retest reliability (Van Lieshout & Goldberg, 2007).

The Green et al. Paranoid Thoughts Scale (GPTS-8; Bianchi & Verkuilen, 2021)

Paranoia was measured using the 8-item version of the GPTS (Bianchi & Verkuilen, 2021). The measure comprises of two subscales (ideas of reference and ideas of persecution) made up of 4 items (e.g. 'I was distressed by being persecuted'). Items are scored on a five-point scale (0 – "not at all" to 4 – "totally"). Higher scores indicate higher levels of paranoia. Psychometric evaluation showed the measure had excellent internal consistency (α = .90) and good construct validity (Bianchi & Verkuilen, 2021; Raffard et al., 2023). In the current study, Cronbach's alpha was good (α = .89).

The Patient Health Questionnaire (PHQ-8; Kroenke et al., 2009).

The PHQ-8 is a widely used measure of depression. Each item asks participants to rate how prevalent specific experiences (e.g. 'feeling down, depressed, irritable or hopeless') have been over the last two weeks on a 4-point scale from 0 (not at all) to 3 (nearly every day). Higher scores indicate more severe levels of depression. The scale has strong internal consistency (α = .87; de la Torre et al., 2023) and good construct validity (Kroenke et al., 2009). In the current study, Cronbach's alpha was good (α = .88).

Statistical Analysis

Statistical analyses were conducted using IBM SPSS Statistics (version 30.0) software. To investigate whether there were differences in degree of identity

integration between voice-hearers with low or high IS, an ANCOVA was carried out controlling for time since voices started, severity of voices, paranoia and depression. The clinical cut-off on the ISMI-9 was used to divide participants into two groups based on their scores: 1.00-2.50 (reports low IS) and 2.51-4.00 (reports high IS). IS was treated as a dichotomised variable in this study as research shows individuals with high IS experience significantly worse clinical, psychosocial and identity-related outcomes than those with low IS (Hogg et al., 2024; Livingston & Boyd, 2010; Yanos et al., 2010). Further, the two-category method has been recommended and applied by other researchers in the field for both the longer version of the measures and version used in this study, providing precedent and comparability (Boyd et al., 2014; Getinet Alemu et al., 2025; Krajewski et al., 2013; Ritsher & Phelan, 2004). Other methods of dichotomisation were considered but not used due to several limitations. Firstly, median splits, whilst commonly used in research, are sample-dependent and arbitrary and reduce statistical power (McClelland et al., 2015). Alternatively, removing participants whose scores fell within one standard deviation of the mean would have the benefit of increasing between-group contrast, however, it reduces the sample size by excluding participant data, which was considered ethically inappropriate. Therefore, the chosen method of dichotomisation was favoured, as it balances methodological rigor, maintains clinical relevance and upholds ethical standards.

To examine whether perceptions of out-group empathy were positively associated with identity integration, a regression analysis was conducted. Next, a hierarchical multiple regression analysis was carried out to establish the amount of variance in identity integration that was accounted for by IS and perceptions of out-group empathy after statistically controlling for time since voices started, severity of

voices, paranoia and depression. With social identity integration as the dependant variable, covariates were entered into the model in block one, IS at block two and perceptions of out-group empathy at block three.

Results

One-hundred participants took part in the study; however, 14 participants were excluded from the analyses due to incomplete data. Therefore, 76 participants were included in the final analyses. Socio-demographic and clinical information can be found in Table 1. All participant data were reviewed for consistency and reliability.

Participants ranged in age from 18 to 77 (*M* = 37.7, *SD* = 13.2). Of the total sample, 71.1% (*n* = 54) were female, 67.1% (*n* = 51) were White British and 53.9% (*n* = 41) were single. Participants' identification as a voice-hearer ranged from 1 to 7 (*M* = 2.3, *SD* = 1.6), with lower scores indicating stronger voice-hearer identification. In terms of clinical variables, the time since participant's voices started ranged from 0 to 76 years ago (*M* = 17.6, *SD* = 15.5). Most participants (88.2%, *n* = 67) had a diagnosis that in their view related to hearing voices and 46.1% (*n* = 35) were receiving professional support for hearing voices at the time of taking part in the study.

Of the 76 participants, only 73 were included in the primary analysis due to missing covariate data from three participants. Participants were split into two groups (high IS (*n* = 50) and low IS (*n* = 23)) based on ISMI-9 scores. Socio-demographic and clinical information for the high versus low IS subgroups are shown in Table 1.

Table 1.

Participant Socio-demographic and Clinical Characteristics.

	Total (N = 76)		High IS group (n = 50)[a]		Low IS group (n = 23)[a]		Test statistic	
Variable	*M (SD)*	Range	*M (SD)*	Range	*M (SD)*	Range	*U*	*p*
Age (in years)	37.7 (13.2)	59 (18-77)	37.5 (14.6)	59 (18-77)	39.0 (13.4)	47 (23-70)	536	.639
Years Since Voices Started	17.6 (15.5)	76 (0-76)	18.3 (16.7)	76 (0-76)	17.5 (13.2)	50 (3-53)	543	.704
	N	%	*n*	%	*n*	%	X^2	*p*
Gender							.986	.611‡
Male	18	23.7	10	20.0	7	30.4		
Female	54	71.1	37	74.0	15	65.2		
Other	4	5.3	3	6.0	1	4.3		
Ethnicity							.012	.912‡
White British/White Other	63	82.9	43	86	20	87		
Black/African/Caribbean/Asian/ Other	13	17.1	7	14	3	13		
Relationship Status							.009	.926
Partnered (Married/Cohabiting/ Other)	28	36.8	19	38	9	39.1		
Unpartnered (Divorced/Separated/Widowed/ Single)	48	63.2	31	62	14	60.9		
Education Completed							3.82	.148‡
None	2	2.6	2	4	-	-		
Basic (Primary/Secondary)	40	52.6	29	58	9	39.1		
Higher Education (UG/PG)	34	44.7	19	38	14	60.9		
Employment Status							2.72	.099
Unemployed/Retired	43	56.6	32	64	10	43.5		
Employed	33	43.4	18	36	13	56.5		

Related Diagnosis								.090[†]
Yes	67	88.2	43	86.0	23	100.0		
No	9	11.8	7	14.0	-	-		
Past Support							3.48	.062
Yes	54	71.1	33	66.0	20	87.0		
No	22	28.9	17	34.0	3	13.0		
Current Support							1.34	.248
Yes	35	46.1	21	42.0	13	56.5		
No	41	53.9	29	58.0	10	43.5		
Currently on Medication							.217	.642
Yes	50	65.8	32	64.0	16	69.6		
No	26	34.2	18	36.0	7	30.4		

Note. Numbers have been rounded to one decimal place. Where Chi-Squared statistics are missing, sample size is too small to compute.
[a] Demographic and clinical information shown for high IS and low IS subgroups based on sample used in primary analysis (n = 73) due to missing covariate data.
[‡]Two or less cells had expected counts of less than five.
[†]Fisher's Exact Test was used due to Chi Square assumptions being violated.

Hypothesis One

An ANCOVA was run to determine the effect of high and low levels of IS on extent of identity integration after controlling for time since voices started, severity of voices, paranoia and depression. Three participants were excluded from this analysis due to missing covariate data (n = 73). All assumptions were met (Appendix C9). After adjustment for the covariates, descriptive statistics indicated levels of identity integration were lower in the high IS group (M = 24.19, SE = 1.63) compared to the low IS group (M = 28.47, SE = 2.58*)*. Although this difference was in the expected direction, it did not reach statistical significance ($F(1, 67) = 1.687$, p = .198, partial η^2 = .025), and so our primary hypothesis was not supported.

Hypothesis Two

A simple linear regression was carried out to examine the relationship between perceptions of out-group empathy and identity integration. The total sample (N = 76) was included in the analysis. All assumptions were met (Appendix C9).

Perceptions of out-group empathy were significantly associated with social identity integration (F (1, 74) = 6.68, p = 0.012) and accounted for 7% of the variance (R^2 = 0.070), which suggests a small effect size. Specifically, for every one-unit increase in perceptions of out-group empathy, identity integration scores increased by 0.295 units (B = .295, SE .114, t = 2.58, p = .012, 95% CI [0.67, 0.52]), indicating a moderate positive relationship between the variables. Therefore, hypothesis two was supported.

Hypothesis Three

A hierarchical multiple regression was run to test whether IS and perceptions of out-group empathy contribute additional variance in identity integration, when controlling for covariates (time since voices started, severity of voices, paranoia and depression). Three participants were excluded from this analysis due to missing covariate data (n = 73). All assumptions were met (Appendix C9). Covariates were entered into the model in block one, IS was entered in block two and perceptions of out-group empathy was entered in block three. See Table 2 for full details.

The overall model was statistically significant (R^2 = .177, adjusted R^2 = .102, F(6, 66) = 2.364, p = .04). In block one, the covariates accounted for 13.4% of the total variance in identity integration (R^2 = .134, adjusted R^2 = .083) which was significant (F(4, 68) = 2.62, p = .042). The addition of IS in block two increased the total variance to 13.8% (R^2 = .138, adjusted R^2 = .073), though this change was not significant (R^2 = .004, F(1, 67) = .324, p = .571). Adding perceptions of out-group empathy in block three increased the total variance to 17.7% (R^2 = .177, adjusted R^2 = .102) which was also a non-significant change (R^2 = .039, F(1, 66) = 3.14, p =

.081). Taken together, these results suggest that whilst the overall model accounted for a significant amount of variance in social identity integration, only the covariates contributed a significant proportion of this variance. The addition of IS and perceptions of out-group empathy did not explain a significant amount of additional variance.

Table 2

Hierarchical multiple regression predicting degree of social identity integration from demographic and clinical variables, internalised stigma and perceptions of out-group empathy.

Variable	B	95% CI for B		β	R^2	ΔR^2
		LL	UL			
Step 1					.134	.134*
Constant						
Time since voices started	37.272	27.833	46.712			
Severity of voices	-.005	-.170	.161	-.006		
Paranoia	.374	-.526	1.275	.105		
Depression	-.302	-.657	.052	-.226		
	-.439	-.941	.063	-.236		
Step 2					.138	.004
Constant	40.257	26.125	54.389			
Time since voices started	-.009	-.176	.158	-.012		
Severity of voices	.524	-.523	1.571	.147		
Paranoia	-.266	-.644	.113	-.199		
Depression	-.388	-.924	.148	-.209		
Internalised stigma	-2.101	-9.471	5.269	-.100		
Step 3					.177	.039
Constant	23.245	-.443	46.932			
Time since voices started	.052	-.126	.230	.072		
Severity of voices	.153	-.960	1.265	.043		
Paranoia	-.306	-.682	.070	-.229		
Depression	-.254	-.803	.294	-.137		
Internalised stigma	1.668	-6.740	10.076	.079		
Out-group empathy	.275	-.035	.585	.271		

Note: *B* = beta; CI = confidence interval; LL = lower limit; UL = upper limit; β = standardised beta; R^2 = variance in identity integration explained by covariates and independent variables; ΔR^2 = the change in R^2 between models.

* $p < .05$

Discussion

This study aimed to investigate the roles of IS and perceived out-group empathy in the integration of a voice-hearer social identity with other social identities. First, the relationship between IS and social identity integration was examined. Specifically, it was hypothesised that voice-hearers with high levels of IS will have significantly less social identity integration when compared to voice-hearers with low levels of IS, after controlling for potential covariates (time since voices started, severity of voices, paranoia and depression). Results showed the difference in identity integration between high versus low IS groups was non-significant, and so the first hypothesis was not supported.

Whilst the difference between groups not reaching statistical significance, the relationship found between IS and identity integration was in the expected direction, in that voice-hearers with higher levels of IS had lower levels of social identity integration. In line with this, a negative correlation between IS and social identity integration was also found in subsequent analyses. Although the results were non-significant, the trend observed was in line with previous correlational research which showed IS is significantly positively associated with identity compartmentalisation (the penultimate stage of the CDMSII; Amiot et al., 2007; Hogg et al., 2024). The results from this study may offer some tentative support for the CDSMII and its proposed inhibitors (Amiot et al., 2007), however, due to the lack of statistical significance, this interpretation should be treated with caution until more robust evidence is found.

It is possible that the non-significant result reflects a true absence of a difference between groups. This might be due to complex developmental processes and interactions between IS and social identity integration that cannot be fully captured by group comparisons using cross-sectional data. For example, levels of IS can change over time and the extent IS influences social identity integration might depend on when IS is experienced. As such, the CDSMII theory (Amiot et al., 2007) would benefit from further refinement based on longitudinal research to account for the dynamic nature of the proposed inhibitors and facilitators over time to consider when and how these influence social identity integration. Potential clinical implications of this are discussed below.

There were several methodological limitations related to the first analysis. Whilst a sufficient number of participants were recruited for a powered test and all assumptions were met, group sizes were unequal. Also, several participants scored within close range of the cut-off used to determine high and low IS groups, which could suggest the groups are not meaningfully distinct. Whilst this cut-off is widely accepted and applied in research (Boyd et al., 2014; Getinet Alemu et al., 2025; Krajewski et al., 2013; Ritsher & Phelan, 2004), it is yet to be validated. Nonetheless, IS was dichotomised for the primary analysis in place of treating it as a continuous variable as it aligned with the aims of our study and allowed for the potential identification of clinically meaningful differences in identity integration between high and low IS groups. Given that individuals with high IS are known to have significantly worse clinical outcomes, it was plausible to investigate whether similar differences exist in identity integration. Use of clinically informed cut-offs enables clearer clinical interpretation and facilitates practical application. This approach also extends the literature by adopting a group comparison design to

complement prior correlational research and was supplemented by the tertiary analysis in which IS was treated as a continuous variable, offering a balanced methodological approach that enhances overall understanding.

Future research would benefit from the formal validation of the cut-off for the ISMI-9 to allow for more robust conclusions to be drawn. Researchers exploring differences in high and low IS groups would benefit from more balanced group sizes to increase statistical power. However, achieving this remains challenging in this population despite recruiting clinical and non-clinical voice-hearers to try and capture varied levels of IS.

Our second hypothesis was supported by the significant association found between perceived empathy in non-voice-hearers and voice-hearer social identity integration. This is consistent with previous research (Hogg et al., 2024) and suggests feeling understood by others who do not hear voices themselves is protective for those who hold a stigmatised voice-hearer identity. However, our third exploratory analysis showed the overall hierarchical regression model was significant, but neither IS nor perceived empathy in non-voice-hearers contributed a significant amount of additional unique variance in social identity integration beyond that accounted for by the covariates. This finding is inconsistent with previous research, which showed IS and perceived empathy from non-voice-hearers contributed significantly to identity compartmentalisation and identity integration, respectively (Hogg et al., 2024). This difference might be explained by how the present study included relevant covariates in the analysis which could have masked the unique contribution of IS and perceived out-group empathy. Future research should use more robust methods to investigate the relationships between these

variables to explore potential interactive effects and their relative contributions to variance in social identity integration.

Clinical Implications

Given that the present study did not yield statistically significant results regarding the relationship between IS and identity integration, and IS did not significantly contribute to the variance in identity integration, definitive clinical implications cannot be drawn based on these findings. However, the observed pattern might suggest that higher levels of IS are associated with weaker identity integration, which aligns with theoretical expectations and previous research and highlights a potential relationship that warrants further investigation. Future research using larger samples and more robust methodologies is needed to clarify and whether the observed pattern reaches statistical significance and represents reliable relationships. If such results are found, future theoretical and research developments could more fully account for the evolving, potentially time sensitive nature of proposed inhibitors (including IS), which might inform the future development of targeted interventions delivered at critical periods of the identity integration process.

It is important to note that a large proportion of the sample reported high levels of IS. Whilst this study did not include measures of recovery or overall wellbeing, existing literature consistently shows IS is associated with poorer related outcomes in similar populations (Burke et al., 2016; Vass et al., 2015; Vilhauer, 2016; Wood et al., 2017). As such, it may be beneficial to consider interventions that aim to reduce IS to improve clinical outcomes unrelated to identity integration in voice-hearers. Further, wider research suggests that voice-hearers might benefit

from psychosocial interventions that support them to harness the protective effects of the “social cure”, which buffer against the negative effects of discrimination on wellbeing (Branscombe et al., 1999; Molero et al., 2011). For example, studies indicate potential benefits of self-help groups such as Hearing Voices Network, which offer voice-hearers the opportunity to connect and identify with supportive others who share similar experiences and have been found to reduce IS and enhance adaptive coping (Corentin et al., 2023; Corrigan et al., 2013). However, further investigation is needed to explore wider clinical implications.

Finally, given the mixed results in respect to the relationship between perceived empathy in non-voice-hearers and identity integration, caution should be taken when considering potential clinical implications. Voice-hearers might benefit from support to help them recognise and remain open to expressions of empathy from others, including both verbal and non-verbal cues, as well as addressing any mistrust or negative beliefs that might interfere with perceiving empathy from others. Further, interventions and/or campaigns aimed at increasing understanding and empathy towards people who hear voices might also help improve perceptions of empathy in voice-hearers, though further research is required to establish this link. Incorporating the lived experience of voice-hearers into this, particularly of those who are publicly known and well-respected, might help foster acceptance and understanding. The need for such interventions has previously been noted (Reddyhough et al., 2021), however, further work is still required in this area.

Conclusion

This is the first known study to investigate between-group differences in social identity integration for voice-hearers experiencing high versus low levels of IS. Findings offer some tentative support for Amiot and colleagues' (2007) CDMSII, however, more research is required to investigate relationships between IS, perceptions of empathy in others and social identity integration, and further develop the theory, particularly in relation to the influence of the proposed inhibitors and facilitators. Given the non-significant results and methodological limitations noted, caution should be taken in respect to the clinical implications outlined until further research has been conducted to enhance understanding and establish the robustness of these findings.

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Executive Summary

The Role of Internalised Stigma and Perceived Empathy in Social Identity Processes for People who Hear Voices

Background

Hearing a voice (or voices) that others do not hear when there is no speaker around to explain the experience is not uncommon yet is widely stigmatised by society. Research on voice-hearers shows their voice-hearer social identity (how one sees themselves based on the groups they are connected to) has an important role in their wellbeing.

At any one point in time, an individual can hold multiple social identities. These identities can include things such as family roles, professional identities and health related experiences, just to name a few. For example, a person might identify as a mother, artist and voice-hearer. Researchers have shown that when one integrates these different identities so that they fit together well, this can lead to greater psychological wellbeing. On the other hand, when one keeps their different identities separate from one another, this can create tension or conflict for the person which can negatively affect their mental health.

In this study, we explored factors that are thought to either help or hinder the social identity integration process. Specifically, factors such as self-stigma are thought to slow or stop the integration process, making it harder for people to connect their multiple social identities. In contrast, factors such as empathy from other people are thought to facilitate the process.

In addition to looking at how these key factors affect social identity integration, this study also controls for several background factors that might

influence the relationship between self-stigma, empathy from others and social identity integration. These include factors like time since voices started, voice severity, and levels of paranoia and depression. Controlling for these background factors helps us to better understand the specific roles of self-stigma and empathy from others in social identity integration.

Aims

This study aimed to explore the following in self-identified voice-hearers:

1. Whether there are differences in levels of social identity integration between those who report higher levels of self-stigma compared to those who do not.
2. Whether higher levels of perceived empathy in others is related to higher levels of social identity integration.
3. Whether self-stigma and perceived empathy in others predict social identity integration, over and above the named background factors (time since voices started, voice severity, and levels of paranoia and depression).

Methods

Self-identified voice-hearers were recruited via social media and relevant organisations (e.g. Hearing Voices Network) to participate in the study. Participants completed an online questionnaire at a single time point and were asked questions relating to the primary topics of interest (self-stigma, perceived empathy in others,

social identity integration) and other background factors that might affect the results (time since voices started, voice severity, paranoia and depression).

Participants were split into groups based on their self-stigma scores (high- versus low-level) and compared on levels of social identity integration. In addition, the study explored whether participants' self-stigma and perceived empathy in others predict social identity integration over and above the other background factors.

Main Findings

A total of 76 participants completed the study. Firstly, we found no strong evidence that higher self-stigma is linked to lower social identity integration. Next, we found higher levels of perceived empathy in others was linked to greater social identity integration. Finally, we found that levels of self-stigma and perceived empathy in others did not strongly predict social identity integration after accounting for the background factors.

Conclusions

To conclude, out of the three predictions we set out to test, only one was supported by the results, providing some partial support for what we expected to find. Firstly, there was no strong evidence to show differences in levels of social identity integration between voice-hearers with high versus low levels of self-stigma. However, we observed a pattern in the results that was in the direction we expected (voice-hearers with high levels of self-stigma had lower levels of social identity integration), but this was not strong enough to confirm. More research is needed to investigate this relationship further. We found some encouraging signs that higher

levels of perceived empathy in others might be linked to better social identity integration. However, when we took the background factors into account, neither self-stigma nor perceived empathy in others predicted social identity integration on their own.

Taken together, the results were not strong enough to make firm conclusions, and this study highlights the need for further research to better understand the influence of self-stigma and perceived empathy in others on social identity integration. As such, the following suggestions should be approached with caution until more research is done to enhance our understanding. If future research finds stronger evidence that the observed patterns and relationships seen in this study hold true, voice-hearers might benefit from interventions that aim to reduce self-stigma and increase recognition of empathy from others. Public awareness campaigns and interventions aimed at facilitating understanding and empathy towards people who hear voices might also help improve perceptions of empathy in voice-hearers, though more research is needed in this area. Whilst the firm conclusions cannot be drawn, this study adds to what is known about social identity integration processes in voice-hearers and helps guide future research.

Connecting Narrative

I came onto the course with some previous research experience and was looking forward to the opportunity to build on these skills by developing and carrying out my own research. At the time of developing my project ideas, my areas of interest were primarily based on the clinical experience I gained before training which was with adult populations with complex mental health presentations across different settings. However, I was also keen to use this opportunity to try something new and took this opportunity when it presented during my first placement.

The process of completing this thesis was turbulent, with so many ups and downs. Early on, there were times when I felt under confident in my research capabilities, and although this improved over time, it was difficult to sometimes see the areas I had developed in. Upon reflection, I think this might have been to do with the limited time available to stop and reflect due to the difficulty of having to balance the many research responsibilities alongside other clinical and academic responsibilities, which I think was one of the biggest challenges for me with this piece of work. Specifically, I had to develop a skill in being able to switch between quite different areas of focus across my three projects, which also rarely coincided with the type of clinical work I was doing on placement.

Across my studies, I was interested in hearing the voice of the participant/patient. In research, I think it is important to honour lived experience and respect how participants understand, define and/or talk about their own experiences, as this empowers participants by centring their perspectives and experiences. I also valued involving people with lived experience in the development stages of my projects.

Service Improvement Project (SIP)

My SIP was the first project I fully developed and completed. I had my first placement in the service in which it is based and found I thoroughly enjoyed working with the patient group and in a clinical health setting. Because of this, I was drawn to this project and it enabled me to expand my areas of interest by doing research in an area that was new to me.

Being placed within the service during my first year was extremely valuable in understanding the service structure and making sense of the experiences reported by those who participated. I was keen to hear patients' perspectives and views as I believe it is essential when working to improve services. In addition to this, having the opportunity to hear the voices of patients who often shared past experiences of not feeling heard within the healthcare system felt significant. Further, the project felt particularly relevant and important given the recent Women's Health Strategy proposed by the government.

Systematic Review of the Literature (SRL)

Identifying and developing this project was a big challenge for me as the topic I settled on came after several other ideas were explored and developed. Whilst somewhat familiar with the process of conducting a systematic review, I had never completed one myself and had greatly underappreciated how challenging and time-consuming it could be to come up with an idea that was not yet done, feasible, theoretically sound, and interesting to me.

I settled on the topic I chose as it linked in with my previous clinical experience in an AMHT and I personally felt like it was an interesting and important

gap in the literature to address. Like with my service improvement project, I was keen to capture people's experiences and perspectives which made a qualitative methodology most suitable. Whilst this required a lot of reading to try and get my head around different qualitative methodologies and their uses and differences to inform my decision making and critical appraisal, I really valued this experience and it really helped me to develop my knowledge in this area, which I hope to apply in any future qualitative research I carry out.

Theory Driven Research Project (TDRP)

Like with my SRL, I was drawn to the topic of my TDRP from the clinical experience I gained from working in an AMHT and early intervention in psychosis service. During my roles within these teams, I was struck by the impact stigma had on the everyday lives of service users I worked with, and whilst I did not fully appreciate this at the time, how this often became internalised for many. The topic of public and internalised stigma came up during the teaching on psychosis my internal supervisor delivered during first year, which led me to reach out and express my interest in a developing project in this area.

Despite my interest in the chosen topic and initial feelings of excitement about doing a project in a relatively new area that draws on the application of social psychological theory in a clinical population, I found this project the most daunting. This was mainly due to my somewhat large recruitment target for a generally hard to recruit group. As expected, recruiting from this clinical population was quite difficult and took a lot of effort and perseverance. Despite this, I received positive feedback from participants and hearing voices network group facilitators, who expressed that

they felt the project was important and unique. I am very grateful to all those who took the time to participate in and/or disseminate the study.

Importantly, the project taught me the importance of non-significant findings, and how they can still be crucial in shaping our knowledge and understanding, especially in newer, less-researched areas.

Hopes for Future Research

In the future, I hope to carry forward my acquired research skills and build on them further. I recognise that prioritising research in my full-time clinical NHS role will be difficult unless time is protected for this. I intend to take a practice-based, co-produced approach to any future research I carry out within the services and field in which I plan to work. Specifically, I hope to contribute to further service development and/or explore the lived experience of those receiving support.

Acknowledgements

Firstly, I would like to acknowledge and thank every person who offered their invaluable time to consult on or participate in my research.

I would also like to thank my research supervisors for their guidance during this process. Additionally, I would like to thank all my clinical supervisors who each showed me such kindness and support and have helped shaped me on my journey to becoming a psychologist. I would also like to thank my course tutor, Dr Neil Carrigan, for his ongoing compassion and encouragement throughout training.

The solidarity, support and resilience of the 2022 DClinPsych cohort has been crucial to keeping me going over the last three years, and I feel very grateful to have shared this experience with you all. A special thank you to the friends in the cohort I grew particularly close to throughout the three years – you inspire me daily. I would also like to extend my thanks like to my close family and friends for their patience, kind words of encouragement and emotional support throughout training.

Appendices

Appendix A – Systematic Review of the Literature

A1: Author guidelines for the Personality and Mental Health Journal.

Free Format Submission

Personality & Mental Health now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Authors are responsible for checking all references for accuracy and ensuring inclusion in the text before submission. Personal communications need written authorisation (email is acceptable); they should not be included in the reference list. Unpublished doctoral theses may be cited (please state department or faculty, university and degree). No other citation of unpublished work, including unpublished conference presentations, is permissible. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
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All papers published in *Personality and Mental Health* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Manuscript style

The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. Please double-line space your manuscript. Manuscripts should not normally exceed 5,000 words in length, or equivalent in text, references and tables and should include a word count where possible. Longer articles, particularly reviews, may be considered on a case-by-case basis. Please contact a member of the editorial team to discuss before submission. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- The title page must list the full title, a short title of up to 40 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs on this page as Personality and Mental Health operates a 'blind' reviewing system.
- Include the name(s) of any sponsor(s) of the research contained in the paper, along with grant number(s) .
- Enter an abstract of up to 250 words for all articles, except book reviews. This should be a concise summary of the whole paper, not just the conclusions, and should be understandable without reference to the rest of the paper. It should contain no citation to other published work.
- Include up to ten key words that describe your paper for indexing purposes.
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Complex case studies of no more than 2,000 words in length are encouraged. The editors will invite up to three commentaries on the case study (500-1500 words). These commentaries will be drawn from disciplines relevant to each particular case.

Illustrations

Upload each figure as a separate file in either .tiff or .eps format, with the figure number and the top of the figure indicated. Compound figures e.g. 1a, b, c should be uploaded as

one figure. Tints (grey shadings) are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Where a key to symbols is required, please include this in the artwork itself, not in the figure legend. All illustrations must be supplied at the correct resolution:

- Black and white and colour photos - 300 dpi
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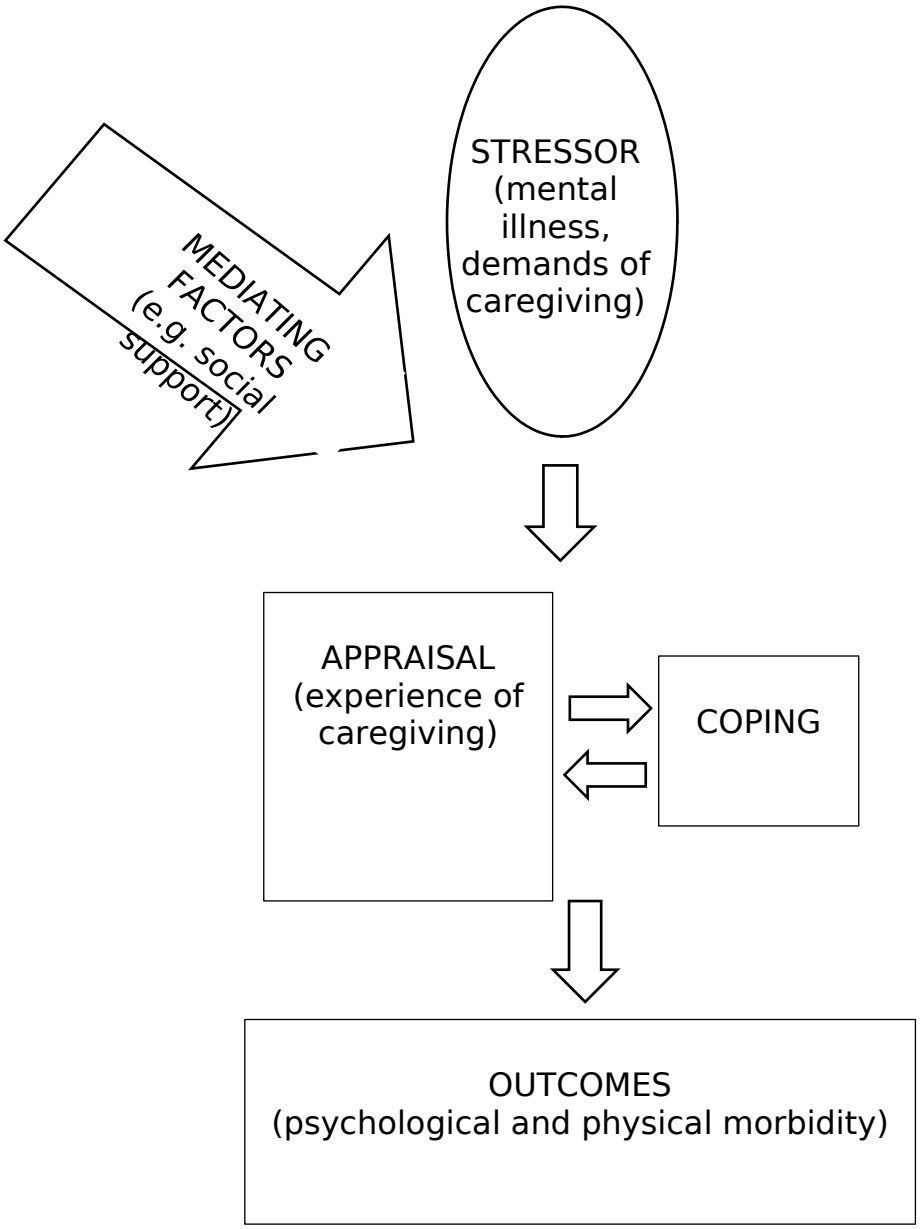
Tables should be part of the main document and should be placed after the references. If the table is created in excel the file should be uploaded separately.

A2: The stress-coping model of caregiving (adapted from Szmukler et al., 1996).



Appendix B – Service Improvement Project

B1: Author guidelines for the BMC Women's Health Journal.

Preparing your manuscript

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

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

Title page

The title page should:

present a title that includes, if appropriate, the study design e.g.: "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review" or for non-clinical or non-research studies a description of what the article reports list the full names and institutional addresses for all authors if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

indicate the corresponding author

Abstract

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

- Background: the context and purpose of the study
- Methods: how the study was performed and statistical tests used
- Results: the main findings
- Conclusions: brief summary and potential implications
- Trial registration: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered

prospectively (before enrolment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

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

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

Methods
The methods section should include:

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

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

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

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

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

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

- Ethics approval and consent to participate
- Consent for publication
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- Funding
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- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.
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Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

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Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets

analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv https://searchrxiv.org/, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

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

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.

BioMed Central strongly encourages the citation of any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information

recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. http://dx.doi.org/10.6084/m9.figshare.853801

With the corresponding text in the Availability of data and materials statement:
The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]

If you wish to co-submit a data note describing your data to be published in *BMC Research Notes*, you can do so by visiting our submission portal. Data notes support open data and help authors to comply with funder policies on data sharing. Co-published data notes will be linked to the research article the data support (example).

Competing interests

All financial and non-financial competing interests must be declared in this section.
See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each authors' competing interests in this section.

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

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Authors' contributions

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

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If you do not have anyone to acknowledge, please write "Not applicable" in this section.

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

Authors' information

This section is optional.
You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.
Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

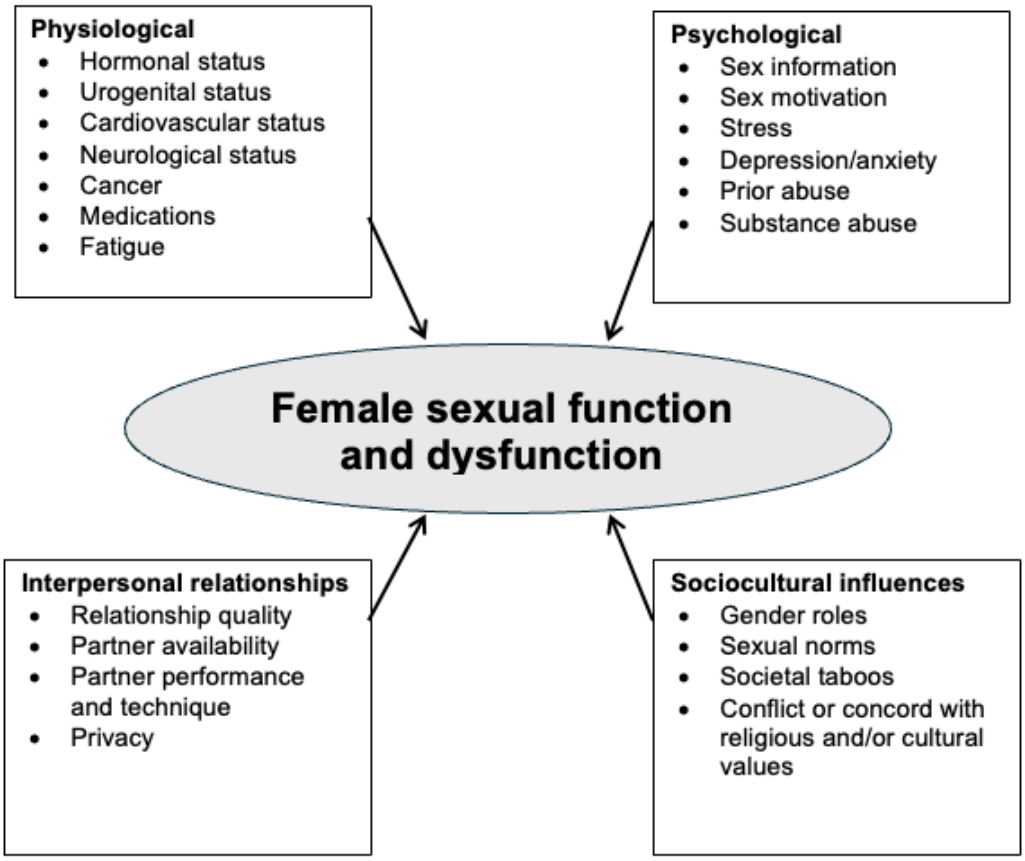
Always use footnotes instead of endnotes.

References

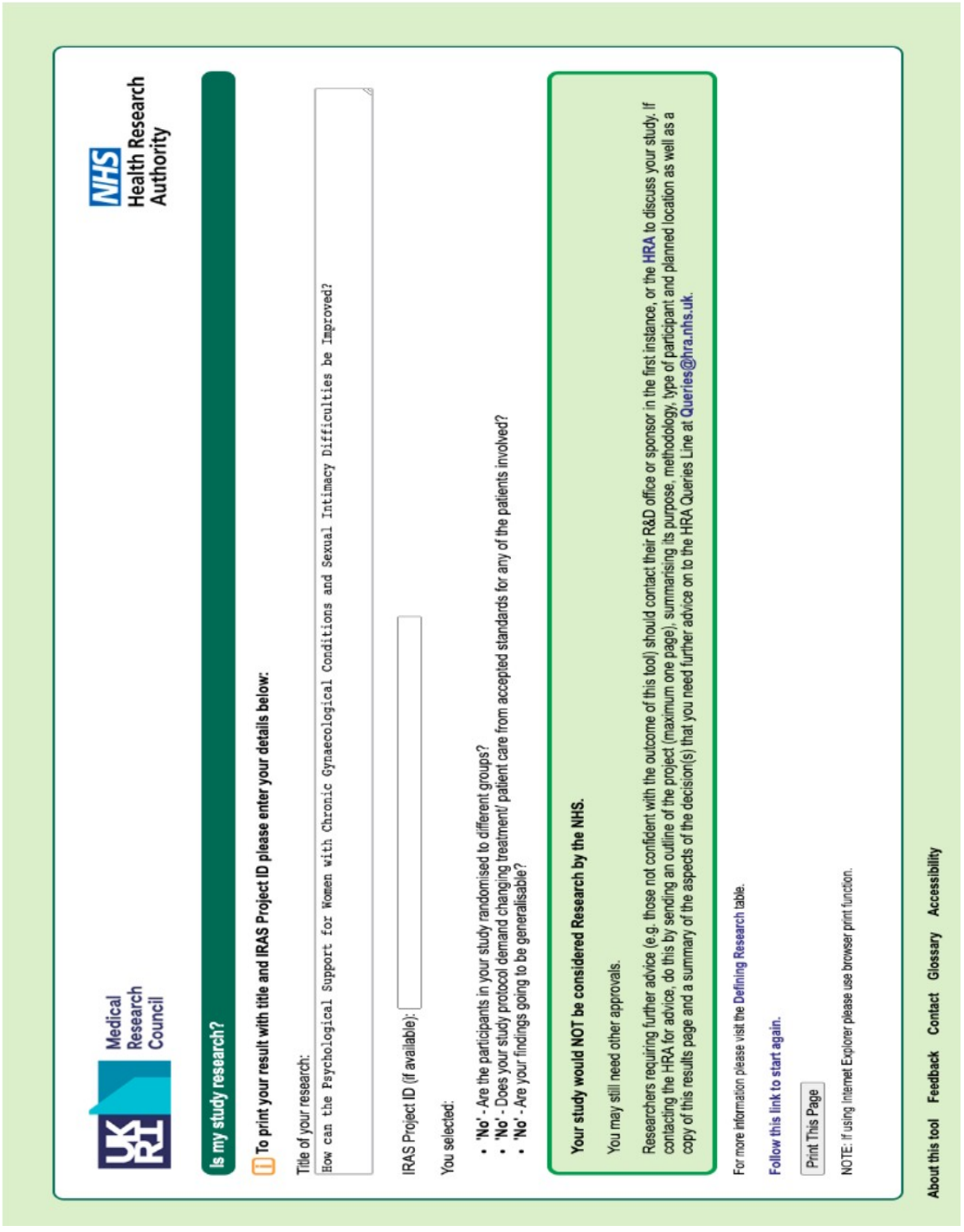
Examples of the Vancouver reference style are shown below. See our editorial policies for author guidance on good citation practice

Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format: The Mouse Tumor Biology Database. http://tumor.informatics.jax.org/mtbwi/index.do. Accessed 20 May 2013. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

B2: The biopsychosocial model (adapted from Zakhari, 2009).



B3: Project classification based on the Health Research Authority decision tool.



B4: The Oxford University Hospitals NHS Foundation Trust's approval.

Title:
How can the Psychosexual Support for Women with Chronic Gynaecological Conditions and Sexual Intimacy Difficulties be Improved in a Gynaecology Department?
Team:
Psychological Medicine / The Gynaecology Department
Aims:
This project will take place within the gynaecology department at the John Radcliffe Hospitals Women's Centre. The aims are as follows: - Understand how psychosexual support for women with chronic gynaecological conditions and sexual intimacy difficulties may be improved, and if this can be done in a cost-effective way. - Gain an insight into staff and patient awareness of current psychosexual support available, and their perceptions of this. - Understand staff and patient views on any unmet psychosexual patient needs and how these may be addressed.
Purpose:
To identity how psychosexual support for women with chronic gynaecological conditions and sexual intimacy difficulties can be improved, and how this may be done in a cost-effective way.
Design/method:
Design Mixed-method study. *Recruitment* Posters will be displayed around the gynaecology department to advertise the study. Relevant staff members will be contacted and invited to share their perspectives on the needs of patients with chronic gynaecological conditions and sexual intimacy difficulties, whether the support currently offered is meeting these needs, and if not, their views on how these might be met. Patients will be provided with study information leaflets at their appointments and will be able to access the online anonymous survey by scanning a QR code on the leaflet or following a link. At the end of the survey, patients will be asked if they consent to being contacted by the lead researcher to be interviewed about their views on the topic. Demographic information will be gathered to contextualise findings (e.g. age, sexual orientation, relationship status, service they are currently under). *Procedure* The project will have the following data collection phases: 1. Informal discussions with staff

Title:
- Information from this phase will be used to shape and inform questions for next phase. 2. Anonymous online survey - Due to the sensitive nature of the topic, participants may prefer to participate anonymously. 3. Online interviews - Participants who provide consent will be contacted and interviewed online by the trainee. It is hoped the interviews will lead to richer data and a more in depth understanding than a survey alone. Survey and interview questions will be co-created with patients with lived experience of chronic gynaecological conditions and sexual intimacy difficulties.
Outcomes:
Demographic information will be outlined descriptively. Quantitative survey data will be analysed using descriptive statistics. Braun and Clarke's (2006) six-step thematic analysis will be used to explore themes in qualitative data using a realist/essentialist approach. Qualitative data from the survey and interviews will be analysed separately. A potential outcome will be implementation of improved psychosexual provision for these patients across the department.
Dissemination/plans:
- Present findings and recommendations to service (e.g. departmental MDT meeting) - Produce accessible project summaries for patients under department - Publish findings in a relevant journal (e.g. Women's Health).

Do you think your proposal falls into the category of:

Research ☐ Audit ☐ Service evaluation X

Please add more information supporting your view below:

Please add text here:
According to the Health Research Authority decision tool (Appendix A), this project does not require IRAS/NHS ethics as it is not classified as research/an audit. This is because the findings will not be generalisable/transferable beyond the Gynaecology Department at the John Radcliffe's Women's Centre, and existing practice will not be measured against any evidence-based clinical standards. This project falls under the 'service evaluation' category as it looks to evaluate the effectiveness of the current psychosexual support available to patients with chronic gynaecological conditions and sexual intimacy difficulties, with the intention of generating information to inform local decision-making (e.g. implementation of the recommendations of how to improve the psychosexual support available to patients).

Dear Amber,

The classification committee reviewed your project today and agreed that it can be classed as service evaluation/improvement.
(Do you want to ***evaluate*** the ***effectiveness*** and or ***efficiency*** of your ***current practice***; the purpose of your ***evaluation*** to provide information of local relevance to inform local decision-making)
As such it is not subject to the Department of Health's *UK Policy Framework for Health and Social Care Research (Nov 2017).* It requires neither sponsorship nor research ethics review.
This opinion can be reviewed by reference to the HRA's algorithm, available at http://www.hra-decisiontools.org.uk/research/ and attendant leaflet, *Defining Research*, or by reference to the Health Care Quality Improvement Partnership (HQIP) *Guide for Clinical Audit, Research and Service Review*.

You should ensure that your department leads are aware of the project and are happy for the activity to take place. For service evaluation/development taking place in the hospital we ask for the project to get registered on Ulysses Oxford University Hospitals NHS Foundation Trust (oxnet.nhs.uk)

All service review activity should comply with clinical governance requirements.

With best wishes

Mel

On behalf of classification committee

NHS
Oxford University Hospitals
NHS Foundation Trust

Joint Research Office
Oxford University Hospitals NHS Foundation Trust
First Floor, OUH Cowley
Unipart House Business Centre, Garsington Road
Oxford, OX4 2PG

Joint Research Office
enabling successful research through collaboration

Mel Brookings
Research Support Specialist
Research and Development
MS Teams: Call I Chat
Email: melanie.brookings@ouh.nhs.uk

B5: Participant information sheet.

Participant Information Sheet

Study Title:
How can the psychosexual support for people with chronic gynaecological conditions and sexual intimacy difficulties be improved at the John Radcliffe's gynaecological department?

You are invited to take part in an online survey. Before you decide to take part, it is important that you understand why the study is being conducted and what participation will involve. We encourage you to take time to read the following information carefully. If you have any questions or would like some further information, please see the contact details at the bottom of the page.

What is the purpose of the study?

The aim of this study is to understand how to improve the psychosexual support available for people with chronic gynaecological conditions and sexual intimacy difficulties, who are currently receiving treatment at the John Radcliffe's Women's Centre.

We know that people living with a chronic gynaecological condition often experience sexual intimacy difficulties.

'Chronic gynaecological conditions' is a term used to cover a range of conditions that affect the female reproductive system for at least three months. This can include (but is not limited to) conditions such as heavy or irregular menstrual bleeding (e.g. endometriosis, adenomyosis) ovulatory disorders which can affect fertility (e.g. polycystic ovary syndrome) and menopause. 'Sexual intimacy difficulties' is a broad term used to cover a range of sexual difficulties that can be encountered. It includes a lack of sexual desire or pleasure during sexual activities, difficulties in getting sexually aroused or reaching orgasm, and/or experiencing pain during sexual activities. These difficulties may be experienced in a sexual relationship/s with another or yourself (e.g. masturbation).

Psychosexual support is known to be helpful for people with gynaecological conditions and difficulties with sexual intimacy. This can include offering people information about the condition, which can be accessed in various formats, such as self-help material, psychological support or psychological therapy.

Why have I been invited to take part?

You have been invited to take part in this study as you have responded to the study advertisements provided to you by staff or displayed at the John Radcliffe's Women's Centre.

To be eligible to take part in this study, you must be aged 18 or over and live in the UK. You must have a chronic gynaecological condition and be an outpatient currently

receiving treatment from a service based at the John Radcliffe's Women's Centre. The treatment you receive must not be from the gynae oncology service or the female genital mutilation service, as it is felt patients accessing these services will likely have specific support needs that go beyond the scope of this project.

In addition to this, you must also identify as someone who experiences difficulties with sexual intimacy. Your participation would be very much appreciated.

What will happen to me if I take part?

Your decision about whether to take part in this study will not affect the care you receive. We will not inform the clinicians involved in your care about whether you have decided to take part.

Part 1
You will be asked to complete a short anonymised online survey which will include a number of questions specific to your views on:

- The support available for people with gynaecological conditions and sexual intimacy difficulties
- How the support available might be improved

It is anticipated that it will take roughly 10-20 minutes to complete the survey.

Part 2
At the end of the survey, you will be given the option to opt-in to a follow-up online one-to-one conversation with the lead researcher. The aim of this would be to gain a more complete, in depth understanding of your views on this topic. One-to-one conversations will be held online at a time convenient to you. They are expected to last up to 30 minutes and will be held over the next couple of months.

Do I have to take part?

Participation in the study is entirely voluntary. It is up to you to decide whether or not to take part in this research study. If you decide to take part, you will be asked to provide your consent before providing any further information. You will be free to change your mind and withdraw at any time during the survey or one-to-one online conversation without giving a reason.

What are the possible advantages of taking part?

The information gained from this study will be used to improve psychosexual support within the John Radcliff Women's Centre. Therefore, by taking part, you will be helping us to improve psychosexual support for yourself and/or other patients who are accessing services at the John Radcliffe's Women's Centre.

What are the possible disadvantages and risks of taking part?

Whilst we don't anticipate there being any risks to taking part in this study, we recognise that for some, being asked about their views on the current psychosexual

support available may lead to difficult thoughts and feelings about the support they have received so far.

As you are unable to be identified from your responses, the researcher will be unable to provide direct support. Therefore, the following information has been provided should you need support:

- It may be helpful to speak with those in you NHS team that are directly involved in your care
- Call Samaritans listening service any time, on 116 123.
- Call NHS 111 by dialling 111.
- Make an appointment with your GP.
- Go to the local Accident and Emergency department if you are feeling suicidal or if you have self-harmed and are concerned about it.

How will my data be used?

All the information collected will be anonymised and will not be linked to you. You will not be asked to provide any personally identifiable information, except for on the consent form which will be kept separate from any other information collected. Any personally identifiable information potentially disclosed in survey answers or during the one-to-one conversation will not be included in any reports.

The survey responses and one-to-one conversations will be coordinated and analysed by Amber Bowen, a Trainee Clinical Psychologist. No member of the research team will see any data that is not already anonymised.

Your anonymised data will be stored securely on the Oxford University Hospital Foundation Trust's One Drive, a secure storage facility, for a maximum duration of 5 years, before it will be deleted.

What will happen to the results of the study?

The data will be analysed, written up and submitted as part of Amber Bowen's research portfolio, as part of the requirements for the Doctorate in Clinical Psychology. A report will also be submitted to a peer-reviewed journal so that the wider medical and psychological community can understand patient views on psychosexual support for people who experience gynaecological conditions and sexual intimacy difficulties, and hopefully use this to improve other NHS services.

Who has reviewed the study?

As participants will be current patients under Oxford University Hospital's NHS Foundation Trust, the study has been reviewed and approved by the Trust's Governance team, Clinical Trials and Research Governance team, and Oxford University Hospital's Psychological Medicine Clinical Governance Committee.

Contact details for further information

I would like to take this opportunity to thank you for taking the time to read this information.

If you would like to discuss any of the above information further, or if you have any questions about participating in the study, please contact:

Amber Bowen (Trainee Clinical Psychologist)
Oxford Institute of Clinical Psychology Training and Research, The Isis Education Centre, Warneford Hospital, Headington, Oxford, OX3 7JX
Email: Amber.Bowen@ouh.nhs.uk
Work Telephone: 07775110957

Susannah Jenner (Clinical Psychologist)
Oxford Institute of Clinical Psychology Training and Research, The Isis Education Centre, Warneford Hospital, Headington, Oxford, OX3 7JX

B6: Participant consent forms for the online survey and interviews.

Consent Form

Study Title:
How can the psychosexual support for people with chronic gynaecological conditions and sexual intimacy difficulties be improved at the John Radcliffe's gynaecological department?

- I confirm that I have read the information sheet dated November 2023 (version 3) for the above study. ☐
- I have had the chance to consider the information, and have been given the opportunity to ask questions about the study and/or my involvement. ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
- I agree to take part in the above study. ☐

Printed Name: .....

Signed: .....

Date: .....

Thank you for providing your consent to take part in the study.

Consent Form

Study Title:
How can the psychosexual support for people with chronic gynaecological conditions and sexual intimacy difficulties be improved at the John Radcliffe's gynaecological department?

You have reached this page because you have chosen to opt-in to a follow-up online one-to-one conversation with the lead researcher. The aim of this would be to gain a more complete, in depth understanding of your views on this topic.

One-to-one conversations will be held online at a time convenient to you over the next couple of months and are expected to last up to 30 minutes. The conversations will be recorded to allow the researcher to transcribe and analyse the results.

If you would like to discuss any of the above information further, or if you have any questions about participating in the study, please see the contact details at the bottom of the page.

- I confirm that I have had explained to me the purpose for recording being made and have been given the opportunity to ask questions. ☐
- I agree to recording being made and for it to be used for the purpose it is being made. ☐
- I understand that the recording will be kept in a secure place and encrypted format and deleted as soon as it has been used for the purpose it is being made. ☐

Printed Name: .....

Signed: .....

Date: .....

Please provide your email and contact number below, and we will contact you soon to arrange a time to talk.

Email: .....

Contact Number: .....

Contact details:

Amber Bowen (Trainee Clinical Psychologist)

B7: Summary of information gathered at phase one of the project.

Staff consultations revealed that awareness of the current psychosexual support available was varied amongst staff. Most staff stated they make outward referrals (e.g. GP, sexual health clinic) for patients who report sexual intimacy difficulties. Whilst some staff members are aware psychosexual support is available for patients under the Pelvic Pain Service, they commented on how it should be available to all patients accessing reproductive health services.

Staff shared the view that there is not enough “in house” psychosexual support, and stated clinicians do not ask patients about their psychosexual needs as they believe there is nothing they can offer in terms of support. All staff members felt as though more needs to be done to address psychosexual needs of patients. Suggestions included providing patients information in leaflets, resources or videos, as well as offering more support in the form of time-limited one-to-one sessions or groups.

B8: The online survey question scheduled used for phase two.

	Question	Format
1.	Are you aware of the current psychosexual support available within the gynaecology department for patients with chronic gynaecological conditions and sexual intimacy difficulties?	Dichotomous question Yes/No If no, skip to question 4a
2a.	How confident are you that the current psychosexual support available would/does meet your needs?	Rating scale 1 – Very unconfident 2 – Somewhat unconfident 3 – Neither unconfident or confident 4 – Somewhat confident 5 – Very confident
2b.	Please provide a reason for your answer to question 2a.	Open text (optional)
3a.	How satisfied are you with the current psychosexual support available for patients who experience chronic gynaecological conditions and sexual intimacy difficulties?	Rating scale 1 – Very dissatisfied 2 – Somewhat dissatisfied 3 – Neither dissatisfied or satisfied 4 – Somewhat satisfied 5 – Very satisfied
3b.	Please provide a reason for your answer	Open text (optional)
4a.	Do you think more psychosexual support should be provided for patients with chronic gynaecological conditions and sexual intimacy difficulties?	Dichotomous question Yes/No
4b.	Please provide a reason for your answer	Open text (mandatory)
5a.	Would you be likely to engage in psychosexual support if it was offered? (see above for more information on types of support)	Dichotomous Yes, I'd be likely to engage in the support

		mentioned above (go to question 5c) No, I'd be unlikely to engage in any of the support mentioned above (go to question 5b)
5b	Please provide a reason for your answer.	Open text (mandatory - go to end of survey)
5c.	From the following options, please select all types of psychosexual support you are **likely** to engage in if they were on offer:	Multiple choice 1. Self help material 2. Resource pack 3. Pre-recorded webinar 4. Live webinar 5. Group support 6. One to one psychosexual support
5d.	Please provide your reason/s for each of your selected answer/s (e.g. what would you find specifically helpful, what interests you?)	Open text (mandatory)
5e.	From the following options, please select all types of psychosexual support you are **unlikely** to engage in if they were on offer:	Multiple choice 1. Self-help material 2. Resource pack 3. Pre-recorded webinar 4. Live webinar 5. Group support 6. One to one psychosexual support
5f.	Please provide your reason/s for each of your selected answer/s (e.g. what are the barriers, what puts you off?)	Open text (mandatory)
5g.	For each of the following options, please rank your choices based on how helpful you think that type of	Rank

	psychosexual support would be, with 1 being the most helpful and 6 being the least helpful.	1. Self help material 2. Resource pack 3. Pre-recorded webinar 4. Live webinar 5. Group support 6. One to one psychosexual support
6a.	If you were invited to group-based support and were in a relationship, would you want your partner to be present?	Multiple choice question Yes No N/A – I wouldn't engage in group-based support or I don't have a partner (go to question 8a)
6b.	Please provide a reason for your answer	Open text (optional)
7a.	If you were invited to a group-based support, would it matter to you what sex/gender the facilitators were?	Dichotomous question Yes/No
7b.	Please provide a reason for your answer	Open text (mandatory)
8a.	Are there any aspects of your identity (such as your age, relationship status, gender identity, sexuality, disability, religious or cultural background) that you think would be relevant to consider when being offered psychosexual support?	Dichotomous question Yes/No
8b.	Please provide a reason for your answer	Open text (optional)
	Is there anything else you would like to add regarding psychosexual support offered in the department for people with chromic gynaecological conditions and sexual intimacy difficulties?	Open text (optional)

B9: The semi-structured interview schedule developed for phase three.

1a.	Can you tell me about how supported you felt in being made aware of the current psychosexual support available for patients with chronic gynaecological conditions and sexual intimacy difficulties?
1b.	Was there anything in particular that helped increase your awareness of the current psychosexual support available?
1c.	In your opinion, what more can be done to better support patients to increase their awareness of the psychosexual support available?
2a	Based on your experience, what are your views on the current psychosexual support available for patients with chronic gynaecological conditions and sexual intimacy difficulties?
2b.	Based on your experience, do you think the current psychosexual support available meets the needs of patients? Can you tell me reason/s for you answer?
3a.	Can you tell me about how you would you feel about engaging in (further) support for sexual intimacy difficulties?
3b.	In your opinion, what should staff consider to help patients feel comfortable to engage in support for sexual intimacy difficulties?
3c,	Can you tell me about whether you foresee there being any barriers to engaging in support for sexual intimacy difficulties?
3d.	Can you tell me if you have any ideas about what might help reduce these barriers or difficulties?
4a.	For the next few questions, I will share my screen to remind you of the different types of psychosexual support that can exist for people with gynaecological conditions and sexual intimacy difficulties (*share screen*). Can you see what I have shared? In your view, what type or types of support do you think would be most helpful or valuable for patients? Can you tell me about the reason/s for your answer?
4b.	In your view, what type or types of support do you think would be least helpful or valuable for patients? Can you tell me about the reason/s for your answer?
4c.	What are your views on patients being offered self-help material or a resource pack whilst they are on the waiting list to be seen by a staff member?
4d.	If you were invited to engage in psychosexual support in the form of group sessions or one to one sessions, would you prefer this to be delivered online or in person? Can you tell me about the reason/s for your answer?
4e.	If you were invited to attend group-based psychosexual support, how would you feel about attending alongside other patients had different gynaecological conditions, whilst having the common experience of sexual intimacy difficulties?
4f.	If you were invited to attend group-based psychosexual support, how would you feel about attending alongside other patients who might differ to you in terms of their age, relationship status, gender identity, sexuality, ability, religious or cultural background?

B10: Reflective and reflexive statement.

The interviews were conducted and analysed by the first author (AB), a 30-year-old white British female currently training as a Clinical Psychologist. AB was on placement in other NHS services during the project, though had a previous placement in the Pelvic Pain Service as part of training which led to the development of the project. All interview participants were informed of AB's trainee status and experience of working service when outlining the rationale for the project. AB had no prior clinical experience with any of the interview participants.

AB entered the process having had no prior experience of qualitative research. AB recognised that the topic of the research was one which required participants to talk openly about a sensitive topic that could be seen as 'taboo' and considered how this, along with participants' unfamiliarity with the researcher and the imbalance of power, might have influenced participants' accounts.

AB used a research diary to record assumptions, expectations, and thoughts and feelings experienced throughout the process. This was also used to reflect on the researcher's standpoint and personal positioning. AB has no direct personal experience of living with a gynaecological condition and receiving gynaecological care, though has second-hand experience via people close in her personal support system. Further, AB has experience of supporting a family member with a stigmatised 'invisible disability' to navigate the healthcare system. It was recognised that the researcher's perspective influences steps taken throughout the research process, particularly when analysing and interpreting the data.

B11: Preliminary analysis of qualitative survey data.

Themes:	Codes:
Improve Access	Not enough support is offered Not enough support is available for PMDD There support is too brief for people with comorbidities More support is needed More support is needed to really address the impact More support means more understanding Long wait for support Differences in opinion on amount of support needed Accessing support in my own time is helpful Access is difficult for people who work
Offer a variety of support	There's value in offering support in different formats
Tailor support to individual needs	Everyone has their individual experience One-to-one support allows for individualised treatment One-to-one support would suit my personal needs best My sexuality should be considered in psychosexual support Interventions that are broad are unhelpful as they are not specific to me
Talking about sexual intimacy difficulties feels unsafe	The topic is uncomfortable to discuss Sex is a private topic and not to be discussed in groups Having a trauma history would make it difficult to talk openly I wouldn't feel able to talk about this topic in a group The topic feels uncomfortable to discuss in a group You wouldn't be able to get personal in a group Differences in identity can make groups feel unsafe Differences in identity don't matter Differences in sexuality should be considered Differences in age should be considered It's difficult to talk to a male clinician Female clinician preferred – it feels more safe Sex of clinician doesn't matter
Connection to others	Not feeling alone is important Talking about the problem with another helps Self-help materials/resource packs are limited as you don't talk to someone

	It would be helpful for my partner to attend I wouldn’t want my partner to attend

B12: Documents used for dissemination.

Subject: Findings from service improvement project: Psychosexual support for gynae patients

Dear XXX,

As you might recall, towards the end of last year you kindly volunteered your time to meet with me to share your views on the current psychosexual support available to women with gynaecological conditions and sexual intimacy difficulties, and how this might be improved. This was part of the service improvement project which aimed to help us understand how the psychosexual support for women with gynaecological conditions and sexual intimacy difficulties can be improved.

The discussions with staff members were part of the first step of the project. Since then, we have heard from several patients about their views on this topic, either via an online survey or in one-to-one interviews with a member of the research team.

I'm pleased to say that we have now completed the project, and we are writing to you to share a summary of the findings and recommendations for next steps.

Please see the attached document for a brief summary of the main findings.

The following recommendations were made based on the findings:

- To increase access to psychosexual support for patients across the gynaecology department and offer a range of support outlined, make a business case to request more resources.
- Should the availability of psychosexual support expand so patients from services across the gynaecology department can access it, a range of steps should be taken to increase awareness of the support amongst staff (e.g. an information leaflet for staff about the psychosexual support on offer, a clear outline of eligibility criteria and referral processes)
- Create accessible psychosexual self-help material or a resource pack containing educational material to offer to patients whilst they are on the waiting list for support.
- Offer a range of psychosexual support, with a mix of online and in-person options to meet different accessibility needs and personal preferences. This includes pre-recorded webinars, more one-to-one psychosexual support with the opportunity to involve partners, and group-based support.
- Signpost patients to online forums and communities to allow patients to foster connection with other people who share similar experiences.

This information will be presented these findings to the Pelvic Pain Service, as staff from the psychology team were involved in the project. We also intend to submit the project for publication in 'Women's Health' and can share the article with you in due course if you would like to know more.

Thanks again for your involvement in the study.

Kind regards,

Amber Bowen (Trainee Clinical Psychologist and Lead Researcher)

How the Psychosexual Support can be Improved at the Women's Centre - Summary of Main Findings

Online Survey

24 patients completed an online survey to share their views:

42% of participants reported they were aware of the current psychosexual support offered.

90% of participants stated that they think more psychosexual support should be provided.

Types of psychosexual support participants are **most likely** to engage in:

Participants ranked one-to-one support as the **most helpful** form of support, and group-based support was ranked as the least helpful.

Interviews

8 patients were interviewed. The following five themes emerged from the data:

Increase Awareness

"I think rather than kind of waiting for people to ask about it I think that it probably should be... advertised more"

Participants emphasised the importance of increasing patient awareness of the psychosexual support.

Improve Access

Participants felt as though access to psychosexual support should be improved.

"I think if they went on longer, erm you probably could get to the bottom of it"

One Size Doesn't Fit All

Participants highlighted that each person will have different preferences and needs to be met by psychosexual support offered.

"For each of the areas, somebody is going to find some value in that. Whether it be a resource pack... self-help material...seeing somebody on a one-to-one basis or in a group"

Talking to Others Can Feel Unsafe

Participants felt as though talking about sexual intimacy difficulties with others can feel unsafe.

"It sort of is still like a taboo subject isn't it, so, getting people to openly talk... is like the first hurdle to getting things going"

Let's be in it Together

Participants described wanting psychosexual support to involve a sense of connection to another, including staff, partners and peers.

"I think it would be good if, the partners will be involved as well..."

Study Summary

A chronic gynaecological condition (CGC) is a term used to cover a range of conditions that affect the female reproductive system for at least three months. Some examples include endometriosis, polycystic ovary syndrome, and chronic pelvic pain. Women with CGCs are more likely to experience difficulties with sexual intimacy. This is usually due to either:

- Sexual dissatisfaction - a negative experience of sexual intimacy due to a lack of sexual pleasure or not feeling connected and/or safe with another person.
- Female sexual dysfunction – difficulties with sexual functioning due to either a lack of sexual desire, impaired sexual arousal, inability to achieve orgasm, or pain with sexual activity.

Psychosexual support is one way a patients' sexual intimacy difficulties might be treated. Psychosexual interventions target a variety of factors (e.g. thoughts, emotions, behaviours, couple interactions) that contribute to sexual intimacy difficulties, to ultimately improve the quality of patients' sexual functioning. Whilst we know that psychosexual interventions are effective at improving sexual function and sexual wellbeing outcomes for women with CGCs and sexual intimacy difficulties, we are yet to understand their views and perspectives on psychosexual support and how it can be improved.

This project is a "service improvement project". This means the project was carried out within a specific health service, with an aim of improving an aspect of that

service. This project was carried out at the John Radcliffe's Women's Centre, with psychologists from the Pelvic Pain Service. The main aims of the project were to:

- Understand patient views on how the psychosexual support for women with CGCs and sexual intimacy difficulties can be improved, and if this can be done in a cost-effective way.
- Explore patient perspectives on engaging in psychosexual support.
- Gain insight into patient views of the current psychosexual support available and their perspectives on any unmet psychosexual patient needs.

Twenty-four patients with CGCs and sexual intimacy difficulties completed an anonymous online survey to share their views on the topic. Eight of these patients chose to take part in research interviews. Once the data was collected, it was analysed and summarised. The survey showed that only 42% of participants reported they were aware of the current psychosexual support offered. Of these, 90% stated that they think more psychosexual support should be provided. Overall, 92% of participants stated they would be likely to engage in psychosexual support. One-to-one support was the type of support most participants would be likely to engage in and was ranked as the most helpful form of support. Group-based support was the type of support least participants would be likely to engage in and was ranked as the least helpful form of support.

The researchers identified five themes from the interview data. The first one 'increase awareness' described how participants felt increasing patient awareness of the psychosexual support was important. 'Improve access' explores the core idea

that access to psychosexual support should be improved by increasing patients' opportunities to access support and by making sure it is reachable. The third theme 'one size doesn't fit all' describes patients views on how each patient will have different preferences and needs to be met by psychosexual support offered. 'Talking to others can feel unsafe' captures the view that talking about sexual intimacy difficulties feels unsafe, and includes the mixed opinions towards what makes group-based psychosexual support feel particularly unsafe. Finally, 'let's be in it together' described how participants typically expressed a desire for psychosexual support to involve a sense of connection to another, whether that was with staff themselves, partners and/or peers.

Overall, all participants who took part in this study outlined improvements that could be made to the current psychosexual support. Based on these outlined improvements, we recommended that the service leading on the project should aim to increase staff and patient awareness of the psychosexual support available using different platforms and resources. We also recommended the service to request more funding and resources to:

- Create accessible psychosexual self-help material or a resource pack containing educational material to offer to patients whilst they are on the waiting list for support.
- Offer a range of psychosexual support, with a mix of online and in-person options to meet different accessibility needs and personal preferences. This includes more one-to-one psychosexual support, with the opportunity to involve partners and group-based support.
- Signpost patients to online forums and communities.

Appendix C – Theory Driven Research Project

C1: Author guidelines for the British Journal of Clinical Psychology.

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.
New submissions should be made via the **Research Exchange submission portal**. You may check the status of your submission at any time by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our **FAQs** or contact **submissionhelp@wiley.com**.
All papers published in the *British Journal of Clinical Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

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

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

2. AIMS AND SCOPE

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

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

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

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

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

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Papers describing quantitative research should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.
In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.
Refer to the separate guidelines for **Registered Reports**.
All systematic reviews must be pre-registered and an anonymous link to the pre-registration must be provided in the main document, so that it is available to reviewers. Systematic reviews without pre-registration details will be returned to the authors at submission.

4. PREPARING THE SUBMISSION

Free Format Submission

British Journal of Clinical Psychology now offers free format submission for a simplified and streamlined submission process.
Before you submit, you will need:
Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer (If you do submit separate files, we encourage you to also include your figures within the main document to make it easier for editors and reviewers to read your manuscript, but this is not compulsory). All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
The title page of the manuscript, including a data availability statement and your co-author details with affiliations. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)* You may like to use this template for your title page.

Important: the journal operates a double-anonymous peer review policy. Anonymise your manuscript and prepare a separate title page containing author details. *(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)*
An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*
To submit, login at **https://wiley.atyponrex.com/journal/BJC** and create a new submission. Follow the submission steps as required and submit the manuscript.
If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission
Contributions must be typed in double spacing. All sheets must be numbered.
Cover letters are not mandatory; however, they may be supplied at the author's discretion.

Parts of the Manuscript
The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page
You may like to use **this template** for your title page. The title page should contain**:**
A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
A short running title of less than 40 characters;
The full names of the authors;
The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
Abstract;
Keywords
Data availability statement (see Data Sharing and Data Accessibility Policy);
Acknowledgments.

Author Contributions
For all articles, the journal mandates the CRediT (Contribution Roles Taxonomy)—more information is available on our **Author Services** site.

Abstract
Please provide a structured abstract under the headings: Objectives, Methods, Results, Conclusions. For Articles, the abstract should not exceed 250 words. For Brief Reports, abstracts should not exceed 120 words.

Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access

the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

Keywords
Provide appropriate keywords.

Acknowledgments
Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Practitioner Points

All articles must include Practitioner Points – these are 2-4 bullet points, following the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.

Main Text File

As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors.
Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTex (.tex) format.

If submitting your manuscript file in LaTex format via Research Exchange, select the file designation "Main Document – LaTeX .tex File" on upload. When submitting a LaTex Main Document, you must also provide a PDF version of the manuscript for Peer Review. Please upload this file as "Main Document - LaTeX PDF." All supporting files that are referred to in the LaTex Main Document should be uploaded as a "LaTeX Supplementary File."

LaTex Guidelines for Post-Acceptance:
Please check that you have supplied the following files for typesetting post-acceptance:
PDF of the finalized source manuscript files compiled without any errors.
The LaTeX source code files (text, figure captions, and tables, preferably in a single file), BibTex files (if used), any associated packages/files along with all other files needed for compiling without any errors. This is particularly important if authors have used any LaTeX style or class files, bibliography files (.bbl, .bst. .blg) or packages apart from those used in the NJD LaTex Template class file.
Electronic graphics files for the illustrations in Encapsulated PostScript (EPS), PDF or TIFF format. Authors are requested not to create figures using LaTeX codes.

Your main document file should include:
A short informative title containing the major key words. The title should not contain abbreviations;
Abstract structured (objectives/methods/results/conclusions);
Up to seven keywords;

Practitioner Points: Authors will need to provide no more than 2-4 bullet points, written with the practitioner in mind, that summarize the key messages of their paper to be published with their article;
Main body: formatted as introduction, materials & methods, results, discussion, conclusion;
References;
Tables (each table complete with title and footnotes);
Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below).
Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.
As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors. Do not mention the authors' names or affiliations and always refer to any previous work in the third person.
The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References
This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Tables
Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures
Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.
Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.
Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Supporting Information
Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.
Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the **APA Publication Manual** published by the American Psychological Association. The following points provide general advice on formatting and style.

Language: Authors must avoid the use of sexist or any other discriminatory language. The BPS's Inclusive Language Guidance provides a set of recommendations to support the key principles of inclusivity in writing.

Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Units of measurement: Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.

Effect size: In normal circumstances, effect size should be incorporated.

Numbers: numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

C2: Ethical approval.

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Lorna Hogg & Amber Bowen
Oxford Institute for Clinical Psychology Training & Research (OXICPT)
Isis Education Centre
Warneford Hospital
Oxford

30 April 2024

Dear Lorna and Amber,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R92775/RE001

Study title: The Role of Internalised Stigma and Perceived Empathy in Social Identity Processes for People who Hear Voices

Short title: Stigma and Identity for People who Hear Voices

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures 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 from 30th April 2024 until 29th October 2025.

Insurance-provided indemnity arrangements are in place for the duration of the approval stated above. It is your responsibility to ensure that you request an extension to the end date for indemnity to remain in place should you continue the research beyond the dates covered.

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

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for
Dr Helen Barnby-Porritt
Research Ethics Manager

C3: Participant information sheet.

Oxford Institute of Clinical Psychology Training and Research

Principal Investigator: Lorna Hogg (Clinical Psychologist)
lorna.hogg@hmc.ox.ac.uk

Primary Researcher: Amber Bowen (Trainee Clinical Psychologist)
amber.bowen@hmc.ox.ac.uk

OXCIPT Telephone Number: 01865 226431

PARTICIPANT INFORMATION SHEET

Stigma and Identity for People who Hear Voices

CUREC Approval Reference: R92775/RE001

My name is Amber Bowen, and I am a Trainee Clinical Psychologist at the University of Oxford. I am currently investigating how stigma experienced by people who hear voices can affect how they see themselves.

To do this, I am working alongside Lorna Hogg (The Principal Researcher), who is attached to the Oxford Institute of Clinical Psychology Training and Research at the University of Oxford and Dr Helena Laughton (Counselling Psychologist) from Oxford Health NHS Foundation Trust.

You are invited to take part in an online survey. Before you decide to take part, it is important that you understand why the study is being conducted and what participation will involve.

Please read through this Participant Information Sheet before agreeing to participate (if you wish to) by ticking the 'yes' boxes below. If anything is unclear and you have any questions, or would like some further information, please email the primary researcher (Amber Bowen) at amber.bowen@hmc.ox.ac.uk.

What is the purpose of this study?

People who hear voices can experience stigma from others in society. The aim of this research is to investigate how stigma experienced by people who hear voices can affect how they see themselves. We're also interested in how empathy from others can affect this.

We hope that learning more about these factors might help address some of the unhelpful attitudes held by members in society towards those who hear voices, and increase our understanding in order to develop better ways of supporting people who hear voices.

Why have I been invited to take part?

You are invited to take part in this study if you are aged 18 years or over, live within the UK and

identify as someone who hears voices.

Do I have to take part?

No, taking part is entirely voluntary. You may withdraw at any point for any reason by pressing the 'Exit' button or closing the browser.

Please note, the answers you provide up until the point you withdraw will be included in the study. As the data you provide is anonymous (which means you will not be identifiable from your answers) it will not be possible to extract your information once it has been recorded.

What will happen if I decide to take part?

If you decide to take part in this online study, you will first be asked to provide your informed consent before you participate. You will then be presented a series of questionnaires. The questionnaires will include some questions about your mental health, your identity as someone who hears voices and how you experience people who do not hear voices themselves. It should take approximately 15-20 minutes to complete the study. No background knowledge is required.

If you are interested in taking part in the study, but are unable to complete the questionnaires online due to accessibility difficulties, please contact the primary researcher (Amber Bowen; amber.bowen@hmc.ox.ac.uk) to arrange a time at your convenience to complete the survey via telephone.

During the telephone conversation, you will be asked to provide oral consent to take part in the research. The primary researcher will then read out the questions for you to answer. The discussion will not be recorded, although your responses to the questions asked will be noted by the researcher. You have the right to withdraw at any point during the telephone call, and your data will not be included in the study. Please note, once the telephone call has ended your data will be unidentifiable (not linked to you). Therefore, it will not be possible to extract your information once the telephone call has ended.

What are the possible disadvantages/risks of taking part?

Whilst we don't anticipate there being any disadvantages or risks to taking part in this study, we recognise that for some, being asked questions about their mental health and identities may lead to difficult thoughts and feelings.

As you are unable to be identified from your responses, the researchers are unable to provide direct support. Therefore, you will be directed to a debrief page at the end of the study that will provide details of organisations able to offer support.

How will my information be used?

If you participate in the survey online, then the data you provide will be anonymous as you will not be asked to provide any information that could directly identify you. Your IP address will not be stored[1].

Alternatively, if you choose to contact the primary researcher to request to complete the questionnaires via telephone due to accessibility difficulties, you will be asked to give some personally identifiable information (e.g. email address, telephone number) to allow the researcher to contact you.

The information provided is the **research data** (e.g. consent forms, questionnaire answers). Any research data from which you can be identified (i.e. email address, telephone number) is known as **personal data.**

Reasonable steps will be taken to ensure the data you provide remain confidential. The data you provide will only be accessible to the researchers identified on this form. All data will be stored in a password-protected electronic file on University of Oxford secure servers. No personal data will be included in academic publications, conference presentations or reports for external organisations.

Research data will be stored for 3 years after publication or public release of the research in line with the University of Oxford research data policy. After this point, research data will then appropriately deleted and destroyed.

Personal data (only required if you complete the questionnaires via telephone) will be stored until the telephone takes place. Once the telephone call has ended, this data will be deleted and destroyed.

Data protection regulation requires that we state the legal basis for processing the information about you. 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 research. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from https://compliance.admin.ox.ac.uk/individual-rights.

What will happen to the results of the study?

Using the **research data**, the results will be written up by Amber Bowen (Primary Researcher and Trainee Clinical Psychologist) and submitted towards the partial fulfilment of the Doctorate in Clinical Psychology. In addition to this, we hope to report our findings in academic publications or conference presentations, or present them to relevant charities. If you found out about the study via Facebook forums or the Hearing Voice Network, we hope to make the results accessible on these platforms.

Please note, you will not be identified in any reports or publications arising from the study. All **personal data** will be removed or changed before information is shared with other researchers and the results are made public.

Who has reviewed this research?

This research has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee [R92775/RE001].

Who do I contact if I have a concern or I wish to complain?

If you have any questions or concerns about any aspect of this research, please speak to Amber Bowen (Trainee Clinical Psychologist; amber.bowen@hmc.ox.ac.uk) or their supervisor Lorna Hogg (Clinical Psychologist; lorna.hogg@hmc.ox.ac.uk), and we will do our best to answer your query. I/ 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 University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

Please note that you may only participate in this survey if you are 18 years of age or over.

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

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

☐ Yes, I agree to take part

C4: Online and oral consent forms.

Oxford Institute of Clinical Psychology Training and Research
Principal Investigator: Lorna Hogg (Clinical Psychologist)
lorna.hogg@hmc.ox.ac.uk

Primary researcher: Amber Bowen (Trainee Clinical Psychologist)
amber.bowen@hmc.ox.ac.uk

OXCIPT Telephone Number: 01865 226431

UNIVERSITY OF OXFORD

ONLINE CONSENT FORM

Stigma and Identity for People who Hear Voices

CUREC Approval Reference: R92775/RE001

Thank you for your interest in participating in our study. As a reminder, this study will aim to investigate the how stigma experienced by people who hear voices can affect how they themselves and the extent to which their identity as a voice hearer fits with the important social groups in their life.

Please read through the following statements, and check 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 3 dated February 2024 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without penalty.	☐
3	I understand that if I withdraw from the study, the responses I provide up until that point will be included in the study.	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data.	☐
5	I understand who will have access to the 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 I will not be identifiable from any publications or conference presentations or reports.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I confirm that I have read the above information and am willing to continue to take part in this study	☐

Oxford Institute of Clinical Psychology Training and Research

Principal Investigator: Lorna Hogg (Clinical Psychologist)
lorna.hogg@hmc.ox.ac.uk

Primary Researcher: Amber Bowen (Trainee Clinical Psychologist)
amber.bowen@hmc.ox.ac.uk

RECORD OF ORAL CONSENT

Stigma and Identity for People who Hear Voices

CUREC Approval Reference: R92775/RE001

Interviewee Number:

Date:

Project Explained (Yes/No):

Participant agreed to the researcher noting their responses (Yes/No):

Participant agreed to their information being included in the study once the telephone call ends (Yes/No):

C5: Debrief form shown or read to participants at the end of the study.

Oxford Institute of Clinical Psychology Training and Research

Principal Investigator: Lorna Hogg (Clinical Psychologist)
lorna.hogg@hmc.ox.ac.uk

Primary Researcher: Amber Bowen (Trainee Clinical Psychologist)
amber.bowen@hmc.ox.ac.uk

DEBRIEF

Stigma and Identity for People who Hear Voices

CUREC Approval Reference: R9775/RE001

Thank you for taking part in this study. We really appreciate your help!

If you know anyone else who might like to participate in this study, please send them the following link to the information sheet for further details:

https://psychiatryoxford.qualtrics.com/jfe/form/SV_4Og0Y9q37gWcSkC

This study aimed to investigate how stigma experienced by people who hear voices can affect how they see themselves. We're also interested in how empathy from others can affect this. We hope that learning more about these factors might increase our understanding of the experiences of voice hearers and help us develop better ways of supporting people.

As a reminder, if you participated online then all your results are anonymous. If you opted to participate via telephone, we deleted your personally identifiable information (e.g. email address or telephone number) as soon as you completed the survey. All survey responses are stored in a password-protected electronic file on University of Oxford secure servers that can only be accessed by the research team.

Further advice and support

We hope that you enjoyed taking part in this study and we very much appreciate your contribution to this research, However, if you are affected by the questions asked in this study or are concerned about your mental health more generally, we encourage you to speak to your general practitioner (GP) who can then refer you for further specialist help, or call the NHS 111 helpline.

Alternatively, if you are already receiving support from NHS mental health services, we encourage you to speak to a professional from the team who is involved in your support.

You may also wish to contact the organisations below who offer support to people, including people who hear voices or have other unusual experiences or beliefs that some find hard to understand:

Samaritans
Telephone: 116 123 (24 hours a day, free to call)
Email: jo@samaritans.org
Website: www.samaritans.org
Provides confidential, non-judgemental emotional support for people experiencing feelings of distress or despair. Get support from a trained volunteer via telephone or email, or by writing a letter.

SHOUT
Text: 85258 (24 hours a day, free to text)
A free, confidential text service for anyone in the UK who is struggling to cope with difficult feelings.

Saneline
Telephone: 0300 304 7000 (4pm-10pm daily)
Website: www.sane.org.uk
A national out-of-hours mental health helpline offering specialist emotional support, guidance, and information to anyone experiencing difficulties with their mental health.

Mind Infoline
Telephone: 0300 123 3393 (9am-6pm Monday to Friday)
Email: info@mind.org
Website: www.mind.org.uk/information-support/helplines/
An information and signposting service that people can use to talk to a trained volunteer about mental health, where to access further help, potential treatment options, advocacy services and welfare benefits.

Hearing Voices Network
Email: info@hearing-voices.org
Website: www.hearing-voices.org
Hearing Voices Network offers information, support and understanding to people who hear voices, and can put you in contact with a local support group.

Voice Collective
Telephone: 020 7911 0822
Email: info@voicecollective.co.uk
Website: www.voicecollective.co.uk
A UK-wide project that supports people aged up to 25 who hear voices, see visions, or have other sensory experiences or beliefs. They provide information, online support, and peer support groups and forums,

Contact details

If you have any further questions about this study, please contact the lead researcher Amber Bowen (Trainee Clinical Psychologist; amber.bowen@hmc.ox.ac.uk), or their supervisor Lorna Hogg (Clinical Psychologist; lorna.hogg@hmc.ox.ac.uk), who will do their best to answer your query.

If you have any concerns about anything related to this study, or you wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

C6: The Perceived Empathy Scale (adapted from Nambisan, 2011).

During my interactions with others who don't themselves hear voices, I felt other non-voice hearers to be:

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Unsympathetic Sympathetic

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Insincere Sincere

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Not compassionate Compassionate

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Not heart-felt Heart-felt

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Intolerant Tolerant

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Insensitive Sensitive

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Cold Warm

I----------I----------I----------I----------I----------I----------I

1 2 3 4 5 6 7

Not supportive Supportive

C7: The Integration Subscale (adapted from Yampolsky et al., 2016).

My identity as a voice hearer fits within a broader identity	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
My identity as a voice hearer and my other social groups complement each other	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
My voice hearing and other social groups are connected	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
I have an identity that includes all my different social groups, including my identity as a voice hearer	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
My social groups, including my identity as a voice hearer, are all part of a broader group identity	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly

My social groups, including my identity as a voice hearer are part of a more global identity	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
I draw similarities between my identity as a voice hearer and my other social groups	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly
The differences between my identity as a voice hearer and my identity based on other social groups complete each other	1. Not at all 2. Slightly 3. A little 4. Moderately 5. Quite a bit 6. Mostly 7. Exactly

C8: The Negative Voice Impact Subscale (adapted from Van Lieshout & Goldberg, 2007).

How bad are the things the voices say to you?	0 ----- 1 ----- 2 ----- 3 ----- 4 Least severe Most severe
How much do the voices interfere with your daily activities?	0 ----- 1 ----- 2 ----- 3 ----- 4 Least severe Most severe
How distressing are the voices that you hear?	0 ----- 1 ----- 2 ----- 3 ----- 4 Least severe Most severe

C9: Assumptions testing for analyses.

ANCOVA assumptions

The assumption of linearity was met as there was a linear relationship between each covariate and extent of identity integration for both low internalised stigma and high internalised stigma group, as assessed by visual inspection of a scatterplot. There was homogeneity of regression slopes as there was a non-significant interaction between internalised stigma and each covariate (time since voices started, $F(1, 63) = 0.403$, $p = .528$; severity of voices, $F(1, 63) = 0.484$, $p = .489$; paranoia, $F(1, 63) = 1.344$, $p = .251$; depression, $F(1, 63) = 0.201$, $p = .655$). Standardised residuals for the overall model were normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$). There was homoscedasticity and homogeneity of variances, as assessed by visual inspection of a scatterplot and Levene's test of homogeneity of variance ($p = 0.510$), respectively. There were no outliers in the data, as assessed by no cases with standardised residuals greater than $\pm$ 3 standard deviations.

Regression assumptions

The assumption of linearity was met, as assessed by visual inspection of the relationship between the two variables. There was homoscedasticity and normality of the residuals. Casewise diagnostics revealed no outliers.

Hierarchical multiple regression assumptions

The assumption of linearity was met, as assessed by visual inspection of the relationship between the variables. There was independence of residuals, as

assessed by a Durbin-Watson statistic of 2.023. Visual inspection of these two plots indicated a linear relationship between the variables. There was homoscedasticity and normality of the residuals and no multicollinearity. Casewise diagnostics revealed no extreme outliers were present. Two cases exhibited leverage values above the commonly accepted safe threshold of 0.2 (values of .34001 and .25352). However, inspection of Cook's distance values indicated that these cases fell below the standard cut off of 1.00, meaning none of the cases had undue influence on the regression results. These cases were retained in the analysis and the assumption of no significant outliers was met.