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By

Jenny Elsa Liss Lisshammar

The Oxford Institute of Clinical

Psychology Training and Research

Harris Manchester College

University of Oxford

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Abstracts

A Systematic Review of the Research Literature

Identified Risks of Retraumatisation in, and Trauma-informed Adaptations to, Routine Secondary Gynaecological Care for Adult Women who have Experienced Sexual Violence: A Narrative Synthesis

Background: Sexual violence against women is associated with post-traumatic sequalae, including retraumatisation where trauma reminders may be present, such as in gynaecological care. Trauma-informed care guidelines remain absent for routine gynaecological care provided by the British National Health Service.

Methodology and Aims: A narrative synthesis was completed, which aimed to document evidence-based care-modifications for reduction of retraumatisation in routine gynaecological care. Full-text, peer-reviewed, English language articles reviewing risks and mitigating factors of retraumatisation in women aged 18+ who had experienced sexual violence, and who were seen in routine gynaecological care settings, were eligible for inclusion. These were identified via Ovid SP, Scopus, and Web of Science between January 2022 and March 2023. Quality assessments were undertaken using The *Standard quality assessment criteria for evaluating primary research papers from a variety of fields: Quantitative studies.*

Findings: 18 articles were included. 100% employed a survey methodology, with four including case-control comparisons. Prevalence of women with a history of sexual violence was higher in samples than estimated by clinicians, and a history of sexual violence was rarely taken, despite women requesting such a discussion. A multitude of triggers were identified, reflecting their relationship with the

individual's original trauma experiences. However, several common triggers were identified. Clinicians trained and confident in working with women who have experienced sexual violence were found to be the most effective modifier to reduce retraumatisation, alongside discussion about individual triggers and aids to inform modifiable examination procedures.

Discussion: This review contributes a synthesis of evidence-based, trauma-informed modifications to date. It is registered on PROSPERO (CRD42022299821). It is not funded. It identifies the significant positive developments which have occurred in this field over the last two decades. More research, employing a broader methodological range, remains warranted to inform development of accessible and implementable trauma-informed routine care guidelines.

Service Improvement Project

Patient Experience of Patient-Clinician Dialogue Concerning Sexual Intimacy: A Qualitative Investigation of Women with Chronic Gynaecological Conditions

Background: Sexual dissatisfaction is common in women living with chronic gynaecological conditions. While increasingly recognised as part of holistic care, it remains infrequently spoken about in clinical consultations. Clinicians attribute this to not recognising its relevance, feeling embarrassed, or feeling insufficiently skilled.

Methodology and Aims: This service improvement project was set at the John Radcliffe Hospital's Women's Centre, UK. It sought to understand patients' experiences of conversations about sexual intimacy. It explored individual and dyadic processes contributing to these experiences. Six patients with chronic gynaecological conditions participated in semi-structured interviews. Their accounts were analysed using Interpretative Phenomenological Analysis.

Results: Four themes were inferred from analysis. 'Beyond the hospital door' described the day-to-day impact of participants' conditions. 'Ripples of care experiences' recounted participants care being felt to be a single, continuous journey. 'The 'S' word in clinic' spoke of absent, but wanted, clinical conversations about sexual intimacy. Lastly, 'You're an expert, I'm an expert, too', identified participants' beliefs about the meaning of medical expertise, and the value of reciprocal patient-clinician relationships.

Conclusions: Chronic gynaecological conditions significantly impacted women's sexual lives, which was sometimes felt to be unacknowledged in consultations. Women sought clinicians dialogue and support. Power inequality and social and moral stigma inhibited conversations about sexual intimacy. The clinical relationship was imperative to overcoming this. The service was recommended to; explore these findings within the wider patient pool, increase patient involvement in service development, develop a clinician training module and a clinic pro forma.

Theory-Driven Research Project

Differing Self-harm in Younger versus Older People with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan

Introduction: There remains a paucity of research on emotionally unstable personality traits and emotion dysregulation in older people (65+). Whilst clinical lore suggests that older people with emotion regulation difficulties present markedly differently from younger adults, this remains empirically undocumented. This may account for lower-than-expected diagnostic rates in older people, and result in a lack of comprehensive commissioning for care of older people presenting with emotionally unstable personality traits in National Health Service mental health provision.

Aims: This study aimed to explore emotional regulation strategies across the adult lifespan by establishing differences in self-harm behaviours employed by younger versus older adults with high degree emotionally unstable personality traits; and whether these differences interacted with preferentially employed cognitive emotional regulation strategies. Developmental functionalism theory was introduced as one account of these hypothesised differences.

Methodology: A cross-sectional methodology was employed. 18 younger (age 18-28) and 18 older (65+) (total N = 36) participants, scoring above clinical cut-off on the Borderline Symptom List, completed an adapted version of the Self-Harm Inventory, and the Cognitive Emotional Regulation Questionnaire.

Results: Younger adults were significantly more likely to self-harm using self-injurious means compared to self-neglecting methods, whereas older people where, on average, significantly more likely to use self-neglecting methods preferentially. The frequency of self-neglecting behaviours did not significantly vary between age groups. However, the preferential differences in employment of self-violent behaviours resulted in a significant difference in self-violent methods of self-harm, between age groups. There was no significant difference in cognitive emotional regulation strategies employed, by age or self-harm behaviour.

Conclusions: Non-violent self-harm appears throughout the lifespan in this population. Older people's preferential use of self-neglecting methods may make self-harm more covert and less sensitive to clinical detection. Self-harm behaviours were unrelated to cognitive emotional regulation strategies employed. A broad definition of self-harm should inform clinical provision, commissioning, and future theoretical models of self-harm in this population across the adult lifespan.

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A Systematic Review of the Research Literature

Identifying Risks of Retraumatisation in, and Trauma-informed Adaptations to, Routine Secondary Gynaecological Care for Adult Women who have Experienced Sexual Violence: A Narrative Synthesis

By

Jenny Elsa Liss Lisshammar

Harris Manchester College

University of Oxford

Supervised internally by

Dr Matthew T. Knight

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Abbreviations Used

HCP: Healthcare Professional

NHS: National Health Service

PTSD: Post-traumatic stress disorder

SRGC: Secondary Routine Gynaecological Care

TIC: Trauma-informed Care

WHO: World Health Organisation

Embedded Abstract

Background: Sexual violence against women is associated with post-traumatic sequalae, including retraumatisation where trauma reminders may be present, such as in gynaecological care. Trauma-informed care guidelines remain absent for routine gynaecological care provided by the British National Health Service.

Methodology and Aims: A narrative synthesis was completed, which aimed to document evidence-based care-modifications for reduction of retraumatisation in routine gynaecological care. Full-text, peer-reviewed, English language articles reviewing risks and mitigating factors of retraumatisation in women aged 18+ who had experienced sexual violence, and who were seen in routine gynaecological care settings, were eligible for inclusion. These were identified via Ovid SP, Scopus, and Web of Science between January 2022 and March 2023. Quality assessments were undertaken using The *Standard quality assessment criteria for evaluating primary research papers from a variety of fields: Quantitative studies.*

Findings: 18 articles were included. 100% employed a survey methodology, with four including case-control comparisons. Prevalence of women with a history of sexual violence was higher in samples than estimated by clinicians, and a history of sexual violence was rarely taken, despite women requesting such a discussion. A multitude of triggers were identified, reflecting their relationship with the individual's original trauma experiences. However, several common triggers were identified. Clinicians trained and confident in working with women who have experienced sexual violence were found to be the most effective modifier to reduce retraumatisation, alongside discussion about individual triggers and aids to inform modifiable examination procedures.

Discussion: This review contributes a synthesis of evidence-based, trauma-informed modifications to date. It is registered on PROSPERO (CRD42022299821). It is not funded. It identifies the significant positive developments which have occurred in this field over the last two decades. More research, employing a broader methodological range, remains warranted to inform development of accessible and implementable trauma-informed routine care guidelines.

Introduction

Sexual violence can be defined as attempted sexual contact to which the recipient does not consent, regardless of the relationship between involved persons, or setting (Krug et al., 2002). Its practical application varies for legal, medical, and research purposes. For research purposes, the World Health Organisation (WHO) suggests employment of the definition developed through its multi-country study (García-Moreno et al., 2005). It includes data on sexual violence from 15 countries and over 24,000 individuals. It defines sexual violence as physical contact which an individual is coerced into by means of physical, psychological, or emotional abuse. It excludes sexual trafficking and genital mutilation.

Individuals of female sex are more likely to have experienced sexual violence; ~40% of women have experienced sexual violence globally (Borumandnia et al., 2020). In the UK, it is estimated that 20% of females, and 4% of males, have experienced sexual violence (Office of National Statistics, 2019). Sexual violence is underreported by both sexes (Pino & Meier, 1999). Therefore, reliable prevalence figures by sex may be incomplete. Presentations of sexual violence sequalae are also believed to vary by sex, through different effects of heteronormative gender hegemony and related gender-specific anticipated and internalised stigmatisation (Kalra & Bhugra, 2013; Reed et al., 2014). Sexual violence is therefore considered gender-based violence, warranting sex-segregated research if the aim is to capture normative, social, or health frameworks impacted by its occurrence (Office of the High Commission of United Nations Human Rights, 2014).

Sequalae of sexual violence

The array of negative psychological sequalae of sexual violence is well-documented (Heimer & Tung Hermelin, 2010; Koss et al., 2003). Post-traumatic stress disorder (PTSD) is the most common mental health diagnostic sequalae, with prevalence rates ~20–50% (Creamer et al., 2001; Perez Benitez et al., 2009; Walsh et al., 2012). 94% of women report symptoms of PTSD during the first two weeks post-assault, and 30% continue to experience symptoms at nine months (Davidson & Foa, 1993; National Centre for Posttraumatic Stress Disorder, 2005). The 11th International Classification of Diseases defines PTSD as reliving symptoms (dissociative flashbacks and nightmares), hypervigilance, and avoidance of trauma reminders (WHO, 2019b). PTSD also accompanies vulnerability of retraumatisation, that is, the reaction to traumatic exposure impacted by cognitive processes and adaptational styles shaped by previous trauma (Danieli, 2010; Kammerer & Mazelis, 2006).

Retraumatisation in Gynaecological Care

The risk of burden of PTSD- and retraumatisation, for women who have experienced sexual violence, is topical in gynaecological care. Retraumatisation can occur in response to practical or physical shared characteristics of the original trauma, as well as psychological reminders of lack of self-agency; such as complementary patient-healthcare professional (HCP) relationships echoing the sexually violent power-relationship (Watson, 2016). Psychological triggers are thought more likely to provoke retraumatisation (Coles & Jones, 2009). Consequently, women who have experienced sexual violence may avoid gynaecological care (Farley et al., 2002).

This proves a challenge for secondary gynaecological care services. Service providers, including the British National Health Service (NHS) (2019), are working

to increase trauma-informed care (TIC)-provision to reduce retraumatisation and increase effective service. The British Royal College of Obstetricians and Gynaecologists (RCOG), have recently developed draft guidelines for trauma-informed maternal care, and have requested similar such developments in other areas of gynaecological care (2022). TIC entails that staff receive training on trauma-related health and psychological challenges and acknowledge the need to understand patient experiences in order to provide effective care (Havig, 2008). This may improve patient care-engagement, treatment adherence, positive clinician contact, and reduce healthcare provider stress (Jennings, 2004; Menschner & Maul, 2016). Practical clinical adjustments include patient-involvement in treatment processes, routine trauma screening, and trauma-informed staff training.

Guidelines for reduction of retraumatisation risk following sexual trauma exists for emergency (Royal College of Emergency Medicine, 2015), urgent (<24h) (Kerr et al., 2003) and obstetrician care (Royal College of Midwives, 2020; Ward, 2020). Guidelines are specific to each area of care. This is largely attributable to the differing psychosocial mechanisms and needs of women accessing each service (Watson, 2016). By comparison, the literature outlining trauma-informed secondary routine gynaecological care has yet to inform NHS care guidelines (Caal et al., 2012; Park et al., 2013).

The Routine Secondary Gynaecological Care Setting

Secondary Routine gynaecological care (SRGC) is defined as clinical contact with secondary care gynaecology HCP's for a procedure which is not classified as urgent (Kerr et al., 2003) or emergency (Beckmann & Groetzinger, 1990) and is typically accessed through a prebooked appointment (RCOG, 2016). This largely

includes preventative measures and non-diagnostic screening (Ledbetter, 2018). Such practices may also take place in primary care services such as General Practice. However, due to the breadth of care provided in primary care, retraumatisation factors in SRGC may not be relevant in primary care – including familiarity with the practitioner, influence on and control over when appointments are booked, and setting – hospital versus community clinic (Brooks et al., 2018). Further, guidelines available to date are consistently service-specific, rather than intervention-specific (RCOG, 2016). Given the aim of the current study – informing guidelines – the current synthesis has adopted a similar focus and aims itself toward SRGC. However, general and other primary care practitioners may likewise find this text informative and useful.

Current Study

This study aimed to summarise SRGC practices thought to increase risk of retraumatisation, for adult women who have experienced sexual violence; and to identify potential TIC-modifications. Narrative synthesis was employed, including publications from 1993 to 2023. It summarises evidence-based, trauma-informed, modifications in a highly topical area, to inform future development of accessible and implementable trauma-informed SRGC guidelines for NHS services.

Methodology

This study was registered on PROSPERO (CRD42022299821) and conducted in accordance with an approved protocol. Synthesis was completed in accordance with the PRISMA statement guidelines (Moher et al., 2009) A percentage of articles at each stage were second rated by ES. Acceptable inter-rater agreement was determined as $\kappa > .81$ (very good) (Altman, 1991).

Eligibility Criteria

Studies involving female adults (18+ years), accessing routine secondary gynaecological care, as defined by the RCOG (2018), were included. These were limited to full-text, peer-reviewed articles published in English within the last 30 years (1993-2023) and employing a quantitative methodology (Table 1).

Table 1 Definitions of selection criteria used for data extraction

Criterion	Definition
Females aged 18+	Participants with reproductive organs warranting access to gynaecological services, with a biological age 18+
Routine gynaecological care	Care in accordance with the Royal College of Gynaecology and Obstetrics (2016) definition, excluding emergency, urgent (<24hours), and obstetrician care; either reported as such or in line with the Royal College of Emergency medicine (2015) definition.
Sexual violence history	All forms, temporally undefined. Violence needs to be specifically defined as "sexual" and data needs to be extractable from other forms of violence.
Retraumatisation	Reporting risk identification/ reduction of retraumatisation in study objectives.
Quantitative	Numerical data, (mixed methodology included if data is reported separately), no reporting of secondary data
Peer-reviewed	Published in a scientific journal (defined as "journals" by Oxford university Bodleian libraries).

Search Strategy

Data extraction was planned together with a specialist librarian at the Bodleian Libraries, Oxford, UK. Articles were identified from OVID SP (Embase 1974 to present; Medline (Ovid MEDLINE® Epub Ahead of Print, In-Process & Other Non-

Indexed Citations); Ovid MEDLINE® Daily; Ovid MEDLINE® 1946 to present, and PsycINFO 1806 to present), Scopus, and Web of Science. Initial searches were completed in January 2022. An updated search was completed in March 2023. Five sets of search terms, separated by "OR", were combined using "AND" or "NOT" Boolean operators (Appendix A for complete search strategy). Wildcards were employed for spelling alternatives. The first set identified "*Female*", "*Adult*" patients. Subsequent sets identified studies including *"Sexual Violence", "Routine Gynaecological Care",* and *"Retraumatisation",* while employing the NOT Boolean operator to exclude: "**natal", "veteran", "education", "emergency", "ER", "paediatric", "pregnancy", "dental", "breastfeeding".*

Selection Process

Search results were exported to reference management software and merged to discard duplicates. Titles and abstracts were reviewed to determine eligibility. ES reviewed 30% (κ = .864; 97.14% agreement). Full texts of relevant articles were acquired and assessed against inclusion and exclusion criteria. ES reviewed 25% (κ = .84, 96.55% agreement). Disagreement was resolved by discussion between raters to understand rationale, and resulting agreement was sought if possible.

Quality Assessment

All eligible articles were included in quality assessment and data extraction, to provide an overview of overall the quality and robustness of available literature to date. As this review aimed to inform development of new clinical care guidelines, high-quality, robust research was warranted. 30% of articles were second-rater quality assessed (κ = 1, 100% agreement).

The *Standard quality assessment criteria for evaluating primary research papers from a variety of fields: Quantitative studies* (Kmet et al., 2004) was employed to assess article quality. It was selected for its ability to accommodate a variety of studies by allowing each quality component to be marked as present (two points), partial (one point), absent (no points), or not applicable. If a component is marked as not applicable, two points are removed from the article's maximum possible score. Each publication thus receives two scores: the quality score and maximum possible score. Articles are thus not rated as of lower quality for applying less robust, but still appropriate, methodologies such as survey-design. To indicate quality, each fraction is indicated as a percentage out of 100%, which indicates best possible quality (see Appendix B). Comparative quality was defined as number of standard deviations from the mean percentage (see Table 2 on page 31).

Data Extraction

Narrative synthesis was selected as the approach of choice due to its ability to accurately represent the social and cultural variation of papers, as well as report the literatures largely descriptive nature (Green et al., 2006). It was reported using the PRISMA phase reporting checklist (Moher et al., 2009).

Data Extraction Process

Data was extracted from identified articles using the definitions shown in Table 1. ES second-rated 50% of extracted data ($\kappa = 0.82$, 92.71% agreement). Findings were combined and summarised in line with guidance for completing a narrative synthesis (Popay et al., 2006) – see reference for full details. This process was undertaken by both JL and ES when extracting data. A narrative description of each

included paper was initially created, using a breakdown of study aims, design, participants, intervention, outcomes, and conclusions. This, to gain an overview of the studies. Each paper was subsequently tabulated, comparing each paper (row) and each item in the review questions (column), including retraumatisation risks and interventional modifiers identified. Retraumatisation risks were defined as components of any aspect of the gynaecological contact which was rated by study participants as reminding of a previous sexually traumatic experience (definition derived from Danieli (2010)) and contact modifiers was defined in line with the Substance Abuse and Mental Health Services Administration (SAMHSA) (2012) definition of trauma-informed approaches, which involve a change to care which acknowledges trauma, recognises its impact, or which makes a change to care in response to identification of a retraumatisation risk factor. Information from each paper was extracted (by sentence or group of sentences) and marked as relevant to at least one item from a review question. All extracted sections were highlighted in the main text to identify extraction. Upon completion, each study was reviewed again to ensure correctness of data extraction. Finally, each extracted piece of information was organised, using colour coding, into empirically or conceptually similar clusters. These were visually organised using Concept Mapping (Mulrow et al., 1997) to ensure uniform conceptuality. These concepts where then organised in order of events which might be occur in a typical SRGC consultation, from identifying trauma history to undertaking the intervention itself. These concepts then lay the foundation for headings and subheadings employed in the Narrative Synthesis, and each section written from its concept map.

Results

Study Selection

Database searches yielded 671 articles after duplicate removal. 557 were deemed ineligible for inclusion after review. 114 articles were reviewed for eligibility using full-text screening. 18 articles were eligible for inclusion (see Figure 1 for study selection process).

Characteristics of Included Studies

Characteristics of the 18 included studies are shown in Table 3. 100% had an observational survey design. Of these, twelve (66.67%) were retrospective, four (22.22%) were case-control studies, one (5.56%) had a within-subjects repeated methodology, and one (5.56%) was a prospective survey to develop a new psychometric tool. Five papers (27.78%) looked at sexual violence occurring prior to adulthood, one (5.56%) at sexual violence towards adults only, and twelve (66.67%) included sexual violence regardless of age. Twelve studies (66.67%) collected data from gynaecology outpatient clinics, three (16.67%) from community advertisement, two (11.11%) from US Veteran Health Medical Centres, and one (5.56%) from a charity supporting women who had experienced sexual violence.

One study employing community sampling (Robohm & Buttenheim, 1997) remarked that this was a conscious decision as women with a history of sexual violence are likely to avoid gynaecological care, and may therefore be excluded from participation if this is the selected recruitment method.

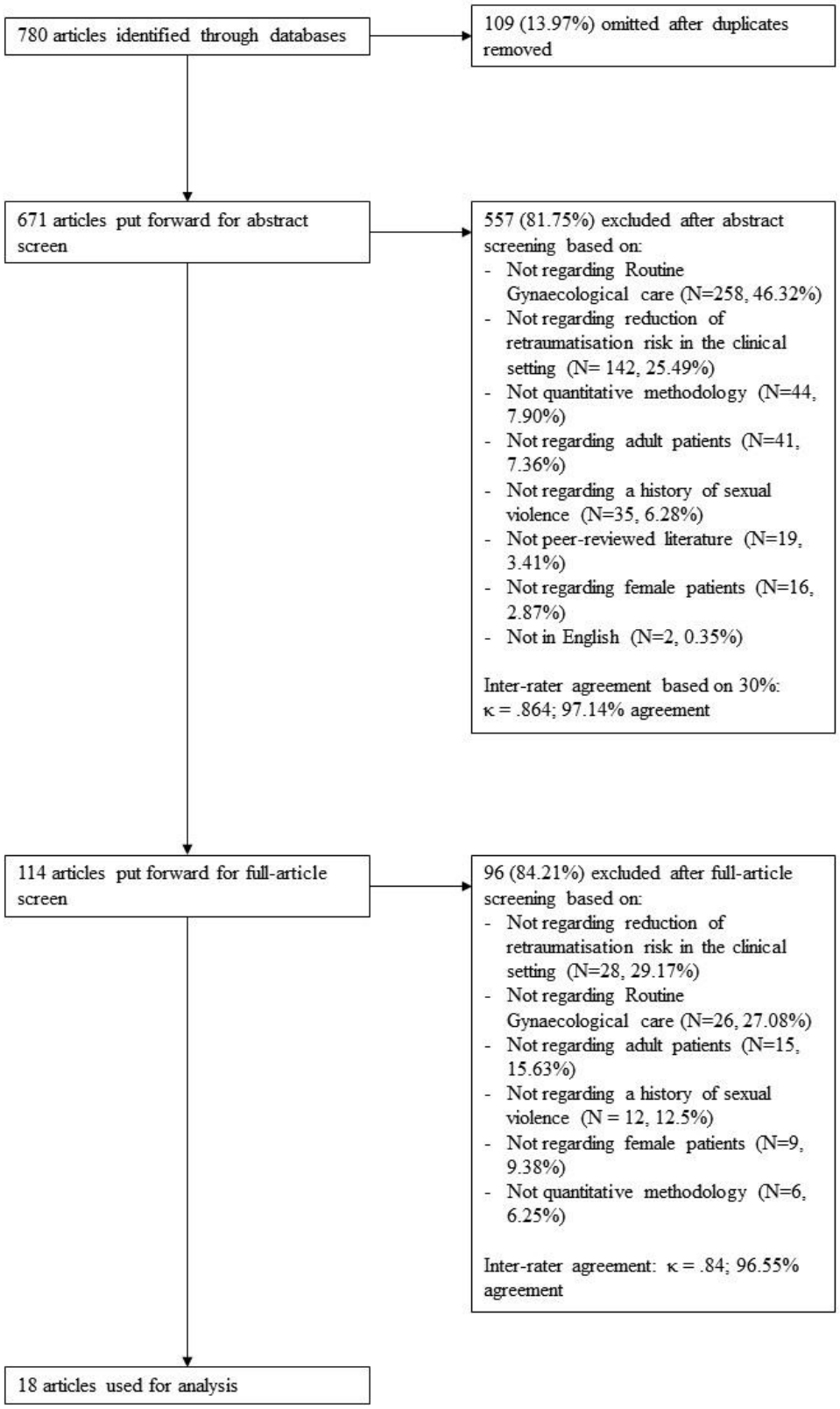


Figure 1 Flow diagram of study selection process

Quality of Included Studies

This is reported in detail in Appendix B.

Total Possible Scores

Total possible scores ranged 16-26 (*Mdn* = 18). 100% of studies scored "not applicable" on questions six and seven, which regarded interventional blinding of participants and researchers. This was not applicable to any study as they either did not employ random allocation due to single-sample survey design (14 studies, 77.77%), or participants were allocated to test conditions depending on their sexual violence history, which was known to the participant and the researcher. 13 studies (72.22%) scored "not applicable" on question nine, regarding sample size. This is also due to survey-design, for which the chosen quality tool recommends the "not applicable" response to this query.

Quality Scores

Studies varied in quality, scoring between 8 to 22 (*Mdn* = 17). The most frequent reasons for low scores were insufficient detail about the sample or employed questionnaires. Limited sample information may be attributed to consistent employment of survey-design and large sample sizes, where identifying information was conservatively collected to increase study-participation and safeguard identity. 12 (66.67%) studies employed an idiographic questionnaire to measure retraumatisation, three (16.67%) used the NorVold abuse questionnaire (Pikarinen et al., 2007; Simmons & Swahnberg, 2022; Swahnberg et al., 2011), one (5.56%) used the State-Trait anxiety inventory and Exam-experience questionnaire (Robohm & Buttenheim, 1997), one used the Modified-abuse assessment screen (Peschers et al., 2003), and one, a modified version of the Index of Dental Anxiety

and Fear, to capture gynaecological experiences, and an idiographic binary healthcare-avoidance questionnaire (Schnur et al., 2017). Only one (8.30%) study included their idiographic questionnaire in the article.

Percentage Scores

The percentage quality indicator ranged 33-100% (M = 81.05%, SD = 15.96%, *skewness* = -2.07, *kurtosis* = 6.28). Fry et al. (1996) scored 33%, which produced a leptokurtic distribution. This low score was due to insufficient detail regarding intervention, recruitment method, and case versus control group comparisons. Further, data analysis was insufficiently described, and there was insufficient acknowledgement of these limitations. However, this is the only study to date to experimentally test the impact of clinician gender on the SRGC experience of women with a history of sexual violence. It is one of only three studies employing non-survey methodology. This publication was therefore retained in analysis, to provide knowledge to date of the impact of clinician gender, which is a concern raised in several survey studies, as well as to inform future research.

Qualitative Definition

Quality was differentiated by standard deviation (15.96%) from the mean quality percentage (81.05%) – see Table 2.

Table 2: Quality distribution of studies by quality percentage

(Achieved score out of possible score)

Quality	Publications
>= 95%, "higher than average" (>M+1SD)	(Schnur et al., 2017; Simmons & Swahnberg, 2022; Weitlauf et al., 2010)
81-94%, "high average" (Within M+1SD)	(Cadman et al., 2012; Hilden et al., 2003; Peschers et al., 2003; Swahnberg et al., 2011; Walker & Allan, 2014; Walker et al., 1993; Weitlauf et al., 2008; Wijma et al., 2003)
66-80%, "low average" (Within M-1SD)	(Leeners et al., 2007; McGregor et al., 2010; Pikarinen et al., 2007; Robohm & Buttenheim, 1997; Smith & Smith, 2000; Wijma et al., 2000)
<65%"lower than average" (<M-1SD)	(Fry et al., 1996)

Description of Participants

A total of 13 574 females participated in the included articles. Eleven studies reported the age of participants, which gave a grand mean of 38.11 years. All studies collected data from Global North countries; USA (6), Scandinavia (6), the UK (3), Germany (2), and New Zealand (1). Participant ethnicity was reported by six studies, and there was a temporal influence in reporting participant ethnicity; no studies published before 2007 included this information. White ethnicity was most prevalent, ranging 61.8%–99% of participants, followed by Black (15-22%), Latina (8-18%), and Other (3.80-16.70%) ethnicities.

Table 3: Description of Included Articles, including PRISMA rating (Moher et al., 2009)

--- = missing data not reported in articles

Abbreviations
GOC= Gynaecology Outpatient Clinic
CSS= Cross-sectional survey
NLS= National language speakers

Quality rating
>=95% higher than average
81-94% high average
66-80% low average
<65% lower than average

Authors (Year) **Country** *Age of sexual violence occurrence* Quality Rating	**N,** Participants, *Clinical Setting*	Age [years] M (SD) [range] **Ethnicity**	Methodology	Prevalence **Disclosure** [1]	Factors associated with increasing/decreasing risk of retraumatisation	Factors identified as reducers of retraumatisation
Walker et al., (1993) **USA** *Any age* 94%	**N = 162** NLS females 18+ *GOC*	37.40 (13.70) [18-82] ---	CSS Retrospective	50% **4%**	• Negative/Stigmatising patient beliefs about disclosure or negative/stigmatising HCP responses to disclosure	84% of women wanted to be routinely asked about sexual violence history
Fry et al., (1996) **UK** *Childhood* 33%	**N = 113** Females 18+ *GOC*	31 (---) [18-51] ---	CSS Within-subjects	-- --	HCP gender does not impact likelihood of disclosure (p = .39) Women who disclose experience "reporting fatigue" when asked to re-tell their experiences to new clinicians (p = .04)	

Robohm et al., (1997) **USA** *Childhood* 71%	**N = 68** Women 18+ *Charity for sexual violence survivors.*	---	CSS Case-control	58.30% **30%**	65% of women found the genital exam most retraumatising and/or distressing	• 95% of women wanted to be routinely asked about sexual violence history.
Smith & Smith (2000) **USA** *Childhood* 77%	**N = 69** Women 18+ *GOC*	36.33 (---) [18-65] ---	CSS Between-subjects	--- ---		Use of a modified full-coverage examination gown does not reduce distress in women with sexual violence history (p = "not significant")
Wijma et al., (2000) **Sweden** *Any age* 72%	**N = 649** Non-pregnant Women 18+ *GOC*	35 (11.10) [19-68] ---	CSS Retrospective	15.20% ---	Estimated prevalence of diagnosable PTSD in sample: 17%	
Wijma et al., (2003) **Nordics** [2] *Any age* 94%	**N = 3641** Women 18+, NLS *GOC*	--- (---) [20 – 50] ---	CSS Retrospective	24.10% **3.50%**	98% of women who had disclosed (3.5%) had not spoken or been asked about their sexual violence history at their most recent clinic visit	24.70% of sample felt that disclosure would be helpful
Hilden et al., (2003) **Denmark** *Any age* 85%	**N = 808** Female 18+, NLS *GOC*	--- (---) [18-51] ---	CSS Retrospective	20.70% **7.60%**	Male HCP gender is not significantly associated with greater distress (p= .07)	70% of women endorsed dialogue about triggers and expectations before procedures
Peschers et al., (2003) **Germany** *Any age* 94%	**N = 1057** Women 18+ not reporting being in an abusive relationship *GOC*	41.80 (15.30) [18-54] **76.70% German** **12.90% Other** **5.80% Balkan** **4.60% Turk**	CSS Retrospective	64.50% **6%**	• 50% of sample reported that their clinician responded negatively to disclosure. It outlined motivation for lack of disclosure (reported in more detail in table 4)	• 61% of women wanted to be routinely asked about sexual violence history

Leeners et al., (2007) **Germany** *Childhood* 80%	**N = 111** Women 18+ with capacity to consent, without significant cognitive or mental health impairment *GOC (test), and kindergarten playgrounds (control)*	--- (---) [---] **99% German** **1% Other**	CSS Case-control	43.50% **12%**		• Patient permission to stop the exam (65%) • Routinely asking about sexual violence history (55.80%) • Routinely asking for permission (30%) • Better HCP training (28.80%) • Approachable HCP mannerisms (12.80%) • Option to choose a female clinician (5.80%) • A female clinician was very important to 63.50% of the sample, versus 26.50% of controls (p = .0001)
Pikarinen et al., (2007) **Finland** *Adults only* 78%	**N = 691** Women 18+ *GOC*	41.2 (13.5) [---] ---	CSS Retrospective	12.30% **0.40%**		62% of women did not want to be routinely asked about sexual violence history. This finding is not in line with other publications, where query about sexual violence history was the majority preference.
Weitlauf et al., (2008) **USA** *Any age* 83%	**N = 49** Women 18-65 without psychiatric history *Veteran Health Medical Centre*	42.70 (10.90) [18-65] **78.8% White** **15.4% Black** **11.5% Hispanic** **3.8% Other** **1.9% Asian**	CSS Retrospective	77% ---	Most triggering aspects of care • Undressing (57%) • Genital exam (42.7%) • Lithotomy position (42%) • Conversations about the RGC contact (35%)	

Weitlauf et al., (2010) **USA** *Any age* 100%	**N = 90** Women 18-65 residing in California, USA, without psychiatric history *Veteran Health Medical Centre*	45.20 (11.40) [42-57] **61.80% White** **22% Black** **18% Hispanic** **10% Mixed** **3% Asian** **2% Pacific Islander**	CSS Retrospective	80.50% ---	Negative beliefs about care • The exam will cause me to relive the sexual violence (18%) • The exam is unnecessary in absence of symptoms (11%) • Exam is unnecessary regardless (11%) • Exam is unnecessary as I am not sexually active (9%) Medical instruments will harm me (7%)	
McGregor et al., (2010) **New Zealand** *Childhood* 75%	**N = 61** Women 18+ *GOC*	41.50 (---) [22-65] **70.50% New Zealand** **13.10% Māori** **8.20% Other** **5% Pacific Islander**	CSS Retrospective	93.30% **68.90%**	Women were more likely to disclose sexual violence history to female clinicians (63.6%) than male clinicians (36.7%). Female clinicians are more likely to ask about sexual violence history (66.7%) than male clinicians (33.3%) Female clinicians were perceived as more helpful (46%) in response to disclosure	96.50% of women wanted to be routinely asked by a clinician.

					than male clinicians (27.6%). Male clinicians were reported to be very unhelpful (25%) in response to disclosure than female clinicians (10%) 20% of women did not disclose sexual violence history despite wanting to as they thought they would not be believed. Most triggering aspects of care Vaginal exam (93%), Undressing (72%), Abdominal sonography (28.6%)
Swahnberg et al., (2011) **Sweden** *Any age* 86%	**N = 4384** NLS Women 18+ *GOC*	--- (---) [18-51] ---	CSS Case-control	7% **4%**	• Hypothetical model relating sexual violence trauma with pain during examination • There is a significant relationship between greater than expected pain and likelihood of retraumatisation ($p <$ .01) •

Cadman et al., (2012) **UK** *Any age* 83%	**N = 135** Women 20+ *Website for National Association for people abused in childhood*	34.50 (9.25) [20-59] ---	CSS Retrospective	-- --	• Reasons for non-disclosure, most triggering care aspects • •	• Having conversations about intimate details of the procedure before proceeding (39%) • Familiarity with the clinician before the exam (20%) • If women disclose abuse, the same clinician to be assigned each subsequent time (16%) • More direct involvement with the procedure (11%) • Consistent appointments (12%) • • Plastic, not metal, instruments (10%) • Less clinical environment (10%) • Exam in the lateral, not Lithotomy, position (10%)
Walker & Allan (2014) **UK** *Any age* 88%	**N = 62** Service clinicians *GOC*	--- (---) [---] ---	CSS Retrospective and focus group	--- ---	• HCPs tend to significantly underestimate the prevalence of sexual violence history • Only 62% of HCPs in this sample recalled any trauma-related training • 66% of HCPs reported feeling competent, and 50% reported feeling confident, caring for women with sexual violence history	• • Identification of HCPs requesting more training, including on how to manage psychological distress.

Schnur et al., (2017) **USA** *Any age* 95%	**N = 675** Women 18+ self-reporting a history of sexual violence, *Community sample*	32.60 (10.80) [---] **83.3% White, 16.7% Other** **8.1% Latina**	CSS to inform psychometric tool development	--- ---	Most triggering aspects of care • Genital exam (54%) • Feeling lack of control (52%) • Feeling powerless (43%) • Conversations about intimate details of the procedure (39%) • Angry sounds (38%) • Be treated "as an object" (36%) • Be told "trust me", "it won't hurt" or "please relax" (31%) • Undressing (30%) • HCP is male (28%) • Sensation of the HCPs breath on skin (28%) • Feeling "expected to remain silent" (22%) • HCP appearing rushed (17%)	• Use of "factual, informative language" during any exam or procedure (33%)
Simmons & Swahnberg (2022) **Sweden** *Any age* 100%	**N = 749** Women aged 25-85 residing in the municipality of Östergötland, Sweden	--- (---) [---] ---	CSS Retrospective	17.70% **10.40%**		• 81.30% of women found being asked to be a positive experience. Women's social characteristics significantly predicted the likelihood of their being asked. Women of young age – 25-44 years; low

	Community sample	socioeconomic status, and with history of anxiety or depression were most likely to be asked about such history.

[1] Of sexual violence experienced throughout the lifespan

[2] Denmark, Finland, Iceland, Norway, Sweden

Narrative Synthesis

Retraumatisation relates to individual traumatic experiences, creating a multitude of potential triggers in SRGC. Understanding patients' sexual violence history is important to pre-empt effects on the woman's care experience and risk of retraumatisation. While nuanced, some are more common and share characteristics. This enables clinicians to approach such patients sensitively and modify care proactively.

Sample Prevalence

Eleven studies (61.11%) reported sample prevalence of sexual violence. This ranged 12.3% (N = 691) (Pikarinen et al., 2007) –93.30% (N = 61) (McGregor et al., 2010) (*M* = 42.52%, *SD* = 30.39%). This nears the ~40% global average (Borumandnia et al., 2020). The three highest reported incidence rates, 77% (N = 49) (Weitlauf et al., 2008), 80.5% (N=90) (Weitlauf et al., 2010), and 93.30% (N = 61) (McGregor et al., 2010), were recent publications in the sample. This may suggest a positive temporal trend to disclose sexual violence history. However, the most recent publication (Simmons & Swahnberg, 2022) had a lower reported incidence rate (17.70%, N=749). This is the only study conducted in Europe, whereas Weitlauf et al. (2008, 2010) were conducted in North America, and McGregor et al. (2010) in New Zealand. This may suggest differing rates of incidence, disclosure, or likelihood to participate in clinical trials, between continents. Simmons et al. was also the only study of these four which recruited from a community sample. Weitlauf et al. (2008, 2010) collected data from US Veteran Health Service clinics, the only articles to do so. Veterans are at increased risk of experiencing sexual violence (Fontana & Rosenheck, 1998).

Walker and Allan (2014) asked routine gynaecology HCPs (N = 62) to estimate their patient pool prevalence rate of sexual violence history. 26.7% estimated that prevalence was >10%, while 73.30% estimated single-digit prevalence. This suggests low HCP prevalence awareness.

Disclosure

Seven studies (41.17%) reported sample disclosure rates to a routine gynaecological HCP; 2% (N = 3641) (Wijma et al., 2003) –68.90% (N=61) (McGregor et al., 2010) (*Mdn* = 7%). Apart from the 68.90% disclosure rate, the only other publication to report double-digit disclosure percentages was Robohm and Buttenheim (1997)– 30% (N = 68). This is one of two studies to have collected data from a community sample. They reported that this was due to women with sexual violence history being less likely to access SRGC.

Non-disclosure was motivated by several reasons related to both the clinician and patient themselves (Table 4). Leeners et al. (2007) and Peschers et al. (2003) reported that 50% of women who spontaneously disclosed experienced HCP responses as "uncomprehending", "disapproving", "indifferent", or "incompetent".

62% (N = 62) of clinicians recalled a spontaneous patient disclosure (Walker & Allan, 2014). Five studies reported whether their sample had been asked about sexual violence history by a HCP; with affirmative responses ranging 0.001% (N = 691) (Pikarinen et al., 2007) – 19% (N=61) (McGregor et al., 2010) (*Mdn* = 4%). As above, numbers were low (0.001%-4%) for most papers, with McGregor et al. (2010) and Robohm and Buttenheim (1997) reporting higher numbers; 19% (N = 61) and 15% (N = 68) respectively.

Table 4: Female patients stated reasons for non-disclosure

Reason	Percentage agreement	Sample (N)	Publication
Irrelevance to care	55.10%	1057	(Peschers et al., 2003)
Embarrassment	53%	162	(Walker et al., 1993)
Clinician did not ask	51%	1057	(Peschers et al., 2003)
Fear	30.50%	1057	(Peschers et al., 2003)
Clinician being "unavailable to tell"	21%	162	(Walker et al., 1993)
Clinician "would not understand"	20%	135	(Cadman et al., 2012)
Clinician "would not believe [the patient]"	20%	61	(McGregor et al., 2010)
Clinician was male	16%	162	(Walker et al., 1993)

Querying Sexual Violence History

Eight articles reported patients preference for routine querying about sexual violence history ranging 48% (Pikarinen et al., 2007) -96.50% (McGregor et al., 2010) (M = 81.33%, SD = 20.41%). Pikarinen et al. (2007) was the only study where the majority of the sample did not want to be asked about sexual violence history. It was also the study with the lowest number of participants who had actually been asked (0.001%, 1 out of N = 691). The authors acknowledged this discrepancy from remaining literature, and theorised that this was due to the high rate of abuse history in the sample; although other studies with similarly high findings did not have a similarly

low rate endorsing routine querying (McGregor et al., 2010; Weitlauf et al., 2008; Weitlauf et al., 2010). Other studies with data collection in Scandinavia (Simmons & Swahnberg, 2022; Wijma et al., 2003) reported that the majority of participants favoured being asked – indicating that this is not a cultural artefact of the study setting. Despite the high number of women not wanting to be asked in this particular study, the authors concluded that it remained "correct" to ask women about sexual violence history – at odds with their findings. Simmons and Swahnberg (2022) explored the experience of being asked in further detail; 81.3% of their female sample (N = 749) reported that their previous experiences in clinical settings of being asked, had been a positive experience, whereas 7.50% found it to be a "predominantly" negative experience, and 11.3% reported it as an "only" negative experience. This sample also explored the social characteristics of women who had been asked. Women who were younger (25-44 years) were most likely to have been asked (Odds ratio (*OR*): 2.58 [95% CI 1.84-3.63]) versus women aged 45-64 (*OR* 1.82 [1.32-2.50]) or aged 65+ (*OR*: 1) as were women of lower socioeconomic status (*OR:* 2.23 [1.35-3.69]), with a history of depression (*OR:* 2.45 [1.20-5.04]) or a history of mixed anxiety and depression (*OR*: 2.16 [1.09-4.31]). This indicates that clinicians may be more comfortable asking women of younger age about abuse history, and may associate depression, anxiety, and low socioeconomic status with a higher likelihood of sexual abuse history. Women who had been victims of sexual violence on more than one occasion ('polyvictimisation') were also more likely to have been asked, compared to women who had experienced sexual violence on one occasion (*OR*: 2.85 [1.53-5.30]).

Free-text responses on to how to improve queries of sexual abuse history, across studies who collected them, suggested asking either on an intake form or in the room while the woman remained fully clothed (Cadman et al., 2012; Robohm & Buttenheim, 1997). Further, free-text responses stated that "if providers do not ask [about sexual violence history], they could not understand the experience or were unprepared to hear the answer" (Robohm & Buttenheim, 1997) and that "[the clinician] will not understand, so disclosure would be a form of self-harm". Some women who had disclosed to multiple HCPs described "reporting fatigue" when asked to describe details on multiple occasions (Fry et al., 1996). They suggested that detailed health records would allow HCP-awareness without subjecting women to repeated disclosure.

Effects on Care

Women with a sexual violence history were more likely to describe SRGC as highly distressing (37.7%) than women without this experience (3.50%; $p < .0001$), and 52% reported that it influenced their ability to access SRGC (N = 111) (Leeners et al., 2007). However, sexual violence history did not significantly decrease numbers of women accessing SRGC (70.6%) compared to control group women (87.60%; $p > .05$) (Leeners et al., 2007).

Experience of Physical Pain

Women with sexual violence history were more likely to report significant fear of physical pain during routine gynaecological procedures (90%) compared to women without such experiences (49%)(N = 68) (Robohm & Buttenheim, 1997). ~10-20% (N range = 135-4384) reported pain during examination beyond what would be expected for the type of procedure being performed, and significant pain during

SRGC-provision was a significant predictor of retraumatisation ($p < .01$), which was suggested as an indicator to a clinician of a high likelihood of sexual trauma history (Cadman et al., 2012; Leeners et al., 2007; Swahnberg et al., 2011). Swahnberg et al.'s (2011) preliminary psychological model outlined the relationship between historical sexual violence and pain during SRGC (Figure 2). It is suggested that sexual trauma reexperiencing increases physical discomfort and negative impressions of SRGC, which reinforces negative experience beliefs. This relationship is modified by number of independent flashbacks (estimated PTSD severity) and previous, abusive healthcare experiences. Physical pain is suggested as a proxy marker of retraumatisation risk in SRGC.

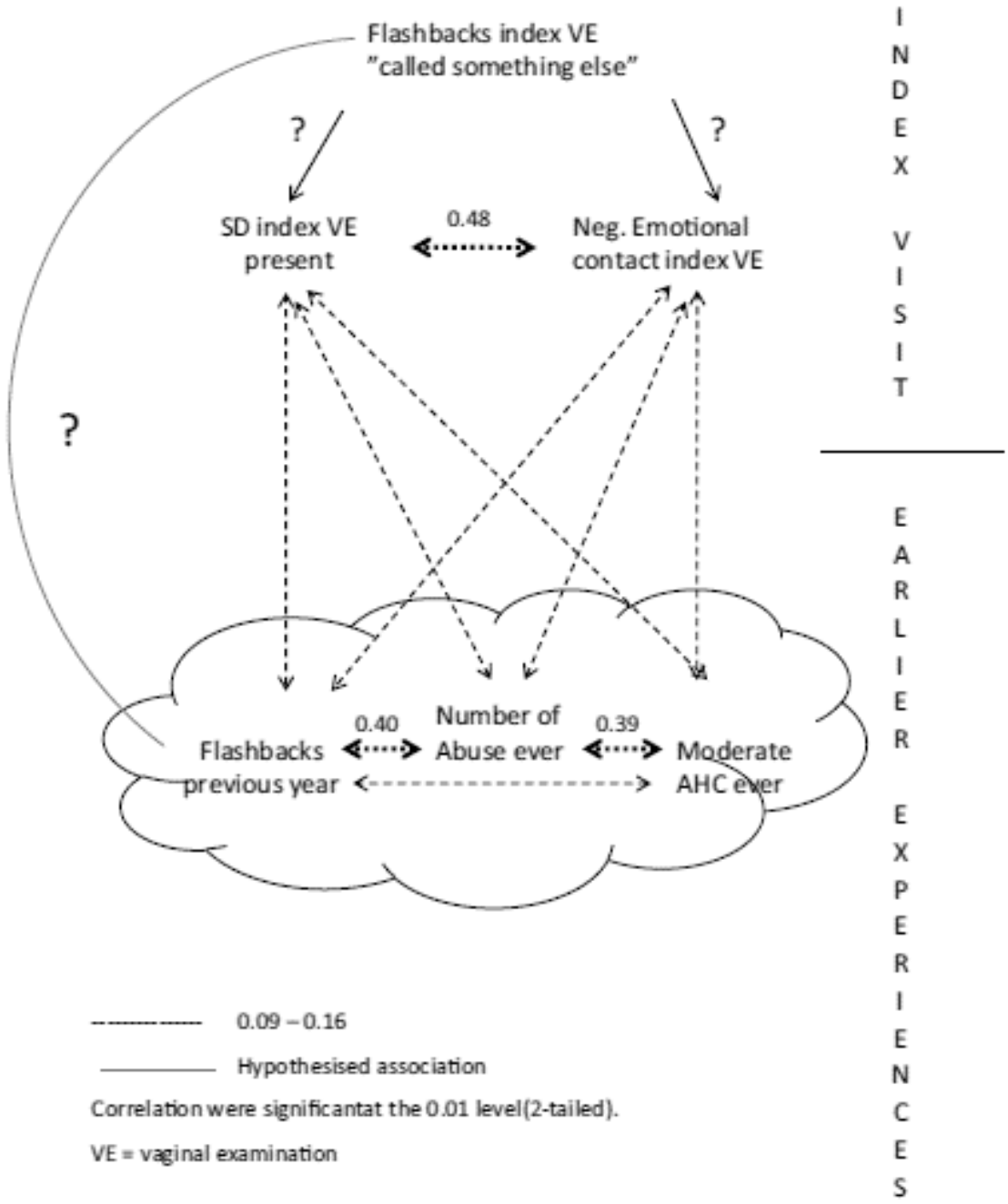


Figure 2 Key variables in the relationship between sexual abuse history and pain during gynaecological examination (Swahnberg et al., 2011).

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AHC = abuse in healthcare

VE = vaginal examination

SD = strong discomfort

Retraumatisation Frequency

Retraumatisation in SRGC appears common. 44% (N = 68 – 111) of women with sexual violence history reported trauma-reliving during SRGC (Leeners et al., 2007; Robohm & Buttenheim, 1997), 55% (N = 68) reported experiencing dissociation (Robohm & Buttenheim, 1997), and 45% (N = 4384) reported feeling unsafe to communicate distress or pain to their clinician (Swahnberg et al., 2011). The estimated prevalence rate of diagnosable PTSD in one sample was 17% (N = 90) (Weitlauf et al., 2010), with ~10-18% (N = 135- 649) of women reporting significant fear of reliving symptoms when accessing SRGC (Cadman et al., 2012; Wijma et al., 2000).

Retraumatisation Triggers

Triggering aspects of RGC are dependent on a multitude of different prior traumatic experiences. However, some aspects are more frequently reported as retraumatising.

Nudity and Undressing

Nudity and undressing were reported to be more triggering for women who had experienced sexual violence (M = 55.77%, SD = 16.89%) than women without this experience (M = 8.80%, SD = 2.30%, N = 49-111) (Leeners et al., 2007; McGregor et al., 2010; Weitlauf et al., 2008). One study reviewed the use of a modified, enhanced-coverage examination gown. It was found to increase overall comfort, measured on a 10-point Likert scale, for all women during the examination, both those with (M = 4.74, SD = 2.30) and without (M = 7.39, SD = 1.93) history of sexual violence (p< .01, N= 69)(Smith & Smith, 2000). Increased comfort was greater for women who had not experienced sexual violence. Women with sexual violence history reported no significant distress-reduction (p = .62) from the gown.

Examination Characteristics

Practical Aspects. The vaginal examination has been reported as the examination component most likely to increase retraumatisation and distress by ~29.4%-93% (N= 49-675) of women (M = 57.48%, SD = 23.70%), compared to a control group (1.20%, p< .0001) (Leeners et al., 2007; McGregor et al., 2010; Robohm & Buttenheim, 1997; Schnur et al., 2017; Weitlauf et al., 2008). Free-text responses report the reason for distress as the nature of the "motionless" and "submissive" Lithotomy position. Abdominal ultrasonography is also frequently experienced as retraumatising (M = 30.75%, SD = 3.04, N= 49-111) compared to 1.70% of control group women (p< .001) (Leeners et al., 2007; McGregor et al., 2010; Weitlauf et al., 2008). Lastly, conversations about intimate procedure details (M = 36.43%, SD = 2.28%, N = 49-675), are experienced as distressing and retraumatising more frequently compared to control group women (15.30%)(Leeners et al., 2007; Schnur et al., 2017; Weitlauf et al., 2008).

Social Aspects. These may be more subtle and difficult for the clinician to identify or modify. Verbal encouragement such as "this will not hurt", "please relax", and "trust me", were reported as retraumatising by ~21-38% of respondents (M = 28%, SD = 6.78%, N = 111-675)(Cadman et al., 2012; Leeners et al., 2007; Schnur et al., 2017). Free-text responses reported this was experienced as "exactly like it used to happen when I was abused". Other reported triggers were the clinician resembling the offender in appearance or behaviour (41%), hearing sounds associated with anger (38%), the sensation of the physicians breath on their skin (23%), and the clinician appearing rushed (17%)(N= 675) (Schnur et al., 2017).

Clinician Characteristics

Women who have experienced sexual violence highlight clinicians communicating knowledge and understanding of the effects of sexual violence as the main characteristic improving their SRGC experience. Secondly, women spoke about clinician gender, although effects of this are less clear.

A clinician who communicated competency in caring for women who have experienced sexual violence was reassuring to most women (M = 66%, SD = 16%, N = 62-135)(Cadman et al., 2012; Walker & Allan, 2014). 21% of women reported significant concern that knowledge of their sexual violence history may cause the clinician to "panic", and 17% feared that their clinician would not be knowledgeable about the impact of their experiences and react "judgementally". These fears may be reduced by a clinician communicating confidence (N = 135) (Cadman et al., 2012).

Walker & Allan (2014) reported that 94% of clinicians in their SRGC sample (N = 62) wished for teaching on sexual violence to be included in standard training. Examples of skills clinicians requested training on were referral pathways (30%), communication and grounding skills (30%), ways to increase women's feelings of control (12%), and increased understanding of affected women's experiences (5%).

Clinician gender reportedly had a less clear impact. 20% of women (N = 675) reported experiencing significant distress if their clinician was the same gender as their perpetrator (Schnur et al., 2017), and preference for a female clinician was significantly more common amongst women who had experienced sexual violence (63.50%) compared to women who had not (26.50%, p< .0001). However, Cadman et al. (2012), in which 5% of their female sample (N = 135) reported female

perpetrators, shared the free-text response that "the assumption that if the clinician is female, it makes it all ok".

McGregor et al. (2010) (N = 61) specifically reviewed clinician gender effects on disclosure. Female clinicians asked about sexual violence more frequently (66.70%) than male colleagues (33.3%). Their responses were more frequently rated as "helpful" (46%) versus male clinicians (27.60%) and were less likely to be perceived as "very unhelpful" (10%) versus male clinicians (25%). However, three studies to date have consistently reported that male clinicians are not significantly associated with decreased likelihood of disclosure (p = .39, N= 113) nor with retrospectively reported distress during the examination (p = .07, N = 808)(Fry et al., 1996; Hilden et al., 2003).

Women's Beliefs about SRGC

Reports from women with experience of sexual violence reflected a similarity between their experience of SRGC and their experience with sexual violence. Cadman et al. (2012) reported that 5% of their sample (N = 135) agreed with the statement that routine gynaecological examinations were "legalised rape". This finding may indicate that a minority of women experience this similarity particularly strongly.

Women reported questioning the necessity of the medical examination, as they did not have symptoms (11%), were not sexually active (9%), or that it was "completely unnecessary regardless" (N = 90) (Weitlauf et al., 2010). Two studies, (Cadman et al., 2012; Weitlauf et al., 2010) employed free-text responses in their survey designs to capture nuances of women's beliefs about SRGC. These indicated

that 25% (N= 135) of women in these samples did not feel "allowed" to access SRGC as they were not "physically normal", "showed signs of abuse and trauma", and that their experiences had "taken away their entitlement to good treatment". 7% (N = 90) also reported a belief that medical instruments would cause physical harm.

Negative emotional impact of SRGC was also an area of concern (Cadman et al., 2012; Hilden et al., 2003; Leeners et al., 2007; Schnur et al., 2017). Four studies (N = 111-808) explored women's emotional experiences during SRGC. All reported that the most common negative experiences were feeling lack of control (52%, N = 111), powerlessness (43%), feeling exposed (38%), and helplessness (19%). These experiences were supported by practical examples in free-text responses where women reported that SRGC made them feel treated "like an object" (36%), and "resembled the control they suffered during the abuse" (29%), that was "something just done to you" (29%), where they were "expected to just remain silent" (22%).

Care Modifications to Reduce Retraumatisation

The individual trauma-dependent nature of retraumatisation warrants discussion with women to determine individual triggers and preferences. However, some modifications are more frequently endorsed by women with sexual violence history.

Clinician Modifications

Few women (5.8%, N = 111) believed that the option to choose a female clinician would have had a significant positive impact on their SRGC experience (Leeners et al., 2007). Rather, women requested increased clinician familiarity; either by seeing the same, designated clinician each time (61%, N = 808), or by having dedicated time to talk about their experience of sexual violence, triggers, and individual helpful care

modifications (70%, N = 808), which were then recorded in clinical notes (Hilden et al., 2003). 40-60% of women (N = 675) also reported a wish for HCPs to receive training on the impact and management of sexual violence, which should include deescalation psychological skills, such as grounding and distraction techniques, to contain patients' intense emotions (Schnur et al., 2017). 40% of women reported that increasing staff familiarity, by the wearing of name badges, having named images of staff in waiting areas, and staff introducing themselves by name, would increase feelings of safety.

Clinician Communication

Successful HCP-patient communication was consistently highlighted as important. 70% of women (N = 808) in one study expressed that dialogue about their retraumatisation triggers, and an explanation of what the procedure would entail, would significantly reduce their discomfort (Hilden et al., 2003). During this dialogue, 53% of women (N = 135) would find helpful the clinician acknowledging their history and that this may cause distress during the examination (Cadman et al., 2012). 46% of women wished for the option of having a chaperone or trusted person present. This is current practice in the NHS. Finally, 22% of women (N = 111) expressed that the most important thing was for the clinician to be "friendly, patient, sensible, and sympathetic" (Leeners et al., 2007).

Returning women's feelings of power and control was expressed as important, such as by giving the patient explicit permission to stop the exam at any time using an agreed stop signal (65%), asking women's permission to proceed with the examination at each new stage (30-45%), and that clinicians were mindful to use "concrete, factual, and informative" language (33%) (N = 111-135) (Cadman et al.,

2012; Leeners et al., 2007). 11% of women requested more direct procedure involvement, such as inserting the speculum themselves, or being allowed to hold instruments alongside the clinician as they were used.

Exam Modifications

There were few well-endorsed modifications to the examination. Some women suggested using the lateral, as opposed to lithotomy position (10%), and the use of plastic, instead of metal instruments (10%) (N = 135) (Cadman et al., 2012). 4% of women stated they would only access SRGC while under deep sedation, although a greater number of women (20%) reported that this would be anxiety-provoking due to greater loss of control (N = 675) (Schnur et al., 2017).

A larger portion of women requested modifications to increase feelings of safety and familiarity, such as greater control over time of year when appointments were booked (53%), and ensuring appointments took place at the designated time (12%) (N = 135) (Cadman et al., 2012). It was also requested that dual appointments be offered when women disclosed a history of sexual violence (31%) and that clinics offered a dedicated private area for women following the exam (21%). A dual appointment system following disclosure of sexual violence history, would dedicate the first appointment to familiarising women with the treating clinician, the procedures, and instruments, and to be told about what she could expect. The procedure itself would be carried out during the second appointment.

A clinician's awareness of women's sexual violence history would 53facilitate later TIC. While retraumatisation triggers are dependent on the individual trauma experience, there are shared themes where triggers are more likely during the SRGC

contact. There are several ways clinicians can make care more trauma-informed; particularly, through open dialogue with the patient, increasing knowledge and confidence on the topic, and by discouraging a complementary patient-practitioner relationship.

Discussion

This study aimed to summarise retraumatisation in SRGC, for adult women with a history of sexual violence; and identify care-modifications to advise future trauma-informed SRGC guidelines. 18 studies were identified. All employed a survey methodology, with four studies including control participants. Three studies calculated inferential statistics, and these either compared specific care modifications (Smith & Smith, 2000), impact of clinician gender on female patients (Fry et al., 1996), or developed a suggested theoretical trauma-model of SRGC (Swahnberg et al., 2011). This highlights the early, observational, stage at which research on trauma informed SRGC remains.

Included articles reported an average sexual history prevalence rate similar to the global average (Borumandnia et al., 2020). Disclosure of sexual violence was infrequent, and few women reported having ever been asked about sexual violence history by their clinician. Most wished to be asked. Even in one study where the majority did not want to be asked (Pikarinen et al., 2007), the authors concluded that it was still appropriate to routinely query this – in line with the majority of research. This, as disclosure has been identified as an important foundation of trauma informed SRGC; as TIC relies on lived-experience input for its development, on HCP-patient dialogue regarding individual trauma triggers, and for treatment modifications (Menschner & Maul, 2016).

Sexual violence history significantly impacted women's experiences of SRGC. Examinations were experienced as more distressing, and more feared. Around half of women with a sexual violence history reported symptoms of retraumatisation during SRGC, and one study reported a prevalence rate of 17% of participants (N = 90) from one SRGC clinic fulfilling diagnostic criteria for PTSD (Weitlauf et al., 2010).

While some practical aspects of the SRGC, such as vaginal examination, abdominal ultrasonography, and nudity, were identified as distressing by significant portions of women, modifying these aspects is unlikely to be sufficient, although their retraumatising frequency should be known. Rather, women reported that a good patient-HCP relationship and open dialogue was most likely to reduce retraumatisation (Cadman et al., 2012). Thus, conversation about sexual violence history should occur as routine.

HCP-gender was not reported to have a significant effect on care quality or experience. While women frequently reported preferring a female clinician, retraumatisation risk was greatest when the clinician reminded the woman of the original perpetrator, either due to gender, appearance, or mannerisms. 5% of women (N = 135) in one article reported that their perpetrator was female (Cadman et al., 2012). A male HCP was also not found to negatively impact disclosure or increase feelings of distress (Fry et al., 1996), although male HCPs were more often described as "unhelpful" in their responses to disclosure (McGregor et al., 2010). Male HCPs may consider that their sex could be a reminder of male perpetrators, and this should inform discussions around individual triggers. Equally, female clinicians should not assume that their gender cannot be triggering to patients.

Both patients and clinicians requested better HCP training on working with women who have experienced sexual violence (Walker & Allan, 2014). Clinicians reported this would increase feelings of confidence, and a large portion of women requested clinicians who communicated familiarity and confidence working with experiences of sexual violence.

Lastly, several women highlighted the power imbalance between HCP and patient. This often reminded them of the experienced loss of power in the original sexual violence trauma. Many modifications could equalise this power imbalance, particularly an open dialogue and increased involvement in medical procedures.

Limitations

This review relied on studies which included women in Global North countries; where healthcare may be more accessible, developed, or affordable. Whilst the evidence reported in this review outlines the importance of a reciprocal HCP-patient power balance, it is limited by excluding variation in culture and gender normativity. Six studies reported ethnicity distribution of the sample, of which four included women living outside their country of origin. Minority groups may experience greater barriers to care; both practical such as language barriers, as well as cultural (Szczepura, 2005). It is important to consider how these women's SRGC experience may have been particularly impacted. No study broke down data by ethnicity, therefore, this remains unknown.

Further, all studies included women living in countries with similar beliefs about sexual violence stigma and female gender hegemony. It is also restricted by

being limited to English language studies. Findings are therefore unlikely to be universally applicable.

Strengths

This review is the first to offer an overview of the quality of the existing literature, and evidences that SRGC can be modified in line with TIC definitions (Menschner & Maul, 2016). It anchors women's experiences in existing trauma literature, and is informed by a theoretical trauma model of SRGC (Swahnberg et al., 2011). The decision to include all eligible studies, regardless of quality, was conscious. This, to indicate that the body of available literature is small and of limited methodological and qualitative range. This review may guide future researchers to where additional research efforts are most needed.

Future Directions

The current review suggests that prevalence and disclosure rates should be routinely recorded in research to increase awareness and valid estimates. Disclosure is important to successful TIC and should be facilitated. Further, the survey methodology of all included articles indicates that research remains largely explorative. These have asked a broad range of questions which have contributed to the collective pool of knowledge summarised in this review. They have also indicated triggers and modifiers in samples spanning several geographical locations and populations.

Future research efforts may explore a trigger or modifier in isolation using studies of greater methodological robustness. Three studies lead on developing this area from survey to experimental research (Fry et al., 1996; Smith & Smith, 2000;

Swahnberg et al., 2011). The quality of these studies was variable, which may be impacted by current research best-practices versus at time of publication and limited information access. However, they illustrate that experimental research in this area is both valuable and possible. Of further future research interest may be the effects of HCP-patient discussion about individual triggers and modifiers on distress, patient involvement in components of the SRGC process, and impact of HCP training on care of patients with sexual violence history.

This narrative synthesis contributes to the area of TIC SRGC by highlighting ways to move this field forward, both in terms of informing future research, and providing insight to clinicians regarding actions they may consider in their own practice.

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Service Improvement Project

Patient Experience of Patient-Clinician Dialogue Concerning Sexual Intimacy: A Qualitative Investigation of Females with Chronic Gynaecological Conditions

By

Jenny Elsa Liss Lisshammar

Harris Manchester College

Supervised internally by

Dr Matthew T. Knight

Supervised externally by

Dr Emma Evans

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Abbreviations used

CGCs: Chronic Gynaecological Conditions

HCP: Healthcare Providers

IPA: Interpretive Phenomenological Analysis

Embedded Abstract

Background: Sexual dissatisfaction is common in women living with chronic gynaecological conditions. While increasingly recognised as part of holistic care, it remains infrequently spoken about in clinical consultations. Clinicians attribute this to not recognising its relevance, feeling embarrassed, or feeling insufficiently skilled.

Methodology and Aims: This service improvement project was set at the John Radcliffe Hospital's Women's Centre, UK. It sought to understand patients' experiences of conversations about sexual intimacy. It explored individual and dyadic processes contributing to these experiences. Six patients with chronic gynaecological conditions participated in semi-structured interviews. Their accounts were analysed using Interpretative Phenomenological Analysis.

Results: Four themes were inferred from analysis. 'Beyond the hospital door' described the day-to-day impact of participants' conditions. 'Ripples of care experiences' recounted participants care, experienced as a single, continuous journey. 'The 'S' word in clinic' spoke of absent, but wanted, clinical conversations about sexual intimacy. Lastly, 'You're an expert, I'm an expert, too, identified participants' beliefs about the meaning of medical expertise, and the value of reciprocal patient-clinician relationships.

Conclusions: Chronic gynaecological conditions significantly impacted women's sexual lives, which was sometimes felt to be unacknowledged in consultations. Women sought clinicians dialogue and support. Power inequality and social and moral stigma inhibited conversations about sexual intimacy. The clinical relationship was imperative to overcoming this. The service was recommended to; explore these

findings within the wider patient pool, increase patient involvement in service development, develop a clinician training module and a clinic pro forma.

Key terms: women's sexual health; psychological sexual function; gynaecological care; interpretative phenomenological analysis; patient-centred gynaecological care

Introduction

Chronic Gynaecological Conditions (CGCs) affect the female reproductive system beyond three months (O'Halloran et al., 2004); frequently being psychologically impactful (Bryant et al., 2014; Kessler et al., 1993). Women report identifying as "unreal" or "pseudo" women because their reproductive organs are physically or functionally different (Kaler, 2006; Marriott & Thompson, 2008). CGCs can also be stigmatising when heteronormative hegemony associates female sex to childbearing abilities (Nguyen et al., 2015). Beliefs that CGCs result from socially deviant sexual behaviours may stigmatise and deter women from speaking with partners or healthcare providers (HCPs) (Matías-González et al., 2021; Quinlivan & Lambregtse-van den Berg, 2021).

Sexual dissatisfaction is defined as a negative experience of sexual intimacy; either the individual components of pleasure, sexual desire, and positive sexual self-view, or dyadic processes of connection, safety, and expression of sexual desire (Pascoal et al., 2014). CGCs are accompanied by sexual dissatisfaction-rates ranging from 40-100% (Audette & Waterman, 2010; Jia et al., 2013). Only 18% of women report overcoming these difficulties without professional support (Haboubi & Lincoln, 2003). This can independently increase feelings of shame, low self-esteem, clinical anxiety, and depression (Bryant et al., 2014; Rosen & Bergeron, 2019; Shallcross et al., 2018).

Sexual dissatisfaction in CGCs is increasingly understood as transdiagnostic and unrelated to physical disease burden (Daker-White & Donovan, 2002). Clinical conversations about sexual intimacy have been found to increase positive sexual experiences in the continued presence of pathology, indicating that HCPs

knowledgeable in discussing psychosocial compounds of CGCs are imperative (Atallah et al., 2016; McCabe et al., 2016; Pitcher et al., 2020).

Many HCPs in gynaecological care acknowledge this. One survey of 813 clinicians in the British National Health Service found that 79% of questioned HCPs agreed that supporting patients with post-diagnostic sexual adjustment was important, and 90% felt it should be addressed as part of holistic care (Haboubi & Lincoln, 2003). Only 9% reported feeling comfortable initiating such conversations. This hesitancy has been attributed to practical issues of time constraints (Stead et al., 2003) and inadequate training in sexuality and sexual issues (Haboubi & Lincoln, 2003); unawareness that sexual satisfaction is a clinical matter (Berman et al., 2003), or a belief that the topic is irrelevant to physical healthcare (Sobecki et al., 2012). Both clinicians and patients report feeling embarrassment and uncertainty about how appropriate such conversations are.

There is a paucity of literature on how absent dialogues impact patients. In other areas of medicine, absent clinical conversations about patients' post-diagnostic sexual adjustment increased their feelings of being sexually "abnormal" and disappointment in HCPs treating them (Gilbert et al., 2016). Clinical conversations about sex increased patients' self-confidence as sexually active individuals and facilitated similar discussions with sexual partners (Perz et al., 2014; Stead et al., 2003).

Current Study

This service improvement project took place at the John Radcliffe Hospital's Women's centre in 2022. This was in response to patients with CGCs voicing that

conversations about sexual intimacy was a need unmet by the service. This project had three aims: to understand how patients had experienced clinical discussions about sexual intimacy, the individual and dyadic factors that had influenced those experiences, and to receive feedback on the service's current approach.

Methodology

This study employed an Interpretive Phenomenological Analysis (IPA) of participants' accounts. IPA involves forming a detailed understanding of individuals' experiences and derived meanings of a phenomenon (Smith et al., 2009). By interpreting the group narrative, generated data becomes an intimate, idiosyncratic account of how a phenomenon is experienced, co-constructed with the researcher (JL; self-reflexivity statement in Appendix A).

Ethical Procedures

The project was registered as a clinical audit in Oxford University Hospitals NHS Foundation Trust. The trust's Patient Experience Team approved participant-facing documentation. All participants gave informed verbal and written consent, which they could withdraw at any time without it impacting medical care.

The study was co-produced with an Expert by Experience consultant (MP)- a Women's Centre patient. A service gynaecologist, urogynaecologist, and the psychosexual clinic lead consulted on study development.

Interview Schedule

A semi-structured interview schedule was constructed by JL, MK, and MP (Appendix B). It explored participants' experiences of their clinical diagnoses (Q1,2),

of care at the Women's Centre (Q3), and of sexual intimacy discussions with clinicians (Q4-6). Question seven more directly sought service feedback.

Sampling

IPA encourages small, homogenous, purposive sampling to facilitate in-depth analysis of idiosyncratic experiences of a shared phenomenon (Smith, 2003; Smith & Eatough, 2006). This was employed for recruitment. Study information was spoken about in clinics (EE, JL) and individually emailed to women after clinic attendance. Six participants were recruited. This is cited as an appropriate sample size for comparable projects (Caal et al., 2012; Noon, 2018). Inclusion criteria are in Table 1.

Table 1: Participation criteria

Inclusion criteria • Accessing care at the Women's centre, which provides care to adults • Chronic (beyond three months) gynaecological condition (O'Halloran et al., 2004) • Self-defined sexually active past 12months The literature temporally defines being sexually "active" as sexual acts including another party, occurring in the last 4-52 weeks (Kaida et al., 2015; Ponholzer et al., 2008). Our definition also acknowledged the study's temporal proximity to the COVID-19 pandemic, and that sexual avoidance may be more common in this group • Living in the county of Oxfordshire • To ensure appropriate follow-up support could be offered as needed •
Exclusion criteria • Accessing the Oxford Rose Clinic for Female Genital Mutilation • Accessing gynaeoncology services • Both these conditions are believed to have a different, idiosyncratic impact on sexual intimacy.

Data collection

Data collection took place in single-opportunity, individual interviews over Microsoft Teams. All interviews were undertaken and transcribed by JL. Interviews lasted 47-68 minutes (M = 55 minutes) and concluded with debriefing. JL recorded post-interview recollections (Smith et al., 2009) (Process statement in Appendix C).

Participants

Six women participated in the study. Five additional women were recruited but did not participate; four due to time constraints, and one did not disclose. Participant demographic details and pseudonyms are in Table 2. All participants reported being in committed, monogamous, opposite-sex relationships at time of interview.

Table 2: Participant information and pseudonyms

Pseudonym	Age	Ethnicity	Years with symptoms	Gynaecological presentation
Lucy	24	White British	9	Endometriosis
Sarah	50	White European	20	Post-hysterectomy loss of bladder control
Maria	47	White British	28	Endometriosis
Dana	38	Asian 'Other'	0.5	Heavy vaginal bleeding – diagnosis unknown
Elisabeth	51	Black Caribbean	14	Heavy vaginal bleeding – fibroids
Ana	30	White British	3	Endometriosis and Vaginismus

Data Analysis and Evaluation

Recordings were manually transcribed (JL). Analysis followed the common analytical process of IPA outlined in Smith et al. (2009, pp. 82-99). This guide acknowledges that the analytic end-product is a co-production of participants' sense-making of their experiences and the analyst's secondary sense-making of these accounts.

The transcript of JL's post-interview reflections was read, before each participant transcript was read twice, with the audio-recording played back while reading the first time. This increased familiarity and included the participant voice in transcript. To decontextualise text and highlight linguistic or semantic patterns,

each transcript was then read once backwards. Preliminary themes were clustered on common meaning and validated by participant quotes.

This process was repeated for each transcript. Subsequent analysis identified shared phenomena of superordinate themes. This was done by processes of contextualisation- identifying common shared narratives, and subsumption- identifying themes of shared descriptive, linguistic, or semantic content. This parallel process acknowledged the study's service-evaluation aspect, warranting identification of both phenomenological and practical themes.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) were employed as quality guidelines. This is believed to be the most comprehensive guidelines to date, comprising data from twenty-two previous quality assessments. JL kept a reflexive journal throughout the research process (Ortlipp, 2008). Theme development was discussed, in anonymised format, with MP and MK.

Results

Four superordinate themes were extracted from participants' interviews (Table 3).

Table 3: Superordinate themes and subthemes within them

Superordinate theme	Subthemes
Beyond the hospital – stories untold in clinic	
	Day-to-day
	Sexual intimacy
	Partners as co-patients
Ripples of care experiences – life alongside the Women's centre	
	Battles and fights
	Is it all in my head?
The 'S' word in clinic – stigmatisation and support	
	No sex in clinic, please
	Sexual matters, matter
You're an expert, I'm an expert, too – reciprocal care	
	What is it to be an expert?
	I am human, you are human, too?
	Reciprocal relationships

Superordinate Theme 1: Beyond the Hospital–Stories Untold in Clinic

All participants described their CGC's substantial day-to-day impact. They rarely spoke to clinicians about this, but thought that if clinicians had a better understanding of the psychosocial impact of their CGC, this would in itself be therapeutic, and , it could improve their care.

> I wish they just knew the impact this has had on my life, then maybe, they would have cared a bit more and showed a bit more empathy. (Maria)

Subthemes reflect experienced daily struggles of patients and partners. These themes highlight how CGCs were experienced by women in our sample and capture what our participants would have liked to have shared in conversations about sexual intimacy in clinic. This informs the reader of the array of areas in daily life that are directly impacted, and which indirectly impact sexual intimacy, which may be relevant to consider when raising the topic of sexual intimacy when speaking to women with CGCs.

Day-to-day

Adjusting life around symptoms was described as "taking over" participants' lives; often being harder to cope with than symptoms themselves. Participants felt that a more holistic understanding of this impact by clinicians, would have aided conversations about sexual intimacy, and made the topic easier to approach. They felt communication of this day-to-day impact had not taken place in their previous clinical contacts. Participants described the financial burden of sanitary products, new clothes, and underwear. Work was impacted for all employed participants; to have no control over when or for how long appointments were booked and being reprimanded for time taken for appointments. Three participants had required periods of extended sick leave. Ana had changed employment due to symptom severity.

> I had to leave and get a job where I was full-time remote, because between the bathroom stuff, and the periods and everything, it just isn't, it wasn't feasible. (Ana)

Participants recalled humiliating incidents where they had soiled clothes with blood or urine. As a result, they either avoided social situations, or modified their behaviour.

> It's embarrassment again, of going out and soiling your clothes, and therefore I have to wear a panty liner every day. It's just, endless. Just, just, endless. (Elisabeth)
>
> On that weekend I wet myself about six times…as soon as I laugh you know, that's why it happens so now, I'm getting to the stage where I'm like, do I stop laughing, do I stop drinking? (Sarah)

Participants felt alienated and alone as they rarely spoke about these experiences.

Sexual intimacy

All participants reported that their sexual lives had changed due to their CGC. Vaginal-contact sex was often impossible or cut-short by symptoms or negative emotions. They described forgetting what it felt like to feel sexually aroused and have sexual interest.

For Ana, who identifies as asexual, gynaecological symptoms impacted her sex life more than her sexual orientation. Many participants shared her experience, feeling they were no longer 'competent' wives or partners and 'missing out' on full relationships.

> When I have to say, 'you know, I am bleeding again', emotionally, that just kills me, because then I have to disappoint the person that I love. (Elisabeth)

No participant had felt able to speak to clinicians about these experiences.

Partners as co-patients

Participants spoke about partners as co-experiencing their conditions. Maria's partner attended medical appointments with her, and she described their interlinked experience using terminology such as "we worried" or "we thought". Lucy also described her partners involvement in her care, that he was "knowing everything, and I mean everything, to a T." Lucy felt guilty about this.

Many participants wanted support for partners from gynaecological services. If this wasn't possible, participants wanted clinicians to invite partners to be part of the care contact and explain to them why their sexual relationships had changed. Elisabeth described what this conversation could look like:

> Invite your husband on your next visit, so we can talk to him or provide some information to him, because sometimes it's not because you don't tell them, it's because they need reassurance from someone else, from a clinician to say, this is what your wife is going through. You might feel as if you have been pushed aside, or you know, you are not being loved…but this is what she is experiencing…but you know, that wasn't offered. (Elisabeth)

Lucy and Ana had spoken to clinicians about their partners' experiences. Both reported these conversations had improved their sexual experiences, despite symptoms remaining unchanged.

Superordinate Theme 2: Ripples of Care Experiences - Life Alongside the Women's Centre

All participants described contact with the Women's Centre as a single care journey, rather than as individual events or epochs. Their condition chronicity created a sense of life being lived alongside the Women's Centre. Participants felt that this sensed continued experience impacted their ability to form relationships with clinicians, and subsequently impacted their ability to speak about sensitive topics such as sexual intimacy.

Battles and fights

Five participants described their care journey as at some point having been a "battle" or "fight". Sometimes, this was a quasi-literal fight. Maria described lobbying the prime minister to ensure the Women's Centre had the necessary provision for her care. For others, it was an emotional battle which impacted their psychological health. These experiences became frames of reference with which participants approached future clinical contacts, even with clinicians they had not previously had contact with. Such frames of reference had both encouraged and hindered previous conversations about sexual intimacy, and participants wanted clinicians to be aware of these impacts if and when they approached the topic in future conversations.

> I was scared to go to my appointments, or I dreaded them and that's what it felt like, it felt like it didn't help with my mental health. I just felt like it wasn't helpful because I didn't get anything out of it except stress…It was so tiresome just fighting in an appointment which is about helping me, not making things worse. (Lucy)

Participants carried the experience of 'fighting' between clinical contacts, making them less likely to engage with clinicians and sometimes, not follow medical advice.

> After this fight to get referred, it just went out the window completely, and I just discharged myself against medical advice. But within 24 hours, I had to be readmitted. It was horrible. (Maria)

These emotional experiences became frames of reference which subsequent clinical contacts were compared with. Participants described now entering clinical contacts prepared for further 'battles.' For participants who had formed positive relationships with clinicians, discussed in subtheme *Reciprocal relationships,* this narrative was less salient, but remained present throughout.

Is it all in my head?

Maria, Lucy, and Ana were initially told their gynaecological problems were symptoms of psychological distress. Whereas Ana and Maria 'knew' this to be incorrect and continued seeking help via different channels until they were referred to gynaecology, Lucy believed for several years that something was psychologically 'wrong' with her, because of her experiencing sexual abuse in adolescence.

> He was like oh okay, I see you are also on anxiety medication, and I was like yeah, and then immediately he was like oh this is all in your head, it's because you are afraid of

> sex, you have got complex psychological issues and he refused to refer me, to the John Radcliffe…like gynaecology, of any kind. (Ana)

This occurred before contact at the Women's Centre. However, it was something participants described bringing with them into care there. They experienced receiving gynaecological diagnoses as validation of their symptoms.

Conversely, Sarah was never told her symptoms related to her psychological health. Like Lucy, she had experienced sexual abuse in adolescence, and now wondered whether her assessment was 'incomplete'. She wanted clinicians to ask about her history.

Participants wanted to speak about psychological aspects of their CGCs, but felt the topic warranted sensitive addressing, and that gynaecological and psychological difficulties were not mutually exclusive.

Superordinate Theme 3: The 'S' word in clinic – stigmatisation and support

All participants wanted clinical conversations about sex. Experiences of clinicians' perceived reluctance to do this are described in the subtheme *No sex in clinic, please.* The meaning of being asked, for participants views of themselves and clinicians, is described in *Sexual matters, matter.*

No sex in clinic, please

Four participants felt that clinicians did not understand or want to speak about the impact of their CGCs on sexual intimacy. Sometimes, they thought it was

because clinicians felt uncomfortable talking to patients about sex, but participants felt it was the clinician's responsibility overcome this.

> I am sure they must find it awkward and embarrassing, and I know that they are, but I think that they need to get to a point where they can settle in. (Maria)
>
> Why isn't it asked as a general question? Like what's your job sort of thing, why are these things not normal questions, is should be a normal question because it's a normal thing to do. (Lucy)

Participants had tried to raise sexual difficulties in clinic, and felt rejected by their clinician, having to research symptoms themselves.

> That was funny talking to my doctor about that [*a symptom*] and him telling me what it was, but not explaining what it was, just telling me to look it up when I got home, and then did nothing to help me. (Sarah)
>
> Why there is like, for me a lack of interest in having some sexual intercourse, so I shouldn't have to look it up myself, yeah, it would have been helpful if, you know, what are the…symptoms of my condition. (Dana)

Some participants reported that clinicians had recently asked about sex. This was felt to be so unusual that participants described being "shocked" and "surprised". Even when the question was asked, it felt tokenistic.

> Well, he, I was expecting him to go a little bit deeper, further…but he didn't, he didn't say anything…My answer was like, that's all he wanted to know. (Elisabeth)

Participants shared the discomfort they thought clinicians might feel, speaking about sex. However, they felt that it would have been easier to speak to a clinician than anyone else.

Sexual matters, matter

All participants wanted conversations about sexual intimacy to be in person. This conversation was not just about conveying information, but equally about building relationships.

> Once you answer something like that, you do feel closer to the person, because you are sharing something that is very, very personal to you, so…you form some sort of bond. (Sarah)

Participants described feeling unable to raise the topic themselves. Partly, because they thought they were alone with the problem and partly, because participants felt that clinicians indicated that it was an uncomfortable topic, and participants worried they would be judged for raising it.

> No one ever asked, never spoke about it, like it just didn't happen, and I was young, I was a teenager, and as now I feel if I brought it randomly, I would have been judged…it just felt like it was just a no-go topic. (Lucy)

Participants who had spoken about sexual intimacy felt it was then easier to revisit.

> I definitely feel like less of a freak if that makes sense. I feel that it's not something I have to deal with on my own, like there are people who can help me. (Ana)

Clinicians asking about sexual intimacy seemed to normalise the topic, which participants found empowering and relieving.

Superordinate Theme 4: You're an Expert, I'm an Expert, too – Reciprocal Care

There was shared meaning-making of the clinician as an expert, and uncertainty about the boundaries of this expertise. Participants whose clinicians addressed psychosocial concerns described more reciprocal relationships with them.

What is it to be an expert?

Participants experienced clinicians as holding considerable power on account of their medical expertise. It impacted participants' behaviour in consultations. One participant felt the clinician's expertise made her anxious about getting the consultation 'wrong' and using a pre-clinic questionnaire to rehearse her responses beforehand.

Sometimes, clinician-expertise made participants feel like they could not, or did not need to, express thoughts and opinions about their care.

> I was like really young at the time, and I was like, I don't want that…so you just carry on and just do as the medical professional says because that's what they are there for. (Lucy)
>
> I was not asked, but…I was just quite open with the suggestion from the consultant because they are the expert and I trust their expertise. (Dana)

Clinician expertise could also be positive and comforting if it indicated that the clinician was experienced. Expertise by experience eased the participant into an active patient role, whereas expertise by training made participants feel less knowledgeable and more passive.

> I am seeing people now who are, specialists in this kind of thing, like, that makes it easier to talk about, because you know that this is the stuff they hear all the time. (Ana)

Power in the clinical relationship influenced the way expertise was perceived. If the patient role was experienced as one where medical expertise could be questioned or contributed to, patients were more likely to find it positive.

I am human, you are human, too?

Participants reflected on their 'human sameness' with clinicians. This included wondering to what extent clinicians thought of them as 'human', beyond being patients. Likewise, participants reflected on clinicians' humanness, which impacted how they responded to them.

They wanted to build reciprocal relationships with clinicians, where conversation could move beyond medical topics. When this didn't happen, it could create feelings of friction.

> I still can't build relationships with them, they don't want to I suppose, it's not that they don't know what they're doing, its more that they are not aware that it's a person on the table. (Maria)

It could also create confusion, as a lack of a relationship implied the appointment was not an appropriate space to speak about 'personal' topics, such as sex.

> It doesn't really occur to me to ask them those questions, yeah, because I thought it was just like a personal thing. (Dana)

Sometimes, participants also refrained from speaking about 'personal' topics because they wanted to protect clinicians. They worried that clinicians would either be emotionally overwhelmed, or that clinicians chose to focus on medical aspects because their humanness limited their ability to comprehend the patient's holistic experience.

> It wasn't that I wanted help with everything. I just wanted them to be aware that things are so bad and affected because of those other things instead of that being lost and

> them focusing just on one area…you just have to, not throw everything at them 'cause they are still human. (Lucy)

Four women felt that relationships with female clinicians were easier, due to their shared experience of being female. They felt this could facilitate sympathy with their experiences.

> I know that they are consultants so they are already experts on the reproductive system or something like that, but when it comes to pain and more intimate, person things, I think the female, they are quite like…maybe not as abrupt as a male…and maybe he couldn't understand the shame and yeah, the gentleman. (Dana)

Despite the participants' thoughts about what it meant that their clinicians were human, no one rejected seeing a clinician due to their characteristics.

Reciprocal relationships

Many participants described positive clinician relationships as the most important aspect of their care. Lucy, Ana, and Sarah described having such relationships currently. These relationships continued to focus on care provision, but care occurred within a reciprocal relationship, with both patient and clinician as experts co-producing care. These positive frames of reference were described as important factors which had encouraged previous therapeutic conversations about sexual intimacy.

> I feel really included in everything and understand everything that is happening, like my plans that she set out are so, like there is so many like different options, like if this doesn't work, we've got another one that's just like, I am not just left in the lurch if something doesn't work. (Lucy)

These clinicians' care had not necessarily improved medical symptoms. Participants felt accepting of this, as they knew their clinician was there to support them. They also knew they had care plans in place, which they understood and had agreed to. As a result, participants felt able to see lack of medical improvements as temporary setbacks.

Interpersonal connectedness was also valued, where the relationship was fluid and interactive. There were many examples of this happening already; being given permission to take one's time, to express one's emotions, to say no, and to use humour, as well as clinician body language being open and receptive.

> If you think that they are genuinely interested in what you have to say, then you feel very comfortable speaking to somebody, you know, and as long as you see them writing something down, because that shows they are taking in what it is you are saying…they turn their chair around and they face you and they are not just sat at a desk and it's not like very regimental. (Sarah)
>
> Knowing that I could say no, to anything, made me feel like I was in a better position because I felt properly informed about what they were going to do and what they were going to ask me. (Ana)

Maria, who described a painful, 20-year experience at the Women's centre, described a single 'compassionate' clinical relationship.

> He always knew my name. And I know…you're just a number in the system. Before you go in the room, he always said, *Maria, welcome*, whereas other clinicians, as you sat down, would look at their page and say, you know, *Maria*. The way that he used to do things was different. (Maria)

Maria's experience captured being acknowledged as a human, not a patient. Her description of being "just a number in the system" was a phrase also used by Elisabeth and Lucy. It was always said with certainty, that "you are", rather than "feeling like", a number in the system. It indicated an experienced barrier between the patient and clinician which reciprocal relationships counteracted.

Overall, conversations about sexual intimacy were important for participants; both to communicate emotionally painful experiences which were impacting their relationships, but also as symbols of reciprocal relationships.

Discussion

This study explored how women with chronic gynaecological conditions (CGCs) experienced discussing sexual intimacy in gynaecology clinic.

Four themes were inferred from analysis. The first two themes spoke to participants' experiences of their condition. They spoke about the impact of symptoms on life having greater influence than the symptoms themselves. All participants' sexual lives were significantly impacted, similarly to previous studies

of sexual intimacy in CGC's (Audette & Waterman, 2010; Jia et al., 2013). As in other published accounts, participants struggled to overcome these difficulties (Haboubi & Lincoln, 2003).

Participants described a continuous journey lived alongside the Women's Centre. This experience may not translate in medical notes, where time passes between contacts, or when patients are discharged and re-referred. Participants described this journey as a 'battle'. Themes one and two illustrate the broad psychosocial impact of CGCs on participants lives and sexual lives, and how conversations about sexual intimacy should preferably encompass a holistic view of sex, beyond physiological function.

The third theme covered participants' experiences of clinical conversations about sex. No participant felt able to initiate conversations about topic, and only 9% of clinicians feel comfortable asking patients about sex (Haboubi & Lincoln, 2003), although many recognised its importance (Sobecki et al., 2012). All our participants wanted clinicians to ask. They thought that clinicians didn't ask because they felt embarrassed or that it was inappropriate. Previous research indicates that clinicians do report feeling both embarrassed and insufficiently skilled to speak about sex (Haboubi & Lincoln, 2003).

Cultural stigmatisation of conversations about sex likely facilitates this shared avoidance. Stigma can be viewed as a morality issue whereby individuals feel they and others have responsibility to adhere to social normativity (Yang et al., 2007). It also increases value of what is at risk if the stigmatised concept is engaged with. For

both patients and clinicians, the thing 'at risk' might be clinicians' fitness to practice, and patients' access to care.

Themes three and four captured how this inferred moral impasse may hinder conversations about sexual intimacy. To our knowledge, this is the first study to account how conversations in gynaecology clinic about sexual intimacy impact patient's sexual lives in the absence of diagnostic improvement. Participants who had had such conversations reported greater confidence to speak about sexual intimacy. Similar outcomes are described elsewhere (Perz et al., 2014; Stead et al., 2003).

Participants spoke about to what extent shared humanness was recognised in the patient-clinician dyad. This reminded of the concept of common humanity – seeing oneself as part of a larger, connected, human experience (Neff, 2003). Beliefs in common humanity have been found to increase patients' active involvement in their own care (Akin, 2009). Participants described recognition of clinicians' medical expertise and uncertainty whether clinicians could look beyond this to engage with patients' lived experience. Themes one and two reflect how participants saw their experiences of sexual intimacy through this holistic 'lived experience' lens, and that they felt that clinicians focus on physiological function, excluding psychosocial aspects, could inhibit successful conversations about sexual intimacy. Participant perceptions of clinicians' own lived experience increased their confidence in the clinicians' capacity to engage with patient's lived experience. Clinicians could indicate capacity to engage with participants' lived experience by cultivating

reciprocal relationships; acknowledging that participants' lived experience also made them experts.

Some participants reported feeling deferent in medical contexts. Despite preferences for clinician characteristics, or clinician relationships rupturing, no participant had requested to change clinicians. Some did not know they were "allowed". This evidenced a medical relationship power imbalance. Such imbalances have been described in medical literature (Canter, 2001). It has been suggested that patients' physical distress and need for care may subjugate their psychosocial needs, and influence acceptance of otherwise unacceptable care. As the clinician is essential to care provision, their position may become 'unchallengeable'.

Service Recommendations

These outcomes have informed recommendations for the Women's Centre (Table 4).

Table 4: Service recommendations for the Women's Centre

As first steps, it is recommended that the service;
• Consolidate these findings, from a small sample, with the patient pool by disseminating a brief patient-survey in clinic (suggestions in Appendix D). This survey should be repeated in 12 months to evaluate implemented changes. • Develop an Expert by Experience voluntary patient pool, to co-produce protocols for supporting patients with questions around sexual intimacy. • Pilot live sessions for patients and partners to discuss physical and psychosocial impacts of various conditions on sexual intimacy. If well-received, consider regular virtual and in-person sessions, to accommodate the importance of in-person contact and accessibility needs. • Reviewing check-in and appointment scene-setting procedures with the Expert by Experience pool, to explore further emphasis on patient focus.

Once this is in place, to consider working alongside the Expert by Experience pool to develop:

- Explore current barriers for clinicians to speak about sexual intimacy training, and scope for clinician training on the psychosocial impact of chronic gynaecological conditions. Consider a brief training if relevant, to increase clinician confidence implementing didactic learning in practice, consider a practical training element using vignettes and role-play.
- a pro forma of questions regarding sexual intimacy that clinicians should ask at each clinical contact (suggestion questions in Appendix E).
- a list of resources specifically on difficulties with sexual intimacy. Leave these in clinic areas to indicate that sexual intimacy is a welcome topic of conversation in appointments. Clinicians can also give these to patients who do not want to speak about sexual intimacy in person.

To our knowledge, this is the first study of clinical conversations in gynaecology clinics about sex for women with CGCs. It demonstrates that research on such stigmatised topics is feasible and wanted by patients. It was a co-production between clinicians and an expert by experience consultant. Participants' accounts summarised years of lived experience. Richness about certain experiences was likely uncaptured within the scope of this study. Future research may focus on women's experiences at different stages of their clinical journey.

IPA is fundamentally idiographic; therefore, this work does not represent all women discussing sexual intimacy in gynaecology clinics. Rather, this study may increase clinicians' reflexivity when working with women with CGCs. We hope reading participants' stories are also of benefit to women living with CGCs.

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A Lay summary of the Service Improvement Project

A chronic gynaecological condition impacts women's sexual organs chronically, e.g., for a long time. It is typical for women with such conditions to be unhappy with their sex life. This can be due to physical symptoms, such as pain or bleeding, or due to psychological parts of their condition, such as feeling there is something "wrong" with them or they are "weird", or even "unreal" as a woman. Most doctors think patients sex lives are important part of treatment and think this is an important topic to speak to their patients about. However, many doctors do not start conversations about patients' sexual lives. They mention that often, this is because they feel embarrassed or like they don't have the skills. A minority of doctors also don't think it is relevant to their area of healthcare.

This project is a "service improvement project". That means that it is a piece of research within a specific health service, which aims to improve an aspect of that service. This project was set at the John Radcliffe Hospital's Women's Centre, UK. It aimed to understand patients' experiences of conversations with their doctors about sexual intimacy. It wanted to understand the processes that contributed to that experience, both individual and interpersonal processes. Six patients with chronic gynaecological conditions took part in the research interviews.

We, the researchers, identified four themes when we analysed the data. The first one, 'Beyond the hospital door' described how participants felt their conditions impacted their daily lives at work, home, and with their partners. 'Ripples of care experiences' recounted how all participants felt their contact with the gynaecology service was one, long, experience, not individual appointments. 'The 'S' word in clinic'

was about how all women who took part wanted conversations about sexual intimacy with their doctors, but these conversations were rare. Lastly, 'You're an expert, I'm an expert, too, described how many participants felt that their doctor being a "medical expert" is powerful. It made them respect the doctor and worry about challenging them. This theme also spoke about how relationships between patients and doctors where they are both equal, and seen as experts on the same problem, are good for overcoming these worries.

Overall, women in this study, who all had chronic gynaecological conditions, felt their condition had changed their sex lives. Sometimes they felt that doctors didn't acknowledge this when they met for appointments. All women who took part wanted to talk about their sexual problems, in doctors' appointments. They wanted support and advice from their doctors.

We think a reason why this is not happening in doctors' appointments right now, is because of power imbalance and stigma. This means that people feel that people do not feel able to talk about what they want because they worry they might offend or challenge the other person. The topic is 'taboo'. However, women who had safe, equal relationships with their doctors were often able to overcome this and talk about their sex lives in doctors' appointments.

We recommended the service double-check findings with more patients, to understand if this is the opinion of many people. We also recommended they include more patients in their planning and service development. Lastly, we thought it was a good idea for the service to offer a training course to doctors and give

them prompts for how to talk about sex in clinic. We hoped this might make doctors feel more skilled and less embarrassed.

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Theory-Driven Research Project

Differing Self-harm in Younger versus Older People with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan

By

Jenny Elsa Liss Lisshammar

Harris Manchester College

University of Oxford

Supervised internally by

Dr Sarah Lack

Supervised Externally by

Dr Stephanie Capon

With special thanks to

Dr Stephanie Lawrie

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Abbreviations used

APA: American Psychiatric Association

CMHT: Community Mental Health Team (also known as Adult Mental Health Teams)

EUPD: Emotionally Unstable Personality Disorder

EUPTs: Emotionally Unstable Personality Traits

ERS: Emotional Regulation Strategies

B-ERS: Behavioural Emotional regulation strategies

C-ERS: Cognitive Emotional regulation strategies

ICD: International Classification of Diseases

NICE: National Institute for Health and Clinical Excellence

NHS: National Health Service

OP: Older People

PWA: People of Working Age

YA: Younger Adults

WHO: World Health Organisation

Embedded Abstract

There remains a paucity of research on emotionally unstable personality traits and emotion dysregulation in older people (65+). Whilst clinical lore suggests that older people with emotion regulation difficulties present markedly differently from younger adults, this remains empirically undocumented. This may account for lower-than-expected diagnostic rates in older people, and result in lack of comprehensive commissioning for care of older people presenting with emotionally unstable personality traits in National Health Service mental health provision.

This study aimed to explore emotional regulation strategies across the adult lifespan by establishing differences in self-harm behaviours employed by younger versus older adults with high degree emotionally unstable personality traits; and whether these differences interacted with preferentially employed cognitive emotional regulation strategies. Developmental functionalism theory was introduced as one account of these hypothesised differences. A cross-sectional methodology was employed. 18 younger (age 18-28) and 18 older (65+) (total N = 36) participants, scoring above clinical cut-off on the Borderline Symptom List, completed an adapted version of the Self-Harm Inventory, and the Cognitive Emotional Regulation Questionnaire.

Younger adults were significantly more likely to self-harm using self-injurious means compared to self-neglecting methods, whereas older people where, on average, significantly more likely to use self-neglecting methods preferentially. The frequency of self-neglecting behaviours did not significantly vary between age groups. However, the preferential differences in employment of self-violent behaviours resulted in a significant difference in self-violent methods of self-harm,

between age groups. There was no significant difference in cognitive emotional regulation strategies employed, by age or self-harm behaviour.

Non-violent self-harm appears throughout the lifespan in this population. Older people's preferential use of self-neglecting methods may make self-harm more covert and less sensitive to clinical detection. Self-harm behaviours were unrelated to cognitive emotional regulation strategies employed. A broad definition of self-harm should inform clinical provision, commissioning, and future theoretical models of self-harm in this population across the adult lifespan.

Introduction

Emotionally Unstable Personality Disorder (EUPD), or Borderline Personality Disorder, was long described as a diagnosis of exclusion in Older People (OP; aged 65+) (Scott & Kemp, 2010). EUPD describes a patient experience of fluctuating self-image, marked impulsivity, intense interpersonal relationships, and pervasive emotional dysregulation, which may be self-managed using emotion regulation strategies (ERS) such as self-harm (International Classification of Diseases 10th Ed (ICD-10): F60.3; World Health Organisation (WHO) (2004)). The ICD (11th Ed.) - which has informed clinical practice since 2022 - defines personality disorders on continua rather than as static diagnoses, but retains clinical labelling of "Borderline Pattern Qualifiers" of disordered personality (WHO, 2019a). It acknowledges that EUPD represents emotionally unstable personality traits (EUPTs) with potential to become intolerable and burdensome to the individual, rather than being a static psychopathology.

Prevalence of EUPD across the Lifespan

The National Health Service (NHS) estimates clinical prevalence rates of EUPD to be 10-35% in people of working age (PWA; 18-65 years) (National Institute for Health and Clinical Excellence, 2007 (NICE)). This, compared to ~1-10% in services for OP (Morgan et al., 2013; Videler et al., 2019). Prevalence disparities have prompted beliefs that EUPD is a diagnosis of exclusion in OP (Scott & Kemp, 2010). 30% of PWA with an EUPD diagnosis are young adults (YA; aged 18-28 years) (Biskin, 2015; Walker-Harding et al., 2017). Despite this, a growing body of literature reports EUPD-like presentations in OP as an "emerging crisis" of underdiagnosis (Beatson et al., 2016; Morgan et al., 2013; Valdivieso-Jiménez, 2018). Low diagnostic rates mean

that NHS services for OP are not consistently commissioned to support individuals with high-degree EUPTs. Patients may resultingly be denied appropriate care, and clinicians may be unable to offer evidence-based interventions.

EUPD in OP

Causes of undiagnosed EUPD in OP are debated. Such presentations have been suggested to evidence the existence of "late-onset personality disorders" (Rosowsky et al., 2019). Several conglomerating factors have been suggested to contribute to late onset, including physical health decline, bereavement, and loss of systemic roles and support such as employment and spouses; which may have previously served to emotionally and relationally scaffold the individual (Bangash, 2020; Videler et al., 2019).

Such presentations may alternatively be a re-emergence of previously undiagnosed EUPD. Suggested reasons why the condition may have remained undetected include recovery (Zanarini et al., 2010), early mortality (Temes et al., 2019), and less overt symptomatology (Powers et al., 2013). Further, EUPD was introduced in diagnostic manuals in 1980, meaning that the diagnostic label would have been unavailable to those currently 65+, in youth. In addition, expression of EUPTs to a degree warranting an EUPD diagnosis is not static (Biskin, 2015). Over a decade, a significant majority of patients with traits warranting diagnosis experience remission lasting at least two months, with most remaining in remission for over a year (Gunderson et al., 2011) Patients may also relapse; around 50% relapse after remission spanning <2 years; which declines to 10% after remission spanning >8 years.

There is growing evidence that the clinical presentation of OP with EUPTs varies from that of PWA (Bangash, 2020). This makes identification more challenging for clinicians in OP-mental health services and for OP themselves. The NHS Long-term plan aims to increase access to secondary care mental health provision for all individuals with personality disorders (NHS England, 2019a, 2019b). However, differences in identification mean that sufficient service provision is not in place, and that individuals who need services lack access as they do not have the necessary diagnosis. This is particularly true of diagnostically led services. This impacts on availability of treatment resources, evidence-based treatments, as well as commissioning not recognising the needs of OP.

Definition and Prevalence of Self-harm in EUPD

Intentional self-harm is defined as any self-directed, intentional, harmful behaviour (Plener et al., 2015). The need for intention to cause death is disputed (Kapur et al., 2013; Madge et al., 2011). The DSM-5 requires non-suicidal intent as a definitional prerequisite (American Psychiatric Association (APA), 2013), while NICE (2004) does not.

Due to differing definitions (APA, 2013; NICE, 2004), identifying mortality risk from self-harm in individuals with high-degree EUPTs is challenging. Death by self-harm is estimated to be between 3-10 %, but the non-suicidal premature deathrate is higher: ~15% (Gunderson et al., 2011; Paris, 2019; Temes et al., 2019). Individuals with a diagnosis of a 'personality disorder' make up 44% of suicide cases in OP (Harwood et al., 2006), which highlights the significance of understanding self-harm in this age group.

Self-harm in OP

There is observational evidence that OP may self-harm in different ways compared to YA (Beatson et al., 2016). Self-harm is reported as less overtly harmful, including disordered eating behaviours and intentional treatment non-adherence. This poses a diagnostic challenge, as self-harm is a cardinal diagnostic feature of EUPD. It may also be a barrier to care access: some services require a recent incident of life-threatening self-injurious behaviour for referral acceptance. Self-harm remains poorly understood as an emotional regulation strategy in OP. This may be because OP use different emotional regulation strategies compared to YA, but existing research is inconclusive (Brummer et al., 2014; Cheavens et al., 2008; Gross, 2003).

Development of Emotion Regulation - the Process Model

The distinction of self-harm suggests that EUPTs are dependent on and evident of a broader impairment in emotional dysregulation, for which currently adopted emotional regulation strategies are insufficient (Battle et al., 2004; Hughes et al., 2012; Linehan, 1993; Widom et al., 2009; Zanarini et al., 2006).

The Process Model of Emotional Regulation (Gross, 1998a, 2014, 2015) defines emotional regulation strategies (ERS) as cognitive or behavioural interventions employed to influence how and when emotions are expressed. The emotional response precedes behavioural and cognitive "response modulatory" ERS. ERS can be employed to reduce, strengthen, or maintain experiences of emotional valence depending on current needs and goals. Evidence-based therapies, including Cognitive Behavioural Therapy, and Dialectical Behavioural Therapy for this population, draw on this theory of emotional regulation (Grecucci et al., 2020).

Garnefski et al. (2001) have proposed nine conceptually distinct Cognitive Emotional Regulation Strategies (C-ERS) based on Process Model theory: self-blame (e.g., "I feel that I am to blame when…"), other-blame, rumination, catastrophizing, putting into perspective (e.g., "I also look for positive sides when…"), positive refocusing, positive reappraisal, acceptance, and planning. Alongside these, Behavioural Emotional Regulation Strategies (B-ERS) describe actions, such as crying, exercising, or distraction, which individuals employ to regulate emotion (Kobyli ska & Kusev, 2019). Self-harm is a B-ERS. When healthy B-ERS are insufficient, or not learned, individuals may draw on self-harm such as cutting or starvation, which may function to numb emotional intensity and distract from emotive thinking. By contrast, passive suicidal ideation is a C-ERS, as it does not involve an intent to carry out an activity, and instead may serve to give the individual a sense of emotional agency, or provide feelings of familiarity and comfort (Colle et al., 2020; Harmer et al., 2022; Urnes, 2009). Suicidal behaviour may function as the penultimate way to escape overwhelming emotion.

Development of ERS underlying high-degree EUPTs

Typical emotional regulation development relies largely on B-ERS in childhood (Zeman et al., 2006). Through development of Theory of Mind, successful caregiver modelling, and socio-emotional problem-solving, children learn to adopt C-ERS as response modulators alongside B-ERS (Gross, 2014; Newton-Howes et al., 2015). Navigating attachment to and help-seeking from primary caregivers is thought to be one of the first developmental challenges across the lifespan, and is a necessary and innate process which facilitates emotional regulation learning – including flexible adoption of C-ERS (Bowlby, 1969; Crowell et al., 2009; Kobyli ska & Kusev,

2019; Reinecke & Ehrenreich, 2005; Spangler & Zimmermann, 1999). This increases availability of appropriate and helpful ERS. All humans rely on C- and B-ERS throughout the lifespan, as no ERS are wholly effective and adaptive (Bonanno & Burton, 2014).

Lack of environmental support to develop, and caregiver modelling of, C-ERS employment may underlie EUPTs in individuals with a diathesis to develop such traits – as outlined in the Biosocial Theory of EUPD (Linehan, 1993; Reinecke & Ehrenreich, 2005). The resulting impairment of emotional self-regulation is described as a "skills deficit", which, alongside heightened emotional sensitivity, are cardinal formulation features of EUPD.

Changes to Emotion Regulation across the Lifespan - Developmental Functionalism

Developmental Functionalism, an evolutionary theory of emotion regulation (Consedine, 2011), theorises emotions as conditioned responses to previous challenges; whereby a stimulus becomes coupled with the emotional response experienced at initial exposure (Barrett, 1998; Nesse, 1990). It has informed several theories of emotion and psychopathology, amongst them the Biosocial Theory of EUPD (Linehan, 1993), where it is described as an individual's 'learning history'. It posits the basic function of emotion as self-preservationist (Crowell et al., 2009; Gruenewald et al., 2007).

C-ERS require sufficient cognitive resources and capacity to flexibly regulate emotions in response to emotional or situational stressors (Gross, 1998b). Lifespan transitions are often resource intensive, among them, from adolescence to early

adulthood, and from working-age adulthood to older adulthood (Carstensen, 1992; Miller, 2010). Transitions qualitatively change the individual's systemic role and introduce novel demands. In transition from child to working age adulthood, possession of "online" C-ERS, such as planning, help navigate processes of increased financial, social, and legal autonomy (Schreiber et al., 2012). Such C-ERS drive active, interventional behaviour. Transitioning from working age to older adulthood requires a shift to "anticipatory" C-ERS, such as acceptance, which are adaptive for a less active social role, changed socioeconomic expectations, management of physical decline, and closeness to end of life (Turk-Charles & Vernimmen, 2021). Anticipatory C-ERS allow the individual to take a more passive approach to managing events. Age-related cognitive decline also warrants more cognitively resource-efficient C-ERS in older adulthood (Birditt & Fingerman, 2005; Blanchard-Fields et al., 1997).

Current investigation

The current study theorises that less successful adoption and inflexible application of C-ERS underlie high degree EUPTs. This becomes most evident during lifespan transitions, where the individual needs to transition flexibly to C-ERS appropriate for their new stage of life. This study seeks to explore whether:

- There is a difference in types of self-harm B-ERS employed by YA and OP with high degree EUPT's.
- Favoured C-ERS significantly differ between YA and OP by type of self-harm.

Based on existing research, it is hypothesised that:

- Self-harm B-ERS are employed by both groups, but that age promotes different methods (self-violent versus self-neglecting) (Morgan et al., 2013). This remains inferentially untested.
- YA and OP who report age-appropriate C-ERS to a greater extent, will present with different self-harm B-ERS than those who do not report age-appropriate C-ERS.

Methodology

Design

A between-participants methodology was employed to compare C-ERS and self-harm B-ERS in use by YA and OP who presented with high degree of EUPTs, with measures obtained at a single time point. The study was co-produced with an expert-by-experience, who was involved with study design, execution, and interpretation of results.

Participants

An a priori power analysis was conducted using G*Power (V3.1) (Faul et al., 2009) and indicated a minimum required sample size of 34 individuals (17 per group; $\alpha = 0.05$, $\beta = 0.8$). This was based on an *F*-test (MANOVA was planned) and pre-determined to detect a medium effect size, based on previous research in this population (Brickman et al., 2014; Kothgassner et al., 2021; Mojahed et al., 2018; Morgan et al., 2013)

A total sample size of N = 36 (N = 18 for YA and N = 18 for OP) was recruited. Participant groups were identified within Community Mental Health Teams

(CMHTs). Clinicians were made aware of inclusion/exclusion criteria (Table 1) and asked to identify individuals who fit the relevant profile. Patients who expressed interest were contacted via telephone with further information and engaged in a brief screening using the Borderline Symptom List (BSL) to determine eligibility.

Participants were not required to have a clinical diagnosis of EUPD, which is reported to be significantly underdiagnosed in OP. Data was instead collected from individuals with high degree EUPTs, defined as a score >.64 on the BSL. This cut-off has been found to have the strongest ability to identify EUPTs that would warrant an EUPD diagnosis (Kleindienst et al., 2020).

Table 1 Study Eligibility criteria

Inclusion criteria
Aged 18-28 (younger adults) or 65+ (older people)
Scoring above clinical cut-off (>.64) on the Borderline Symptom List (Kleindienst et al., 2020)
Able to verbally communicate in English to a degree where an interpreter was not required.
Current patient of Community Mental Health Teams in Oxford Health NHS Foundation Trust
Able to participate without increased risk and have capacity to consent to participate.
Exclusion criteria

Diagnosis of mental disorder due to: Known physiological condition (F0X); Mild cognitive impairment, psychotic disorder (F2X), or Intellectual disability (F7X) (WHO, 2004).

Psychometric measures

The Borderline Symptom List (BSL) (Bohus et al., 2009) is a 5-point Likert-scale which was employed as a screening tool to identify individuals with high degree EUPTs. Its psychometric ability to identify EUPTs to a degree warranting a diagnosis of EUPD has been previously validated against the Structural Clinical Interview for BPD; the gold-standard measure of diagnosis (NICE, Kleindienst et al., 2020; 2015). It has excellent validity to identify both healthy (AUROC = 0.99) and clinical presentations (AUROC=0.84). It has excellent internal consistency (= 0.97), and test-retest reliability ($r = 0.82$, $p < 0.0001$).

The Cognitive Emotion Regulation Questionnaire (CERQ) (Garnefski & Kraaij, 2007) is a 36-item 5-point Likert-scale which indicates frequency of employment of nine types of C-ERS (self-blame, acceptance, rumination, positive refocusing, refocusing on planning, positive reappraisal, putting into perspective, catastrophising, and other blame). It has two subscales, positive C-ERS (acceptance, positive refocusing, refocusing on planning, positive reappraisal, and putting into perspective; and negative C-ERS (self-blame, other blame, rumination, and catastrophising). It provides a score of 4-20 to indicate frequency of use of each strategy; enabling identification of preferentially used C-ERS It has good reliability (Cronbach's α = 0.77), and construct validity (= 0.80).

The Self-Harm Inventory (SHI) (Sansone et al., 1998) consists of yes/no response and frequency indicators to determine frequency of intentional employment of 22 self-harm behaviours. It has good validity (= 0.71) and accuracy (= 0.81). It is the most detailed psychometric measure of self-harm behaviours, to date.

The adapted Self-Harm Inventory

Psychometric measures of self-harm consistently focus on physical acts of self-harm ("self-violent"). The lack of breadth of self-harm behaviours in validated scales has been cited as a challenge for research in this area (Latimer et al., 2013).

Given the recency with which identification of non-self-violent self-harm has been identified in OP (Scott & Kemp, 2010), no such measure has yet been developed to accommodate for the breadth of self-harm behaviours seen in this age group. Despite several studies (Morgan et al., 2013; Troya et al., 2019; Videler et al., 2019) identifying that self-harm presents differently in OP, which has been termed "self-neglecting" presentations (Beatson et al., 2016; Troya et al., 2019), psychometric measures incorporating these remain to be developed - likely due to the absence of inferential statistics establishing this alternate self-harm behaviour to date. Doing this is one of the aims of the current study.

Therefore, the SHI was selected as it is the most extensive measure. Following data collection, factor analysis was undertaken to identify subscales from the measure, as the original SHI contains no subscales. Two main subscales were found to have high reliabilities, which were terms self-violent (8 items) and self-neglecting (7 items) in line with the literature. The remaining seven items did not have

significant high reliabilities with other variables, nor was there evidence in the literature for their association with a particular self-harm type, or age group, and as such, were classified as 'other' and were not included in analysis. This, as the current study hypothesised differences between "self-violent" and "self-neglecting" behaviours. A Cronbach's $\alpha < .7$ was determined as acceptable (Field, 2013; Kline, 2013).

Based on this, a self-violent self-harm subscale = .776 and a self-neglecting self-harm subscale = .762 where identified. These were in line with reports from previous literature. See Appendix F for full expansion of the adapted measure, and summary of exploratory factor analysis results.

Procedure

Following informed consent, participants completed the CERQ and the SHI to determine self-harm behaviours and employed cognitive emotional regulation strategies. After data collection, participants received a debrief sheet including consent withdrawal procedure, the complaint process, and contact details for psychological support. The same researcher placed a follow-up wellbeing call 48 hours after data collection and any risk concerns were reported to the participant's treating clinician.

Data analytic plan

Analyses were carried out using IBM SPSS v28 (IBM Corp., 2021). Shapiro-Wilks tests were employed to determine data distribution. Multivariate outliers were identified based on measures of skewness (+/-1 range), kurtosis (+/-1 range), Q-Q plots, and standardised residuals (+/-2). Levene's test was employed to assess

homogeneity of variance, and sphericity was assessed using Mauchley's Test of Sphericity. Where the Mauchly's Test indicated that the assumption of sphericity was violated, degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity. Where Levene's test for homogeneity of variance was significant, the Kruskal-Wallis H test was used. Cohen's *d* was used to calculate effect size. The alpha level was set to <.05 for statistical significance for all analyses.

Two MANOVAs were employed; ; (1) with severity of self-harm behaviours (self-violent or self-neglecting) as continuous dependent variables, and age group (young versus older) as a between-subjects factor; (2) with negative CERQ-subscales as continuous dependent variables, and age group as a between-subjects factor.

Two within-participants Student's t-tests compared differences in self-harm behaviours (self-violent or self-neglecting) within each age group (YA or OP).

A Mixed Model-ANOVA (MM-ANOVA) was employed, with self-harm behaviours as the dependent variable, CERQ-scores as the within-subjects factor independent variable, and age-group as the between-subjects factor independent variable, Significant results were followed up with post-hoc Student's t-tests. A Kruskal-Wallis H test, with positive CERQ-subscale scores as a continuous dependent variable, and age group as a between-subjects factor was employed. This, as positive CERQ-subscale data did not have a Student's t-distribution.

Ethical approval

The study obtained ethical approval from the Essex NHS Research Ethics Committee (304357-22/EE/0004). Approval was also obtained from the Oxford Health NHS Foundation Trust Research and Development department (PID-15857).

Results

Sample characteristics

There is very limited demographic data to present, which is a limitation, as ethics review recommendations were to collect as little identifying information as possible due to the sample's vulnerable nature.36 (18 younger and 18 older) people took part in the study. All were accessing care within CMHTs in Oxford Health NHS Foundation Trust. YA were aged 18-28 (M = 23.50 years, SD = 3.22), and OP 65-82 (M = 72.83, SD = 4.97). They were a mix of male and female participants. No patients were inpatients in psychiatric facilities, care homes, social, or forensic settings during testing. No other identifying information was collected.

A total of 46 people were recruited to the study. Ten individuals did not complete the study due to changing their mind after screening but before date of testing (N= 3), deteriorating mental health during testing (N=3); refusing to provide consent (N=2); withdrawing consent after completing the study (N=2)Four people did not meet cut-off on the BSL. The final sample consisted of 36 participants across both groups, (YA, N = 18; OP; N = 18).

Self-harm behaviours between age groups

A MANOVA was employed with self-harm incidences as continuous dependent variables and age group as a between-subjects factor. Shapiro-Wilks tests indicated that each dependent variable was approximately normally distributed (self-violent self-harm $W(36) = .94$, $p = .06$; self-neglecting self-harm $W(36) = .94$, $p = .06$). No outliers were identified. Levene's test of homogeneity of variance, based on the

median, indicated that error variance of dependent variables was approximately equal (self-violent $F(1,34) = .55$, p = .46; self-neglecting $F(1,34) = .34$, p = .56).

Using Pillai's trace, there was a significant difference between self-harm behaviours employed between younger adults and older people $V = .64$, $F(2,33) = 29.15$, $p < .001$. (Figure 1).

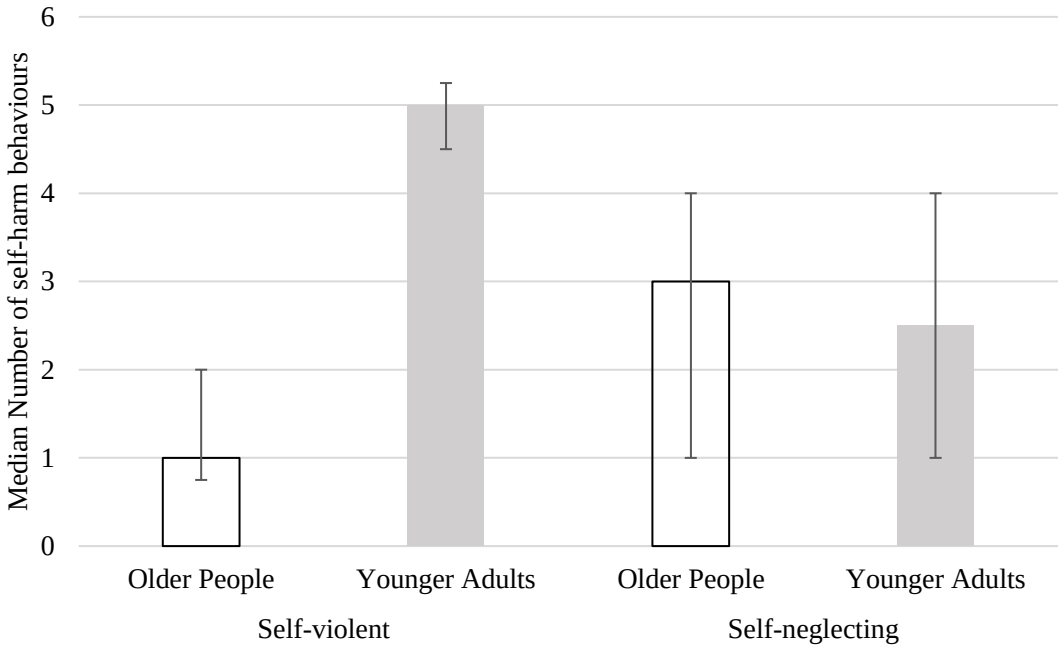


Figure 1 Differences in self-harm behaviours by age group.

Displayed is the median, with 95% bootstrapped confidence intervals employed as measures of dispersion.

Separate Student's t-tests on the outcome variables revealed that YA were significantly more likely than OP to employ self-violent methods of self-harm $t(34) = -7.56$, $p < .001$ (Table 2). There was no significant difference between YA and OP use of self-neglecting behaviours $t(34) = -.36$, $p = .73$.

Table 2 Frequency of self-violent and self-neglecting self-harm by age

Med = Median, CI = 95% confidence interval, Effect size = Cohen's d)

	YA	**OP**	**Difference**	**Effect size (*d*)**
Self-violent	Med: 5, CI: 4.50-5	Med: 1 CI: 1-2	Med: -3.111, CI: 3.95- -2.27	2.52
Self-Neglecting	Med: 2.50, CI: 1-4	Med: 3 CI: 1-3.50	Med: -.222, CI: -1.50, 1.05	.12

Self-harm behaviours within age groups

Two within-participants Student's t-tests measured differences in mean employment of self-violent and self-neglecting self-harm behaviours in (1) YA and (2) OP.

On average, younger adults engaged in more self-violent (M = 4.72, SE = .31) methods of self-harm compared to self-neglecting methods (M = 2.72, SE = .47). This difference of 2.00, (BCa 95% CI: 1.00-2.83) was significant $t(17) = 3.96$, $p = .001$, and represented a large effect size $d = 1.00$.

Likewise, on average, older people engaged in more self-neglecting (M = 2.50, SE = .41) methods of self-harm compared to self-violent methods (M = 1.61, SE = .27). This difference of .89 (BCa 95% CI: .05-1.67) was significant $t(17) = 2.16$, $p = .045$, and represented a medium-sized effect, $d = 0.78$.

Negative cognitive emotional regulation strategies by age

A MANOVA, with negative CERQ-subscales as continuous dependent variables and age group as a between-subjects factor was used. Shapiro-Wilks tests indicated that each dependent variable was approximately normally distributed (self-blame $W(36)$

= .91, p = .09; rumination $W(36)$ = .90, p = .06; catastrophising $W(36)$ = .97, p = .80; blaming others $W(36)$ = .92, p = .12). Levene's test of homogeneity of variance, based on the median, indicated that error variance of dependent variables was approximately equal (self-blame $F(1,34)$ = .51, p = .47; rumination $F(1,34)$ = .44, p = .51; blaming others $F(1,34)$ = .78, p = .38; catastrophising $F(1,34)$ = 1.11, p = .29).

Using Pillai's trace, there was no significant difference in negative CERQ scores employed between YA and OP $F(4, 31)$= .102, p = .98 (Table 3; Figure 2).

Table 3 Negative C-ERS on the CERQ distribution, by age.

M: mean; SD: standard deviation

Dependent Variable	**Younger adults**	**Older People**	**Difference**
	M (SD) *range*	*M* (SD) *range*	**in means**
Self-blame	16.33 (3.27) *9-20*	16.22 (4.02) *5-20*	.22
Rumination	16.22 (3.36) *10-20*	16.83 (2.81) *12-20*	.61
Catastrophising	12.11 (3.72) *5-18*	12.50 (5.01) *4-20*	.39
Blaming others	12.61 (5.49) *4-20*	13.00 (6.25) *4-20*	.39

The CERQ scale ranges 4 (no agreement) - 20 (full agreement)

Positive cognitive emotional regulation strategies by age

A Kruskal-Wallis H test, with positive CERQ-subscale scores as continuous dependent variables and age group as a between-subjects factor, was employed, as data did not hold a Student's t-distribution. Shapiro-Wilks tests indicated that the dependent variables were not normally distributed (acceptance $W(36)$ = .793, p =

.011; positive refocusing $W(36) = .723$, $p = .001$; refocusing on planning $W(36) = .723$, $p=.011$; positive reappraisal $W(36) = .854$, $p=.001$; putting into perspective $W(36) = .839$, $p=.001$). Distribution of the independent variable indicated that the test could be employed to compare medians.

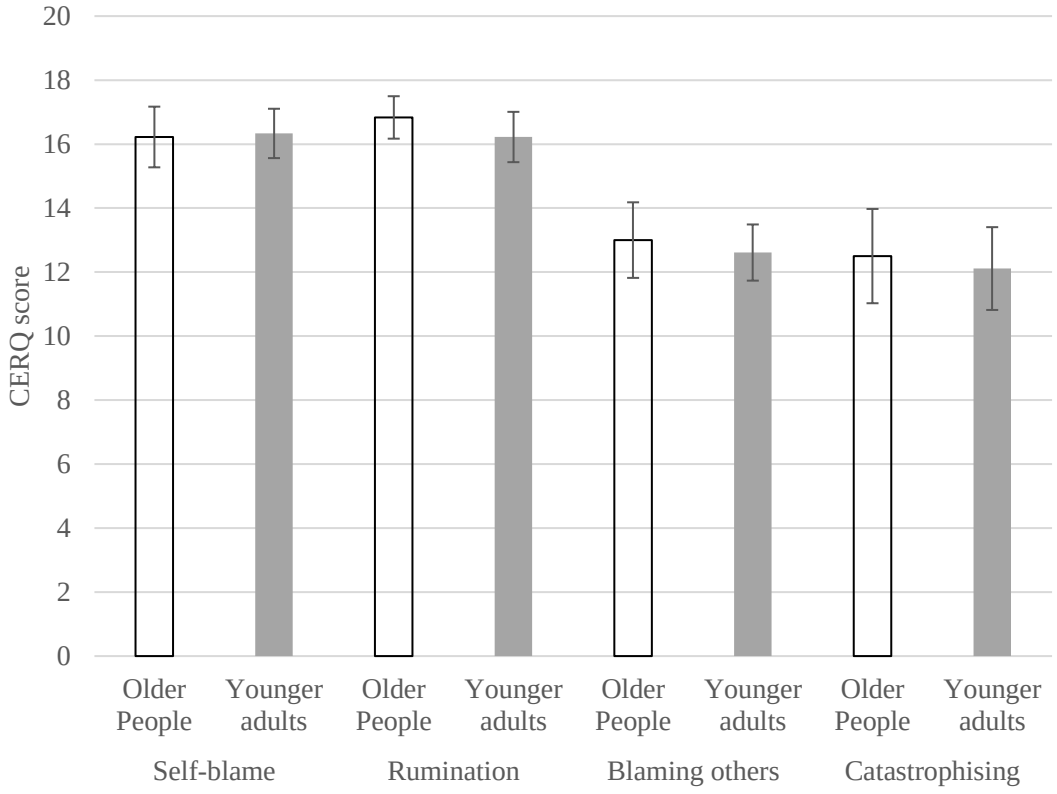


Figure 2 Mean scores in negative CERQ's by age group.

Error bars indicate 95% confidence intervals

Visual inspection of histograms indicated positive skewness across all variables, indicating that most individuals employed positive C-ERS rarely, with a few individuals reporting frequent use.

The Kruskal-Wallis *H* Test showed no statistically significant differences in positive CERQ-scores by age (acceptance $X^2(1) = .002$, $p = .96$; positive refocusing

$X^2(1) = .36$, $p = .55$; refocusing on planning $X^2(1) = 1.85$, $p = .17$; positive reappraisal $X^2(1) = 1.83$, $p = .23$; putting into perspective $X^2(1) = 2.93$, $p = .09$) (Table 4).

Table 4 Positive C-ERS by CERQ distribution by age.

M: mean; SD: Standard deviation

Dependent Variable	**Younger adults** *M* (SD) *range*	**Older People** *M* (SD) *range*	**Difference in means**
Acceptance	7.67 (4.75) *4-19*	7.33 (4.22) *4-20*	.34
Positive refocusing	5.72 (2.16) *4-12*	7.17 (4.49) *4-20*	1.45
Positive reappraisal	6.78 (2.10) *4-11*	5.44 (2.09) *4-11*	1.34
Putting into perspective	7.94 (3.28) *4-13*	6.22 (2.98) *4-13*	1.72
Refocus on planning	7.72 (4.53) *4-12*	5.72 (3.36) *4 -11*	2.00

The CERQ scale ranges 4 (no agreement) - 20 (full agreement)

CERQ-scores by age group and self-harm behaviour

A MM-ANOVA, with self-harm behaviours as the dependent variable, CERQ-scores as the within-subjects factor independent variable, and age-group as the between-subjects factor independent variable. was employed. Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $\chi 2(2) = 15.46$, $p = .009$. Therefore, degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity. Statistics for other assumptions are described above.

The Greenhouse-Geisser corrected model indicated that there were no significant differences between use of self-violent self-harm $F(1.14, 36.50) = .217$, $p = .833$ or self-neglecting self-harm $F(1.14, 36.50) = .44$, $p = .67$, based on preferentially

employed C-ERS, as expressed by CERQ-scores. There was no significant interaction effect between CERQ-scores and age-group $F(2.28, 73.04) = .17$, $p = .87$, on self-harm behaviours. This generated no noticeable effect size ($\eta_p^2 = .005$). See Figure 3.

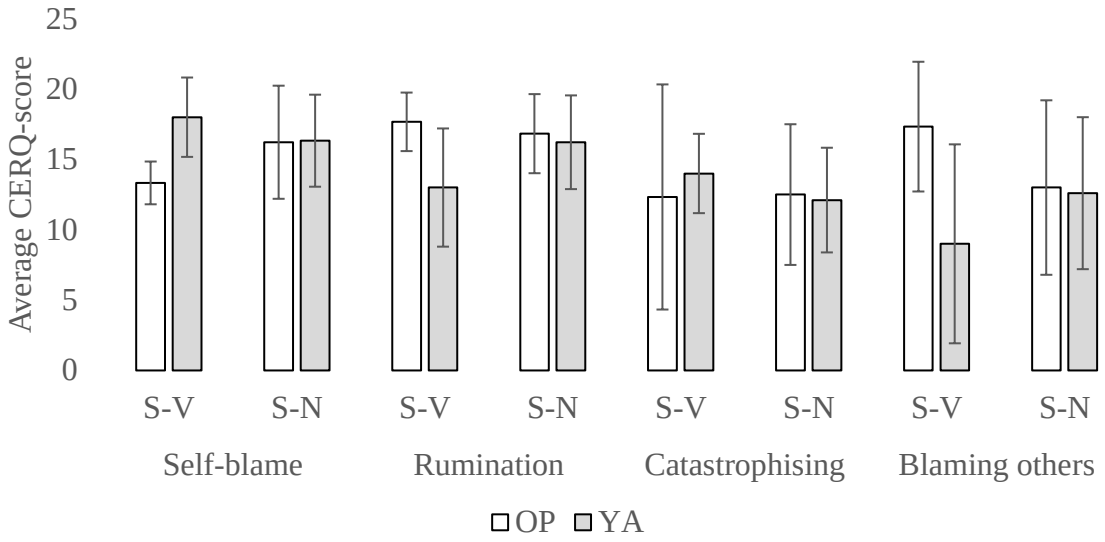


Figure 3 Differences in self-harm types by CERQ-scores and age group.

Error bars = Standard Deviation

Discussion

This study explored differences in self-harm behaviours between YA (aged 18-28) and OP (65+) with high degree EUPTs. Differences in self-harm across the lifespan have not previously been established using inferential analysis, though clinical lore suggests OP self-harm in less overt ways (Avari et al., 2011). The study hypothesised that such differences may be related to usage of C-ERS. It explored differences in positive and negative C-ERS by age group and self-harm behaviours. Previous research suggests there may be differences in C-ERS employed by these age groups

in community samples (Brummer et al., 2014), but this finding has not been consistently established (Cheavens et al., 2008; Gross, 2003).

Self-harm of the current sample partially supports previously recounted clinical observations. YA were significantly more likely to self-harm using violent compared to self-neglecting methods, and OP were significantly less likely to use self-violent compared to self-neglecting means. Both groups used self-neglecting methods to a similar extent. Thus, while self-violent self-harm decreases in frequency throughout the lifespan, self-neglecting methods remain of use throughout the lifespan. Self-harm was previously believed to be rare in OP, but recent evidence suggests that OP do self-harm, but using self-neglecting methods preferentially (Beatson et al., 2016; Videler et al., 2019). These methods are less frequently classified as self-harm and are therefore more likely to miss clinical detection (Valdivieso-Jiménez, 2018). Our findings provide inferential evidence that OP self-harm, but that their methods are often self-neglecting and therefore less overt. These findings support the definition that self-harm may occur without suicidal intent, and that it may function as a standalone emotionally regulating behaviour (APA, 2013). As such, clinicians should employ the definition of self-harm as any self-directed, intentional behaviour an individual does to hurt themselves on purpose (Plener et al., 2015). Services should also consider this, when only allowing patients who have engaged in life-threatening self-injurious behaviour to access services. Applying this broader definition, which focuses beyond physical self-injury, may increase the rates of self-harm identified in OP, help YA receive support for a wider array of self-harm, and acknowledge that level of physical injury

sustained from self-harm is a poor measure of level of distress and need for clinical care.

The current study used an adapted measure of the Self-harm inventory (Sansone et al., 1998), with exploratory factor analysis undertaken to derive subscales found in the current sample data. Two subscales with high reliability were identified; these were in line with previous literature describing self-violent versus self-neglecting behaviours in OP (Beatson et al., 2016; Troya et al., 2019). However, the small sample in the current study reduces the transferability of these findings to the general population. Future research should aim to develop novel psychometric measures encompassing the broader definitions of self-harm identified in the current study.

It was hypothesised that different types of self-harm may be related to differences in C-ERS used by the age-groups (Schreiber et al., 2012; Turk-Charles & Vernimmen, 2021). C-ERS were not found to differ by age or self-harm type and did not modulate these relationships. Both age groups used negative C-ERS, such as self/other blame, catastrophising, and rumination, to a greater extent than positive C-ERS. This finding supports previous literature indicating that individuals with high degree EUPTs, warranting a diagnosis of EUPD, may have a "skills deficit" in applying cognitive strategies, reducing their ability to cognitively regulate emotions (Battle et al., 2004; Hughes et al., 2012; Linehan, 1993). This may lead to feelings of helplessness and lack of emotional agency and generate a continued reliance on self-harm as necessary to compensate for ineffective C-ERS. Alternatively, continued reliance on self-harm may be a secondary outcome from the negative C-ERS

themselves, such as in cases of self-blame and rumination. These were the most frequently employed C-ERS in our group. Such negative C-ERS may also reinforce negative conditioned emotional responses to neutral stimuli by intensifying the negative emotional experience, increasing the likelihood of engaging in unhealthy B-ERS, such as self-harm, not for the purpose of emotional regulation, but with self-punishment as a secondary, related function of self-harm. This may thus generate a self-maintaining cycle of self-harm.

The lack of C-ERS modulation by age is inconsistent with some (Brummer et al., 2014) but not all (Cheavens et al., 2008; Gross, 2003) research in community samples. It is hypothesised that C-ERS flexibly develop in response to lifespan-stage transitions and novel stressors (Consedine, 2011; Kobyli ska & Kusev, 2019; Newton-Howes et al., 2015). The absence of this difference in our sample may reflect that learning to apply C-ERS appropriate for the socioemotional stressors of lifespan transitions has not fully taken place and remains inflexible. This may occur when the individual continues to apply C-ERS which may have been lifespan-stage appropriate, but no longer are, or when learning of such has never occurred – both of which may occur following traumatic or difficult caregiver attachments (Crowell et al., 2009; Reinecke & Ehrenreich, 2005), or impaired development of Theory of Mind (Németh et al., 2018). Both are common in the learning history of individuals with clinical EUPTs.

This is believed to be the first study to test differences in self-harm behaviours between age groups in this population using inferential statistics. It employed a broad definition of self-harm behaviours, which captured a breadth of self-harm

forms and offered a developmental rationale for self-harm. This is an often poorly-understood behaviour by clinicians, the stigmatisation of which generates significant clinician- and self-stigma (Motala & Price, 2022). It is hoped that this research may elucidate the function of these behaviours and reduce stigmatisation. Further, the current study identifies a need for future research to develop novel psychometric measures of self-harm, which include a broader definition of self-harm and its behavioural presentations. The current study has identified patterns of self-violent and self-neglecting self-harm, in line with previous literature, but this must be established in a larger sample. Such a measure would aid future research in this area and aid clinical exploration of a broader methodological range of self-harm.

Our study includes a spectrum of individuals, without relying on diagnosis. This assessed self-harm behaviours in individuals who experience the same difficulties as those with a clinical diagnosis, but who may have been missed from diagnostic assessment. However, treating age as a categorical variable is a limitation. There is a large gap between the ages of 28-65, so future research may wish to consider investigating age on a continuum. A finer review of OP is also warranted. While both the literature and services frequently define anyone over the age of 65 as an OP, this may no longer be consistently defined as a uniform age group. Arguably, the challenges facing individuals aged 65+, compared to those 20 or 30 years older than this, may be very different. This may be particularly topical in an ageing population: the current life expectancy at 65 years is 18.5 years for men, and 21 years for women (Office for National Statistics, 2021). Some research already employs refined categories of youngest-old (65-74), middle-old (75-84) and oldest-old (85+)

(Alterovitz & Mendelsohn, 2013; Lee et al., 2018), although age as a continuum may still be a preferred approach.

Additionally, the sample information collected was very conservative. This was in line with the ethics review board's feedback to collect as little identifying information as possible about this sample on account of their vulnerable nature. Future research should consider ways to invite these participants to partake while both safeguarding their identity and collecting a richer array of data to explore covariate impact. The current study included no covariates, which is a limitation. Of interest would be exploration of differences between sexes and ethnicity, as these factors are known to impact emotional regulation behaviours (Consedine et al., 2005; Weiss et al., 2022). Of further interest would be data on attachment style, history of Adverse Childhood Experiences, and contact during youth with others who self-harmed, to understand the impact of caregiver modelling in individual emotional regulation learning histories (Linehan, 1993).

The small sample size should be acknowledged. While the study met the sample size criterion for an *F*-test, which was undertaken, it is likely not adequate for a full factorial analysis. The adapted SHI should therefore not be seen as a translatable measure. In this regard, the current study should be viewed as a pilot study, being the first to test hypothesised differences in self-harm behaviours using inferential statistics. To further determine the utility of such categories, both for clinical and research purposes, consideration of developing a broader, novel measure of self-harm is paramount. Additionally, the sample was based on a medium effect size. A large body of literature is able to differentiate self-harm

behaviours in EUPD compared to both a healthy sample (Brickman et al., 2014) and with non-self-harming clinical cases (Zimmerman & Becker, 2022) with large effect sizes. However, the literature investigating such presentations in OP is sparse – likely a result of EUPD being viewed as a "diagnosis of exclusion" in OP up until recently. Much of the literature on this population is anecdotal. Therefore, this publication should be viewed as a preliminary analysis of such presentations in OP, which contradicts the "exclusion" of EUPD in OP, and hopefully, generates future research on this group.

This is also the first study exploring differences in C-ERS with this clinical population, thus building on previous research elucidating C-ERS employment in OP. Much of the literature on C-ERS across the lifespan rely on cross-sectional data, including this study. A longitudinal measure of C-ERS employed in different situations, particularly in high- versus low-stressor situations, could elucidate the consistency of C-ERS employment. This may be particularly important in a population with clinical EUPTs, as intensity of such traits are known to wax and wane throughout the lifespan (Biskin, 2015; Gunderson et al., 2011).

Finally, future research may wish to further review the relationship between C-ERS and B-ERS. Our sample used negative C-ERS to a greater extent than positive C-ERS. It would be of value to explore whether individuals with high degree EUPTs, who do not self-harm, generally employ positive C-ERS to a greater extent. It would also be valuable to differentiate between types of B-ERS that are adaptive, e.g., exercise or journalling, versus maladaptive, e.g., cutting or burning.

Conclusively, results are consistent with previous reports of higher-than-believed self-harm in OP. Further directions for research on C-ERS across the lifespan are indicated, and their relationship with self-harm. A theoretical explanation for this poorly understood phenomenon is provided. These findings have implications for informing clinical assessment, commissioning guidelines, and further research of the underlying mechanisms.

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Executive Summary of the Theory-Driven Research Project

Introduction

There remains a paucity of research on Emotionally Unstable Personality traits and emotion regulation in older people (OP; 65+) (Beatson et al., 2016). The existing body of evidence suggests that some cardinal diagnostic features of Emotionally Unstable Personality Disorder (EUPD) are present to a much lesser extent in older adults, particularly, self-harm, suicidality, and impulsivity (Beatson et al., 2016; Valdivieso-Jiménez, 2018). This is in stark contrast to the statistic that 44% of suicide cases in OP have a diagnosis of a 'personality disorder (Harwood et al., 2006). Additionally, individuals with a diagnosis of EUPD make up 10-35% of individuals receiving treatment in secondary care community mental health teams (CMHTs) – of which 30% are younger adults (YA; 18-28 years); compared to 1-10% of cases seen in CMHTs for OP (Biskin, 2015; Morgan et al., 2013; National Institute for Health and Clinical Excellence, 2007; Videler et al., 2019; Walker-Harding et al., 2017). This has generated beliefs of an 'emerging crisis' of missed diagnoses of EUPD in OP. Additionally, self-harm is often used as a cardinal diagnostic feature of EUPD, but there is growing evidence that OP self-harm in less overt, non-violent ways, which may make it less sensitive to clinical detection (Beatson et al., 2016; Troya et al., 2019). This is problematic, as while self-violent self-harm is believed to be less common, risk of completed suicide is highest in OP, across all age-groups.

As a result, commissioning for OP secondary care mental health services may not be adequate to provide care provision for individuals with EUPD. OP may

therefore be denied access to appropriate services and treatment options, and clinicians left unable to provide suitable evidence-based treatments based on presentation – particularly in diagnostically led services. This may be problematic, as the NHS Long-term plan stipulates as an aim for all trusts to increase access to secondary care mental health provision for all individuals with personality disorders (NHS England, 2019a, 2019b).

Aims

This study aimed to explore emotional regulation strategies across the adult lifespan by assessing whether there is a difference in types of self-harm employed by YA versus OP with high degree emotionally unstable personality traits; and whether these interact with preferentially employed types of cognitive emotional regulation strategies (C-ERS). Psychological therapies are the first line of treatment for individuals with high-degree EUPTs (National Institute for Health and Clinical Excellence, 2007). For this, an understanding of the cognitive presentation of individuals are vital, both for provision of current best-practice interventions such as Dialectical Behavioural Therapy, for this population (Crowell et al., 2009; Linehan, 1993), as well as informing development of new theories to inform developments of novel treatments.

Methodology

A cross-sectional methodology was employed. 18 younger (age 18-28) and 18 older (65+) (total N = 36) participants, scoring above clinical cut-off on the Borderline Symptom List (BSL), completed the Self-Harm Inventory and Cognitive Emotional Regulation Questionnaire at a single time point. All individuals were recruited

within CMHTs in Oxford Health NHS Foundation Trust. The BSL was employed as a proxy-measure of EUPD, as the condition is believed to be underdiagnosed in this population (Beatson et al., 2016). The BSL's psychometric ability has been previously validated against the Structural Clinical Interview for BPD; the gold-standard measure of diagnosis (NICE, Kleindienst et al., 2020; 2015), with excellent validity to identify both healthy and clinical presentations.

Results

Younger adults were significantly more likely to self-harm using self-injurious means, compared to older people. Both groups were equally likely to use self-neglecting forms of self-harm. Overall, the sample employed negative C-ERS to a great extent, but the types of negative C-ERS preferentially employed did not vary by age-group of self-harm behaviour. Use of positive C-ERS were rare in the population, again, presenting equivalently across age-groups and self-harm presentations.

Conclusion

Non-violent self-harm appears equally common across YA and OA. Self-harm continues to be a core feature in OP with high degree emotionally unstable traits, but its covertness may make it less evident to clinical detection. This may both complicate access to appropriate treatment, as well as reduce likelihood of a diagnosis of EUPD – where one is indicated, and continue to inform the erroneous belief that OP with EUPD self-harm to a much lesser extent than YA. Further, YA were found to employ self-neglecting methods of self-harm frequently, and not significantly differently from OP. This must also be taken into consideration when

reviewing treatment options offered. A broad definition of self-harm should therefore inform clinical work with this population, across the lifespan.

In this sample, self-harm behaviours were not related to C-ERS employed, and suggestions to inform future research in this area, which is of growing theoretical and clinical interest, were offered. To date, existing research on C-ERS using cross-sectional data, whereas a longitudinal review, particularly across high- versus low-stressor situations, would be indicated to elucidate the flexibility and consistency with which C-ERS are preferentially employed.

These findings have implications for the referral acceptance criteria of services treating EUPD, assessment of self-harm, and the use of self-harm as a diagnostic indicator for EUPD. The differing presentation of high-degree EUPTs, possibly warranting a diagnosis of EUPD, should be considered when establishing suitability for access to specialist services, as well as inform incidence rates of EUPD. This, to ensure commissioning is appropriate, based on a more accurate prevalence estimate, as well as ensuring access to appropriate care services for OP, in accordance with the NHS Long-term plan.

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Connecting Narrative

These three projects are connected. Not by topic, population, or intervention, but by the psychological themes of stigma, relationships with healthcare professionals, and one's relationship to one's own body. I have always been fascinated by the psychological mechanisms which facilitate or hinder our relationships with our bodies, and how we feel able to engage with help when that self-relationship is damaged. In our society, there is shame, stigma, and secrecy associated with having an 'ill' body, harming our own bodies, or when the personal space of our body is sexually violated. Shame, stigma, and secrecy will by default be a challenge to building therapeutic relationships. Secondary to this are also the additional outcomes which these population may present with. Such individuals may struggle to build a trusting relationship with their psychologist, reject psychologically intimate relationships, or withdraw socially overall.

I chose these topics because I wanted my doctoral thesis research to allow me to use and develop therapeutic relationship-skills in a research setting. Developing a trusting relationship in a research setting is quite different from a therapeutic one. The participant likely has little to personally gain from speaking to you. There is also very little time for rapport-building. Lastly, due to the structured nature of data collection, the researcher is limited in the choice of questions asked, and when they ask them. Despite these challenges, I experienced many positive relationships with participants during data collection. I also wanted to use my doctoral thesis to gain better insight into the internal experience of participants in groups which may be faced with stigma and shame. It was a privilege to be invited by participants to hear their stories and understand their experiences.

There may be something I should say about an interest in working with people of female gender. Saying this feels that I am broad brushing my participant groups with lots of untrue beliefs. Not all my participants were female. Not all people who self-harm, have an 'EUPD' label, experience sexual abuse, or experience difficulties with sexual intimacy due to problems with sexual organs, are women. However, these presentations are often associated with the female gender, and by extension, with heteronormative female stereotypes. As a result, they are taken less seriously by caring professionals and associated more frequently with prejudicing labels such as "hysteria" or "lability". I have dedicated limited discussion to this theme in my articles for the above reasons, but throughout this work, I often reflected on how gender and heteronormativity seemed to be modifiers of shame and stigma in consideration of the topics researched.

Below, I summarise my reflections of how these themes presented during completion of each article.

Critical Review of the Literature

I was intrigued by the varied locations the relevant articles came from. I was unsurprised by many coming from the USA; it is an international research hub. It also has a large population of female veterans; a group which are at a statistically higher likelihood of experiencing sexual violence and speaking about it due to their contact with veteran healthcare services. However, an equally large number came out of Scandinavia – a much smaller contributor to the international peer-reviewed literature. I reflected on whether this was related to the relatively progressive views of heteronormativity and feminism I associate with Scandinavian culture, and

whether this has reduced the stigma of both undertaking such studies and participating in them. Of course, Scandinavia also has an excellent personal identity system which facilitates big data collection, often resulting in massive population studies coming out of these countries.

My other reflection was regarding the non-experimental methodology employed by most included papers. This was expected; how does one ethically randomise sexual violence history? It does however mean that this area of research will progress relatively slowly. Positively, I also believe there is much scope for the literature to be truly expert-by-experience led and built on strong involvement of the individuals it represents.

Service Improvement project

It was difficult to not become emotionally involved in this project. Many of my participants said they had never previously spoken about the topics we spoke about in our semi-structured interviews. I was initially worried by the idea of asking such intimate questions in a structured way, but no participant expressed or indicated discomfort. Here, research supervision and my reflective log was paramount for my self-care. I appreciated my supervisor's expertise on qualitative research, and his invitation to not be a detached "professional" in this setting. I was previously relatively uninterested in qualitative research, but this project has made me a staunch defender of the methodology. This newly adopted position has already frequently been challenged when disseminating these findings at conferences. But I have also been positively surprised by the positive response the work has gotten

from the medical community – it indicates what I believe to be a more general realisation in healthcare of the need for more holistic approaches.

Theory-driven research project

In hindsight, I wish this had been a mixed-methodology study. Many participants, particularly older participants, shared a rich narrative of their experiences of having difficulties with emotional dysregulation and self-harm, and the stigma they have faced. They spoke about the difficulty of needing to hide from neighbours, services, and spouses. I was taken by how challenging it must be to need to hide what is essentially a coping strategy from others, or else be stigmatised by those around you. They spoke about how this dynamic made coping difficult. I do not endorse self-harm as a way of managing emotional dysregulation, but I was struck by what a natural part of life it was for many participants. Many fed back that they appreciated having an open, curious conversation with me about their self-harm. It had a big impact on how I will see and work with self-harm in future.

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Acknowledgements

Thank you to my participants. I recognise that speaking about topics which are so often accompanied by grief, emotional pain, and stigmatisation, can be very challenging. They chose to do this to contribute to better care for others who share their journey with similar difficulties. *"I am not doing this for me. I am doing it for the others, the young ones"* (participant 'Maria'). Thank you also to my fantastic experts by experience Madie and Liz, who contributed with insights and thoughtful reflections throughout these studies. A big thank you to all staff in the Oxford Health NHS Foundation Trust Community Mental Health Teams, who endured my recruitment pitch at every multi-disciplinary team meeting during spring and summer of 2022. It made this project possible. Thank you to the team at the John Radcliffe Hospitals Women's Centre for your dedication to improving the care provided to your patients.

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Thank you to Elin and Camille, for always being there. For your dedication to caring for others. For reminding me that there is a world beyond the DClinPsych. To Dr Faheem Malik, who supported me through the end, and who will be there in a new beginning. To *the tardigrades:* Gry, Elnaz, and Maisha. We made it! Most importantly, to Linda, Mari-Anne, and Jon-Evert Lisshammar. This work, is your work.

Appendices

SRL Appendix A: Full Search Terms

Web of science

(((((ALL=("female")) AND ALL=(adult))

AND ALL=("Sexual Violence" OR "Sexual Abuse" OR "Sexual Assault" OR "Rape" OR "sexual aggression" OR "sexual crime" OR "sex* offense" OR "sex* offence" OR "child sexual abuse" OR "sexual trauma"))

AND ALL=("Routine Gyn?colog*" OR "Scheduled Gyn?colog*" OR "Sexual Medicine" OR "care" OR "vaginal examination" OR "gyn?cological exam*"))

AND ALL=("Traum*" OR "Retraumat*" OR "Re-traumat*" OR "Trauma inform*" OR "distress" OR "rape trauma syndrome" OR "post-traum*" OR "posttraum*" "anxiety" OR "psychological aspect" OR "survivor" OR "victim" OR "mental stress" OR "fear" OR "emotional stress"))

NOT ALL=("natal" OR "veteran" OR "education" OR "emergency" OR "ER" OR "Paediatric" OR "pregnancy" OR "dental" OR "breastfeed*")

Scopus

(TITLE-ABS-KEY (female)

AND TITLE-ABS-KEY (adult)

AND TITLE-ABS-KEY ("Sexual Violence" OR "Sexual Abuse" OR "Sexual Assault" OR "Rape" OR "sexual aggression" OR "sexual crime" OR "sex* offense" OR "sex* offence" OR "child sexual abuse" OR "sexual trauma") AND TITLE-ABS-KEY ("Routine Gyn?colog*" OR "Scheduled Gyn?colog*" OR "Sexual Medicine" OR "care" OR "vaginal examination" OR "gyn?cological exam*")

AND TITLE-ABS-KEY ("Traum*" OR "Retraumat*" OR "Re-traumat*" OR "Trauma inform*" OR "distress" OR "rape trauma syndrome" OR "post-traum*" OR "posttraum*" "anxiety" OR "psychological aspect" OR "survivor" OR "victim" OR "mental stress" OR "fear" OR "emotional stress")

AND NOT TITLE-ABS-KEY ("*natal" OR "veteran" OR "education" OR "emergency" OR "ER" OR "Paediatric" OR "pregnancy" OR "dental" OR "breastfeeding"))

OVID SP

((female and adult).af.

and (“sexual violence” or “sexual abuse” or “sexual assault” or rape* or “sexual aggression” or “sexual crime” or offence or offense or “child sexual abuse” or “sexual trauma”).tw.

and (“routine gyn*colog*” or “scheduled gyn*colog*” or “sexual medicine” or care or “vaginal exam*”).tw. and (Traum* or Retrauma* or Re-trauma* or “Trauma inform*” or distress or “rape trauma syndrome” or post-traum* or posttraum* or anxiety or “psychological aspect” or survivor or victim or “mental stress” or fear or “emotional stress”).tw.)

not (Natal or veteran or education or emergency or ER or P*diatric or pregnancy or dental or breastfeed*).tw.

SRL Appendix B: Full Quality Ratings for Each Included Study

The Standard quality assessment criteria for evaluating primary research papers from a variety of fields (for quantitative studies) (Kmet et al., 2004)

Questions	
1. Research Question sufficiently described?	Yes (2)
2. Study Design evident and appropriate?	Partial (1)
3. Method of subject comparison group selection or source of information described and appropriate?	No (0)
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	N/A
5. If interventional allocation was possible, was it described?	(Not applicable)
6. If interventional and blinding of investigators was possible, was it reported?	
7. If interventional and blinding of subjects was possible, was it reported?	
8. Outcome and (if applicable) exposure measure(s) well-defined and robust to measurement/misclassification bias? Means of assessment reported? Survey: description of questionnaires.	
9. Sample size appropriate?	
10. Analytic methods described/justified and appropriate?	
11. Some estimate of variance is reported for the main results?	
12. Controlled for confounding?	
13. Results reported in sufficient detail?	
14. Conclusions supported by the results?	

*Total possible score is a sum of all questions (one point) subtracting questions which are "not applicable" to the current study. This score therefore varies, alongside the total sum of scores received for each quality component. This is true for, for example, survey designs.

Publication	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total Sum	Total Possible Score (%)*
Walker et al. 1993	2	2	2	1 [8]	N/A	N/A	N/A	2	N/A	2	2	N/A	2	2	17	18 (94)
Fry et al. 1996	1[1]	1 [4]	0	0	0	N/A	N/A	1 *Undefined incident"*	1 [10]	1 [5]	0	0 [13]	2	1 [13]	8	24 (33)
Robohm et al., 1997	1[1]	1	2	0	2	N/A	N/A	1	1 [11,12]	1	2	2	2	2	17	24 (71)
Wijma et al. 2000	2	1 [4]	1 [7]	1 [9]	N/A	N/A	N/A	2	N/A	1 [5]	1 [5]	N/A	2	2	13	18 (72)
Smith and Smith 2000	2	1 [5]	2	2	1	N/A	N/A	2	1 [11]	1 [5]	2	2	2	2	20	26 (77)
Wijma et al., 2003	2	1 [4]	2	2	N/A	N/A	N/A	2	N/A	2	2	N/A	2	2	17	18 (94)
Hilden et al., 2003	1 [1,2]	1 [2,6]	2	1 [8,9]	N/A	N/A	N/A	2	N/A	2	2	2	2	2	17	20 (85)

Peschers et al., 2003	2	2	1	2	N/A	N/A	N/A	2	N/A	2	2	N/A	2	2	17	18 (94)
Leeners et al., 2007	2	2	1 *All controls have children, which test participants do not.*	2	N/A	N/A	N/A	2	N/A	2	1 [14]	1 *All controls (but not test participants) are mothers*	1 [14]	2	16	20 (80)
Pikarinen et al., 2007	1 [2, 3]	2	2	1	N/A	N/A	N/A	2	N/A	1 [5]	1	N/A	2	2	14	18 (78)
Weitlauf et al., 2008	2	2	2	1	N/A	N/A	N/A	1 *Small pilot insufficient and scale of a validated test was modified but*	N/A	2	1 [8] *kurtosis inferred*	N/A	2	2	15	18 (83)

							not re-validated								
Weitlauf et al., 2010	2	2	2	2	N/A	N/A	N/A	2	N/A	2	2	N/A	2	2	18	18 (100)
McGregor et al., 2010	0	2	1	2	N/A	N/A	N/A	1 *idiosyncratic measure employed*	N/A	2	N/A	N/A	2	2	12	16 (75)
Swahnberg et al., 2011	1	2	1, *Quasi-random recruitment from one region*	2	2	N/A	N/A	2	N/A	2	2	1 [8]	2	2	19	22 (86)
Cadman et al., 2012	2	1 [5]	1 *Quasi-exclusion criterion applied but not reported*	2	N/A	N/A	N/A	2	2	1 [5]	N/A	N/A	2	2	15	18 (83)

Walker and Allan 2014	2	2	2	1 [9]	N/A	N/A	N/A	1 *Idiosyncratic measure employed*	N/A	2	N/A	N/A	2	2	14	16 (88)
Schnur et al., 2017	2	2	2	2	N/A	N/A	N/A	2	1 [11,13]	2	2	N/A	2	2	19	20 (95)
Simmons & Swahnberg, 2022	2	2	1, *Quasi-random recruitment from one region*	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	19	20 (95)

1 Setting unclear
2 Procedure absent
3 Location unclear
4 Design unclear
5 Unclear but inferred as appropriate
6 Subject descriptions insufficient
7 Sampling strategy unclear
8 Measure of dispersion absent
9 Baseline/Sample summary absent
10 Data analysis insufficient information
11 No power calculation (for case-control studies)
12 Insufficient N (for case-control studies)
13 Confounding introduced
14 Only significant probability values reported

SRL Appendix C: Published Abstract in the British Journal of Obstetrics and Gynaecology

This abstract will be published in the 2023 Royal College of Obstetrics and Gynaecology World Congress edition of the British Journal of Obstetrics and Gynaecology in June 2023.

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Trauma-informed Adaptations to Routine Gynaecological Care of Women who Experienced Sexual Violence

Lisshammar, Jenny E.L. [1,2]

Knight, Matthew T.D. [1,2]

1. University of Oxford, Oxford, UK
2. Oxford Health NHS Foundation Trust, Oxford, UK

OBJECTIVE

Sexual violence against women is associated with post-traumatic sequalae. This includes risk for retraumatisation when accessing routine gynaecological care. Women may be deterred from seeking medical contact due to this risk. Trauma-informed care guidelines remain absent for routine gynaecological care provided by the British National Health Service.

DESIGN

Narrative synthesis was employed to identify relevant literature and provide clinicians with an overview of evidence-based care-modifications to reduce retraumatisation in routine gynaecological care.

METHOD

Full-text, peer-reviewed, English language, articles reviewing risks and mitigating factors of retraumatisation in women aged 18+ who have experienced sexual violence were eligible for inclusion. Only publications relevant to a routine gynaecological care setting we included.

RESULTS

17 articles were included. 100% employed survey methodology, with four including case-control comparisons. Prevalence of women with a history of sexual violence was higher in samples than estimated by clinicians, and a history of sexual violence was rarely taken. Many women want to be asked about sexual violence history and request a dialogue about their individual retraumatisation risk. A multitude of specific triggers were identified, reflecting their relationship with individual's original trauma experiences. Several common factors of retraumatisation were identified. These included aspects of intimate examination, the language used by clinicians, and women's beliefs about the dynamic between patient and clinician. Retraumatisation was reported by 40-50% of women who accessed routine gynaecological care services. Clinicians trained and confident in working with women who have experienced sexual violence were found to be the most effective modifier to reduce retraumatisation, alongside clinician-patient discussion about individual triggers being

a natural part of the care meeting. Flexible working practices, to adjust the clinical contact to reduce the number of individual triggers, was also effective.

CONCLUSIONS

This review contributes a summary of evidence-based, trauma-informed, modifications to date. Many clinicians underestimate the frequency of female patients with a history of sexual trauma. While most retraumatisation triggers are individual to the women's sexual trauma experiences, open patient-clinician dialogue is protective against retraumatisation. More research, employing a broader methodological range, remains warranted to inform development of accessible and implementable trauma-informed routine care guidelines.

SRL Appendix D: The BMJ Author Guidelines

Guidelines are copied from the journal website on 15 May 2023. For the most recent version, please view the guideline webpage: Article types and preparation | The BMJ

Requirements for ALL manuscripts

Please ensure that anything you submit to *The BMJ* conforms to the International Committee of Medical Journal Editors' Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals uniform recommendations for manuscripts submitted to biomedical journals.

Before submitting an article, please ensure that you have followed all guidelines below. We recommend learning about our house style and ways to incorporate images into your submission.

Title page and authorship

The title should be informative and, for research papers, a subtitle with the study design (for example, "a phase III clinical trial" or "a systematic review and meta-analysis").

In this page, please provide for each author his or her name, affiliation (job title) at the time the paper was written, email and, for the corresponding author, the best contact address. All authors must fulfil the ICMJE criteria for authorship. If the number of authors is very large we may ask for confirmation that everyone listed met the ICMJE criteria for authorship. We also offer the option of joint first authorship when two authors meet criteria for such a designation. We reserve the right to require that authors form a group whose name will appear in the article byline. MEDLINE guidance explains that group authorship is acceptable, stating "When a group name for a specific consortium, committee, study group, or the like appears in an article byline, the personal names of the members of that group may be

published in the article text. Such names are entered as collaborator names for the MEDLINE citation."

Word count and style

To encourage full and transparent reporting of research we do not set fixed word count limits for research articles. Nonetheless, we ask you to make your article concise and make every word count. You will be prompted to provide the word count for the main text (excluding the abstract, references, tables, boxes, or figures) when you submit your manuscript.

Original research articles should follow the IMRaD style (introduction, methods, results, and discussion) and should include a structured abstract (see below), a structured discussion, and a succinct introduction that focuses - in no more than three paragraphs - on the background to the research question.

For an intervention study, the manuscript should include enough information about the intervention(s) and comparator(s) (even if this was usual care) for reviewers and readers to understand fully what happened in the study. To enable readers to replicate your work or implement the interventions in their own practice, please also provide any relevant detailed descriptions and materials (uploaded as one or more supplemental files, including video and audio files where appropriate). Alternatively, please provide in the manuscript URLs to openly accessible websites where these materials can be found.

Please ensure that the discussion section of your article comprises no more than a page and a half and follows this overall structure, although you do not need to signpost these elements with subheadings:

• *Statement of principal findings*

• *Strengths and weaknesses of the study*

• *Strengths and weaknesses in relation to other studies, discussing important differences in results*

• *Meaning of the study: possible explanations and implications for clinicians and policymakers*

• *Unanswered questions and future research*

Structured abstract

Please ensure that the structured abstract is as complete, accurate, and clear as possible and has been approved by all authors. We may screen original research articles by reading only the abstract.

Abstracts should be 250- 300 words long: you may need up to 400 words, however, for a CONSORT or PRISMA style abstract. MEDLINE can now handle up to 600 words. Abstracts should include the following headings, but they may be modified for abstracts of clinical trials or systematic reviews and meta-analyses according to the requirements on the the CONSORT extension for abstracts and the PRISMA extension for abstracts, respectively.

• OBJECTIVES - a clear statement of the main aim of the study and the major hypothesis tested or research question posed

• DESIGN - including factors such as prospective, randomisation, blinding, placebo control, case control, crossover, criterion standards for diagnostic tests, etc.

• SETTING - include the level of care, e.g., primary, secondary; number of participating centres. Be general rather than give the name of the specific centre, but give the geographical location if this is important

• PARTICIPANTS (INSTEAD OF PATIENTS OR SUBJECTS) - numbers entering and completing the study, sex, and ethnic group if appropriate. Give clear definitions of how selected, entry and exclusion criteria.

• INTERVENTIONS - what, how, when and for how long. This heading can be deleted if there were no interventions but should normally be included for randomised controlled trials, crossover trials, and before and after studies.

• MAIN OUTCOME MEASURES - those planned in the protocol, those finally measured (if different, explain why).

• RESULTS - main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks.

• CONCLUSIONS - primary conclusions and their implications, suggesting areas for further research if appropriate. Do not go beyond the data in the article. Conclusions are important because this is often the only part that readers look at.

• TRIAL REGISTRATION - registry and number (for clinical trials and, if available, for observational studies and systematic reviews).

When writing your abstract, use the active voice but avoid "we did" or "we found". Numbers over 10 do not need spelling out at the start of sentences. p-values should always be accompanied by supporting data, and denominators should be given for percentages. Confidence intervals should be written in the format (15 to 27) within parentheses, using the word "to" rather than a hyphen. Abstracts do not need references.

Reporting guidelines

Reporting guidelines promote clear reporting of methods and results to allow critical appraisal of the manuscript. We ask that all manuscripts be written in accordance with the

appropriate reporting guideline. Please submit as supplemental material the appropriate reporting guideline checklist showing on which page of your manuscript each checklist item appears. A complete list of guidelines can be found on the website of the Equator Network. Below is the list of most often used checklists but others may apply.

For a CLINICAL TRIALS, use the CONSORT checklist and also include a structured abstract that follows the CONSORT extension for abstract checklist, the CONSORT flowchart and, where applicable, the appropriate CONSORT extension statements (for example, for cluster RCTs, pragmatic trials, etc.). A completed TIDieR checklist is also helpful as this helps to ensure that trial interventions are fully described in ways that are reproducible, usable by other clinicians, and clear enough for systematic reviewers and guideline writers.

For SYSTEMATIC REVIEWS OR META-ANALYSIS of randomised trials and other evaluation studies, use the PRISMA checklist and flowchart and use the PRISMA structured abstract checklist when writing the structured abstract.

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	
Information sources	4	Specify the information sources (e.g., databases, registers) used to identify studies and the date when each was last searched.	
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	
Synthesis of results	6	Specify the methods used to present and synthesise results.	
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e., which group is favoured).	
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g., study risk of bias, inconsistency, and imprecision).	
Interpretation	10	Provide a general interpretation of the results and important implications.	
OTHER			
Funding	11	Specify the primary source of funding for the review.	
Registration	12	Provide the register name and registration number.	

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

SIP Appendix A: Subjectivity statement

IPA focuses both on voicing participants idiosyncratic experiences and offering phenomenological interpretation (Noon, 2018). This process undoubtedly occurs through the lens of the analyst aiming to gain an "insider perspective" of the experiences of the sample. This is acknowledged to aid the readers interpretation of presented analysis (Given, 2008). The researcher's interpretative framework is influenced by her training as a clinical psychologist at time of analysis. Researcher JL undertook all interviews. JL is a current trainee clinical psychologist, undertaking a doctorate in clinical psychology. This is the only route for the qualification of clinical psychologist in the United Kingdom. All interviewees were made aware of JL's trainee status. JL's prior experience with qualitative research is from practical exercises during her undergraduate degree.

JL is born and has grown up in a non-English speaking country. This sometimes complicated interpretations of semantics and figures of speech. JL does not have a strong accent and interviewees were not made aware of JL's cultural background. JL is female. JL had a professional interest in women's sexual health throughout her training; as it intertwines with areas of medicine, but also sociology and gender philosophy which are interests. Further, JL experienced health issues of a similar nature to the participants during data collection. However, this may have introduced familiarity bias with the interviewees. JL's supervisors, one of which was a stakeholder in the service, was made aware of this. They were also part in post-transcript analysis and pre-publication reading. JL's preconceptions were reflected on using a research diary, recording of own thoughts after each interview, and through reflection with AZ. It is recognised that the analysis is influenced by the researcher's

perspective and framework applied to understand the data; specifically, accessing gynaecological services, being female, and having a bias towards valuing the psychological experience of patienthood.

SIP Appendix B: Interview Schedule

Introduction

- Revisit information in the Participant information sheet
- Give time to ask any questions and sign the consent form
- Outline interview boundaries:
- the recording is confidential and published information fully anonymised. I am happy to discuss any thoughts or concerns that come up for you after the interview. If you need to take a break, or stop, please just let me know and we can do that.
- Revisit aim of the interview:
- "The aim of this interview is to gain an in-depth understanding of your experience of the topic of sexual intimacy, in the context of your gynaecological condition, in discussions with clinicians you have met here at the JR Women's Centre. I am interested in your experience, memories, inputs, and reflections. There are no right or wrong answers, and I would like you to be as open and honest as you feel comfortable being. Please take your time thinking about and answering the questions. If I am silent during the interview, it is because I want to give you as much space as possible to speak.

Question schedule

1. Can you tell me about your experience of your medical condition which brought you to receive care at the JR Women's Centre?

a. What kind of health problem do you have? What are the physical effects of that condition? What is that like for you?
b. How do you notice this health problem in your daily life? In your social life? In your intimate life?

2. Can you tell me how you have experienced your medical condition from when it started to your most recent visit at the JR Women's Centre?
   a. How has that changed over time?
   b. What first put you in touch with a medical professional? With a gynaecological specialist? [if relevant: What delayed that process?]

3. What has your experience been of receiving treatment for this condition at the JR Women's Centre?

a. What is it like being a patient here? Can you tell me about a typical clinical contact?
b. Have you experienced clinical contacts differently over time? What has changed?
c. When you were first given a diagnosis/name/explanation for your health problem, what was that like?
d. What did you think of the diagnosis and treatment plan you received? What was similar or different in what you thought about your condition, and how the clinician you met assessed it?

--- Thank you for sharing that with me. I would now like to ask you some questions which are specifically related to clinical discussions about your sexual experiences in the context of [health condition]. ----

4. What conversations about sexual intimacy, if any, have you had with clinicians at the JR WC?

I have had (a) conversation(s) (at the JR WC)

- How did it come up for the first time?

□

Clinician raised it OR

- What was it like to be asked about your sexual experiences by your clinician at the JRWC?

- How did you respond to the clinician raising it?

Patient raised it

- What was it like to raise that topic for the first time?

- What prompted you to raise it?

- How did the clinician respond to you raising it?

□

For all "conversers"

- What is it like having that conversation now? Has it changed over time? How?

I have not had a conversation (at the JR WC)

- Have you had that conversation with a clinician not at the JR WC before?

□

Yes OR

- Why has that conversation not continued at the JR Women's Centre?

- Have you wanted to have that conversation here [at the JR WC]? Why/Why not?

- What have been barriers to that conversation taking place?

- Does it matter if clinicians know about your sexual experiences when you discuss your condition with them? Why does it/does it not matter?

□

No

- Do you experience differences in clinicians' responses to these conversations? What have you noticed?

  ➢ **GO TO Q5.**

- Have you wanted to have that conversation? Why? Why not?
- What has been a barrier to that conversation happening? Why has that been a barrier?
- Does it feel important that clinicians know about your sexual experiences when you discuss your condition with them?

  ➢ **GO TO Q5.**

--- Resume for all ----

5. How has [the experience of having/not having conversation] impacted the way you feel about attending appointments and receiving care at the JR Women's Centre?

a. Are there times you feel more positive/negative about this? Please tell me about these times.
b. Has it impacted the way you feel about clinical discussions about your sexual experience in the context of [health condition]?
c. Has it changed the way you view your condition? How?

6. Has [the experience of having/not having conversation] influenced the relationships you have with clinicians here at the JR Women's Centre? How was it influenced?

a. Are there any particular relationships that come to mind? Could you tell me a bit about them?
b. What are the things that have enabled/caused the relationship to develop in this way?
c. What experiences have you valued?

7. Thinking about the discussions we have just had; do you have any thoughts about what might help clinicians at the JR Women's Centre in conversation, with patients, about sexual intimacy?

a. Is there anything else you would have wanted your clinician to know about or be aware of in previous contacts?
b. Is there anything else you would like to share with me about your experience of being a patient at the JR Women's Centre?

General Probes

Can you tell me a bit more about that?

Can you help me understand that experience better by giving a bit more detail?

Can you give me an example of…?

Is there anything else you would like to say about that?

What was that like for you?

Debrief

c. Highlight what will happen now and who to contact if needed
d. Emphasise to contact me if they want to discuss anything further
e. Offer time to process and reflect on the interview: How did you find it? Do you have any further questions?

Thank them for their time.

SIP Appendix C: Reflective process statement

This statement is separate from the subjectivity statement, although they should likely be acknowledged in tandem.

The etymology of the term 'compassion' (from the Latin *compati,* 'to suffer with') was topical for me throughout the data collection and analysis process. I reflect on whether this comes from participants consistent expression of wanting to build relationships with clinicians, to experience 'human sameness' as discussed in subtheme *I am human, you are human, too?* The way they expressed this communicated tangible feelings of rejection, anger, and aloneness. It made it challenging to not meet them with the 'human sameness' they wanted from clinicians.

It also gave me a flavour for the challenge clinicians face in navigating this 'sameness'. As psychologists, we speak of wearing different 'hats' for different roles. This may be a way of asserting boundaries between multiple responsibilities but may also serve self-protectively. If the role of clinician always included acknowledgement of 'human sameness' with one's patients, it is easy to see how compassion fatigue would quickly develop. Particularly, thinking in the etymological sense, how exhausting it must be to suffer with a group which has experienced the pain, grief, and discrimination, our participants have endured. I absolutely understand why clinicians are not prepared to do that. Some interviews made me cry when reading them back. I was awestruck by how our participants managed to function alongside the difficulties they experienced and create meaning in the areas of life spared from the havoc their gynaecological conditions caused.

I feel gratitude towards our participants for taking part in this study. Recruitment was a challenge. It took eight months. Our Expert by Experience consultant, MP, reflected how this evidences just how stigmatising and difficult it is for women in our culture to speak about sex. Many participants reflected on that they were doing this for 'the others', or 'the young ones.'. I found this statement emotional. It depicted clearly the essence captured in *Ripples of the care experience;* of the clinical journey with a CGC really being a journey which over time becomes more familiar to manage, even if not necessarily easier. I think this was also an attempt at meaning-making by our participants. Carl Jung spoke of the concept of the Wounded Healer. Psychotherapists, he argued, work to heal others because we ourselves are wounded. In this process, we create a sense of meaning for the experienced suffering. I think a similar process was happening for our participants. Perhaps we should speak of patients with experience of chronic health conditions as the *wounded patients,* although I do recognise the semantic issues that arise with this term. However, I feel strongly that this would help clinicians hold in mind the continuity with which our participants, and I am certain patients beyond our group, experience their care.

SIP Appendix D: Example questions to inform initial/follow-up evaluation survey

The Women's Centre is looking to develop the support with provide our patients around the impact of their condition on sexual intimacy. If you feel comfortable, please complete this questionnaire, and leave in [designated space]

1. Does your gynaecological condition impact how your ability to have sex in a way that works for you?

Yes/No

2. Does your gynaecological condition change how you feel about yourself when you are having sex?

Yes/No

3. Did your clinician give you space to talk about your experience of sexual intimacy when you saw them today?

Yes/No/I don't have any difficulties with sexual intimacy

4. Did you feel that the clinician listened to you and understood how these difficulties are impacting you?

Yes/No/I don't have any difficulties with sexual intimacy

5. Are you satisfied with the level of support that came out of this conversation today?

Yes/No/They didn't ask me

6. Were you invited to include a partner or sexual contact in your care, if you wanted to?

Yes/No

SIP Appendix E: Example questions to inform development of clinic pro forma

These are examples, based on feedback from our sample, which the service may consider including in their sexual intimacy pro forma.

- Is your condition impacting your sexual practice and ability to enjoy sexual intimacy?
- What barriers to this have you experienced?
- How is this impacting how you feel about yourself in your daily life?
- How is this impacting how you feel in your relationship with your sexual partner or partners?
- How is it impacting your relationship with your partner or partners?
- Would you like your partner to be more involved in your care?
- Would you like to invite your partner to join you in future appointments?
- Would you find it helpful to have a conversation with a clinician and your partner about how your condition may be impacting your ability to be sexually intimate?
- Is there any other support that you would find helpful from the women's centre?

SIP Appendix F: Additional supporting Quotes

Beyond the hospital – stories untold in clinic

> I'm 24 and like it's just…sex isn't part of my relationship with my boyfriend of [several] years, like we have our own house, I want to be able to do those simple things. (Lucy)

> It was a much more comfortable experience and I felt like they were paying attention to all of the stuff that was relevant, and, uhm, rather than just dismissing huge chunks of what I was saying. (Ana)

> I never had a hysterectomy in the end. I just kept refusing, because you always hold out the hope that you might have children and giving up on that dream is quite difficult. (Maria)

Ripples of care experiences – Life alongside the Women's Centre

> Perhaps you are not doing the kind of sexual activity that people expect from you or your body isn't the way that people expect it to be, so, they sometimes look past your pain, and you know, the pain and the discomfort and the, you know, the general issues that you are having with sex, they then will just assume that is something to do with your identity, and yeah, my experience at the Women's Centre so far is that they are actually a lot more knowledgeable than lots of people I have spoken to. (Ana)

> I was scared going to the appointments. I felt really unconfident and not good in myself and it's like, almost like she, I doubted what I was saying because I felt like she didn't believe me. (Lucy)

It's all very well asking them questions, you know, you've been at the toilet at this time and how much did you drink and how much came out and how much this but is there more behind the scenes that can actually connect all these things together. (Sarah)

The consultant came in, I was in the bed on the right, and they looked at me with dread, walked around the whole room, and they got to me and said "your Endometriosis is at a level where, it's so severe, it's at level 4, you will never have children, have you got any questions? (Maria)

The 'S' word in clinic – shared stigmatisation, a wish for support

It's after you walk away, and you look, and you think, okay there is a definite solution here, you know, you are taking all this information but you are not telling me how you are using it, how does it impact my care, and, and, if it impacts my care, how are you going to help me to move forward? (Elisabeth)

I feel like persons I have spoken to, and medical professionals, and my partner, and now I am kind of thinking oh actually, maybe it's pretty common, and it's not just me having this experience in that I'm not just, uhm, it's not just something terribly wrong with me. (Ana)

But when you're on your own you feel like you're an alien, you feel like why do I feel like this other people don't feel like this it's not normal, I'm not normal (Lucy)

I mean it's like anything isn't it, if you don't understand, how it's been put to you, you are not going to give an answer…so she was very good in the way she, said what she

had to say, and I understood straight away what she meant, and I knew what she wanted from me. (Sarah)

Ask if they are having sex, how is their experience of having sex, you know, do you feel anything after having sex, ask these questions, because I was never asked and I was not that really young but I wasn't really old either, like, ask them and that for me would have opened a huge amount of doors and helped me in so, so many ways that make me think that things would not be as bad now, and I'm like, it's a question, its one little question (Lucy)

If they will [ask], if they would learn more about the history of the patient, and if they would ask more, if you got anything that you want to discuss further, and stuff like that, I think that should help, ask, open up about sexual intercourse and stuff like that. (Dana)

It's really lonely and difficult. So hopefully, they can start making some decision links with the mental, with the social, somehow. (Maria)

If this condition like impact your sexual activities or something like that with your partner so if, the question has been asked, we can open up, we can open up and tell them, what is going on, but it never, questions like that is never been asked. (Dana)

You're an expert, I'm an expert, too – reciprocal care

Well, now…I am going to be prompting back now…I will be, you know, maybe asking for more help and just, letting me be statistics and write up and stuff like that, because that is how I feel. (Elisabeth)

They don't know my body, they think they know better than me, I feel they are constantly withholding treatment. (Maria)

> Especially when it was something you are absolutely dreading, and somebody does not show, not even compassion, but even basic understanding, and you feel like you are inconveniencing them just by being there. And that you, it makes it even worse, because I am not there to waste peoples time, or take up NHS money, you are there because you have to be. And some clinicians are just working through their daily operation schedules, and they are not there to care, or what happens to you. (Maria)

> Because those emotional bits its rarely recognised, and 20 years ago, it would absolutely not have been. But I feel that there has been very little progress, on taking into account a patient's mental health, their social and sexual life. (Maria)

> I am 20 years down the road, it's not really going to help anymore. It would have back then, but now, you know, you learn to live with it and deal with those emotions and work through them. It's too late now. So, it's been a long time, you come to become your own psychologist. (Maria)

SIP Appendix G: Confirmation of study service-evaluation status

Email from the trust's Senior research support manager to the external supervisor confirming service-evaluation status and that regulatory approvals are not required.

From: Franklin, Jo (RTH) OUH <Jo.Franklin@ouh.nhs.uk>
Sent: 18 November 2021 16:07
To: OUH.Sponsorship <OUH.Sponsorship@oxnet.nhs.uk>; Evans, Emma(RTH) OUH <Emma.Evans@ouh.nhs.uk>
Subject: RE: review of study classification

Dear Emma

The classification committee met today and reviewed this project again following amendments to the previous submission.

The committee is happy that the revised project can be classed as service evaluation and therefore no regulatory approvals are required.

You should ensure that your department leads are aware of the project and are happy for the activity to take place. You may also need to register the project with the clinical audit team. Details can be found here: http://ouh.oxnet.nhs.uk/SafetyQualityRisk/Pages/Welcome.aspx

All service review activity should comply with clinical governance requirements.

Please do get in touch with myself or Katie if you have any further queries.

With best wishes

Jo

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

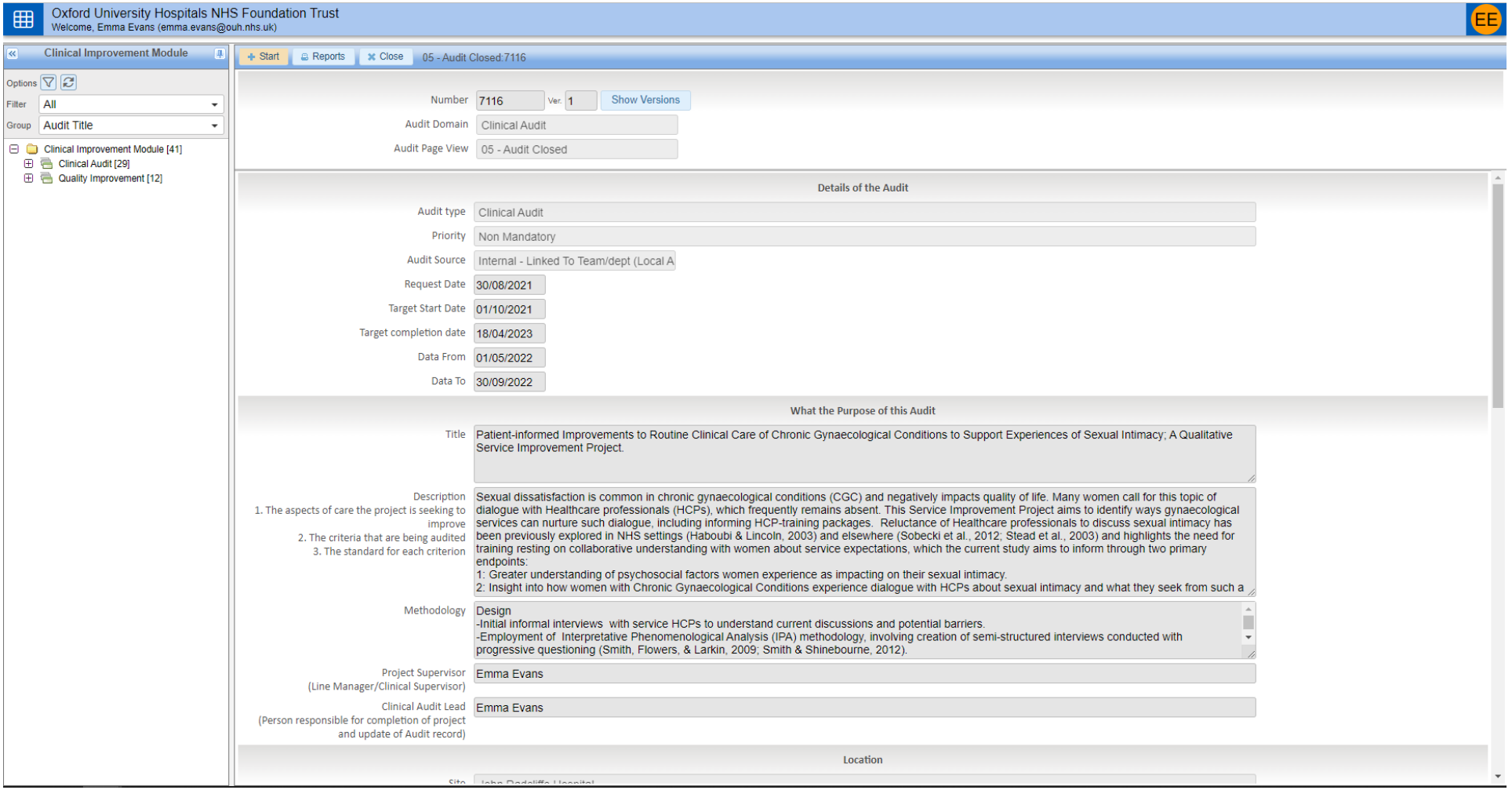
Joint Research Office
enabling successful research through collaboration
Jo Franklin
Senior Research Support Manager
Research and Development
Tel: 01865 572238
Email: jo.franklin@ouh.nhs.uk

Learning | Respect | Delivery | Excellence | Compassion | Improvement

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

SIP Appendix H: Confirmation of Study on Ulysses

Ulysses is the governance system for Oxford University hospital's NHS Foundation Trust.



SIP Appendix I: Disseminated abstract as an oral presentation 4 May 2023

The following abstract was accepted as an oral presentation at the World Congress of Endometriosis. It was presented on 4 May 2023. The abstract was accepted for publication in this form on 4 February 2023. It will be included in the conference proceedings of *Frontiers in Reproductive Health,* due for publication December 2023.

Submitted: 27 October 2022

Accepted: 4 February 2023

Patient Experience of Patient-Clinician Dialogue concerning Sexual Intimacy: A Qualitative Investigation of Females with Chronic Gynaecological Conditions

Lisshammar, Jenny E.L. [1,2]

Knight, Matthew T.D. [1,2]

Evans, Emma [1,3]

3. University of Oxford, Oxford, UK
4. Oxford Health NHS Foundation Trust, Oxford, UK
5. Oxford University Hospitals, Oxford, UK

INTRODUCTION

Sexual dissatisfaction is common in chronic gynaecological conditions. While patients and clinicians increasingly recognise that holistic care warrants dialogue about this, such clinical conversations remain infrequent. Clinicians attribute this to not recognising its relevance, feeling too embarrassed, or insufficiently skilled.

Aims

This service improvement project was set at the John Radcliffe Hospital's Women's Centre, UK. It sought to understand patients' experiences of clinical conversations about sexual intimacy.

METHODS

This study explored individual and dyadic processes contributing to clinical conversations about sexual intimacy. Six patients with chronic gynaecological conditions participated in semi-structured interviews. Their accounts were analysed using Interpretative Phenomenological Analysis.

RESULTS

Four themes were inferred from analysis. 'Beyond the hospital door' described participants' conditions impact on their day-to-day life and their partners. 'Ripples of care experiences' recounted how participants experienced care as a single, continuous journey. 'The 'S' word in clinic' spoke of absent, but wanted, clinical conversations about sexual intimacy. Lastly, 'You're an expert, I'm an expert, too, identified participants' beliefs about the meaning of medical expertise, and the value of reciprocal patient-clinician relationships.

CONCLUSIONS

Chronic gynaecological conditions significantly impacted women's sexual lives, which was sometimes felt to be unacknowledged in consultations. Women sought clinicians dialogue and support. Power inequality and social and moral stigma inhibited conversations about sexual intimacy. The clinical relationship was imperative to overcoming this. The service was recommended to; explore these findings within the wider patient pool, increase patient involvement in service development, develop a clinician training module, and a clinic pro forma.

SIP Appendix J: BMC Women's Health Author Submission Guidelines

Guidelines are copied from the journal website on 15 May 2023. For the most recent version, please view the guideline webpage: BMC Women's Health | Research article (biomedcentral.com)

Research article

Criteria

Research articles should report on original primary research, or present a new experimental or computational method, test, or procedure. Manuscripts reporting results of a clinical trial must conform to CONSORT 2010 guidelines. Authors of randomized controlled trials should submit a completed CONSORT checklist alongside their manuscript, available at www.consort-statement.org. Research articles may also report on systematic reviews of published research provided they adhere to the appropriate reporting guidelines which are detailed in our editorial policies. Please note that non-commissioned pooled analyses of selected published research and bibliometric analyses will not be considered. Studies reporting descriptive results from a single institution or region will only be considered if analogous data have not been previously published in a peer reviewed journal and the conclusions provide distinct insights that are of relevance to a regional or international audience.

BMC Women's Health strongly supports open research, including transparency and openness in reporting. Further details of our Data availability policy can be found on the journal's About page.

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

see Springer Nature's data repository guidance. Where a widely established research community expectation for data archiving in public repositories exists, submission to a community-endorsed, public repository is mandatory. A list of data where deposition is required, with the appropriate repositories, can be found on the Editorial Policies Page.

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

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.

TDRP Appendix A: Confirmation of OHFT Sponsorship

Oxford Health
NHS Foundation Trust

Natalia Jastrzębska
Research Manager
Research and Development Department
Warneford Hospital
Warneford Lane
Oxford
OX3 7JX
Email: research@oxfordhealth.nhs.uk

01/12/2021

Confirmation of Sponsorship

Re: Differing Self-harm in Younger versus Older Adults with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan
Research and Development Reference: 15857

Dear Jenny Lisshammar,

On behalf of Oxford Health NHS Foundation Trust, I am pleased to confirm Oxford Health NHS Foundation Trust will act as a sponsor for the above research as outlined in the application received.

Protocol Version 1 dated 01/12/2021 is recognised as the most current to date.

Conditions of Approval
The following conditions apply to this approval:

a) The study sponsorship is confirmed subject to formal approval from HRA and any other relevant approving body.
b) Should you plan to leave your position in OHFT, you will notify R&D immediately of your plans, to enable discussions around the future of study conduct.
c) The Trust expects the named Principal Investigator to allocate regular support time to the study; this must be agreed with the research team prior to the study commencing. This may be reviewed by R&D at any time.
d) All relevant documents will be maintained and will be sent to research@oxfordhealth.nhs.uk, to facilitate compliance checks, formal audits and regulatory inspections.
e) You will notify R&D via the email above of any amendments.
f) You will promptly inform R&D via the email above of the end of the study.

I wish you every success with the study.

Yours sincerely,



Natalia Jastrzębska
Research Manager

Sponsorship letter v2, January 2020

Page 1 of 1

TDRP Appendix B: Research Ethics Favourable Opinion

Health Research Authority

East of England - Essex Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

21 March 2022

Ms Jenny Lisshammar
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
ISIS Education Centre
Warneford Hospital
Warneford Lane
OX3 7JX

Dear Ms Lisshammar

Study title:	**Differing Self-harm in Younger versus Older Adults with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan**
REC reference:	**22/EE/0004**
IRAS project ID:	**304357**

Thank you for your letter of 16 March 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product

- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of materials calling attention of potential participants to the research	1	01 December 2021
Copies of materials calling attention of potential participants to the research	1	01 December 2021
GP/consultant information sheets or letters [Debrief Sheet for participants]	3	09 March 2022
GP/consultant information sheets or letters [Debrief Sheet for Participants Tracked Changes]	3	09 March 2022
Letter from sponsor		01 December 2021
Other [Questions regarding dementia]		
Other [Letter of response to Provisional Opinion]	V2	24 January 2022
Other [Sponsor response to provisional Opinion]		09 March 2022
Participant consent form	1	24 November 2021
Participant information sheet (PIS) [Care Coordinator Information Sheet]	3	09 March 2022
Participant information sheet (PIS) [Participant Information Sheet]	3	09 March 2022
Participant information sheet (PIS) [Care-Coordinator Information Sheet Tracked Changes]	3	09 March 2022
Participant information sheet (PIS) [Participant Information Sheet Tracked Changes]	3	09 March 2022
Protocol [Protocol]	3	09 March 2022
Protocol [Protocol Tracked Changes]	3	09 March 2022

Summary CV for Chief Investigator (CI) [JL (CI) CV]		01 December 2021
Summary CV for supervisor (student research)		
Validated questionnaire Borderline Symptom List 23		
Validated questionnaire The Cognitive Emotion Regulation Questionnaire, CERQ]		
Validated questionnaire: A proposed severity classification of borderline symptoms using the borderline symptom list (BSL-23)		
Validated questionnaire: The Cognitive Emotion Regulation Questionnaire		
Validated questionnaire: Self-Harm Inventory		
Validated questionnaire: The Self-Harm Inventory Development of a scale for Identifying Self Destructive Behaviors and Borderline Personality Disorder.		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 304357 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely
pp

Tracy Hamming

Dr Niki Bannister
Chair

Email:Essex.REC@hra.nhs.uk

Copy to: Ms Brandy Coote

Lead Nation England: approvals@hra.nhs.uk

TDRP Appendix C: Health Research Authority Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Ms Jenny Lisshammar
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
ISIS Education Centre
Warneford Hospital
Warneford Lane
OX3 7JXN/A

Email: approvals@hra.nhs.uk

22 March 2022

Dear N/AMs Lisshammar

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

Study title:	**Differing Self-harm in Younger versus Older Adults with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan**
IRAS project ID:	**304357**
REC reference:	**22/EE/0004**
Sponsor	**Oxford Health NHS Foundation Trust**

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

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

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

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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

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

What are my notification responsibilities during the study?

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

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

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

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

Your IRAS project ID is **304357**. Please quote this on all correspondence.

Yours sincerely,
Vic Strutt

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Brandy Coote*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Copies of materials calling attention of potential participants to the research	1	01 December 2021
Copies of materials calling attention of potential participants to the research	1	01 December 2021
GP/consultant information sheets or letters [Debrief Sheet for participants]	3	09 March 2022
IRAS Application Form [IRAS_Form_01122021]		01 December 2021
Letter from sponsor		01 December 2021
Other [Questions regarding dementia]		
Other [Sponsor response to provisional Opinion]		09 March 2022
Participant consent form	1	24 November 2021
Participant information sheet (PIS) [Care Coordinator Information Sheet]	3	09 March 2022
Participant information sheet (PIS) [Participant Information Sheet]	3	09 March 2022
Protocol [Protocol]	3	09 March 2022
Summary CV for Chief Investigator (CI) [JL (CI) CV]		01 December 2021
Validated questionnaire Borderline Symptom List 23		
Validated questionnaire The Cognitive Emotion Regulation Questionnaire, CERQ)		
Validated questionnaire A proposed severity classification of borderline symptoms using the borderline symptom list (BSL-23)		
Validated questionnaire The Cognitive Emotion Regulation Questionnaire		
Validated questionnaire Self-Harm Inventory		
Validated questionnaire The Self-Harm Inventory Development of a scale for Identifying Self Destructive Behaviors and Borderline Personality Disorder.		

IRAS project ID	304357

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
This is a single site study sponsored by the participating NHS organisation therefore there is only one site type.	This is a single site study sponsored by the participating NHS organisation. You should work with your sponsor R&D office to make arrangements to set up the study. The sponsor R&D office will confirm to you when the study can start following issue of HRA and HCRW Approval.	This is a single site study sponsored by the participating NHS organisation therefore no agreements are expected.	No external study funding has been sought.	A Principal Investigator should be appointed at the study site.	The sponsor has stated that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore no honorary research contracts or letters of access are expected for this study.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio.

TDRP Appendix D: HRA Declaration of End of Study

NHS
Health Research Authority

Declaration of the end of a study

(For all studies except Clinical Trials of Investigational Medicinal Products)

To be completed in typescript by the Chief Investigator or sponsor representative and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination

For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	Jenny Lisshammar
Address:	ISIS Education Centre Warneford Hospital Warneford Lane Headington OX3 7JX, Oxford
Telephone:	07472093673
E-mail:	Jenny.lisshammar@hmc.ox.ac.uk

2. Details of study

Full title of study:	Differing Self-harm in Younger versus Older Adults with Emotionally Unstable Personality Disorder Traits; Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan
IRAS ID:	304357
Name of REC:	East of England - Essex Research Ethics Committee
REC reference number:	22/EE/0004
Date of favourable ethical opinion:	22/03/2022
Sponsor:	Oxford Health NHS Foundation Trust

3. Study duration

Date study commenced:	**11/05/2022**
Date study ended	**14/02/2023**
Did this study terminate prematurely?	No If yes, please complete sections 4, 5 & 6. If no, please complete section 4 and then go directly to section 7.

4. Recruitment

Number of participants recruited	**36**
Proposed number of participants to be recruited at the start of the study	**34**
If different, please state the reason or this	**We received two additional referrals to the study which fulfilled inclusion criteria and consented to participate in the study.**

5. Circumstances of early termination

What is the justification for this early termination?	

6. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating the study prematurely? Please describe the steps taken to address them.	

7. Final report on the research

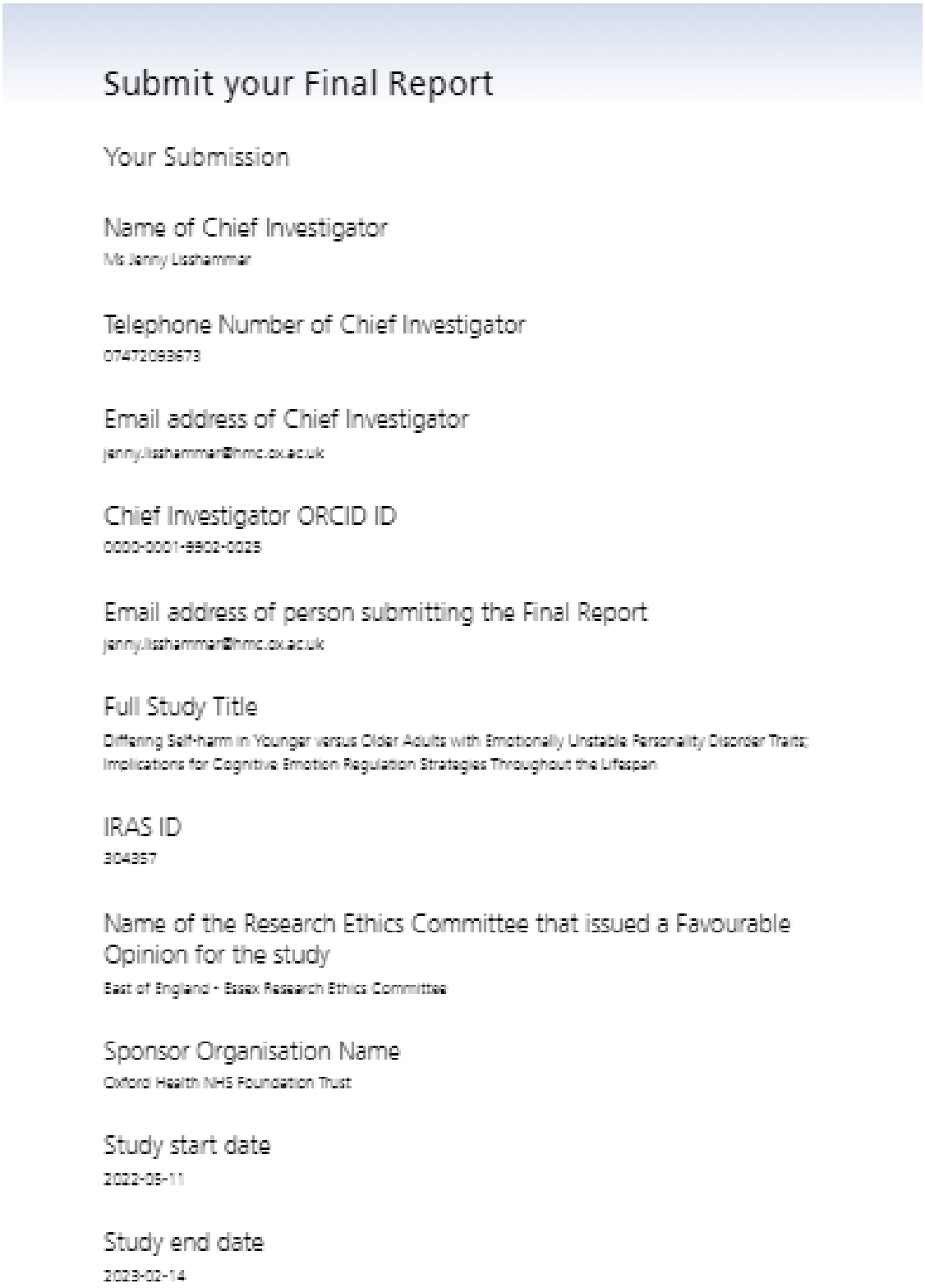
Have you submitted a Final Report?	YES

8. Declaration

*Signature or Electronic Authorisation of Chief Investigator/sponsor representative: *Please print below or insert electronic signature	
Print name:	**Jenny Lisshammar**
Date of submission:	**29/03/2023**

TDRP Appendix E: Submitted Final Report of close of study

Please note that final report is submitted via a webform. This is an image format of the submitted webform.



Submit your Final Report

Your Submission

Name of Chief Investigator
Ms Jenny Lashammar

Telephone Number of Chief Investigator
07472099873

Email address of Chief Investigator
jenny.lashammar@hmc.ox.ac.uk

Chief Investigator ORCID ID
0000-0001-9902-0035

Email address of person submitting the Final Report
jenny.lashammar@hmc.ox.ac.uk

Full Study Title
Differing Self-harm in Younger versus Older Adults with Emotionally Unstable Personality Disorder Traits: Implications for Cognitive Emotion Regulation Strategies Throughout the Lifespan

IRAS ID
304357

Name of the Research Ethics Committee that issued a Favourable Opinion for the study
East of England - Essex Research Ethics Committee

Sponsor Organisation Name
Oxford Health NHS Foundation Trust

Study start date
2022-05-11

Study end date
2023-02-14

Funder's reference number

unfunded study

Name of Registry

N/A

Study Registration Number/Identifier

N/A

Date of registration

N/A

Is the study protocol publicly available?

No

Lay summary of study results

We need more research on Emotionally Unstable Personality Disorder (EUPD) - which is also known as Borderline Personality Disorder (BPD). We wanted to know more about how older people aged over 65 years, who fulfilled the criteria for a diagnosis of EUPD/BPD, coped with difficulties managing their emotions (so-called "emotional regulation strategies"). Some research says that older people who find it difficult to manage their emotions, manage these difficulties in different ways from younger adults. For this reason, older people might not get a diagnosis of EUPD/BPD when they fulfill the criteria for diagnosis, and they feel that such a diagnosis is right for them. Our study aimed to explore emotional regulation strategies across the adult lifespan by establishing differences in self-harm behaviours that younger adults and older adults used. All the people in the study had high degrees of "Emotionally unstable personality traits"; which are the type of personality traits that may be relevant for a diagnosis of EUPD/BPD. We also wanted to see whether younger and older people used different thinking strategies to manage these difficult emotions - and whether these different thinking strategies changed the way they self-harmed. 18 younger and 18 older participants took part. They completed two questionnaires for the study. These were the Self-Harm Inventory and Cognitive Emotional Regulation Questionnaire. We found that younger adults were more likely to self-harm by physically hurting themselves, compared to older people. Both younger and older people self-harmed by "self-neglecting" methods, such as not taking their medication as they should, or starving themselves. Their thinking skills to manage emotions were not related to their age group or their self-harm behaviours. From this, we suggested that non-violent self-harm is common for both younger and older people who may fulfill the criteria for EUPD/BPD. When older people self-harm, it might be less obvious. Health professionals, such as doctors, nurses, and psychologists, might not realise they are self-harming. We suggest that health professionals should keep in mind that self-harm can be lots of different types of things, and think about this when asking questions about self-harm.

Has the registry been updated to include summary results?

No

If no – why not?

Study not on a registry.

Did you follow your dissemination plan submitted in the IRAS application form (Q A51)?

Pending

If pending, date when dissemination is expected

2024-07-31

Have participants been informed of the results of the study?

No

If no, explain why they haven't

And identifying participant information has been deleted as part of the study protocol. It is not possible to notify them directly. In the debrief sheet, we advised that they could contact the researcher if they wanted information on the study results or they could ask the mental health professional who referred them. The outcome of the research will be shared with these mental health professionals once the study has passed viva in July 2023.

Have you enabled sharing of study data with others?

No

If no, explain why sharing hasn't been enabled

This is a sensitive group of potentially vulnerable adults. It was indicated on the initial IRAS form that this would not occur, and participants have not consented to this as it was not included on the consent form.

Have you enabled sharing of tissue samples and associated data with others?

No

If no, explain why

We did not collect tissue samples.

TDRP Appendix F: Adapted Self-Harm Inventory Scale (SHI)

Measure adapted from the Self-harm Inventory (Sansone, et al. 1998). Internal consistency of relevant subscales established using Cronbach's alpha; self-violent self-harm (V; α = .776) and self-neglecting self-harm (N; α = .762). O = other, which were not suitable for either hypothesised behaviour type, and not improving the loading on either subscale. The scale was presented to participants in its original format.

Y	N	Do you ever intentionally, or on purpose	Subscale	Self-violent	Self-neglecting
		Overdose	V	.49	.22
		Cut yourself on purpose	V	.86	.03
		Burn yourself on purpose	V	.60	.00
		Hit yourself	V	.48	.08
		Bang your head on purpose	V	.57	-.11
		Abuse Alcohol	V	.62	.12
		Drive recklessly on purpose	O	.13	.04
		Scratch yourself on purpose	V	.58	.06
		Prevent wounds from healing	N	-.23	.45

Make medical situations worse, on purpose (e.g., skipped medication)	N	.10	.62
Been promiscuous	O	.02	.00
Set yourself up in a relationship to be rejected	O	-.09	.05
Abused prescription medication	N	.32	.64
Distanced yourself from God as punishment	O	.01	.02
Engaged in emotionally abusive relationships	O	.16	.00
Lost a job on purpose	O	.21	.07
Attempted suicide	O	-	-
Exercised an injury on purpose	N	-.19	.44
Tortured yourself with self-defeating thoughts	O	.20	-.13

Starved yourself to hurt yourself	N	.36	.53
Abused laxatives to hurt yourself	N	.00	.41
	α	.776	.762

TDRP Appendix G: Author submission guidelines for the Journal of Personality Disorders

Guidelines are copied from the journal website on 15 May 2023. For the most recent version, please view the guideline here: Instructions to Authors: Journal of Personality Disorders (guilford.com)

Journal of Personality Disorders

Instructions to Authors

Types of Articles

Regular Articles: Reports of original work should not normally exceed 30 pages (typed, double-lined spaces, and with standard margins, including tables, figures, and references). Occasionally, an author may feel that he or she needs to exceed this length (e.g., a report of a series of studies, or a report that would benefit from more extensive technical detail). In these circumstances, an author may submit a lengthier manuscript, but the author should describe the rationale for a submission exceeding 30 pages in the cover letter accompanying the submission. This rationale will be taken into account by the Editors, as part of the review process, in determining if the increased length is justified.

Web-Based Submissions: Manuscripts must be produced electronically using word processing software, double spaced, and submitted along with a cover letter to http://jpd.msubmit.net. Authors may choose blind or non-blind review. Please specify which option you are choosing in your cover letter. If you choose blind review, please prepare the manuscript accordingly (e.g., remove identifying information from the first page of the manuscript, etc.). All articles should be prepared in accordance with the Publication Manual of

the American Psychological Association. They must be preceded by a brief abstract and adhere to APA referencing format.

Tables should be submitted in Excel. Tables formatted in Microsoft Word's Table function are also acceptable. (Tables should not be submitted using tabs, returns, or spaces as formatting tools.)

Figures must be submitted separately as graphic files (in order of preference: tif, eps, jpg, bmp, gif; note that PowerPoint is not acceptable) in the highest possible resolution. Figure caption text should be included in the article's Microsoft Word file. All figures must be readable in black and white.

Permissions: Contributors are responsible for obtaining permission from copyright owners if they use an illustration, table, or lengthy quote (100+ words) that has been published elsewhere. Contributors should write both the publisher and author of such material, requesting nonexclusive world rights in all languages for use in the article and in all future editions of it.

Supplemental Materials: Supplemental materials will run online-only and should be no longer than the manuscript itself. If the material you wish to include is longer than the article, we will instead include a note that all supplemental material can be obtained, by request, from the author. Supplemental materials in the form of tables and figures must comply with the above table and figure instructions for the main article. Remember to include callouts for all figures and tables within the supplemental material. Supplemental material files will be uploaded online as supplied. They will not be checked for accuracy, copyedited, typeset, or proofread.

References: Authors should consult the publication manual of the American Psychological Association for rules on format and style. All research papers submitted to the Journal of Personality Disorders must conform to the ethical standards of the American Psychological

Association. Articles should be written in non-sexist language. Any manuscripts with references that are incorrectly formatted will be returned by the publisher for revision.

Sample References:

Davis, C. G., & McKearney, J. M. (2003). How do people grow from their experience with trauma or loss? Journal of Social & Clinical Psychology, 22(5), 477-492. Dweck, C., & Wortman, C. (1982). Learned helplessness, anxiety, and achievement. In H. Kron & L. Laux (Eds.), Achievement, stress, and anxiety (pp. 93-125). Washington, DC: Hemisphere Publishing Group. Roelofs, J., Meesters, C., Ter Huurne, M., Bamelis, L., & Muris, P. (2006). On the links between attachment style, parental rearing behaviours, and internalizing and externalizing problems in nonclinical children. Journal of Child and Family Studies, 15, 331-344.