Title page

Impacts of Radiotherapy for Gynaecological Cancer on Social, Personal and Sexual Lives: A Qualitative Analysis of Patient Narratives

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Structured abstract

Background: Studies that have gathered patient experiences of radiotherapy for gynaecological cancers have described anguish related to body image, lack of control, social isolation, lack of social support, mystification and self-criticism. Frequently, outward experiences of side effects are presented as 'necessary suffering' hampering opportunities to improve care and support.

Objectives: This project aimed to address gaps in understanding of how radiotherapy impacts on patient bodies and social, personal and sexual lives and to identify priorities for more patient-centred support.

Design: Qualitative narrative study informed by feminist health activism.

Methods: Narratives (written, audio or video recorded journal entries) were collected in the United Kingdom between August 2020 and September 2021. Thirty-four women who had received radiotherapy treatment for cervical, endometrial, vulval or ovarian cancer (up to 25 years previously) submitted written, audio or video recorded accounts. Data were analysed thematically through collaborative, feminist-informed approaches.

Results: The most prominent feature of the narratives related to patients not being listened to or not being heard. Seven principal areas for developing conversations for support were identified which were grouped into four overarching and interlinking themes: *Living Through Treatment and Its Physical Impacts; Shifts in Identity, Sexuality and Intimacy; Navigating Emotional and Psychological Wellbeing; Communication, Dignity and the Practices that Support or Undermine Them*. Physical effects were deeply intertwined with emotional, relational, and identity challenges, and gaps in communication often compounded distress.

Conclusions: Radiotherapy for gynaecological cancer can have enduring and multi-dimensional impacts that are often poorly addressed in current care models. Improving services requires embedding patient voices in care planning, prioritising dignity, and addressing long-term effects through open, ongoing conversations. The findings inform practical recommendations and highlight priorities for future research and policy to embed patient perspectives in radiotherapy services.

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Keywords: Radiotherapy; Gynaecological Cancer; Neoplasm; Narratives; Qualitative Research; Patient Experience; Patient Care.

Introduction

In 2022 approximately 19,000 new diagnoses of gynaecological cancer were recorded in England, accounting for around 12% of all female cancer diagnoses, and approximately 10% of cancer deaths (1,2). Radiotherapy is utilised in approximately 40% of uterine, cervical, vaginal and vulval cancers, with 10 year survival rates ranging from 58% - 71.7% (3). Despite improvements in survival, patients undergoing gynae-radiotherapy face significant physical and psychosocial burdens (4–6). Treatment protocols require strict personal hygiene regimens and preparation (e.g. maintaining a full bladder and empty bowel), which cause considerable stress and inconvenience (7).

Research on patient experiences of radiotherapy for other cancers, such as breast (8) and head and neck (9), has highlighted distress related to body image, feelings of helplessness, social isolation, insufficient social support, unclear communication of risk, and self-criticism. Frequently, these non-therapeutic effects are framed as ‘necessary suffering’ (10,11), which obscures opportunities to understand and improve supportive care.

Quality of life for patients receiving radiotherapy for gynaecological cancers is reported to significantly worsen as patients experience non-therapeutic effects of treatment, improving once transient effects subside (12). However, long-term effects affecting quality of life are reported in approximately 20-50% of patients who have undergone radiotherapy for a gynaecological cancer (13). These include psychosocial and physical symptoms such as depression, anxiety, fear of dying, fatigue, symptoms of the urinary and gastrointestinal tract (pain, bladder dysfunction and irritation, inflammation of the rectum), lymphoedema, narrowing of the vaginal opening, weakening of the vaginal walls, infertility, and premature menopause (4–6,14). Persistent gastrointestinal and pelvic symptoms lasting three months or more is described as pelvic radiation disease (PRD), a condition whose incidence is rising in line with increasing numbers of pelvic cancer patients being diagnosed and successfully treated (15). Yet, the lack of robust measurement tools and patient reported outcome data hampers accurate quantification of PRD prevalence and impact (16).

Fatigue, reported by 60-90% of cancer patients during treatment and persisting in 30% for months after, is especially prevalent in those treated for wards cervical and ovarian cancers (12,17,18). This distressing symptom interferes with an individual's ability to carry out daily activities (17), negatively affecting mood and quality of life (18) and it can lead to anxiety and depression (12). During radiotherapy treatment, the skin on the genitals and pelvic region can appear and feel burned (with dry and moist desquamation) for more than six months following treatment. Beyond physiological effects, research indicates that treatment also considerably affects sexual health, body image, gender role performance (femininity), sexual function and fertility (19).

While technological advances in radiotherapy have rapidly improved precision and efficacy, supportive care addressing physiological and psychological consequences has not kept pace (20). This technical emphasis often sidelines patient voices, minimising attention to lived experiences and concerns relating to sexual wellbeing, mental health and overall quality of life (14). Furthermore, reductions in the time and settings available for supportive care hinder meaningful dialogue, often limiting discussions to more generalised medical terms that fail to capture patients' sexual interests and preferences (21).

Experiences of care are influenced by complex intersectional factors including age, race and ethnicity, dis/ability, gender and sexuality. In part due to the technological drive in radiotherapy, patient voices have been silenced in favour of technoscientific knowledge reflective of the medical and clinical gaze (20,22–25). The paucity of resources and knowledge about non-therapeutic effects restricts patients from being able to make sense of and respond to their experiences (26) and negatively affects the quality of interactions between radiotherapy staff and their patients (27). Embedded in dominant 'cure agendas', a techno-scientific gaze often fails to fully address patient care needs of individuals living with life-changing treatment effects (28). Structural gaps in understanding difference of experience and reaction to radiation treatment leads to paucity of care for many (29).

Although a significant amount of research exists on patients' experiences of cancer broadly, much of this work does not specifically address the unique demands of radiotherapy. Research which positions living with and beyond cancer as a form of 'biographical disruption' (30,31); as 'existential' crisis (32,33); as stigmatising (34–36); marginalising (37); as a 'suffering' (10,38) has tended to focus on chemotherapy burdens or diagnostic impacts. Whilst prehabilitation interventions to address multifaceted challenges faced by those undergoing gynaecological radiotherapy (39,40), significant gaps remain in understanding lived experiences of communication, emotional wellbeing, intimacy, and social support (40), areas explored in the present study.

Recent research on brachytherapy highlights wide variation in patient experiences, from minimal discomfort to severe pain, psychological distress, and prolonged aftereffects, often linked to treatment duration, applicator type, and care quality (41). Related work on chronic bowel symptoms after pelvic radiotherapy demonstrates similar patterns: participants reported loss of control, embarrassment, anxiety, and social withdrawal, leading to impacts on intimacy, work, and broader quality of life (42). Our study differs by adopting a feminist, narrative approach**,** centring patient voices to explore how gynaecological radiotherapy intersects with identity, agency, and everyday life. This perspective provides a foundation for activist research that demands transformation of the policies, practices, and cultural attitudes that limit patient wellbeing**.**

Feminist approaches to health have argued that silences and lack of understanding of diversity of experience are created because a patriarchal biomedical approach dominates care practices (43–45). Feminist approaches hence focus on collating and sharing embodied experiences of health and illness and adopt a holistic approach that attends to social and emotional aspects of health and illness alongside biological. The aim is to validate diversity of experiences and to empower patients to draw upon their embodied experience as valuable knowledge. This project adopts such a transformative lens to critically engage with radiotherapy practices and assumptions regarding patients' priorities, needs and experiences.

Feminist work on breast cancer has critiqued the lack of understanding of patient experiences (46), the relentless focus on positivity, and the 'pinkification' of the disease that silences suffering (47,48); alongside issues of commercialisation, care resources, environmental causes and overly invasive treatments (48–50). In contrast, gynaecological cancers have received comparatively less attention. Consequently, the (very different) experiences related to diagnosis and treatment of a gynaecological cancer remain poorly understood, partly due to cultural taboos around talking about sexual organs and sexuality (51–53). The breast cancer literature provides a vital historical and feminist framework for understanding these disparities and the need for greater attention to gynae-specific issues.

This study addresses that gap by exploring how radiotherapy impacts on social, personal and sexual lives. It gathered narratives of radiotherapy encounters, creating opportunities for patients to share their lived, real-time experiences, revealing the emotional depths, complexities and subtleties of illness and treatment that are often silenced, ignored, or 'othered' in decision-making processes. By focussing on these affective forces, the study highlights what truly matters to patients, centring their values and meanings in navigating life with cancer, and care (54).

Personal narratives uniquely 'illustrate and illuminate' the complexities of embodied (55)and transient experiences (55), through emphatic witnessing (56) of voices that are traditionally silenced or overlooked. By weaving together biographical threads such as resilience, forbearance and humour, the narrative approach affords the 'assembly of life episodes' (57). Widely used in chronic illness research (58–60), narrative approaches have been effective in transforming private suffering into public awareness and shifting policy (61). To our knowledge, no previous study has collected patient narrative accounts of radiotherapy for gynaecological cancer. This project harnesses storytelling as a powerful form of activism, challenging existing norms and advocating for more patient-centred supportive care.

Methods

Following participatory research method traditions, a workshop was held at the start of the project to co-create a research protocol that was acceptable, relevant, and inclusive (62). Attendees (n=13) at the workshop included people with lived experience of cancer (n=2), third sector organisations including LGBTQI+ support officer from a cancer charity (n=3), radiotherapy and research practitioners (n=4), and members of the research team (n=4). One of the people with lived experience of cancer had lived experience of gynaecological cancer. As a result of the co-creation event the timing, project requirements and support materials needed were developed. Further details of the workshop are included in Appendix 1. This co-design process shaped not only the study protocol but also the recruitment materials, consent process, participant guide and flexible narrative collection methods, ensuring that participants could contribute in ways that felt safe and accessible to them.

Two recruitment routes were used to gather two data sets: (1) contemporaneous narratives during radiotherapy treatment and (2) reflections on experiences of radiotherapy treatment. These are explained in detail in turn. The rationale for collecting two data sets was that recruitment for the contemporaneous study was significantly disrupted by the suspension of research activity in secondary care during the COVID-19 pandemic. To address this, a second, online project was developed to capture retrospective reflections from a wider pool of participants.

(1) Contemporaneous narratives during radiotherapy treatment (Contemporaneous Project)

The contemporaneous study was undertaken in a large National Health Service (NHS) tertiary cancer centre in the North West of England, providing on-site radiotherapy and specialist gynaecological oncology services to a population of 2.4million. Patients were identified from the hospital medical systems by the Clinical Effectiveness Team (CET) on a weekly basis. Personal information screened for included: name, date of birth, contact details, cancer diagnosis, and whether they were scheduled to receive radiotherapy treatment. The CET highlighted potential participants to a research radiographer and lead research nurse. Potentially eligible participants were first approached by the lead research nurse/research radiographer who discussed the study with them and offered them the Participant Information Sheets. At this time, patients could choose to consent to take part in the study or they may opt to take more time to consider participation and consent at a later stage. For reasons of participant confidentiality, the name of the hospital is not disclosed.

Once a patient provided written consent to take part in the study, the patient contact details, and demographic information was shared with the research team at Lancaster University. Following consent, a researcher from the University contacted participants to follow up and provide further information about participation in the study, including sending a participant guide (included in supplementary materials).

Recruitment was aimed at individuals referred for radical or palliative radiotherapy for any gynaecological cancer representing a range of experiences.

Recruitment was set to continue until at least one journal entry had been collected from 30 patients. However, due to the suspension of research studies at the hospital site during the COVID-19 pandemic, the period for recruitment was limited. A second, online project was developed that recruited patients who had treatment for radiotherapy at any point in the past, from any radiotherapy centre in the UK.

Inclusion Criteria:

- Diagnosis of gynaecological cancer
- Scheduled to receive radiotherapy treatment for gynaecological cancer (including brachytherapy, adjuvant and neo-adjuvant chemotherapy)
- Capacity to independently consent to involvement in the study
- Able to demonstrate understanding and respond to verbal and written material in English

Exclusion Criteria:

- Under 18 years of age
- Unable to communicate in spoken and written English

(2) Reflections on experiences of radiotherapy treatment (Online Project)

Participants were recruited to the online project through advertising on social media sites and via various cancer charities. Potential participants were asked to contact the research team by phone or email, following which they were provided with a digital participant information sheet and digital consent form provided online. To register to take part in the study, participants were required to complete the consent form, at which point, a researcher from Lancaster University contacted them by phone/email to provide further information about participation in the study. A participant guide was also emailed to participants following consent.

The number of journal entries submitted differed for each patient, based on individuals' experiences, and covered the period from start of radiotherapy to 25 years post treatment. No upper limit was set for time since treatment, as the study aimed to capture diverse experiential accounts of gynae-radiotherapy rather than generate temporally bounded or statistically transferable findings. Some patients who consented did not submit a journal entry. If a patient did not submit a journal entry within the first two months of taking part in the study, a reminder was sent. If there was no response to the reminder, the patient was removed from the study. A safeguarding check of all narratives was performed by the research team and, should a concern have been identified, the patient's nominated clinician (provided at consent) would have been contacted. No concerns were identified.

<u>Inclusion Criteria:</u>

- Diagnosis of gynaecological cancer
- Had received radiotherapy treatment, for gynaecological cancer in the United Kingdom (including brachytherapy, adjuvant and neo-adjuvant chemotherapy) or cared for someone who had received radiotherapy
- Capacity to independently consent to involvement in the study
- Able to demonstrate understanding and respond to verbal and written material in English

<u>Exclusion Criteria:</u>

- Under 18 years of age
- Unable to communicate in spoken and written English

Ethical approval for the contemporaneous project was granted by the East of Scotland Research Ethics Committee (20/ES/0008). Approval for the online project was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC19086). Both studies aimed to recruit patients until 30 narratives for each were received, however we anticipated that the contemporaneous study would not reach that number due to COVID-19 pandemic disruption. No formal statistical sampling frame was applied; the focus was on including a wide range of lived experiences of gynae-radiotherapy, regardless of time since treatment, to ensure diversity of perspectives rather than statistical representativeness.

The study was conducted between May 2019 and September 2022. The start date refers to the commencement of protocol development, and the end date marks the completion of data analysis. Participant recruitment took place between August 2020 and September 2021. 35 participants were consented for the contemporaneous project and narratives were received from 16 participants (one participant did not submit a demographics form). There were 18 participants for the online project, restricted by the time frame available to complete the project. While our approach was narrative rather than semi-structured interviewing, our achieved numbers are consistent with published guidance suggesting that 9–17 qualitative interviews are often sufficient for thematic saturation (63). We attempted to recruit carers for the on-line project but, although some showed interest, no carers consented to take part and are therefore not included in the dataset.

All journal entries submitted for the study were made anonymous by removing any direct identifiers and using pseudonyms.

Participants were able to select a correspondence method from handwritten entries, voice or video recordings and electronic journal methods, switching between recording approaches if they chose to. For voice recordings, participants were provided with an encrypted digital recording device, which they sent to the team at the end of the study. Video recordings were password protected and sent via email.

Participants were asked to contribute narrative accounts on topics important to them in as many narrative entries as they wished. Participants were asked to provide a short “about me” section to identify whether they are a patient, carer or significant other and to contextualise their accounts in terms of diagnosis and treatment and time since treatment. From that point, content was solely directed by participants and, in line with previous research, the form, length and content varied (64).

Analysis

Consistent with the feminist and participatory ethos of the study, analysis was conducted collaboratively to ensure that multiple perspectives, including those of a patient researcher, informed interpretation. To reduce bias in analysis, all narratives were collaboratively analysed by members of the multidisciplinary research team, which included sociologists (LAA, HS, VS, MK-F), Radiotherapy Practitioners (DH, LS, LAA), and a Patient Researcher recruited from the initial methods workshop (CS). Video and audio narratives were transcribed verbatim prior to analysis.

The processes was guided by an analytical frame developed from the study aims and research questions, and was used to explore:

- Practical, physical, emotional and social demands placed upon those receiving gynae-radiotherapy treatment;
- Impacts on carers and significant others;
- When, how and why difficulties arise for patients;
- How demographic, cultural, and social factors shape experiences;

- How individuals mobilise official and interpersonal resources to cope with treatment;
- The priority concerns and/or anxieties of patients and their significant others.

Analysis combined a primarily deductive approach, directed by this framework, with flexibility to identify new or unanticipated themes emerging from the narratives. This included adopting abductive insight, in which instances that disrupted expectations or appeared surprising were actively explored to generate new insights and deepen interpretation. This hybrid approach ensured that the findings addressed the study objectives while remaining responsive to participants' lived experiences. Initial coding categories were derived from the analytical frame, but were iteratively expanded, refined, and reorganised as new patterns and meanings were identified within the data.

All transcripts were read in full by at least two team members. Coding was conducted collaboratively rather than by independent double coding of all transcripts; pairs or small groups of researchers worked together to code each transcript in detail. Throughout the analysis phase, the research team held regular meetings to compare interpretations, resolve discrepancies, refine codes, and develop thematic categories**.** These discussions formed a process of reflexive analytical dialogue, where differences in interpretation were explored, in line with qualitative approaches that prioritise depth and meaning over inter-coder reliability metrics. This iterative process, illustrated in Figure 1, involved continual movement between coded data, the analytical frame, and original narratives to preserve the richness and context of participants' experiences.

The findings were subsequently collated into a free to access book with seven (short) sections, each led by a different member of the research team, including co-author and patient researcher (CS) (65)[1]. Content was developed through a collaborative writing process, including a week-long writing sprint to work together on developing the book content and generate key recommendations. This approach ensured that recommendations reflected both the research evidence and the experiential expertise within the team. The project's steering group, comprising clinicians and researchers, reviewed the draft recommendations prior to finalisation, reinforcing the applicability of the findings for practice, policy and advocacy.

The reporting of this study conforms to the Standards for Reporting Qualitative Research (SRQR) checklist ensuring comprehensive and transparent qualitative research reporting (66).

Results

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[1] The book is available to order from https://lancasteruk.estore.flywire.com/products/we-need-to-talk-aboutradiotherapy-for-gynaecological-cancer-303838

The contemporaneous study collected 45 narratives from 16 women who were invited to submitted narratives from the start of their treatment and up to six months after ending treatment. The online, study collected a total of 33 narratives from 18 participants. All participants had received treatment radiotherapy for a gynaecological cancer. The median number of narratives submitted was one and the maximum submitted for one participant was five, as some participants chose to write their narratives over several weeks. One participant submitted their narrative as a video and a verbatim transcription was made. One narrative was submitted as an audio recording and all other narratives were submitted as electronic text. Participants had all received radiotherapy for gynaecological cancer up to 25 years previous. Table 1 shows the demographic details of participants. Given participants identification as women, they are referred to as such in the following results section, however it is recognised that not all people who receive treatment for gynaecological cancers identify as women.

Analysis identified seven principal areas for developing conversations for support, consolidated into four overarching, interconnected themes for this paper: *Living Through Treatment and Its Physical Impacts; Shifts in Identity, Sexuality and Intimacy; Navigating Emotional and Psychological Wellbeing; Communication, Dignity and the Practices that Support or Undermine Them*. Participant quotes illustrating each theme are presented in Table 2.

(1) Living Through Treatment and Its Physical Impacts

The narratives describe many and varied demands of treatment, including emotional, physical, and social challenges. Anxiety was common, for example, prior to hospital appointments, about the treatment itself, about getting to and from the hospital (including parking), and about family and work commitments. Many women described normalising or enduring pain and discomfort, reflecting a culture of resilience in the face of treatment. Reflecting on her treatment, one woman described feeling obliged to, “just get on with it,” while another rationalised her pain through comparison to experiences of pre-existing health conditions.

Many women sought support, but when they did, they reported that professionals’ used generic phrases, such as “it will get worse before it gets better”. These phrases or clichés did not fully address their needs or concerns nor reflect the evolving situation. Some women felt professionals selected a phrase from a ‘library’ of responses to encourage them to persevere, rather than providing person-centred, tailored support. This led some women to feel that they had not been heard.

Although the physical side effects of radiotherapy are well-documented in clinical literature, the experience of late effects often came as a shock, and women were surprised by their persistence and intensity. Changes to bladder and bowel continence, including leaks and urgency, disrupted expectations of life post treatment and had tangible psychosocial consequences, including limitations at work, social isolation, and reduced self-esteem. Many spoke about the lack of recognition for their bowel and bladder issues amongst professionals, the upset it caused to family and friends, and the embarrassment and humiliation they experienced. They planned their days to ensure they were close to toilets, carried spare underwear, panty-liners, and water for washing, avoiding public transport, and feeling extremely isolated. Some women had felt obliged to return to work before they were ready, due to lack of support and understanding from employers, and due to their financial situation. Some women described the difficulty of having conversations with employers after treatment, requiring repeated conversations about needs such as being near a toilet, having to discuss intimate subjects with managers multiple times because messages were not passed on or needs unaccommodated. One participant was relieved to work from home, where she could move freely and avoid a car commute.

The women's narratives show that the consequences of cancer treatment can be permanent and impact many areas of life. This came as a shock to many of the women, as they had expected that finishing treatment and recovering would mean moving on. Most follow-up appointments end five years after treatment, often before late effects start. This means that late effects are rarely linked to radiotherapy, and women are treated by various separate professionals. As a result, women reported feeling as if they are each unique in their suffering and have nowhere to turn for validation.

Some radiotherapy treatments for gynaecological cancer (especially brachytherapy) can cause vaginal narrowing, while surgery can shorten vaginal length. Many women described being told to use dilators after treatment. Several women said that dilator use was explained in terms of enabling future medical examinations. They felt this clinical perspective ignored their relationship with their own body and sexual self, both physically and emotionally. Women described feeling less feminine; that their vaginas had been medicalised and problematised, and some felt embarrassed. Using the dilators was "far from comfortable," sometimes painful, and that they could not use the larger dilators. Nevertheless, most used them despite discomfort and pain to maintain their sexual selves. These physical impacts often cascaded into changes in women's identities, sexual selves, and intimate relationships, which are explored in the next theme.

(2) Shifts in Identity, Sexuality and Intimacy

Several of the women described disruptions to identity and how treatment changed how they saw themselves. One woman described how her humorous self conflicted with the seriousness of her cancer diagnosis, and how her treatment conflicted with her identity as a professional. Others described how being viewed as a “patient” was disruptive. The women’s narratives showed that these disruptions can lead to feelings of guilt and anger alongside gratitude at both being able to have treatment, and to family and friends for their support.

Making sense of these conflicting emotions was not straightforward for patients or their family and friends. Many women described changes in relationships following diagnosis and treatment: some grew stronger, while others struggled. Women reflected that family and friends sometimes found it hard to respond appropriately. While wanting to show care, their expressed concerns could have the opposite effect. For some, being able to work and having supportive managers and colleagues significantly impacted their experiences. Many women described how life continues alongside the disruptions. They often tried to hold on to some kind of normality while also experiencing chaos of treatment and life after treatment. One woman described how difficult the daily commute and work routines were, and that emotional expressions of concern were disruptive for herself and others.

The women’s experiences of their sexual self during and after treatment were diverse, including not being sexually active, masturbation, relationships with others and with their own bodies, the loss of vaginal sex and development of new intimacies, and gaps in care. Many women wanted acknowledgment of their sexual selves, having found treatment “life changing in more ways than one.” Some women described loss of self-confidence, feeling unattractive and “un-sexy.” Some felt alienated from their bodies, experiencing loss of control and choice about their sexual self, resulting from diagnosis, treatment, or premature menopause. For one participant, treatment induced infertility made her feel like her body did not belong to them, negatively impacting intimacy with her boyfriend and their relationship. Other women described putting their sex life on hold and sex lives being “switched off” due to skin damage. However, some women found pleasure in alternatives to vaginal sex and their relationships changed in some positive ways, becoming closer through supporting each other.

Pain, and fear of pain, prevented some women from having a sexual self. For some women and their partners, thoughts of sex promoted thoughts of cancer. Many wanted a sexual self and some felt guilty for it. When they were able to have sex, some felt fulfilled. The commonly used language of ‘vaginal vault’ and ‘stump’ made some women feel alienated from their bodies and caused a sense of loss of intimacy and control over their own body. Some women reflected on the lack of communication and acknowledgment treatment’s impact on sexual lives and sexual pleasure. Others described the lack of opportunities to talk to their clinical team about sexual wellbeing resulting in feelings that they did not have the right to speak about, or do anything about, their sexual selves. Women described seeking advice elsewhere, due to the perceived embarrassment of the clinical team they concluded that the medical team should not be expected to offer any guidance about sex and a sexual self, even though this had been affected by her treatment. One woman suggested the need for guides to having sex whilst having cancer treatment, noting most booklets focus on signs that you may have cancer, or sex after treatment. Disruptions to identity and intimacy often intersected with emotional wellbeing, sometimes amplifying distress or shaping coping strategies, as discussed in the next theme.

(3) Navigating Emotional and Psychological Wellbeing

Many women described fear and worry as a part of having treatment. For some women, these feelings eased, while for others they lingered for months or years after ending treatment. Women had different emotional responses to treatment and varied ways of living with the treatment in the short and long term. Their narratives show that what is right for one person was not necessarily right for another, and what works now may not work later. Many of the women highlighted that having conversations about mental health is important, not only with healthcare professionals, but also with family and friends. Though family and friends may struggle to fully understand, these conversations helped them feel understood and supported.

Many of the women had felt obliged to be “strong” and “just put up with it,” which was difficult for mental health. They described feeling angry that life would never be the same again and frustration that others did not understand that the treatment being "over" did not mean everything was back to normal.

Some narratives disclosed feelings of trauma, including both explicit and implicit comparisons between brachytherapy and rape or sexual trauma. The distress of the women in these narratives was clearly articulated and whilst these may not be universal experiences of radiotherapy, their narratives provide opportunities to reflect on how radiotherapy could become ‘trauma informed.’ One woman, who had an oncology nursing background, wrote very strongly on the adaptations that could be made to brachytherapy to reduce feelings of vulnerability describing the experience of brachytherapy as being “impaled on a radioactive dildo”. After treatment completed, she reported feeling very emotional, tearful, and shaken by her experience, and that she would have welcomed a follow up chat from staff to check on her emotional wellbeing. Unfortunately, she reported that staff were only concerned with treatment side effects. While awareness of brachytherapy’s potential trauma exists, knowing how to prepare and respond to these patients requires further work. How these emotional and psychological experiences were acknowledged—or overlooked—by professionals was closely tied to communication, dignity, and support systems, explored in the final theme.

(4) Communication, Dignity and Practices That Support or Undermine Them

Some women expressed dissatisfaction with the consent process. Their narratives suggested that fully informed consent requires ongoing conversations that consider individual priorities, including the weight individuals may attach to different outcomes, and how that may change when considering the permanency of late effects.

The women's narratives revealed subtle lapses in care that undermined dignity, a fundamental human right. The Radiographers' Code of Conduct and Ethics stresses respecting individual dignity, to prevent behaviour that causes physical, emotional, or psychological distress or damage to anyone. Yet women regularly described micro-infringements of their dignity, ranging from forgetful moments, mundane practices, intentional and unintentional incidents. Such lapses are sometimes presented as inevitable or embedded into structures and routines of care. As a nurse, one participant reflected on her own experience of giving care. She talked of a lack of control after brachytherapy and said that "small things" could have been done to support her. Women often presented neglect of "small things" such as their warmth, comfort, adequate covering of their body, that represent micro-infringements that cumulatively impacted their sense of dignity.

Within their experience of chaos and unpredictability of treatment, women described how their bodies were managed industrially or 'processed'. Women described feeling like they were on a conveyor belt, where service efficiency overshadowed individual experience. This industrial approach masked systemic problems, such as appointment times and transport, and hindered open discussion about issues such as dealing with treatment effects or changes in sexual wellbeing. Women also reported a lack of control over appointment changes or treatment delays, which threatened plans and routines and led to feelings of disrespect. Despite the challenges, women talked about activities they did to maintain some control: healthy eating, exercise, breathing, relaxation, and afternoon snoozes. These wellbeing promoting techniques are often recommended and many of the women described how helpful they were.

Communication played a crucial role in experiences of dignity and control. The women's experiences emphasised that getting the right information, at the right time, in the right way, influenced how information is processed and responded to. Many women first received NHS or Macmillan leaflets, which some found helpful, while others felt they were too general and did not meet their needs. Leaflets were sometimes given in response to questions deemed irrelevant by clinical staff, or considered to fall outside of treatment appointments, leaving gaps in information that caused anxiety and a sense of being uninformed. However, an issue that spanned many narratives was how much information was the ‘right’ amount. Some thought it was better not to know, while others wished for more accurate information. Many women also felt they were not “taking it all in” and potentially blamed themselves for not processing what they had been told. There was a difference between knowing about radiotherapy and acute/late effects abstractly and believing they would personally develop them.

Many women reported poor communication about concerns, harming trust between patients and practitioners. Some were told not to worry, or felt their concerns were dismissed and described an absence of empathetic and sincere communication and compassion in clinical encounters. Well-meaning loved ones and practitioners sometimes downplayed worries with phrases like “be brave” or “grin and bear it.” These phrases, though well-meaning, could stifle communication and dismiss significant feelings and experiences. One women suspected she had insufficiency fractures, but these were initially dismissed as these were not visible on an X-ray. She also described suffering bladder and bowel inflammation and incontinence, her consultant responded dismissively, “You can always wear incontinence pads, can’t you? Well, you’ve had radiotherapy, what do you expect??” Such dismissals undermined trust and confidence in clinical teams. Overall, these narratives highlight that dignity, control, and effective communication are closely connected. Structural pressures and routine care practices sometimes challenged women’s autonomy and sense of self, but women’s strategies to maintain control demonstrate their resilience and the importance of person-centred, empathetic communication.

From Findings to Action

The accounts point to systemic gaps in communication, respect, and recognition of patients’ lived realities. Responding to them demands clear, patient-driven commitments. Drawing directly from participants’ accounts, these commitments were distilled into the “Manifesto for Change,” printed on the back cover of the project book. The manifesto sets out practical, values-based demands to guide radiotherapy services and ensure the best possible experience for all.

1. Practice radiotherapy as an on-going conversation between patients and practitioners. Solicit and invite patients’ questions: view every question as important and requiring an answer (not just a leaflet).

2. Acknowledge that every patient trajectory is unique: non-linear, emotional, social, intimate and physical. It begins before diagnosis and extends beyond treatment.
3. Prioritise what the patient is feeling and experiencing over the goals of the treatment.
4. Begin every interaction by appreciating that illness and treatment disrupts patients' lives in countless ways.
5. Give space and time for each patient to be upset and feel heard, and value their particular experiences.
6. Demand services that promote and prioritise dignity.
7. Remember that attending to the sexual self is part of caring for and treating gynaecological cancer.
8. Demand acknowledgment of and care for late effects.
9. Avoid language that unnecessarily medicalises parts of the body.
10. Demand equal patient access to all services.
11. Given the disclosures made by participants which were distressing and indicative of trauma, we recommend a consideration of how delivery of radiotherapy services may become trauma-informed.

Discussion

This research sought to explore the multifaceted social, personal, and sexual consequences of gynae-radiotherapy, offering the first detailed patient-narrative account focused specifically on this treatment. By adopting a feminist, narrative approach, the study centred patient voices to understand how radiotherapy intersects with identity, agency, and everyday life, highlighting structural and cultural influences on experience while informing the development of holistic, patient-centred supportive care.

Findings reinforce that, despite advances in radiotherapy technology, patients' experiences of sexual wellbeing, emotional support, and social concerns remain insufficiently addressed. Technical precision has not automatically translated into holistic support, leaving persistent gaps in communication, attention to lived experience, and individualised care. The four identified themes reflect overlapping and mutually influencing dimensions of the radiotherapy experience. Physical impacts shaped identity and emotional wellbeing, while communication influenced experiences of dignity and support. Trauma permeated emotional, physical, and relational domains. For example, bladder incontinence (Theme 1) undermined sexual confidence (Theme 2), contributed to feelings of isolation and low mood (Theme 3), and was often minimised by professionals (Theme 4). This integrated thematic framework provides an understanding of women's lived experiences and highlights areas where systemic, cultural, and policy change is needed to improve holistic, patient-centred care.

The physical, sexual, and psychosocial effects of gynaecological radiotherapy are well documented (14,41,42,67,68), yet the persistence of medicalised descriptions of effects has not engendered a change in practice. Participants in the present study described feeling unsupported, unheard, and unable to address concerns about intimate, emotional, and social impacts of radiotherapy treatment for gynaecological cancer. Participants frequently reported not being listened to or not being heard or their experience was portrayed as ‘necessary suffering,’ or feeling abandoned post-treatment, which chimes with other research findings (10,11,69,70).

Our study extends this literature by showing how ‘enforced positivity’ shapes patient behaviour and the care they receive. Encouragement to adopt positive thinking, including concepts such as “posttraumatic growth” and “teachable moments” (71), can generate pressure for patients to present a publicly positive persona. This was evident in the narratives collected, where women undergoing radiotherapy for gynaecological cancers felt unable to express distress or concerns about intimate and physical impacts of treatment. While well-intentioned, such expectations can minimise suffering and silence distress, as also critiqued historically in breast-cancer literature (47).

Symbolic cancer awareness campaigns, such as coloured ribbons for ovarian, cervical and other cancers, and survivorship narratives, what Segal has termed ‘cancer triumphalism,’ (72) can obscure real distress, reinforce invisibility and normalise care that infringes dignity or ignores lived experience. Cultural pressures have practical effects, silencing negative accounts and encouraging patients to accept pain and suffering, as revealed in the findings of the present study. Such narratives maintain myths that undermine the lived experience of living with and beyond cancer. Accounts of triumph over adversity, ‘making it through’ against the odds and validating achievements, could influence societal expectations of behaviour and set up feelings of inadequacy for those who do not feel as positive, or who are positioned differently in society and face diverse and intersecting external and/or structural demands. Moreover, such accounts can make it difficult for patients to have open conversations, especially conversations that include pain, distress, damage, and long-term effects.

The findings of this study demonstrate the importance of initiating and sustaining meaningful conversations about radiotherapy treatment and its diverse effects. The findings revealed that conversations can be difficult to initiate or are easily closed down and yet many issues could be resolved through careful conversations. A subsequent study by our team further explored these issues, focusing on enhancing practitioners' ability to engage in meaningful conversations about sexual wellness and pleasure with patients undergoing radiotherapy for gynaecological cancers (73), highlighting a pathway to practice improvement.

The move by the UK Royal College of Radiologists to introduce standardised radiotherapy consent forms has ensured the content of consent conversations has been given attention, enabling a move towards standardisation of information provided as part of informed consent (74,75). Yet, focussing consent on completing a medicalised form further highlights the tendency of providers to discuss treatment in medical and generalised terms. Without systemic change to support patient-centred consent and shared decision-making, completing the form may take precedence over the small, meaningful conversations, further drowning out concerns that matter most to patients.

Reflexivity and Researcher Positionality

The study was informed by a feminist epistemological approach that recognises knowledge as situated and shaped by researchers' social, professional, and embodied positions. Several members of the team had personal or professional experience of cancer care. The patient researcher (CS), who had lived experience of gynaecological cancer and radiotherapy, contributed throughout the study, including the co-design workshop, development of study materials, data interpretation, and refinement of themes. Her experiential knowledge was central in ensuring that the analysis remained grounded in patient priorities and in identifying issues that may otherwise have been overlooked, particularly around late effects, sexuality, and everyday impacts of treatment.

Clinical members of the team reflected on how engagement with the narratives challenged taken-for-granted practices within radiotherapy, including the use of standardised language, time-pressured interactions, and limited discussion of sexual wellbeing. This prompted critical reflection on their own professional roles and assumptions, particularly where care practices may unintentionally silence or minimise patient experiences.

Researchers from social science backgrounds brought a feminist and critical lens to the analysis, attending to issues of power, voice, and the marginalisation of embodied knowledge within biomedical contexts. For some team members, personal experiences of cancer (albeit different diagnoses) shaped empathetic engagement with the data, while also requiring reflexive awareness to avoid over-identification with participants' accounts.

Reflexivity was embedded throughout the analytic process via collaborative coding, regular team discussions, and the inclusion of a patient researcher in interpretive decision-making. This iterative approach enabled the team to critically examine how their perspectives shaped data interpretation, while prioritising participants’ narratives as the primary source of insight. Each member of the research team wrote a personal reflection which was included in the co-authored book (65).

Strengths

This study offers one of the most detailed qualitative examinations of the social, personal, and sexual impacts of gynaecological radiotherapy to date. Using a feminist methodological approach, the research was co-produced with stakeholders, including patients, patient representatives, and members of a project steering group, ensuring that the voices of those most affected shaped every stage. Collaboration with clinical teams ensured that the insights generated were not only authentic to lived experience but also directly translatable into actionable changes in practice. This integration of experiential expertise, clinical knowledge, and feminist critique produced findings that go beyond description, providing a foundation for activist research that demands transformation in policies, practices, and systems that affect patient wellbeing, principles that underpin the manifesto for change.

Limitations

The lack of demographic diversity is a clear limitation. Despite targeted outreach through charities specialising in LGBTQI+ cancer experience, all participants identified as white, heterosexual women. Perspectives from sexual minorities, non-binary individuals, ethnically diverse groups and those with varied socioeconomic, disability, and age profiles are therefore absent. This demographic homogeneity is reflected in the limited discussion of sexual pleasure beyond heterosexual experiences, producing silences that are important to acknowledge. Such silences reflect broader politics of research exclusion, connected to the silencing of traumatic or shameful experiences, compounded by intersecting exclusions via ableism, racism and cis-heteronormativity (76–79).

Recruitment was further constrained by the COVID-19 pandemic, which limited face-to-face recruitment opportunities but also intensified barriers for underrepresented groups, many of whom faced heightened health vulnerabilities, digital exclusion, and competing priorities during this period. These factors compounded existing systemic challenges in engaging marginalized populations within health research.

Participants in the on-line study self-selected by contacting the research team, which may mean those with more significant issues were more motivated to participate, potentially shaping the emphasis and intensity of experiences reported. Shifting the study design due to the impacts of COVID-19 enabled more insight into longer term effects of treatment and revealed experiences as remembered by participants. However, the original aim of the research, to gather contemporaneous accounts, was not realised in accounts submitted as part of the second study. The temporal heterogeneity adds strength to the data set showing how participants reflect on their experiences of treatment. Their recall of treatment provides important considerations for consent and experiences of care. In the context of this study, how people look back on treatment became more important than how accurate their retelling of care was. We did not specifically examine whether time since treatment influenced the nature or frequency of concerns raised, as the study was not designed or powered to make such comparisons. While some participants reflected on changes in their experiences over time, these were not analysed systematically.

Narratives were submitted in multiple formats (written, audio, and video), which may have influenced the depth, style, and content of accounts, although all were transcribed and analysed consistently. The use of multiple data collection modalities supported more inclusive participation and enabled participants to express their experiences in ways that suited them.

Future research should adopt more proactive, culturally sensitive, and community-engaged recruitment strategies, including building trusted partnerships with diverse communities and leveraging multiple outreach modalities.

Conclusion

Informed by a feminist approach, the project aimed to increase understanding of how gynae-radiotherapy impacts on social, personal, and sexual lives, and to improve patient experiences of living with the social and personal impacts of radiotherapy. Building on a tradition of feminist health activism, it treated patient experience as a vital form of expertise and reframed care as more than the delivery of treatment, something to be shaped, questioned, and improved through active participation in service design and decision making. Through the collection of patient narratives, it was found that radiotherapy creates often silenced burdens on patients. In taking a feminist approach to understanding experience, the study attended to social and emotional aspects of gynae-radiotherapy alongside biological. The project findings were not wholly positive, and it was important to reject the pressure to cleanse and downplay the distress of treatment for a gynaecological cancer when presenting the narratives. Playing down private suffering and presenting a positive public image, often to protect loved ones and not alienate support or jeopardise care, ignores the lived realities of cancer. This act of ‘censoring accounts’ is done to prioritise other people’s comfort and can create a burden of emotional work for a cancer patient.

The study demonstrates the importance of embedding patient voices and experiential knowledge into the design and delivery of radiotherapy services. For research, it highlights the need for inclusive studies exploring the intersection of gynaecological cancer, sexuality, and emotional wellbeing, with a focus on underrepresented groups. For policy, the findings support integrating trauma-informed, dignity-centred care principles into national radiotherapy guidelines and commissioning frameworks. For practice, the Manifesto for Change offers a patient-driven agenda that can be used to train staff, inform service development, and guide meaningful conversations with patients before, during, and after treatment. By translating lived experience into actionable recommendations, the project exemplifies how patient-led insights can create an agenda for transformative change across practice and policy.

List of Abbreviations

CET	Clinical Effectiveness Team

Statements and Declarations

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We are extremely grateful to all the women who shared their experiences with us. Our fundamental concern has been to treat these narratives with respect and care, ensuring we learn from them to improve care practices and experiences of those undergoing radiotherapy for a gynaecological cancer.

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Author Contributions

This study was designed by LA, VS, HS, MKF, DH and CS. MKF and LS were responsible for participant recruitment for the contemporaneous study. HS was responsible for participant recruitment for the on-line study. Data analysis was carried out by all authors. LA wrote the first draft of the manuscript, VS, HS, MKF, DH, and CS contributed sections and provided comments. VS, HS, MKF, DH, LS and CS approved the final manuscript.

Ethics Approval and consent to participate

This study was performed in accordance with the Declaration of Helsinki and approved by the East of Scotland Research Ethics Committee (20/ES/0008) and Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC19086).

Written informed consent was obtained from all the subjects involved in the study.

Consent for Publication

Written informed consent included consent for publication of anonymised data.

Declaration of Conflicting Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Data Availability

The datasets generated and analysed during the current study are not publicly available due potentially identifiable participant and organisation information through the narratives but are available from the corresponding author on reasonable request.

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