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Understanding the Design Space**

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(Re)discovering Sexual Pleasure after Cancer: Understanding the Design Space

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Figure 1: We collaborated with illustrator Jules van Beurden to visually capture the themes of our paper. The header reflects the core of our research, illustrating how post-cancer sexual health care primarily addresses physiological issues. The drawing, showing a person lying in a pool of chemicals (symbolising both cancer treatment and pharmacological approaches to sexual health), highlights the disconnect between the complex nature of the problem (spanning psychological, social, cultural, and physical dimensions) and the narrow focus of current treatments on the physical aspect. Our work advocates for a holistic approach that integrates these broader dimensions into post-cancer sexual health care.

Abstract

Cancer treatments often lead to sexual health challenges that greatly impact cancer survivors' quality of life. Current interventions primarily address physiological aspects, like medication or vaginal care, overlooking psychological, social, and cultural dimensions. This paper explores how HCI can address this gap by supporting post-cancer sexual health with interventions for survivors and their

partners, considering their lived experiences. Through reflexive thematic analysis of interviews with (N=6) medical sexologists, we identified five themes: perceiving the body as a medical object, the hot potato problem in oncology, sociotechnical sexploration, reuniting what treatment has divided, and designing interventions with openness in a highly situated context. These themes highlight cancer survivors' experiences, the (in)effectiveness of current interventions, and provision of care. This research outlines the design space for post-cancer sexual health by providing specific design directions ("what") and ways for designing them ("how"), while advancing the broader discourse on intimacy and design within HCI.



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CCS Concepts

• **Human-centered computing** → **Empirical studies in HCI**.

Keywords

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1 Introduction

As more people recover from cancer due to treatment advances, it becomes increasingly important to focus on the quality of life after treatment. For many survivors, sexual dysfunction caused by treatment is one of the most common and distressing side effects [19, 61]. Sexuality is a fundamental aspect of human life, encompassing psychological, relational, cultural, and physiological factors [20]. Sexual health¹ issues have a wide variety of causes and impacts such as physical complaints (e.g. low desire, difficulty achieving orgasm, pain [8, 91]) altered relational dynamics (e.g. lack of communication [39]), psychological causes (e.g. body image issues [86]) and culture (e.g. equality, religion [106]). Thus, addressing sexual health after cancer requires a comprehensive bio-psycho-social approach [20], where the situatedness of this multifactorial problem is acknowledged. This approach is key because it recognises the complexity of post-cancer sexual health issues, enabling a more holistic understanding and treatment that goes beyond the physiological.

However, current post-cancer sexual health care often lacks the comprehensive approach needed to address the full spectrum of psychological, relational, and cultural dimensions that are integral to sexual health. For men, first-line treatment involves prescribing pills (e.g., Viagra) [89], and if ineffective or unsuitable, penile injections [68]. Pharmacological approaches for women have not been successful, which is why Carter et al. [31] have outlined several strategies for preserving vaginal health in female cancer survivors, such as moisturising and mechanical stretching of vaginal tissue. This narrow focus on the physiological overlooks the psychological, relational, and cultural dimensions which are as much a part of sexual health [20]. This focus reflects an understanding that, while pharmacological treatments may relieve immediate symptoms, they fall short of addressing survivors' complex needs. Healthcare providers may favour pharmacological solutions because they are more time-efficient, and many providers receive minimal training in sexual health and feel uncomfortable addressing these topics [2, 20, 36, 42, 49, 53]. In the Netherlands, the country of study, cancer survivors initially receive first-line sexual health care from nurses and oncologists [37] and may also seek support through patient organisations that facilitate peer connections. In practice,

¹The WHO defines sexual health as: "... a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." [113].

however, specialists often refer survivors with significant sexual health challenges to medical sexologists, the clinical experts in this area. Unfortunately, the limited number of these specialists makes it difficult to provide comprehensive care for all cancer patients and survivors, limiting the scalability of this specialised intervention². Few interventions have been developed to support or expand the reach of medical sexologists, leaving many survivors and their partners without access to the comprehensive care they need. In conclusion, highly personalised interventions often lack scalability, while scalable designs tend to lose the personalisation necessary for effective care.

By adopting insights from the HCI design community, we can help pave the way toward scalable and personalised care, complementing the work of medical sexologists and addressing the current gaps in post-cancer sexual health interventions. Unlike traditional top-down medical approaches, which develop interventions for broad patient cohorts grouped solely on their illness, the design community within HCI advocates for a bottom-up approach [65, 77, 99]. This approach prioritises the lived experiences and can take into account individuals' unique psychological, relational, and cultural contexts, allowing for more tailored and effective interventions.

The context of post-cancer sexual health issues is underexplored in HCI literature, which presents as a gap in our understanding of how+what to design for this context. Without a clear grasp of the design space, we risk developing designs that are uninformed, ineffective, or even harmful. To avoid this, we need an expert-informed outline of the design space and actionable design directions to guide HCI researchers and designers. This leads to our research question: *What are the opportunities for HCI in addressing the sexual health issues of cancer survivors?* To address this gap, we conducted semi-structured interviews with medical sexologists, clinical experts in sexual health with specialised medical training. Their insights, informed by a broad range of survivor experiences, provide a comprehensive view of their challenges and (in)effectiveness of current interventions.

Our contribution is twofold: firstly, our study provides a deeper understanding of the current post-cancer sexual health landscape for HCI. By analysing the insights from medical sexologists using reflexive thematic analysis [22], we identified 5 themes that open new conversational spaces and highlight potential opportunities for interventions. Secondly, this paper offers insights for HCI to design interventions that address the sexual health needs of cancer survivors, both broadly and within the specific context of medical sexologist practice, by contributing actionable design directions on how HCI can enhance sexual health care practices by developing effective interventions.

2 Related Work

This Related Work section reviews HCI's discourse on interventions facilitating sexual experiences, which has traditionally centred on

²We adopted the term "intervention" from the field of medical sexology, aligning with their practice to ensure future designs fit within the existing healthcare context. In this paper, interventions refer to designs that either directly support the practice of medical sexologists or, more broadly, assist cancer survivors and their partners in post-cancer sexual health. These interventions aim to evoke positive change, helping survivors in the transition from a state of distress to one of improved sexual health.

genital-focused technologies like sex toys. We highlight the need for broader interventions that also address the psychological, social, and cultural aspects of these experiences, particularly in the context of post-cancer. We situate the design space we contribute in discourse addressing similar complex and intimate health contexts. We recognise that related topics are often discussed within feminist HCI, which we align with by advocating a holistic, non-dualistic view of the body and sexual pleasure that goes beyond genitals and penetration. However, we recognise that post-cancer sexual health can also be approached from a more medical angle. We therefore envision that the design space we outline exists both within and outside feminist HCI.

2.1 Epistemological commitments: theoretical perspectives on sexual pleasure and illness

Post-cancer sexual health presents complex challenges that extend far beyond physical recovery. Survivors often face significant changes in bodily function and sensation, making it difficult to reconnect with their bodies and reclaim sexual pleasure. Addressing these challenges requires a multidimensional approach that considers not only the physical but also the psychological, relational, and social dimensions of sexual health [19, 20, 61].

The depth of these challenges is poignantly illustrated by Audre Lorde's reflections on her mastectomy after breast cancer. As a Black lesbian feminist, Lorde articulates the emotional and sensory loss she experienced, writing: *"what is it like to be making love to a woman and have only one breast brushing against her? [...] What will it be like making love to me? Will she still find my body delicious?"* She recalls feeling overwhelmed by sadness, saying: *"My right breast represented such an area of feeling and pleasure for me, how could I bear never to feel that again?"* [69]. These reflections highlight the intertwining of physical and emotional dimensions in post-cancer sexual health.

Feminist and crip theories offer valuable frameworks for understanding these experiences by challenging normative assumptions about sexuality, bodily function, and ability. Sex-positive feminist perspectives critique genital-centered, penetrative views of pleasure that reinforce power imbalances and reduce women's sexuality to a passive role [7, 87]. Instead, they advocate for a broader, more inclusive understanding of pleasure that is particularly relevant for survivors facing functional losses, such as dyspareunia or erectile dysfunction. Crip theory complements this by questioning ableist norms that equate pleasure with heterosexuality and conventional bodily functions [62, 74]. Following calls to resist the impulse to "cure, fix, or eliminate disability" [50, 81], we aim to counter the curative and solutionist narratives often seen in sexual health care for cancer survivors. Current medical approaches frequently address sexual health issues through pharmacological solutions, such as Viagra or vaginal care, which focus narrowly on physiological treatment. In contrast, we center the lived experiences of survivors and their partners. This perspective aligns with recent HCI research that foregrounds the experiences of disability, challenging reductive, treatment-focused solutions in favor of holistic, user-centered design [6, 56, 115].

A somatic approach further enriches this understanding by treating the body as a site of lived experience rather than a mere instrument [38, 97]. Trauma, particularly when it involves intimate areas, can disrupt one's sense of bodily coherence [80]. Somatic approaches prioritise reconnecting with the body through awareness and mindfulness, encouraging survivors to explore their physical sensations without judgment [55]. This is especially crucial for individuals whose experiences include physical trauma or dissociation.

By grounding our work in feminist, crip, and soma theories to complement conventional medical approaches, we aim to help survivors reclaim sexual pleasure as a holistic and embodied experience. This approach transcends the physical limitations imposed by illness and treatment, focusing on the importance of connection, acceptance, and exploration in the recovery process.

2.2 HCI's interventions facilitating sexual experiences

For this work, we adopt the definition of sexuality provided by Rathus et al. [85] as *"the way in which we experience and express ourselves as sexual beings"*. Sexuality, a fundamental aspect of human experience, has increasingly gained recognition as a critical area of inquiry within HCI [13, 14, 18, 24]. Scholars highlighted that we need to consider the human body not just as a cognitive and functional entity but as a medium for subjective experiences [88], which includes sexuality [41].

HCI has explored a range of interventions to facilitate sexual experiences, with a significant focus on sex toys [14]—devices designed to stimulate the body and evoke sexual pleasure [41]. These toys, such as vibrators [58, 117], generally focus on providing pleasure by stimulating genitalia.

Beyond sex toys, the discourse has ventured into other forms of intimate technology, including but not limited to sex robots [93, 105], and embodied designs like embroidered textiles aimed at guiding female masturbation [57]. Várhidi and Rauhut [111] contributed an educational game focused on vulva pleasure. While these innovations push the boundaries of technology's role in sexual interaction, much of the literature remains genital-focused, particularly highlighting persons with vulvas.

Recent work has called for a broader, more inclusive perspective on pleasure technologies. For instance, recent work advocates for a shift beyond heteronormative and genital-centric views of sexuality [103], proposing alternative forms of pleasure technologies. Similarly, Campo Woytuk et al. [28] highlight the challenges in designing technologies for the vagina, proposing a reframing of traditional penetration narratives. Drawing on feminist and posthuman perspectives, they introduce the concept of "circclusion," which repositions the vagina as an active participant rather than a passive recipient in interactions with technology.

This growing discourse highlights a critical shift in HCI toward more inclusive, diverse, and holistic approaches to designing for sexual experiences. While existing work has laid important groundwork, our work seeks to extend this space by exploring how HCI can engage with the embodied, relational, and contextual dimensions of sexual health, particularly in underrepresented areas like post-cancer intimacy. By addressing these complexities, we aim to contribute to the development of interventions that are not only

innovative but also deeply attuned to the lived experiences and diverse needs of individuals.

2.3 Designing for post-cancer sexual health

Building on HCI's exploration of sexuality, we turn to the specific challenges of designing for post-cancer sexual health.

Many survivors feel they are in a transitional phase, often describing themselves as *"not quite there yet"* [114], partly due to ongoing monitoring for cancer recurrence [112]. Survivorship involves phases: an initial period focused on reassurance from consistent, clear test results, followed by the restoration of daily routines and mental adjustment [112]. In this return to normalcy, survivors often experience personal transformation, feeling changed by physical and emotional challenges, more present, and grateful for life [34, 114]. Amidst these shifts, they encounter issues that can diminish their sexual health.

To support them in this, current medical care primarily focuses on physical recovery, often prescribing pharmacological solutions like Viagra for men [89] and recommending moisturising and tissue stretching for women [31]. However, these treatments focus narrowly on the physiological, frequently overlooking the psychological, social, and cultural dimensions that are essential to comprehensive sexual health care [15, 17, 20]. This limited scope can leave survivors without support for the broader challenges they face, such as body image concerns [86] and changes in relational dynamics [39]. Expanding the scope of care to include these factors allows interventions to move beyond physiological treatment and support survivors more effectively.

While HCI has explored sexuality through sex toys and intimate technologies, these efforts primarily address the individual's immediate physical experience and rarely engage with survivors' broader psychological and social needs. Additionally, the cultural stigma surrounding sex and sex toys [41, 58] reinforces taboos, discouraging open conversations around sexual recovery.

To support post-cancer sexual health more effectively, intimate technologies could extend beyond the body's functionality to consider psychological, social, and relational dimensions. Approaching sexual health as bodily-rooted yet socially experienced [102], aligns with medical literature advocating for holistic care [23, 27, 66], ensuring interventions support survivors as they rebuild intimacy and pleasure in the wake of treatment.

2.4 New perspectives to designing for complex and intimate health contexts

Beyond sex and toys, HCI has expanded into designing supportive care technologies for complex and intimate health contexts. This section highlights recent HCI work exploring intimate topics through innovative perspectives and approaches. Balaam et al. [12], for example, focus on supportive care technologies for early menstruations [102] and pelvic floor health [100]. Their concept of "intimate touch" challenges the prevailing tendency within the field to reduce the body into abstract data. Instead, using soma design, they create tools that foster new forms of knowledge and intimacy, re-centering the body as a site of lived experience and personal growth. Similarly, Campo Woytuk et al. [29] explore cervical mucus sensing as a method to support fertility tracking, highlighting

the tactile, messy realities of bodily fluids and offering design concepts that encourage users to engage with their bodies in more personal, non-medicalised ways. These contributions exemplify how embodied and interactive technology can challenge societal taboos, supporting self-care by making intimate exploration accessible, educational, and empowering. This reflects a broader trend in HCI, where the design of interventions is increasingly attentive to the material and embodied aspects of intimate health, including but not limited to Almeida et al. [5], Ciolfi Felice et al. [35].

Together, these works illustrate a growing recognition within HCI of the need to design technologies that engage with the body in a holistic manner, fostering intimacy and health in ways that are respectful of individual experiences. Our research builds on this trend by exploring the design space for these technologies in the specific context of post-cancer sexual health.

3 Methodology

This section details the study design, participant recruitment and selection, data collection, and analysis. Additionally, we address ethical considerations and provide a positionality statement.

3.1 Design

To answer our research question, *what are the opportunities for HCI in addressing the sexual health issues of cancer survivors?*, we conducted semi-structured interviews with medical sexologists in the Netherlands. We did this to gather in-depth qualitative data on their thoughts, experiences, and practices. The interviews focused on patient experiences from the medical sexologists' perspectives, core values in their care, and their views on technological interventions. Sexual health issues can arise after any type of cancer [25], which is why we have not limited our focus to a specific cancer type in this study.

Given the sensitive nature of the topic, we interviewed medical sexologists as proxy participants to gain insights into cancer survivors' sexual health experiences. Their extensive training and clinical experience with diverse patients provided a comprehensive understanding of the challenges survivors face, as well as valuable perspectives on the (in)effectiveness of current sexual healthcare interventions. Following Chen et al. [33]'s principles of trauma-informed computing, we adopted proxy participants to explore this sensitive space, minimising the risk of retraumatisation (psychological harm triggered by past trauma) for cancer survivors and their partners. This approach aligns with Chen et al.'s commitment to mitigating technology-related trauma and avoiding unnecessary burdens on vulnerable communities.

While we acknowledge the limitation of not engaging directly with survivors, the depth and breadth of insights provided by medical sexologists offer a unique and rich understanding that aligns closely with the study's objectives. Similar proxy methods have been successfully employed in previous research [4, 92].

3.2 Participants & recruitment

Experts were recruited via purposive sampling through the central organisation (NVVS), which issued a call on a digital bulletin board, and via snowball sampling [82, 108]. Due to the rarity of the profession, the sample size was small (N=6), representing 14% of the

sexologists treating post-cancer sexual health in the Netherlands. This sample size is comparable with HCI studies involving experts in specialised fields, such as oncologists (N=7) [110], demonstrating the feasibility of small samples for eliciting specialised knowledge.

Participants' professional experience ranged from 1–10 years (n=2), 20–30 years (n=2), to 30–40 years (n=2). They worked in various types of hospitals: university hospitals (n=4), a medical center (n=1), and a hospital/research institute (n=1). Their clinics operated under departments such as gynecology/reproductive health, psychological support, or as independent outpatient clinics. Only medical sexologists (professionals with specialised medical training who regularly treat cancer survivors (self-reported)) were included in this study. The participants' diverse professional backgrounds—including healthcare psychology, gynaecology, and psychotherapy, combined with their specialisation as medical sexologists, provided a broad perspective on post-cancer sexual health.

For the remainder of this paper, these six participants will be referred to as P1-P6 (randomly assigned).

3.3 Data collection & analysis

The semi-structured interviews, following an interview guide peer-reviewed by the co-authors and other academics who have extensive experience with this method, focused on three main areas:

- (1) Patient experiences from the sexologists' perspectives
- (2) Core values in sexual healthcare care and how they manifest in medical sexologists' practices
- (3) Views on and use of (technological) interventions, along with ideas for new designs

Interviews lasted 60–90 minutes and were conducted via video conferencing with Microsoft Teams³. Interviews were conducted in Dutch, and later translated, audio-recorded with an external recording device, first transcribed using machine transcription and then manually corrected, and analysed using reflexive thematic analysis [22]. We applied Braun and Clarke [22]'s six-phase approach, adopting a constructionist perspective focusing on underlying patterns. The analysis involved familiarising with the data (first author); generating initial codes (first author); searching for themes (first author); reviewing themes (first, second, fourth author); defining and naming themes (first author); and reporting (first author). In qualitative research, the thickness and richness of data are prioritised, with emphasis on the variety, consistency, and integrity of themes [26]. Data saturation, defined by Fusch and Ness [44] as the point at which no new data or themes emerge, was achieved in this study. Themes consistently surfaced across interviews, offering a nuanced and comprehensive understanding of the object of study.

In the final stage of analysis (Step 5: defining and naming themes), we collaborated with a visual artist (third author) to communicate the highly experiential themes through an additional modality. The first author discussed each theme's meaning with the artist, who interpreted them into drawings that complement the written themes. Given the sensitive and experiential nature of the topic, we felt that words alone were insufficient to fully convey certain themes. The visual representations materialise the findings, providing a more nuanced and emotionally resonant understanding for the reader.

Data familiarisation involved four steps: listening to the interviews, transcribing them, reviewing the transcripts, and conducting an initial reading. The transcripts, created verbatim, served as the primary data source for subsequent research steps. Initial coding was done in two rounds. The first author coded all transcripts analogue, with fineliner, markers, post-its and a notebook. Main and subthemes were collaboratively identified, developed, and reviewed by the first, second, and fourth authors. Several codes were discarded as deemed irrelevant by any of the authors. The first author primarily defined and named the main and subthemes, which other authors then reviewed. To support the themes, illustrative quotes were translated from Dutch to English and paraphrased for participant anonymity. The first author handled the translation and paraphrasing, with all authors reviewing the final versions. Lastly, the report was drafted by the first and reviewed by all authors.

3.4 Ethical considerations

Given the small number of medical sexologists in the country of study, we presented participants' years of experience in ranges to protect their identities. The research team held internal discussions to determine what information could be disclosed to ensure confidentiality.

To prevent any possibility of tracing data back to individual patients and to ensure that sensitive information remained confidential, we anonymised all specific cases or examples discussed during the interviews. Identifying details were removed or replaced with aliases to protect confidentiality.

We informed the participating medical sexologists of the study's objectives, their right to withdraw at any time, and the measures taken to protect their identities and the privacy of the cases they discussed. We obtained written consent, and all data was securely stored and accessible only to the research team. The study received approval from the relevant ethical review board under ID 4386.

3.5 Positionality statement

Our work is informed by feminist and trauma-informed perspectives that challenge normative assumptions about sexuality, pleasure, and recovery. While none of the authors have personally experienced post-cancer sexual health, one author's non-normative sexual trajectory shaped by trauma has deepened our understanding of the complexities of reclaiming sexual pleasure. This has shaped our commitment to viewing pleasure not as a fixed endpoint but as a dynamic, embodied process reclaimable even after disruptive life events.

Drawing on feminist theories [78], we see sexuality as an integration of biological, psychological, and social dimensions, rejecting dualistic framings of body and mind [70]. This perspective challenges dominant narratives around function and performance.

As Western interaction designers, artists, and researchers, we recognise how privilege and cultural context shape our perspectives. Rather than prescribing solutions, we aim to open dialogue and create space for designerly inquiry that centers the lived experiences of cancer survivors and their partners.

³<https://www.microsoft.com/en-us/microsoft-teams/video-conferencing>

4 Results

In this section, we present 5 themes from our interview data analysis.

Theme 1: perceiving the body as a medical object (Subsection 4.1) explores how cancer treatment can be transgressive, causing disconnection from bodily pleasure and autonomy. **Theme 2: the hot potato problem in oncology: addressing the silence surrounding sexual health** (Subsection 4.2) addresses the mutual reluctance between patients and healthcare providers to initiate conversations about sexual health, which highlights the need for open communication and culturally sensitive interventions. **Theme 3: sociotechnical sexploration** (Subsection 4.3) describes how interventions can help patients and their partners explore new forms of sexual pleasure beyond traditional norms, adapting to changes in bodily function. **Theme 4: reuniting what treatment has divided** (Subsection 4.4) focuses on the need for interventions that help restore intimacy between partners and reconnect patients with their bodies post-treatment. **Theme 5: designing interventions with openness in a highly situated context** (Subsection 4.5) emphasises the importance of creating interventions that are sensitive to the unique cultural and personal contexts of each patient.

4.1 Theme 1: perceiving the body as a medical object

Cancer treatment profoundly affects patients, often leading them to perceive their bodies as medical objects rather than sources of pleasure and autonomy. This disconnection highlights opportunities for design interventions that foster reconnection with the body as a source of positive, sensory experiences. This theme explores the invasive nature of treatments that transgress bodily autonomy, the resulting disconnection between mind and body, and the gender-specific challenges patients face in self-acceptance. As P1 aptly put it: *“Your body can do many things, but the question is whether you can. Often, the limitation is more in the mind than in the body.”*

4.1.1 Cancer treatment: transgressing bodily autonomy. P2 explained that cancer treatment often involves boundary-crossing and invasive procedures that can strip away a patient’s sense of autonomy. *“Their body has become something like a medical object that has undergone many procedures. They experience it as something that does not function well and has to endure things, leading them to lose the sense that their body can bring pleasure.”*

P2 described that these treatments, while necessary, can be deeply intrusive and traumatic. They mentioned procedures like brachytherapy, where a radiation device is inserted into the vagina, as examples of such boundary-crossing experiences. The constant need for medical personnel to access intimate areas and ask invasive questions can further exacerbate this feeling of violation.

P3 added that physical touch during hospital stays often becomes associated with pain, as each touch from medical staff is linked to examinations, punctures, or cuts. This repeated invasion of personal space can leave patients feeling helpless and dependent on medical staff. *“In my lessons to nurses and doctors, I always say, you touch patients who lie there helplessly in pain, dependent on you for treatment. It’s all very boundary-crossing, and it’s important to be aware of that”* (P3). As a result, these experiences can profoundly

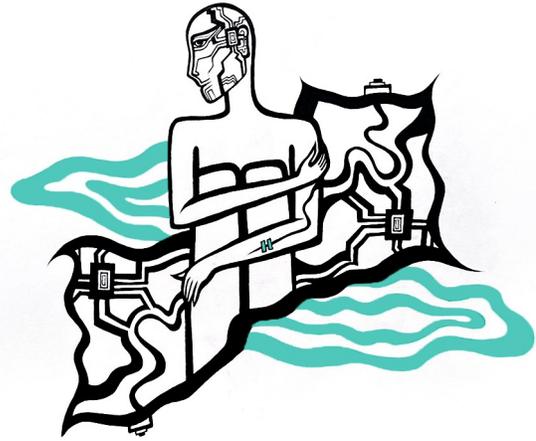


Figure 2: This figure depicts a patient in pain, connected to a care pathway via an IV, symbolising the invasive and depersonalising nature of medical treatment. The blue bodily fluid represents discomfort and the body’s transformation into a medical object, the averted gaze conveys disconnection from bodily agency.

affect a patient’s relationship with their body, eliciting a sense of disconnection and loss of control.

4.1.2 Disconnection between mind and body. Cancer treatment can disrupt patients’ ability to experience their bodies as sources of pleasure and normalcy, leading to a mind-body disconnection. P3 described this: *“Some people cope by dissociating from the entire area, and later they want to enjoy it again but cannot because they have mentally shut off that part of their body.”*

P3 highlighted that to enjoy an embodied experience, one must be present without distracting or intrusive thoughts. Negative emotions like disgust towards one’s body can prevent patients from reconnecting and experiencing their bodies positively. P1 shared a transformative moment in sex therapy: *“She kept saying her vagina wouldn’t work, and I asked if she hated her vagina. She said yes. I then asked what her vagina thought of her, and she fell silent. That was a turning point.”* This turning point occurred when the patient was asked to consider her body not as an object of her frustration but as an active part of herself, deserving of care and respect. By reframing her perspective, the patient began to challenge her negative emotions and open a pathway for reconnection.

Patients may feel anatomically inadequate and struggle to reconcile their minds with their bodies (P1). They need to shift their focus from loss of function to kindness and appreciation, as echoed by P3. P2 noted that a lack of trust in their bodies can lead patients to believe that engaging with their bodies can be hurt and harmful.

4.1.3 Gender differences and self-acceptance. Cancer treatment often leaves lasting physical marks, such as surgery scars, amputations, stomas, and altered body functions, impacting self-image and through this intimacy (P4, P5). P4 noted that these changes

can lead to feelings of unattractiveness and fear of pain, inhibiting patients' willingness to engage in sex. Women may feel particularly affected due to societal pressures to maintain a certain appearance, with early menopause, weight gain, and hair loss further diminishing their sense of attractiveness, also echoed by P2. Additionally, changes such as a shorter or more sensitive vaginal canal can make penetration painful or impossible (P2).

Men face their own challenges, such as erectile dysfunction following prostate cancer treatment, which can greatly affect their self-esteem and intimacy (P1, P2). Both men and women may develop a lack of trust in their bodies, believing that engaging in intimacy will be painful or disappointing (P6).

Gender differences significantly affect how these physical changes are perceived and managed. P4 elaborated that women often feel a greater societal pressure to be attractive, making it difficult for them to cope with visible changes like stomas or scars. Partners of surviving women are generally more accepting of their partners' physical changes than the patients themselves. Many women fear their partners will find them unattractive due to an amputated breast, although their experience indicates this fear is often unfounded. P4 concluded that there is often a large gap between what women think their partners feel and the partners' actual feelings.

4.2 Theme 2: the hot potato problem in oncology: addressing the silence surrounding sexual health

Sexual health is a taboo topic, particularly challenging to address when patients are already vulnerable due to cancer. This theme explores the barriers preventing open discussions between healthcare providers (e.g. oncologists, nurses) and patients. It covers the double taboo experienced by both parties and how societal stereotypes and cultural differences influence treatment and care-seeking behaviours. These sub-themes highlight the necessity for interventions that promote open communication and culturally sensitive approaches to support all patients equitably. This underscores the need for interventions that lower communication barriers and normalise discussions about post-cancer sexual health.

4.2.1 Double taboo - unaddressed by both parties. P4 explains that both healthcare providers (e.g. oncologists, nurses) and patients consider sexual health a taboo topic, each expecting the other to initiate the conversation. P5 elaborates, "Healthcare providers often avoid the topic due to time constraints, lack of knowledge, or fear of patient discomfort. Patients, on the other hand, find it intimidating and are unsure if it's appropriate to bring up." P4 adds, "Both patients and their partners often see it as the healthcare professional's responsibility to start the discussion." This mutual hesitation creates a barrier to addressing sexual health issues, leaving many patients without proper psychosocial care (P2, P5).

This double taboo stems from the societal perception of sex as a taboo topic (P5). Additionally, specialists may fear not knowing the answers or how to handle the topic (P6). P3 highlights, "Doctors are often afraid of crossing boundaries.", echoed by P4. Age and gender dynamics between the patient and provider can further influence this hesitation. P6 observes, "People find it difficult to discuss these issues if the healthcare provider is of a similar age or much younger."



Figure 3: This figure depicts a patient in emotional pain, unable to safely express their feelings due to the taboo surrounding sexual health. The yellow drops symbolise suppressed tears, the hand covering the mouth conveys the silence and mutual hesitation that prevent open discussions about post-cancer sexual health.

P5 notes that while some patients actively seek a referral to a medical sexologist, most are referred on their doctor's initiative, saying, (P5 mimicking a common patient response): "Yes, I don't really know, the doctor thought it was a good idea." They note that the severity of sexual problems does not differ between people who actively seek out referral and people who do not, but the taboo around sexual health issues makes it challenging for patients to seek help independently.

To address this issue, P6 developed an online informational tool for sex after cancer, designed to lower the barrier for discussing these topics. The tool includes animated videos offering general information on how cancer affects the body and its impact on sexual activity, along with tips on how to raise the topic of sexual health and where to seek further resources. They explain, "By providing a digital intervention, it prompts healthcare providers to address it, making it easier to bring up. Providers can ask, 'Did you receive the information about cancer and sexuality? Do you have questions about it?' This lowers the threshold for both patients and healthcare providers." This approach addresses the hot potato problem by using an informational tool as a vehicle for discussion and normalisation. This tool was developed by P6 based on reflections from her practice and extensive experience with patients. Future designs could benefit from a co-design process involving experts like P6 to better tailor the tool to its context and enhance its effectiveness in facilitating discussions.

4.2.2 Societal stereotypes reflected in the treatment room. Interestingly, half of the participants noted that their medical sexology outpatient clinic fell under gynecology. All participants reported that a majority (around 60/40) of their patients were women, despite men not necessarily having fewer complaints.

P5 explained that gynecologists are generally more trained to consider broader psychosomatic issues, whereas urologists, being more surgically focused, tend to opt for quick medical solutions like pills for men. This difference in training might contribute to the higher number of women seeking help.

Some suggested that in the country where the study took place, it is more accepted for women to seek psychosocial help than men. They also observed cultural differences in seeking help, noting that people from non-Western cultures are less likely to seek help compared to Western cultures. P6 explains that different cultural backgrounds have different norms and values regarding sexuality. P4 echoes this, stating that certain cultures may discuss sexual issues more openly among same-gender peers than with their partners, indicating cultural differences in communication norms within intimate relationships.

4.3 Theme 3: sociotechnical sexploration

This theme explores how interventions could support cancer survivors and their partners reconnect and discover new forms of sexual pleasure beyond traditional penetrative sex. This encourages survivors to adapt to bodily changes and redefine intimacy, highlighting sociotechnical opportunities for fostering connection and achieving sexual fulfillment. By promoting a *more-than-genital* view of sex, these interventions align with feminist and soma design perspectives that approach pleasure as a holistic and embodied experience. *“Yes, I believe that living a beautiful life includes enjoying its pleasures, with sex being one of the greatest. You can experience tremendous pleasure, and that comes from your body. Your body has the capacity to experience wild things. And if you want to make a lot of noise along with it, then you should definitely do that. But you should feel free in it.”* (P1).

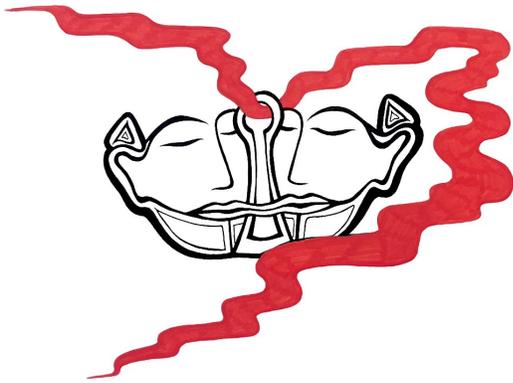


Figure 4: This figure depicts a survivor and their partner facing each other but separated by a keyhole, symbolising the barriers to rediscovering intimacy after cancer treatment. The keyhole represents the potential for new pathways in sexual connection, capturing the need for interventions that help partners explore beyond traditional norms and reconnect through adapted, non-goal-oriented intimacy.

4.3.1 Intimacy beyond intercourse. P2 noted that many patients initially have a narrow view on sex, equating it with penetrative intercourse leading to (male) orgasm, which can lead to avoiding all sexual contact if penetration becomes difficult or impossible due to treatment-related changes. P1 shared, *“So I had a man in my office who says, ‘Yeah, I don’t get erections anymore, so I can’t do anything with my wife.’”* Broadening this view is key for rediscovering intimacy and sexual pleasure. P4, P5, and P6 echoed this sentiment.

P2 further explained that adjusting to changes in sexual function involves exploring new ways of experiencing pleasure beyond penetration. This involves encouraging patients to find enjoyment in different forms of sexual expression.

P6 highlighted that for some, penetrative sex has often been the primary method of achieving orgasm. Learning to achieve satisfaction through other means is an important part of sex therapy. P6 stated, *“What factors can we influence, and which ones can’t we? We need to accept what we can’t change and focus on what we can do. People often see many problems and need to be reminded of the core question: Why do you have sex? Many are function-focused, like ‘my erection doesn’t work’ or ‘I can’t reach orgasm.’ By focusing on why they have sex, which is often about pleasure, we can shift the focus from function to pleasure. When pleasure is present, function often returns.”* This therapeutic strategy involves shifting the focus from lost functions (e.g., erections, orgasms) to the underlying motivations for sex, such as pleasure and connection. By reframing intimacy as an experience centered on pleasure rather than performance, sex therapy encourages patients to explore non-penetrative forms of intimacy and adapt to bodily changes, as P2 reinforced. They noted, *“It is about adaptation to change, accepting that it will not be exactly as it was before. It is ultimately about pleasurable sex in any form. Sex therapy is actually kind of encouraging people to tap into an adaptive capacity and support that.”* These insights describe the importance of interventions that help survivors and their partners move beyond a performance-oriented view of sexuality.

P6 also explained that reframing intimacy to include non-sexual expressions of affection is vital. Patients can misinterpret gestures like a kiss or touch as demands for (penetrative) sex, causing anxiety. Encouraging patients to see a kiss or touch as a sign of love rather than a request to penetrative sex can show them being intimate in a different light.

4.3.2 Expedition for new pleasures. Cancer treatment often leads to physical changes that disrupt familiar sexual experiences, causing pain and discomfort (P5). Addressing these challenges requires adaptability (P2).

P2 explained the importance of relearning what brings pleasure to the body, understanding new limitations and possibilities, and finding ways to enjoy sex comfortably. P3 gave an example of a patient who, after a breast amputation, needed to discover new erogenous zones.

The mental aspect is also important. P1 explains that patients are encouraged to move from their “rational brain” to their “emotional brain”. They elaborate; *“How does it feel to have an erection? How can you surrender to these bodily sensations, without worrisome thoughts?”* P2 suggests that meditative and relaxing erotic stimuli can help put people in the right state of mind. They suggest sex toys, audio and visual aids can help here. P3 taps in a similar vein, *“We talk*

about seeking sexual stimulation, which is a deeply personal journey. Stimulation can be physical, like touching your body or clitoris, but it's not just about the genitals. The most important part is mental: fantasies, memories, stories, or videos you watch. It's all in the mind."

P1, P2, P3, P5, and P6 discussed using sensate focus [72, 83] exercises, involving non-sexual touching and stroking, to help patients and their partners rediscover physical intimacy without performance pressure. Open communication with partners about these new experiences is essential. P2 noted, *"It's about discovering and sharing what feels good."* P1 highlighted that mutual exploration could improve satisfaction for both parties, emphasising the importance of being open and curious about what brings joy and satisfaction (P2, P6).

4.4 Theme 4: Reuniting what treatment has divided

This theme explores the separations caused by cancer and its treatment, focusing on the rift between partners and patients, and patients and their bodies. It highlights the necessity of involving both partners in addressing sexual problems and re-establishing a positive relationship with one's body through designed interventions. Such interventions could stimulate intimacy and bodily awareness, encouraging active engagement and collaboration between partners. This theme points to the importance of partner-inclusive designs and embodied practices that reestablish emotional and physical connections.



Figure 5: This figure depicts a survivor and their partner seated on broken purple strings, symbolising fractured connections caused by cancer and its treatment. These strings, now supporting their intertwined bodies, represent the potential to heal and rebuild intimacy. The image conveys that even fractured connections can become fertile ground for restoring emotional and physical bonds.

4.4.1 Bringing partners closer together. P4 noted: *"I do not accept just seeing the patient alone because you cannot work on a sexual problem that way."*

P1, P2, P4, and P5 agreed that most patients seeking help from a medical sexologist are in relationships. P4 explained that relational sexual problems involve both partners, and discussing sex and intimacy can be challenging, leading to non-verbal avoidance and misconceptions about each other's thoughts on sex. P5 added: *"A sexual problem combined with a communication problem can put significant pressure on a relationship."* P1 emphasised their role in comparison to digital interventions: *"I'm old school. Why can a sexologist help couples? Because we are safe. Computers are not safe. When a couple comes in struggling to talk about sexual issues, I can make it discussable. Demonstrating how to talk about bodily functions like erectile dysfunction in person makes it normal, which you can't achieve with a computer."*

P2 highlighted that partners also endure the illness process, struggling with their loved one's suffering. They often need to rediscover each other as partners, not just as patients and caregivers. P2 continues that partners may worry about what is possible and fear causing pain, leading to anxiety and doubt. P1 exemplified: *"They (patients) often have a partner who thinks, 'My partner has been through such terrible things, I shouldn't expect to ever have a good shag with her again.' So then the avoidance is actually completely non-verbal, right?"* This highlights the importance of interventions that foster open communication and help couples navigate these unspoken challenges, encouraging them to reconnect emotionally and physically.

4.4.2 Bringing people closer to their bodies. P5 highlighted that while tools like vaginal dilators are sometimes recommended, they prefer patients to use their fingers. *"But my preference is to practice with your own fingers, then you get to know your body and feel what is happening. You see, the dilator feels nothing, and with the dilator, you can keep everything at a distance and purely functional."*

P1 reflected on the perception many patients have of their body as a medical object. They pointed out that fostering a positive relationship with one's body can enhance overall well-being and sexual satisfaction. *"That the relationship, that intimacy between you and your body, is a fundamental part of your life."* This perspective underscores the importance of interventions that encourage mindful, personal engagement with the body, helping survivors move beyond a clinical or utilitarian view to one of acceptance and care.

4.5 Theme 5: designing interventions with openness in a highly situated context

The participants elaborated on the need to create interventions that are sensitive to the unique cultural and personal contexts of patients. This emphasises the importance of understanding and aligning with patients' norms, deploying a collaborative approach, and recognising the limitations of standardised protocols in the context of sexual health issues. This theme reveals how context-sensitive design can facilitate meaningful support in sexual health care.

P1 explained that sex is seen and communicated through the lens of culture and time. P6 stressed: *"It's important as a caregiver to recognise that you should not work according to your own norms but*



Figure 6: This figure, created by the illustrator who engages with spirituality, depicts (from left to right) the designer, the partner, and the survivor, supporting each other at the lower back—a symbolic reference to the sacral chakra. In spiritual traditions, the sacral chakra governs emotions and connection to others. A closed sacral chakra reflects challenges in intimacy and emotional detachment. The image highlights the collaborative, context-sensitive approach vital for designing meaningful sexual health interventions.

to the patient’s.” According to P6, this alignment begins by asking patients what they want and what is important to them, focusing on questions like “Why do you have sex? What is important for you in the context of sex?” This approach helps understand their norms. Being curious, checking assumptions, and normalising their experiences are key. P6 continued that people are generally open when approached sincerely and appreciate genuine interest.

P5 shared their views on providing situated care: “Well, I don’t really like being confined to a strict box myself. But yes, I also see that my patients don’t fit into a standard protocol, that’s not how they are. Protocols work like a charm, but only for a small group that fits them exactly.” P5 emphasised that effective care for sexual health is about working together to find the path that suits the individual or couple: “It’s not about me telling them how things are and what to do. No, it’s about working together. We need to find the path that suits that individual or couple together. [...] The other person is the focus.”

P5 explained that how someone handles intimacy is influenced by many factors: religion, upbringing, past sexual experiences, self-image, etc. They expressed that each individual’s sexual health issue is, therefore, unique. Related to that, P6 described their interactions with patients as a dialogue, instead of one-way communication: “At the end, I summarise and check if they agree or have additional points. This collaborative approach often helps patients understand their problem and what they can do about it, which is very therapeutic.”

P5 and P6 noted that they can be surprised by patients’ sexual preferences. P5 further explained that even when they are taken aback by explicit descriptions, they always try to approach patients

with respect and empathy.

These findings offer a nuanced understanding of the complex, multidimensional challenges cancer survivors face as they navigate post-treatment sexual health. In the Discussion, we explore how HCI can leverage these insights to design interventions that address this, bridging personalisation and scalability through a user-centred approach.

5 Discussion

In this paper, we sought to answer the research question: *what are the opportunities for HCI in addressing the sexual health issues of cancer survivors?* Through interviews with medical sexologists, we describe themes which uncover underexplored opportunities for HCI to engage with the embodied and relational aspects of sexual health. While much of HCI’s prior work has focused on genital-centered technologies like vibrators and sex toys [14, 41], our findings expand this scope to include non-penetrative forms of intimacy. By addressing survivors’ bodily changes, relational dynamics, and cultural taboos post-cancer, we highlight novel opportunities to design interventions attuned to these complexities, extending the design space for sexual health technologies in HCI.

Our approach is grounded in feminist, crip, and soma theories, which provide critical perspectives on the interplay between bodies, pleasure, and societal norms. Feminist theories challenge genital-centered, performance-driven narratives, advocating for inclusive understandings of pleasure and agency [7, 87]. Crip theories reject ableist assumptions of “normal” bodily function, emphasising the need to design for diverse, evolving experiences of intimacy [62, 74]. Soma design complements these frameworks by treating the body as a site of lived experience and connection, rather than an object to be “fixed” [97]. Together, these commitments guide the design of technologies that foster connection, acceptance, and exploration, countering reductive or stigmatising solutions.

As established in the Introduction (Section 1), there is a need for interventions that are both personalised and scalable to effectively support survivors and their partners. While personalised sex therapy can address individual needs, its resource-intensive nature limits its scalability. Conversely, scalable interventions, such as pharmacological treatments for erectile dysfunction [68, 89] and vaginal care [31], often neglect the psychological, social, and cultural dimensions critical to comprehensive care [20]. Although personalisation and scalability may seem at odds, they can be aligned; delivering personalised care via adaptive technologies is demonstrated in research on digital personalised care pathways [30, 32].

This discussion addresses these gaps by outlining the design space for post-cancer sexual health, detailing both the “what” (design directions, Subsection 5.1) and the “how” (developing the interventions, Subsection 5.2).

5.1 What: design directions

5.1.1 Leveraging soma design for mind/body re-connection. The experiences of cancer survivors, as described in *perceiving the body as a medical object* (Subsection 4.1) and *reuniting what treatment has divided* (Subsection 4.4), could benefit from the principles of

HCI's soma design, which view the body as “*the medium of all perception*”[97]. Survivors can struggle with a disconnection between mind and body, due to invasive treatment (Subsection 4.1), a challenge that soma design can address through its non-dualistic integration of mind and body as inseparable aspects of lived experience [70]. This has the potential to fulfill the need expressed by medical sexologists for cancer survivors to reconcile their minds with their bodies (Subsection 4.1). Our interview data reveals that medical sexologists observed that cancer survivors often struggle with feelings of disconnection from their bodies (Subsection 4.1), further complicated by the taboo surrounding sexual health issues (Subsection 4.2) and altered intimacy in relationships post-treatment (Subsection 4.4). This parallels the work of Søndergaard et al. [101] on menstrual cycles, demonstrating how soma design can address health as bodily rooted, yet socially experienced. Medical sexologists advocate for a transition from a rational, function-focused mindset to one that embraces bodily sensations and pleasure (Subsection 4.3). This aligns with Schiphorst's somatic focus on shifting from outward awareness to an inward, body-focused awareness [94]. Rather than positioning technology as an intermediary between survivors and their bodies or partners, we propose leveraging it as a facilitator of embodied and relational experiences. For instance, tactile tools could guide survivors in rediscovering touch, not as a replacement for human interaction but as a complement that nurtures intimacy and connection, as seen in demonstrated in other somatic contexts [64].

Soma design might not be a universal solution for all survivors, but can serve as a research tool to explore the nuanced relationships between survivors, their bodies, and technology. It could foster mindfulness, non-goal-oriented pleasure, and bodily agency by empowering survivors and their partners to explore their bodies and sexuality independently with no/less support from medical sexologists. This research tool has the potential to focus on self-exploration and self-expression, helping individuals reconnect with their bodies and redefine intimacy on their own terms.

By prioritising independence and agency, soma-informed technologies reduce reliance on external interventions, guiding survivors to take ownership of their recovery. Designs that support partners in rediscovering touch or exploring new forms of pleasure together require minimal ongoing input by medical sexologists, making them inherently more scalable than the current offering. This focus on empowerment and adaptability establishes soma design as a practical framework for creating long-term, self-sustaining care practices in post-cancer sexual health.

While soma design offers great potential for mind-body reconnection in cancer survivors, its application demands careful consideration. Encouraging introspection on bodily experiences potentially linked to trauma poses ethical challenges, such as the risk of re-traumatisation. To navigate these risks responsibly, it is crucial to collaborate closely with experts in sexual health and trauma, ensuring that interventions are effective and safe for everyone.

Balaam et al. [11] describes that entering emotionally charged spaces (somatically) also presents risks for researchers and designers. Engaging with traumatic topics like post-cancer sexual health can expose researchers to secondary trauma and emotional exhaustion, making it critical to establish safeguards for their well-being.

This requires clear boundaries to protect researchers from the emotional weight of the work; for considerations, see Balaam et al. [11], Moncur [75].

Soma design often involves taking a first-person perspective [59, 79, 104], which can be especially risky in sensitive contexts like post-cancer sexual health, as it involves self-disclosure which can be vulnerable. Agrawala et al. [3] describe their challenges of studying pornography interfaces, such as concerns about colleague judgment and the stigma tied to first-person sexuality research. Their hesitation to use this perspective due to potential backlash underscores the vulnerability of sexuality research in HCI. As Forlano [43] aptly point out, while first-person accounts are personal, they are not confessional; researchers retain the agency to decide what to share and what to withhold.

5.1.2 Guided exploration for rediscovering sexual pleasure post-cancer. As outlined in *sociotechnical exploration* (Subsection 4.3), survivors can struggle with maintaining sexual intimacy when traditional forms of sexual expression become difficult or impossible due to treatment-related physical changes (Subsection 4.3). HCI has explored how technology can facilitate sexual experiences, with a focus on genitalia like through sex toys [14, 41, 58] and other erotic stimuli.

Our findings describe that interventions should move beyond rational, functional approaches like focusing on achieving orgasms to include an emphasis on the emotional and sensory aspects of sexual experience. Subsection 4.3 reported that shifting from the “rational brain” to the “emotional brain”, using (meditative) erotic stimuli, can help patients reconnect with their bodies and partners.

HCI could contribute to the design of interventions that normalise and celebrate diverse forms of sexual expression by promoting a *more-than-genital* view on sex, fostering connection, arousal, and pleasure in ways that are sensitive to the lived experiences of cancer survivors. Instead of focusing solely on genital stimulation, designers could draw inspiration from artistic and experiential practices that engage the body holistically. For instance, *When The Body Says Yes* by Melanie Bonajo ⁴, a somatic sex coach and feminist sexological bodyworker, combines immersive video and interactive environments to explore touch, sensory engagement, and non-traditional forms of sexual pleasure. Bonajo's work offers methods for reconnecting with the body and redefining intimacy, which can inspire interventions that incorporate tactile, auditory, and visual stimuli to evoke pleasure and emotional closeness.

These approaches could be particularly transformative for survivors struggling with traditional forms of intimacy. For example, as detailed in Subsection 4.3, a male survivor felt unable to engage in any sexual activity due to erectile dysfunction. Interventions that shift focus from specific outcomes like erection or orgasm to exploring broader forms of pleasure with a partner could help survivors reconnect and adapt. Similarly, reframing non-sexual gestures of affection, such as kissing or touching, as expressions of love rather than precursors to intercourse could reduce anxiety and avoidance, fostering intimacy (Subsection 4.3). Broadening the sexual horizon for survivors and their partners creates opportunities to restore a sense of connection, pleasure, and emotional fulfillment.

⁴<https://www.labiennale.org/en/art/2022/national-participations/netherlands>

In addition, interventions inspired by the *sensate focus* technique by Masters and Johnson [71, 72] could address this issue. The technique involves couples touching each other while abstaining from sexual intercourse, focusing on their own sense experiences rather than performance or orgasm. Initially, touch excludes the breasts and genitals, with an emphasis on mindful awareness of skin texture and warmth. This guided process fosters non-penetrative sexuality through touch, talking, hugging, kissing, and engaging the senses of taste, smell, and sound to build emotional connection. Rather than conventional sex toys, interventions should guide users in exploring bodily sensations while adhering to trauma-informed computing principles [33]. Conventional sex toys, often centered on genital stimulation and orgasm, may inadvertently reintroduce performance pressures or discomfort, particularly for cancer survivors navigating significant bodily and emotional changes.

Trauma-informed technologies should prioritise safety, trust, and empowerment, minimising the risk of retraumatisation [33]. Somaesthetic design approaches, such as Windlin et al. [116]’s work integrating haptics, heat, and movement, offer a valuable model for fostering mindful, gradual reconnection with the body. By focusing on non-goal-oriented pleasures and inclusive tools, these interventions can help survivors rediscover intimacy and pleasure.

Opportunities for HCI here include interventions like guided partner exploration with personalised pacing (recognising that each couple follows their own path and timeline, Subsection 4.5), and games incorporating sensate focus techniques to encourage exploration (addressing the need for discovering non-traditional intercourse, Subsection 4.3). Guided reflection tools that help verbalise experiences could tackle the communication barriers between survivors and partners (Subsection 4.4). Suggestions like these can be seen as interventions in themselves, but also as probes to further understand the context.

Designing interventions for post-cancer sexual health requires navigating its inherent complexities. As Kannabiran et al. [63] point out, the challenge lies not in the “naughty” nature of sexuality but in its complexity, which demands rigorous design methods. Ciolfi Felice et al. [35] advocate for resisting medicalisation and fostering embodied, socially shaped experiences. Their work underscores the importance of engaging individuals in accepting and reconnecting with their bodies, offering a pathway to normalise changes without reducing them to clinical symptoms. Similarly, Søndergaard et al. [102] demonstrate how participatory approaches that utilise intimate materials, like their “Menarche Bits,” can encourage comfort and bodily attunement through shape-changing wearable technologies. These methods exemplify how design can enable users to reclaim agency over stigmatised experiences by creating exploratory and tactile interactions. Extending this, Campo Woytuk et al. [29] introduce the concept of “tactful feminist sensing,” challenging traditional medicalised paradigms with playful, tactile, and curiosity-driven designs. Their finger-worn sensor for cervical mucus conductivity avoids reductive, goal-oriented lenses to instead foster care, curiosity, and agency through non-invasive, and aesthetically ambiguous materials. Such design qualities are particularly relevant to post-cancer interventions, where survivors often navigate physical and emotional vulnerabilities.

What these explorations have in common is that they use design to bring individuals closer to their bodies. Rather than designing a “technical wall”, where design comes between persons and their bodies, these designs facilitate exploration, supporting people to connect and get reacquainted with their bodies. This is also reflected in our findings (Subtheme 4.4.2), where several medical sexologists advocate for similar approaches.

Applying these principles to post-cancer sexual health interventions, we envision interactive tools that prioritise curiosity and comfort. These tools could facilitate non-goal-oriented exploration of bodily sensations, encouraging survivors to rediscover pleasure at their own pace. Inspired by Campo Woytuk et al. [29]’s emphasis on fluid and messy realities, such designs could also normalise the diverse and evolving experiences of intimacy, enabling survivors to redefine connection on their own terms.

5.1.3 Restoring connection through partner-inclusive design. As described in *reuniting what treatment has divided* (Subsection 4.4), cancer and its treatments can strain relationships between survivors and their bodies and partners. Our findings highlight the need to involve both partners in sex therapy, as sexual health issues are often relational. This suggests an opportunity for HCI to design interventions that restore intimate connections in post-cancer sexual health.

Studies on digitally facilitated intimacy have largely focused on tools for long-distance couples [10, 118, 119], with less attention to co-located partners [21, 109]. These tools often bridge physical separation through technologies like audio and video calls [10], virtual reality [119], robotics [118], and smart objects [45]. Some even focused on enhancing physical intimacy by mimicking actions such as kissing through haptics [90]. Key insights from this work relevant to post-cancer sexual health include the idea that play encourages exploration and ambiguity, which can foster intimacy and facilitate emotional closeness to stimulate desire. However, these tools were designed for couples separated by distance, and as Subsection 4.4 describes, both partners being physically present and communicating is critical for survivors and their partners to feel emotionally connected in the aftermath of cancer treatment.

Participatory design [95] offers potential for developing interventions that address the complex relational dynamics of post-cancer intimacy by involving both survivors and their partners. Medical sexologists highlighted the importance of in-person interaction to create a safe space where partners can openly discuss concerns and rediscover each other as sexual beings, rather than patient and caregiver (Subsection 4.4).

While participatory design is valuable, it requires caution. As discussed in Subsection 4.2, survivors already face challenges discussing these topics with healthcare providers, which may be amplified when interacting designers who are unknown and lack confidentiality obligations. Ethical concerns also arise around revisiting traumatic experiences. To mitigate these risks, we propose using design probes that gather insights without re-traumatising participants by exploring affordances rather than deeply personal experiences. A similar method was used to explore mental health in young participants [60]. Additionally, involving therapists or medical sexologists in the sessions, or having them facilitate, could

ensure the process is handled ethically. This approach of incorporating everyone involved, aligns with the findings from *designing interventions with openness in a highly situated context* (Subsection 4.5).

5.1.4 Bridging the provider-patient gap with tools for conversation. As highlighted in *the hot potato problem in oncology* (Subsection 4.2), mutual hesitation between healthcare providers and patients to discuss sexual health creates a “double taboo,” leaving many patients without adequate psychosocial care. Addressing this gap requires provider-focused interventions that normalise conversations and reduce stigma.

One promising example comes from P6, who developed an online informational tool (Subsection 4.2) that not only provides information but also affords healthcare providers to prompt conversations, such as “Did you receive the information about cancer and sexuality? Do you have any questions?” By offering neutral ways to broach the subject, such designs reduce stigma and hesitation surrounding sensitive topics. Similarly, the designs discussed in Subsections 5.1.1 and 5.1.2 can be integrated into provider-patient interactions to serve as conversation starters.

The importance of human interaction remains vital, as P1 highlighted the unique safety provided by in-person care (Subsection 4.4). While technology can complement care, it cannot replace the relational trust built through direct engagement. However, healthcare providers often hesitate to address sexual health due to a lack of expertise and confidence in managing complex or sensitive issues [40, 54]. This underscores the need for targeted education and training, particularly inclusive curricula that address the needs of minority groups, including individuals with intellectual disabilities, LGBTQ+ individuals, and older adults [1, 46, 47, 54, 84].

Beyond training, creating supportive environments (such as displaying posters or leaflets) can empower patients to initiate conversations and signal providers’ openness to addressing sexual health [1, 46, 54, 98].

Collectively, these strategies help bridge the provider-patient gap, normalise discussions about sexual health, and improve psychosocial care for post-cancer survivors.

5.2 How: designing the directions

5.2.1 Expanding the scope of sexuality in HCI. Current HCI interventions for sex, as outlined in Section 2.2, remain predominantly focused on genital-oriented designs, which does not do the complexity sexual experience justice. As discussed in Subsection 4.3, medical sexologists advocate for a broader, *more-than-genital* approach, such as the sensate focus technique, that includes diverse sexual expressions beyond penetration. While HCI has explored intimacy extensively, sexuality itself remains underdeveloped [63], particularly for individuals like cancer survivors, for whom traditional intercourse might no longer be possible.

We argue that HCI should address these issues directly under the umbrella of sexuality, rather than intimacy, to avoid prudishness or euphemisms that overlook core sexual challenges. Expanding the discourse of sexuality to include a *more-than-genital* perspective is crucial, especially for cancer survivors. Intimacy alone does not address concerns like the loss of sexual function or the emotional toll of changes in sexual expression. This broader perspective also

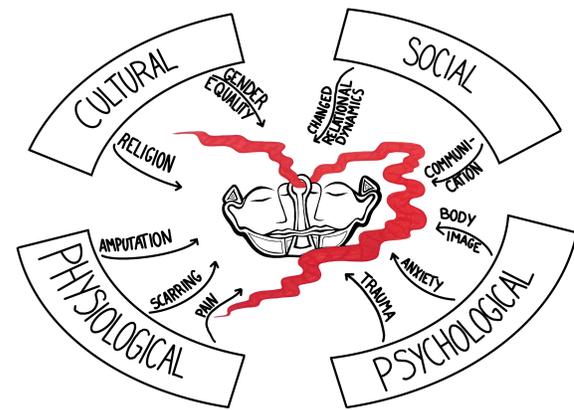


Figure 7: This map, created by the first and third author, illustrates the four dimensions of sexual health—physiological, psychological, social, and cultural—showing how each could affect survivors and their partners [15, 20]. It guides designers to account for the complex interplay of these factors, ensuring no single dimension is overlooked in interventions. The map is not intended to be an exhaustive overview of factors but serves as an illustrative example.

benefits healthy individuals facing more mundane sexual issues, such as performance anxiety [9] or post-childbirth sexual health issues [96].

5.2.2 Deploying the bio-psycho-social model for interventions for post-cancer sexual health issues. Our findings show that cancer survivors’ experiences are deeply influenced by psychological, social, and cultural factors. Psychologically, theme 1 (Subsection 4.1) illustrates how invasive treatments can cause survivors to dissociate from their bodies, viewing them as medical objects rather than sources of pleasure, complicating physical intimacy and post-treatment reconnection. Socially, theme 4 (Subsection 4.4) highlights the strain on partners, who, fearing they might cause pain, often avoid intimacy, reinforcing the caregiver-patient dynamic. Culturally, theme 2 (Subsection 4.2) reveals the silence around sexual health, where both healthcare providers and patients hesitate to discuss these issues due to cultural taboos, leaving survivors’ sexual health concerns unaddressed.

These findings reaffirm the bio-psycho-social model for intervention [15, 17, 20, 52], which emphasises that “*sexuality is a multi-causal, multi-dimensional, complex phenomenon*” [73] requiring physiological, psychological, social and cultural treatment strategies [20]. This model, conceptualised in figure 7, can serve as a map for HCI designers and researchers, guiding the design of interventions by illustrating how they impact the dimensions which all interconnectedly influence the experience of survivors and their partners. Whether interventions target all dimensions simultaneously or focus on specific aspects, this model ensures that the broader implications for post-cancer sexual health are always considered, preventing any part of the experience from being overlooked.

5.2.3 A caution against techno-optimism. While the previously mentioned design directions are promising, our findings highlight the need for a nuanced approach. Technological designs, while appealing, must be applied with caution, especially in sensitive areas like post-cancer sexual health. As noted in Subsection 4.4, inappropriate implementation of technology could potentially do more harm than good.

Elaborating, Subsection 4.4 highlighted that in-person interaction is crucial for creating a safe space to discuss sexual issues, a context they believe digital interventions cannot fully replicate. This sentiment reflects a broader critique within HCI against the assumption that technology alone can solve complex social problems—a perspective often referred to as techno-solutionism [16, 67, 76]. Critiques include the risk of prioritising technological fixes that overlook complex realities of the communities they intend to serve [67], and the detachment caused by focusing on “state-of-the-art solutions” without considering lived experiences of those affected [51]. Their advocacy for participatory design underwrites a bottom-up approach where interventions are co-created with survivors and partners, ensuring lived experiences guide the design, putting “designing with” rather than “designing for” [120] into practice.

Adopting a techno-neutral lens to sexual health means recognising that not all designs need to be technological [63]. Prioritising contextual needs over our familiar technological solutions allows HCI to more effectively meet the nuanced needs of post-cancer sexual health, ensuring interventions truly support survivors and their partners.

As seen in projects addressing similar sensitive topics like sexuality [41, 111], vaginal health [29, 100], and menstruation [102], technology can either serve as the outcome—the “what”—or be interwoven into the process—the “how”—through exploratory methods like probes or data donation to elicit knowledge [48, 60, 107, 109]. The focus shifts to using HCI to enable context-appropriate interventions rather than forcing technology into the design.

5.3 Limitations

The cultural context of this study, involving medical sexologists from a Northern European country and researchers with comparable backgrounds, limits the generalisability of our findings. Since cultural norms heavily influence how we view, experience, and discuss sexual health, future research should explore how different cultural contexts affect post-cancer sexual health through cross-cultural studies.

This study primarily addresses shared sexual experiences, as most participants visited medical sexologists with a partner, potentially underrepresenting solo sexual health issues, an important area for future research. Additionally, our data lacks insights into diverse relationships, such as queer, polyamorous, and other non-heteronormative relationships. Future studies should explore these contexts for a more inclusive understanding of post-cancer sexual health.

Another limitation is the sample of six medical sexologists. While they represent 14% of the national experts in post-cancer sexual health, their perspectives may not capture the full range of patient experiences. Additionally, since these sexologists primarily interact with patients who actively seek help, the experiences of those who

do not engage with medical sexologists are not included. Future research should explore a broader spectrum of patient experiences, particularly those who might not seek professional assistance.

This study presents the perspectives of medical sexologists, providing an expert view on post-cancer sexual health. Future research should include patients and their partners, other medical professionals like oncologists and nurses, and e-health developers to triangulate these insights and potentially identify a wider range of opportunities for addressing sexual health issues.

6 Conclusion

This study outlines the design space for addressing post-cancer sexual health, highlighting the need for interventions that extend beyond physiological approaches to embrace a holistic, pleasure-oriented perspective. Through interviews with medical sexologists, we identified key themes that describe the complexity of post-cancer sexual health issues and the necessity for interdisciplinary, context-sensitive interventions. Our findings suggest that HCI can play a pivotal role in developing personalised, scalable solutions that are deeply informed by the lived experiences of survivors and their partners, ensuring that interventions are effective, by resonating with the nuanced realities of post-cancer life.

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