

# A qualitative study of sexual health and function of females with pelvic cancer

Niki Oveisi<sup>1</sup>, Zeba Khan<sup>2</sup>, Lori A. Brotto<sup>3,\*</sup>

<sup>1</sup>Faculty of Pharmaceutical Sciences, University of British Columbia, 2405 Wesbrook Mall, Vancouver, BC V6T 1Z3, Canada

<sup>2</sup>Faculty of Medicine, University of British Columbia, 2329 West Mall, Vancouver, British Columbia, V6T 1Z4, Canada

<sup>3</sup>Department of Obstetrics and Gynaecology, University of British Columbia, 2775 Laurel Street, 6th Floor, Vancouver, British Columbia, V5Z 1M9, Canada

\*Corresponding Author: Department of Obstetrics and Gynaecology, University of British Columbia, 2775 Laurel Street, 6th Floor, Vancouver, British Columbia, V5Z 1M9, Canada. Phone: 604.875.4111 ext. 68901. Fax: 604-875-4869. Email: Lori.brotto@vch.ca

## Abstract

**Background:** Pelvic cancers are among the most common cancers, impacting millions of individuals worldwide annually. However, little is known about the impact of more rare pelvic cancers on the sexual health of females.

**Aim:** In this study we explored sexual health experiences of female pelvic cancer survivors (FPCS) and their healthcare providers (HCP) in order to identify the most salient impacts of pelvic cancer on sexual function.

**Methods:** In this qualitative study, semi-structured online interviews were conducted with 15 female patients with vulvar, vaginal, uterine, ovarian, endometrial, cervical, bladder, and/or colorectal cancers. Additionally, semi-structured online interviews were conducted with HCPs who treat pelvic cancers ( $n = 9$ ). For data analysis, qualitative framework analysis was used.

**Outcomes:** We used the collected data and analysis of findings to establish recommendations including ways to improve sexual health and function in female survivors of pelvic cancer.

**Results:** Most FPCS experienced negative impacts on their sexual health and function through increased pain and dryness, bleeding due to atrophy, decreased libido, and psychosocial issues such as body dysmorphia. Females with the rarer vulvar and vaginal cancers faced additional challenges to their sexual health such as shortening of vaginal canals, high levels of neuropathy, lack of sexual activity with their partners, and suicidal ideation. FPCS had unmet sexual health needs, which can be attributed to lack of appropriate training by HCPs and lack of resources and availability of services. Although HCPs recognized the importance of providing sexual healthcare, they lacked confidence in their ability to facilitate a conversation on sexual health with their patients, and often avoided this topic.

**Clinical implications:** The sexual health outcomes of FPCS can be improved by providing targeted training for HCPs, developing standard resources for sexual health, and integrating tiers of support, including group interventions and counseling.

**Strengths and limitations:** The main strength of this study is that data were collected from HCPs as well as FPCS, thus providing a more in-depth overall picture of the current strengths and weaknesses of the resources for sexual health support available for this patient population. A limitation of this study is that the experiences of transgender men were not captured.

**Conclusions:** Sexual difficulties are very common in all FPCS, particularly survivors of vulvar and vaginal cancers. Improvement of sexual health outcomes is needed in this patient population, which can be achieved by providing more training for HCPs, developing robust resources for FPCS and their sexual health, and providing more opportunities for tiered support.

**Keywords:** pelvic neoplasms; cancer survivors; sexual health; sexual dysfunction; psychological; sexual dysfunction; physiological; genital neoplasms; female.

## Introduction

Female pelvic cancers include vulvar, vaginal, uterine, ovarian, endometrial, cervical, bladder, and colorectal cancers.<sup>1</sup> These diseases include female gynecological cancers, which are cancers that can have significant impacts on sexual function due to treatment impacts and proximity to female sexual organs. These cancers collectively make up some of the most common cancers, impacting millions of females worldwide every year.<sup>2</sup> Due to advances in treatment, survival rates have greatly improved. It is known that 90% of pelvic cancer survivors experience significant side effects in the long term, with the most common and distressing symptom of their diagnosis and treatment being sexual dysfunction.<sup>3,4</sup> As survival rates improve, the side effects of cancer treatment on lifelong health

outcomes, particularly sexual function, are an extremely necessary and relevant area of research to increase understanding of how best to support patients in their survivorship journey.<sup>5</sup>

Sexual dysfunction symptoms are commonly triggered along with pelvic cancer treatment and often persist long into survivorship.<sup>6,7</sup> Common modes of treatment are surgery, chemotherapy, hormone therapy, and radiation, which can be used individually or combined.<sup>6</sup> Treatment involving surgery for pelvic cancer can involve removal of the uterus, ovaries, bladder, or other organs in the abdomen or pelvis that are affected by the cancer. Although modern techniques ensure minimal nerve damage, patients still experience neuropathy as well as changes in sensation during sex.<sup>6</sup> Chemotherapy induces alopecia, weight loss, and other stressors during

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treatment.<sup>6</sup> Posttreatment, the impacts of chemotherapy on hormones produced by the ovaries prevails, resulting in early menopause, hot flashes, and vaginal dryness. Similar symptoms are seen in hormonal treatment.<sup>6</sup> Radiation treatment has impacts on hormones, and when directed at the pelvis it also causes scarring and narrowing of the vagina, resulting in painful sex.<sup>6</sup> Overall, the sexual health and function impacts of cancer treatment on the cancer survivor can be visible and invisible. Visible physical changes may include vaginal fibrosis, removal of vaginal anatomy, and bleeding during penetration. Invisible changes are related to chemically induced menopause and may include vaginal dryness, reduced desire, pain during penetration, body image changes, and deterioration in overall mental health of FPCS.<sup>4</sup> These side effects negatively impact the sexual quality of life of FPCS and their partners, and may influence their decision to undergo treatment.<sup>8</sup> Moreover, impairments in emotional wellbeing and quality of life, caused by sexual dysfunction, could lead to higher rates of morbidity and mortality.<sup>9,10</sup>

Although research on treatments to address sexual dysfunction in prostate cancer is well established, the sexual health needs of patients with other pelvic cancers, such as female pelvic cancers, have been studied considerably less.<sup>7</sup> Both cisgender women and transgender men are susceptible to female pelvic cancers.<sup>11</sup> Among female pelvic cancers, gynecologic cancers are associated with a variety of psychosexual problems<sup>7</sup> such as sexual distress, which affects >50% of survivors.<sup>12</sup> Despite the prevalence of sexual concerns in pelvic cancers, qualitative research on the salient experiences of FPCS and the role that the healthcare system plays in their survivorship is scarce.<sup>7</sup> Vulvar and vaginal cancers in particular are even more rare gynecologic cancers that have been studied minimally when it comes to sexual health sequelae.<sup>13-16</sup> Due to more invasive treatment methods, the biggest source of suffering for females following treatment is sexual difficulty and its direct impact on psychosocial morbidity,<sup>17,18</sup> and more in-depth research is required to improve resources as survivorship improves.<sup>7</sup>

Furthermore, literature suggests that because they serve as the portal to healthcare resources, HCPs play a critical role in FPCS access to sexual health treatment.<sup>13</sup> However, HCPs face barriers to addressing sexual health (e.g., lack of time and training in sexual healthcare, embarrassment) that limit the potential of FPCS to obtain appropriate care.<sup>13,19,20</sup> In a study by Bal et al., the authors USED qualitative methods to explore sexual problems of patients with gynecological cancer.<sup>21</sup> Participants noted issues with body dysmorphia, sexual functioning, reproductive ability, and gender norms. Additionally, they expressed the desire for more information and increased involvement from HCPs. This study did not include survivors of vulvar and/or vaginal cancer, nor did it include HCP perspectives. Due to their immense involvement in progression through treatment and posttreatment care, it is vital that HCPs be included in research regarding the sexual health and function of FPCS.

Existing literature indicates the following: (1) diagnosis and treatment of patients with female pelvic cancers cause major sexual health concerns and require long-term management,<sup>21-24</sup> (2) vulvar and vaginal cancers, although rare, have sexual health and functional impacts that are largely unexplored,<sup>13-16</sup> and (3) HCPs play an important role in the trajectory of sexual health and function both during and after treatment.<sup>13</sup> Given the established impact of pelvic cancer on

sexual health and function, the objective of this study was to use qualitative methods to gain a deeper understanding of the perspectives of FPCS and HCPs regarding the impact of female pelvic cancers on sexual health and function. In particular, we focused on the rarer vulvar and vaginal cancer types that are often overlooked in research.<sup>13-16</sup> Additionally, in this study we explored the role of the healthcare system in the trajectory of sexual health and functional difficulties after a diagnosis with female pelvic cancer. Our findings will be used to establish recommendations for improving sexual health and functional outcomes in survivors of female pelvic cancer.

## Materials and Methods

### Design

Semi-structured online interviews were conducted among females with a diagnosis of pelvic cancer who are no longer receiving treatment. A framework analysis was then completed on the interview transcriptions.<sup>25</sup> This study was approved by the Behavioural Research Board of the University of British Columbia (H20-02276).

### Sampling Strategy

FPCS' inclusion criteria were: self-reported history of one or more of the following pelvic cancers vulvar, vaginal, uterine, ovarian, endometrial, cervical, bladder, and/or colorectal; identifying as a woman or transgender man with female sex assignment at birth; age older than 18 years; having received treatment for pelvic cancer within Canada; and English fluency. FPCS were recruited through the following methods: (1) A cancer registry held by the British Columbia Cancer Registry of all treated cancers over the past 5 years, (2) direct referral from one of the gynecologic cancer physicians at the University of British Columbia, and (3) social media managed by the research lab.

HCPs were eligible to participate if they met the following inclusion criteria: being a healthcare provider practicing in Canada who treats one or more of the following pelvic cancers: vulvar, vaginal, uterine, ovarian, endometrial, cervical, bladder, and/or colorectal; older than 18 years; and fluent in English. HCPs were recruited with advertisements through the University of British Columbia gynecologic oncology physician networks, performing internet searches and emailing potential participants, and social media posts.

### Data collection

Semi-structured interviews were held by the first author on Zoom, due to the restrictions put in place by the COVID-19 pandemic. Topics probed with open-ended questions included impact of sexual health and function on the individual, role of relationships in sexual health and function outcomes, interactions with the healthcare system, and potential target points to improve sexual health and function outcomes. Interviews were a maximum of 60 minutes long and conducted between February 2021 and May 2021. All identifiable data were stored in Microsoft OneDrive.

### Data analysis

Once the recordings were transcribed verbatim, the data were analyzed through the framework analysis, a multistage method for analyzing data.<sup>25</sup> The framework analysis consisted of 5 steps: (1) Familiarization: went through the

transcripts and gained a deeper understanding of the data. (2) Coding: each transcript was read line by line, and a label (i.e., a code) was applied to each line of data (a rough coding framework for this stage was developed based on the questions of the interview). (3) Finalization of a working analytical framework including themes and subthemes: after coding a few of the transcripts, the working analytical framework was finalized, this framework contained the themes and subthemes under which all participant quotes were placed. (4) Application of the analytical framework and indexing: the framework was then applied and all transcripts were coded, and the relevant participant quotes were placed in a document under each appropriate theme and subtheme, and each was labeled with the participant number. (5) Charting: in order to summarize the data, a spreadsheet was used to generate a matrix wherein the data were charted, highlighting the quotations that captured the discussion in its entirety. Two authors individually completed each step of the coding for each transcription in order to avoid bias. Where there were conflicts, discussions were held until an agreement was reached.

## Results

### Participant characteristics

The study sample contained 15 FPCS (Table 1) and 9 HCPs. The FPCS had an average age of 48.7 years, ranging from 39 to 59 years. Participants had been treated for vaginal, vulvar, endometrial, uterine, cervical, colorectal, and/or ovarian cancers. All FPCS identified as cis-gender, were in remission status from their pelvic cancers at the time of the interview, and had undergone a combination of one or all of the following treatments: chemotherapy, radiation, surgery, and/or brachytherapy. The FPCSs were diverse in terms of relationship status, as individuals were married ( $n = 7$ ), single ( $n = 3$ ), in a relationship ( $n = 3$ ), and common-law ( $n = 2$ ). HCPs in this sample were surgical oncologists ( $n = 4$ ), medical oncologists ( $n = 1$ ), radiation oncologists ( $n = 3$ ), and sexual medicine physicians ( $n = 1$ ). All HCPs had experience working with pelvic cancer patients. In this section, 3 themes (Impact on Survivor, Role of Relationships, and Interactions with the Healthcare System) are reviewed for survivors of endometrial, cervical, colorectal, uterine, and/or colorectal cancers and survivors of vulvar and/or vaginal cancers. Last, themes of potential levers of change that arose in data collection along with supporting quotations are reviewed across all cancer types (Figure 1).

### Experiences of FPCS: endometrial, cervical, colorectal, uterine, and colorectal cancers

#### Theme 1: impact on survivor

The impacts of all phases of the cancer journey on the pelvic cancer survivors were explored in depth. Overall, almost all FPCS felt an impact on their sexual health due to their cancer and its treatment. Mental health issues relating to their sexual health function were prevalent, with some FPCS using various coping strategies to relieve some of the stress. The impact of time as well as gender norms on their sexual health experience throughout survivorship were also prevalent.

#### Sexual health and function.

Sexual function was explored as issues with pain and/or discomfort, arousal, lack of desire, difficulty reaching orgasm,

**Table 1.** Age and pelvic cancer type of survivor participants ( $n = 15$ ).

Participant ID	Age, years	Cancer type	Relationship status
3	47	Endometrial	Married
6	51	Vulvar	Married
7	39	Cervical	Married
8	52	Cervical	Married
9	52	Vulvar	Married
10	42	Vulvar and vaginal	Single
11	51	Cervical	In a relationship
12	45	Colorectal	Common law
13	41	Cervical	In a relationship
14	52	Uterine and ovarian	Single
15	40	Ovarian	Single
18	47	Cervical	Married
19	59	Vulvar	In a relationship
20	56	Uterine	Married
21	57	Cervical (metastasized to vagina and T5)	Common law

and any other complaint that the survivor denoted. Nerve and tissue pain, bleeding due to atrophy, decreased libido due to induced menopause, body dysmorphia, and the trauma of diagnosis and treatment were frequently mentioned as sexual function concerns. FPCS posed issues with their sexual function as mechanical, psychological, and/or hormonal. Almost all FPCS said they had little to no sexual function during their treatment and recovery.

*“I believe there is a psychological part to this because my whole relationship towards sex has somehow changed, and I used to like being close to my husband, I used to enjoy a really healthy sexual relationship, but because I think this cancer had something to do with my sexual organs, I have lost connection to that part of my body.”* 7, cervical cancer.

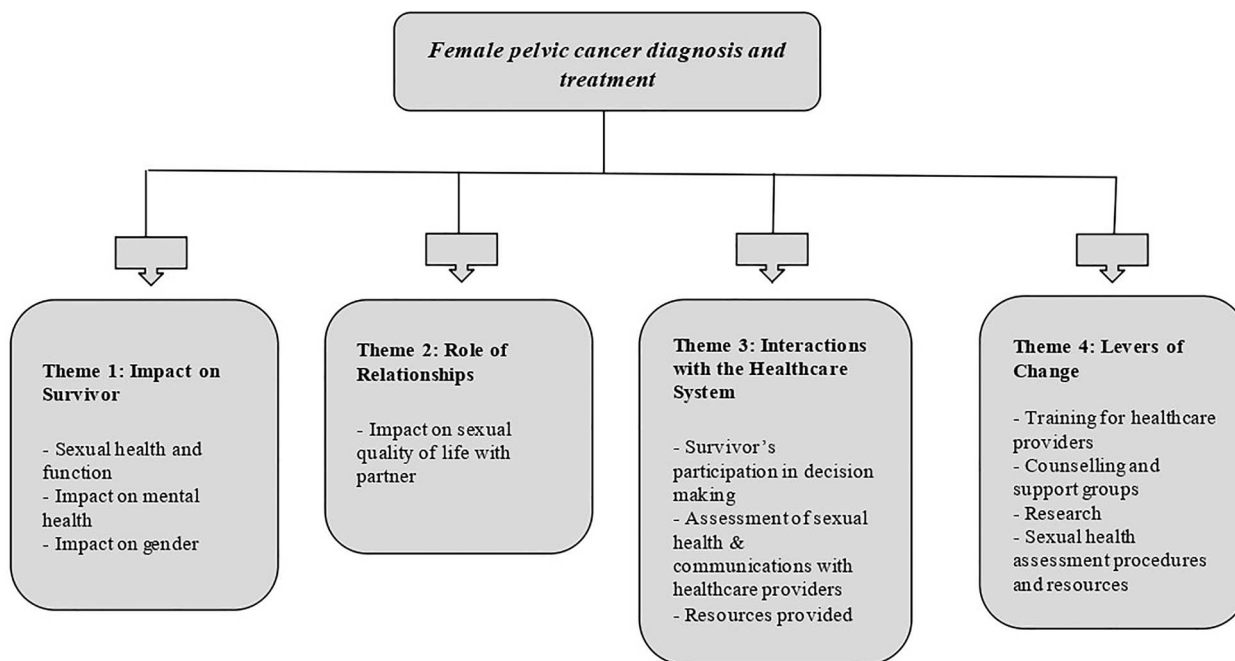
In contrast, a few FPCS noticed an increase in sexual function during remission, as their cancer negatively impacted their sexual function prior to diagnosis and treatment. Some credited this increase to a heightened appreciation for their partner and a strengthened emotional connection.

*“Well, I think, to be honest it actually made it better, because I was having so many problems with the cancer. I was—it was always interfering and not knowing I had cancer, of course, it was a lot of bleeding all the time so that was really awful and there was more pain for sure before treatments before surgery.”* 3, endometrial cancer.

Several FPCS noted that physical sexual health symptoms (e.g., dryness, bleeding, and pain) improved with time; however, psychological symptoms were more mixed, with several participants denoting that their sex drive had not returned throughout time, whereas others reported improvements as they learned to cope.

#### Impact on mental health.

Participants spoke fluently about the impact of their sexual health symptoms on their mental health. Themes of anxiety, depression, depersonalization, PTSD (posttraumatic stress disorder), suicidal ideations, and body dysmorphia were frequent. All individuals who experienced negative changes to their sexual health also experienced a negative impact on



**Figure 1.** Coding tree outlining themes and subthemes of framework analysis.

their mental health. Words such as “loss,” “guilt,” “anxious,” “depressed,” “sad,” and “trauma” were often utilized by FPCS when they described the impact of decreased function on their mental health. These mental health issues often spiked during times of sexual activity or when symptoms of decreased sexual function were heightened.

*“The first year, 18 months, 2 years [after treatment] were rough...like I said I’ve never cried during sex before, and I’d seen blood everywhere and I’d just weep...I’d just be overwhelmingly sad.”* 13, cervical cancer.

Several participants expressed feelings of guilt, as their decreased sexual function had a negative impact on their relationship. A few participants denoted that although their relationship with sex had completely changed posttreatment, they feared losing their partners, and would have sexual activity in order to cope with that fear. At times, this would cause more mental health issues for the survivor.

*“You know I just do the bare minimum for the sake of my relationship, and I do it because I feel I should. Generally, I dread the thought of having sex. And when we have it, I don’t enjoy it, and I even tear up and I would like to run back to the washroom afterwards and maybe shed a few tears.”* 7, cervical cancer.

#### *Impact on gender.*

FPCS frequently mentioned themes of how the treatments impacted how they felt as women. Those who had surgical excision of parts of the genitals expressed that they no longer fit the norm of a woman’s physique, which led to body dysmorphia and low sexual self-esteem. Additionally, the difficulties FPCS faced in engaging with sexual activity resulted in them not feeling like a complete woman, especially in the context of relationships with their partners.

*“I think as a woman, you feel a little inadequate in the sense that you feel something’s been taken from you. You’re not able to be that person of that excitement of what you were. Do you want to go throw on a negligee? Absolutely not.”* 20, uterine cancer.

One survivor, who identified as asexual, described how her hysterectomy had more of an impact on her gender identity as opposed to her sexuality.

*“I kind of feel like it’s-like the whole thing with like surgeries and stuff like that has been a bit more impactful on like gender identity than sexuality.”* 15, ovarian cancer.

#### **Theme 2: role of relationships**

The role of relationships with partners were explored in interviews with FPCS and HCPs. The majority of FPCS noted major changes to their sexual quality of life with their partners. Additionally, the support of partners had a major impact on the overall journey of navigating changes to their sexual health.

#### *Impact on sexual quality of life with partner.*

The majority of FPCS noted that their sexual quality of life with their partners was impacted greatly by their diagnosis and treatment. Almost all of the impacts were negative and heavily changed multiple aspects of their sex lives. Decreased sexual activity was the most prevalent symptom of the changes to their sexual health.

*“For me now, even though I’m able to share the love with my husband, and feel close with him, which is a nice feeling, I don’t think it will ever be to the degree of what we shared together. You know the real passionate lovemaking, the really hanging on to each other, the closeness, the being still and looking at one another and staring at each other*

*when you're in the most heated moment, the feeling of it. It's gone and not because it's gone on my part it's gone because I can't. My body doesn't obviously function the way that it used to, so I will never be able to get that back—the emotions and feelings. The really intense lovemaking that you feel is something that I can't give and I won't be able to obviously because of all the reasons of cancer, the being forced into menopause, no estrogen, all of that.” 20, uterine cancer.*

There were also instances where FPCS did not have the drive for sexual activity but engaged in it due to feelings of guilt. This in turn resulted in a decreased state of mental health, as well as feeling isolated from their partner. Additionally, FPCS indicated that their partners often felt sad and did not feel wanted as they too could sense the lack of connection during sexual activities. This was heightened by FPCS not feeling understood by their partners and fearing that they may lose the relationship due to lack of sexual activity.

*“My partner and I've been together for 14 years and we did have an active sex life before cancer, and I think after cancer and after the treatment, I feel guilty, because I haven't had the desire. We still have sexual intercourse or sexual acts and he gets pleasure from it, but I'm not involved in that—I feel like there's no connection there. My partner's very understanding, and he knows obviously everything I've been through. I guess just because we kind of lost that connection, I think maybe it makes him feel bad.” 12, colorectal cancer.*

It is important to note that there were instances of improved sexual quality of life, when treatment alleviated the symptoms of cancer that were preventing regular sexual activity such as bleeding and/or obstructions. This was heightened with one participant, for whom her sexual quality of life improved due to a stronger emotional connection.

*“Actually, in all honesty we were surprised because it became better after. It's probably not just the physical aspect of it, but more emotions, because he almost lost me, and for me I just want to seize the moment.” 14, uterine and ovarian cancer.*

### **Theme 3: interactions with the healthcare system**

FPCS interactions with the healthcare system following a cancer diagnosis were also explored, specifically during the treatment phases and during remission. Many FPCS expressed their dissatisfaction with the lack of shared decision making, HCP assessment of sexual health, and gaps in communication related to sexual health. FPCS highlighted several gaps in the healthcare system when it comes to supporting their sexual functioning post-cancer.

#### *FPCS participation in decision making.*

Some FPCS felt that they did not have the opportunity to participate in the decision making regarding their cancer treatment. Additionally, FPCS reported that they had to use dilators even though they were not comfortable with them. They also shared that they felt as if they were “pushed” through the system without having any opportunity to voice their concerns. In contrast, a few FPCS have expressed that

they had the opportunity to choose to accept or decline treatment options presented to them.

*“I don't feel comfortable with the dilator. What else can I do, you know? They [HCP] say, I had to do it, I said but I don't like it, I don't feel comfortable. I don't want to do it, so I stopped doing that [using a dilator] and it was a problem because the vagina was closing...” 8, cervical cancer.*

*“Although they [HCP] recommended that I have a hysterectomy, I didn't have one. They wanted to do more radical and invasive treatments and I just declined.” 13, cervical cancer.*

Many FPCS reported having to do their own research, particularly for sexual health-related concerns and postcancer treatment. Through their own research, FPCS discovered treatment options like using dilators to prevent vaginal stenosis, and massage therapy and acupuncture for pain management. FPCS described bringing these treatment options up with their healthcare providers themselves.

*“Yeah! And I had no idea about this, and apparently after radiation you're supposed to start inserting this dilator inside you right away, and the dilator comes with different sizes and it starts small to large. I think there's like 5 or 6 different sizes, but no one told me, so I read about it, and I was like oh my goodness! So I bought one on Amazon, and then I started it but, mind you, this was maybe like a year after and I was worried that maybe the scar tissue had started to develop because I think you're supposed to use it right away to help keep you open.” 12, colorectal cancer.*

*“There was one point where she [HCP] had said that, maybe I should go on the pill and I am just strongly against it, so that wasn't an option. But why is it that I was the one who ended up thinking of the IUD, right?” 3, endometrial cancer.*

#### *Assessment of sexual health and communications with HCPs.*

Six out of 9 HCPs interviewed stated that they inquired about sexual health during a consultation. HCPs who had a practice of assessing the sexual health of individuals with pelvic cancer asked open-ended questions to guide the conversation, and many HCPs had their patients fill out a questionnaire on sexual health prior to the visit. Three physicians stated that they used a modified version of validated questionnaires that are typically used to assess a patient's quality of life. If a sexual health-related issue that requires further investigation had been brought up during the consultation, patients were referred to a specialist.

*“...I ask them if they're having intercourse, I ask them...are you using your dilator, are you having issues with discomfort... and you know usually that's kind of the starting point” 16, radiation oncologist.*

Six of the 15 FPCS interviewed felt that they had to initiate the conversations regarding their sexual health and ask for resources and referrals to psychiatrists, gynecologists, and other specialists.

*"I had one follow-up with him [HCP], and that was in 2019 in the fall. And then nobody talked to me at all about sexuality. Nobody. Absolutely. Nobody, nobody did a, gyn exam."* 21, cervical cancer (metastasized to vagina and T5).

FPCS expressed that when HCPs could answer their queries regarding sexual health and provide appropriate resources, they felt comfortable and satisfied with their interaction with the HCP.

*"He [HCP] still asks that, are you sexually active, you know, so he's been asking that since I completed all the treatments. And so I can tell him, yes or no, and how often and he just asks me some very open questions and I'm okay sharing with him, because 1, I think he needs to know, 2, I mean, it gives me a peace of mind if I ask him a question and then he answers."* 11, cervical cancer.

Two HCPs expressed that they worried about making the patient uncomfortable by inquiring about their sexual health, especially if they had not been able to establish a long-term doctor-patient relationship. Others were worried about not having enough training or knowledge to provide sexual health support and were deterred from inquiring about it. HCPs who did not specialize in sexual health issues expressed that they viewed their roles as conversation starters. They also recognized the importance of sexual healthcare and creating an environment where FPCS can ask questions. When sexual function was discussed, the HCP mostly discussed the use of estrogen, dilators, etc.

*"...I am not a sexual health expert. It's more complex. It's nuanced. It requires more time and effort beyond, you know, a surgical follow-up or consultation. And although I feel like I'm comfortable talking about it and I can give patients a safe space to talk about it. I'm not going to solve all of the problems, and I see myself more as providing that initial openness, sometimes initiated, but sometimes also reacting to questions and, you know, providing the level of help that I can by acknowledging their challenges by encouraging them, for speaking up."* 26, surgical oncologist.

*"My side is the sort of apprehension I would have about not being all that knowledgeable about some questions or even you know who to reach to in the community to provide a better support or answer than myself, so I would say that's probably—my guess would be that's, the, the chief thing."* 4, medical oncologist.

We asked HCPs to discuss their experiences discussing sexual health among patients who were transgender men but unfortunately our sample reported limited experiences working with transgender men diagnosed with pelvic cancers. In the few instances where HCPs provided care for this population, they indicated that they at times felt discomfort when discussing matters of sexual health and avoided bringing the topic up with them. However, HCPs reported that they used similar techniques when discussing sexual health with transgender men and tried to pay attention to the psychosocial

aspects of sexuality, as well as respecting the correct use of pronouns.

*"I just take an approach of openness and inclusion and not to make assumptions at the get-go about their sexuality, and try to get to know them as a, as a person...if you can take a little bit of time to know their social history and take the time to ask about their sexuality, I think that's my general approach. I haven't really encountered any specific concerns of trans patients as opposed to general sexual health. So I think those issues, I would approach them the same way as for a someone in a cis-relationship."* 28, surgical oncologist.

#### Resources provided.

In most cases, radiation oncologists were responsible for conducting postcancer treatment follow-ups with FPCS. During this follow-up, HCPs provided resources such as dilators and estrogen creams, if applicable. However, HCPs expressed that they found it challenging to offer appropriate resources due to limited availability and awareness.

*"I find that it is something that is missing in terms of our routine follow-up and I don't have any resources at our center that I can actually send them."* 17, radiation oncologist.

Patients who required additional support for sexual health management were referred to a sexual health specialist or counselor. In our interview with a sexual medicine specialist, they reported that the wait times for a sexual health consultation at their clinic were lower than expected. However, survivors did denote that sometimes referrals were missed, and they did not hear back from specialists. Wait times are dependent on barriers such as the survivor's location of residence (i.e. rural vs urban), or inconsistencies in the referral and follow-up processes.

*"And the student helper said to me that we will send a request to... sexual health [clinic] -I don't know which department it was. Nothing ever came back so this was supposed to be a referral."* 7, cervical cancer.

### Experiences of FPCS: vaginal and vulvar cancers

Although vaginal and vulvar cancers are rare, their impacts on sexual health are monumental due to the direct impact on vulvovaginal anatomy. Here, we explore this impact in more detail by sharing experiences by the 5 participants who had been diagnosed with vulvar and/or vaginal cancers.

#### Theme 1: impact on survivor Sexual health and function.

All 5 FPCS with vaginal or vulvar cancer histories experienced major changes to their sexual health and function due to diagnosis and treatment. Those with vaginal cancer had to undergo brachytherapy as treatment, which meant that vaginal canals had shortened as well as atrophied. Half of those with vaginal cancer reported no longer engaging in sex. Those with vulvar cancer had undergone surgeries to remove portions or all the vulva (including the clitoris and labia), resulting in major nerve pain, or neuropathy. Of the three vulvar cancer survivors, none of them reported currently

having sex. All FPCS interviewed who had vaginal or vulvar cancers reported a decrease in sexual activity, and treatments such as dilators, lubrication, and painkillers provided limited benefit.

*“Oh I have pain so severe it’s not funny. It’s nerve pain from all the surgeries they’ve done. And the pain is the worst like I can’t even explain how bad the pain is—especially after they removed the clitoris. I get these horny feelings, and I can’t release it and it causes so much pain that I’m vomiting for hours.”* 9, vulvar cancer.

#### *Impact on mental health.*

The majority of FPCS with vulvar and/or vaginal cancer in this sample described major changes to their sexual self-esteem and confidence. When queried about impacts on their sexual self-esteem, participants expressed not feeling as sexy, not feeling like the same person, and grieving the loss of who they were.

*“I don’t feel as complete as a woman, and it is not as joyful and it’s not quite the celebration. My partner never says anything, whether he feels it and doesn’t say it, I don’t know. But those are the feelings that I wrestle with.”* 19, vulvar cancer.

#### *Impact on gender.*

Vulvar cancer FPCS described feeling symptoms of body dysmorphia, which caused them to avoid sexual interactions, not relate to their body, and not feel like a woman anymore. This group also reported significant concerns regarding the fact that their surgeries are mainly external and visible, and how they negatively impacted the look of their genitals.

*“On the outside [of the vagina], there’s really nothing. You know what I mean? I feel like I’ve been backed up. I don’t want my husband to see because I just don’t feel normal. Right? It’s not normal. It’s really hard.”* 6, vulvar cancer.

*“You don’t feel like you’re fully a female anymore. You lose a lot of contact with people. Even when my husband goes to give me a hug now, I jump because I’m not used to being touched.”* 9, vulvar cancer.

#### **Theme 2: role of relationships**

In this sample of FPCS with vaginal and/or vulvar cancer, the participants noted that the changes they felt to their sexual health had a major impact on their relationships. Those who were in relationships reported reduced sexual activity after diagnosis and treatment. Vaginal and/or vulvar FPCS who were not currently in a relationship noted that they are now much more selective in who they engage with romantically and sexually, due to the major physical and psychological changes they experienced. There were also instances where vaginal and/or vulvar FPCS feared having to start a new relationship, as they were not sure if their next partner could understand the depth of what they have gone through.

*“Before I was diagnosed with cancer, we had sexual activity probably about 4 times a week and it was very easy and*

*uninhibited. And now it’s like, oh my God, like I’m scared. So I have to use the dilator beforehand and make sure that there’s lots of lubricant. Then he’s scared to hurt me and there’s a lot to it. So basically, it’s only been once every 2 weeks.”* 21, cervical cancer (metastasized to vagina and T5).

*“I don’t want to say I’m more introverted in the way that I don’t want to be with anybody, but it’s definitely made me reevaluate some things. You know I could be alone for the rest of my life...unless I find somebody that’s going to be understanding. I’d rather be alone and happy than with someone and miserable.”* 10, vulvar and vaginal cancer.

#### **Theme 3: interactions with the healthcare system**

One vulvar cancer survivor had grown reliant on opioids to manage nerve pain, a permanent symptom of her clitoris removal surgery, as part of treatment. Due to increasing stressors on the healthcare system from the opioid crisis, her physician recommended weaning her off the medications. This resulted in suicidal ideation and complete detachment from society due to the high levels of neuropathy.

*“I don’t feel like I fit in anymore in the world. With the pain being as bad as it is, it’s such a struggle. I feel suicidal. I said taking me off these medications—you’re just going to find either a person on the streets self-medicating, or you’re going to find me dead, because I’m not going to live like this.”* 9, vulvar cancer.

#### **Theme 4: Levers of change recommended across all participants**

Both FPCS and HCPs shared many opportunities to improve the survivor’s sexual health outcomes and experiences during and after cancer treatment. HCPs discussed the importance of targeted training for both physicians and counselors. Both groups highlighted the need for support groups for sexual health-related concerns following cancer treatment. Additionally, more research on the sexual health experiences of individuals with pelvic cancer was strongly recommended.

#### **Lever of change 1: training for HCPs**

Most HCPs expressed that they lacked adequate training and knowledge to support the sexual health needs of individuals with pelvic cancer, which impacted their ability to ask the right questions and facilitate a discussion about the survivor’s sexual health. Additionally, HCPs found it challenging if the survivor had a rarer type of pelvic cancer, such as vaginal or vulvar cancer.

*“Oh, well, I think it’s [adequate training] an issue. We absolutely, I think I would always find benefit from more specific targeted training in this [sexual health] domain.”* 28, surgical oncologist.

*“We get very little training. I feel like that’s an area that is not taught when we’re doing our training, how to manage these women with vulvar cancer that have had these surgeries that leave them with either significant sexual dysfunction...I don’t have a lot of experience with [individuals*

*with vulvar cancer] because... there's not a lot of teaching of how to manage those patients . . .*" 5, surgical oncologist.

Cancers such as vaginal, cervical, and others that require internal radiation, result in significant stenosis and impact on the integrity of the vaginal canal. These subsequently have major impacts on sexual function in both the short and long term. The majority of HCPs recommended dilators to reduce the impacts of vaginal stenosis, estrogen to alleviate symptoms of induced menopause, and lubricants to assist with dryness of the vagina. However, several HCPs indicated that their lack of training regarding these resources made them reluctant to offer them to patients.

*"You're limited by what you know works right Like I mentioned before, for someone who's had cervix cancer treatment or vaginal cancer treatment, I know that vaginal dilators are an option...but for vulvar cancer I'm really not aware of advice you can give to women that you know that is helpful, so I tend to not to. I'm least likely to bring it up. It's hard if a woman sees that they're struggling with sexual dysfunction because they've lost their clitoris as part of their surgery, you know?"* 5, surgical oncologist.

Both FPCS and HCPs used words like "hard," "cold," "white plastic," "centrifuge tube," "rudimentary," "too wide," "too rigid," to describe the dilators. FPCS shared that they were reluctant to use them and feared that they would be hurtful.

*"...I guess a part of me was afraid to use them just because they were so damn hard and cold...if you're going to create something that is supposed to be a part of the healing...they could have made it a little bit different...I just thought it's gonna hurt..., more than anything, really, but it didn't it just yeah it's just uncomfortable"* 11, cervical cancer.

HCPs felt that structured and specific training would help them understand the needs of FPCS and assess their sexual health. This training should include counselling on dilators, so that HCPs can adequately explain how dilators should be used. Furthermore, programs that provide formal instruction to trainees have received positive feedback. HCPs also felt that follow-up visits with FPCS would be beneficial, especially if FPCS faced any challenges using the dilators.

*"We just started this rotation last year and the feedback that we get is overwhelmingly positive about the usefulness of that rotation for their future clinical practice and that it has significantly increased their comfort level in approaching many sexual health and vulvar health conditions."* 22, sexual medicine physician.

### **Lever of change 2: counselling and support groups**

Most FPCS expressed the need for specific counseling by professionals and support groups to connect with other individuals going through a similar experience. In particular, FPCS emphasized the importance of receiving support to cope with the psychological impact of altered sexual function.

*"I think that the oncologist and the cancer experts are amazing and they are absolutely excellent, but I just feel*

*that, where it falls off the map is you don't get counseling from somebody whose expertise is of a woman who has gone through menopause, a woman that knows the body, you need somebody—not just a counselor, because you need to work through these things."* 13, cervical cancer.

HCPs supported the importance of counselling and support groups for FPCS. HCPs also emphasized that general counselling on cancer survivorship is available to FPCS; however, counsellors should be provided with additional training to support the sexual health functioning and recovery of individuals with pelvic cancer. Both HCPs and patients discussed the survivor's ability to afford counseling and the importance of making counseling accessible to patients regardless of their financial abilities or physical location.

*"I think that from both my personal and professional experience, counseling is probably underutilized and not always affordable. ...The sexual medicine folks do a certain amount of that. But I think that they wouldn't necessarily do it in the frequency or the duration that might be required for some patients. They're a little bit more medically focused. I do think it requires a specific type of training and experience to address sexual concerns, not just a sort of, you know, general practitioner type of counselor."* 26, surgical oncologist.

### **Lever of change 3: research**

The majority of the FPCS highlighted the importance of more research in understanding the sexual health needs of individuals with pelvic cancer, specifically treatment options to regain aspects of their sexual drive, and research that provides more guidance to give HCPs more information on how to help FPCS.

*"If there was more research done on pelvic cancer survivors then maybe there would be some guidelines and, as you mentioned, some policy-related things for the providers. It would help me at least know that it's not a lost cause."* 7, cervical cancer.

Extensive research has been conducted on breast cancer survivorship and its impact on sexual health.<sup>26</sup> FPCS highlighted the similarity of mental health experiences (dealing with survivorship, sense of self) with individuals with breast cancer. However, at the same time, there are many aspects of pelvic cancer that are different, such as the treatments and recovery from pelvic cancer. As pelvic cancer directly impacts the individual's physical ability to have vaginal sex, and breast cancer does not, research findings from the 2 conditions may not be entirely comparable. FPCS emphasized the importance of conducting research specifically to improve the sexual health outcomes of pelvic cancer survivors.

*"...Because, with no breasts, you can also feel on the vagina. You can feel that sensation and everything. But for us, for me, for example, I don't feel anything, I feel just pain, because all the treatment was inside and so research will be helpful because we are going for the treatments and everything but it's not the same sensation I think that . . . yeah it's different."* 8, cervical cancer.



“...Cause it’s not because they [individuals with breast cancer] have any damage to their vagina. They’re able to do the act [sexual intercourse] without any problems. It’s more about the mental, like the acceptance of the changes of their body [that’s similar].” 21, cervical (metastasized to vagina and T5).

#### **Lever of change 4: sexual health assessment procedures and resources**

The addition of pamphlets and resource booklets on the management of sexual health postcancer have been suggested by most FPCS. They have also shared that resources which can assist sexual partners understand the sexual function and recovery postcancer would be useful.

“I guess you know, just maybe information that you go home with in all of your care packages. Just to have a really good, detailed list of information for that person to go home with regarding your sexual health as well.” 3, endometrial cancer.

The use of pamphlets and resource booklets has also been identified as a useful tool by healthcare professionals. Most healthcare professionals expressed that they would like to recommend resources but were not aware of any resources available.

“I mean, that would be ideal if there was some pamphlet or some handout that we could just give the patients that addresses a lot of these common concerns with some initial strategies. And if those strategies are not successful, then a referral would be indicated.” 25, surgical oncologist.

One of the challenges that HCPs faced in supporting sexual healthcare is having adequate time to cultivate the right environment and conduct sexual health assessments. HCPs have suggested that having a dedicated team, for example, nurses, or a separate clinic can be a potential solution. In situations where the patient had been referred to a sexual health clinic, they have had positive experiences.

“The feedback that I get from patients is that they feel that offering this clinic and this service is very valuable to them. And they feel it really provides a holistic sexual approach to their cancer care.” 22, sexual medicine physician.

“I would really appreciate it if we had some centralized place that no matter how long the wait is, even if it’s 6 months or so, at least, they have someone to talk to as a jumping platform to initiate that conversation.” 17, radiation oncologist.

HCPs also highlighted the importance of having a system where the patients are cared for by the same individuals or team so that they can build a good doctor-patient relationship. This can help diffuse any uneasiness that the patient may feel about discussing their sexual health.

“I may not be in the follow-up clinic for their next appointment, and it may be one of my colleagues. ...As you know, these sensitive issues are best when you are able to build up

a longitudinal rapport with patients. So that kind of limits my own learning because I’m not getting that feedback from patients at their next appointment about how things worked or what products they found useful or how things are going. I think we have a few limitations here.” 28, surgical oncologist.

## **Discussion**

This study used qualitative methods to probe the experiences of FPCS with regard to their sexual health and function, with an emphasis on the experiences of vulvar and/or vaginal cancer FPCS. Additionally, the role of the healthcare system and potential levers of change were also explored. Questions were asked that covered aspects of the impact of female pelvic cancer diagnosis and treatment on sexual function and health, relationships with partners, navigating the healthcare system, and levers of change to improve and support sexual health outcomes. The findings from this study showed that although the sexual health and recovery experiences vary among FPCS, most agreed that sexual health concerns remain an unmet need, with heightened distress within FPCS of vulvar and/or vaginal cancer. In most cases, both visible and invisible changes in sexual health and function resulted in reduced sexual activity and negatively impacted the sexual quality of life for both the FPCS and their sexual partners. FPCS of vulvar and/or vaginal cancers in this study felt an additional burden on their sexual health and function. This group faced a large reduction in sexual function due to neuropathy as well as vaginal stenosis. Additionally, this group experienced heightened changes to sexual self-esteem and confidence, to the point where they experienced heightened difficulties navigating through society due to overwhelming pain and changes to sexual health.

Participants reported that these concerns are not adequately addressed during postcancer follow-ups with HCPs. This inadequacy can be attributed to the lack of training; unavailability of resources such as pamphlets, guidebooks; and the limited time available during follow-ups. Some HCPs expressed that they avoided discussing topics on sexual health with FPCS, and this finding is congruent with existing literature that explores HCP roles in sexual health assessment for individuals with breast cancer.<sup>9</sup> This avoidance of the topic leads to FPCS feeling dissatisfied with the support and attention given to their sexual health.

In cases where sexual health is assessed and resources are provided, many do not meet the expected standards. For example, this study showed that FPCS find dilators uncomfortable and did not follow through with their clinician’s recommendations on using them, which may lead to further complications in their sexual health function. Sexual health comes second in the priority given the crucial circumstances that often surround cancer recovery. FPCS, nonetheless, should have access to adequate support and information to improve their quality of life after cancer treatment. Based on this study, and existing literature, it is evident that sexual health requires greater attention and plays a critical role in FPCS quality of life after cancer treatment.

As HCPs play a key role in determining FPCS quality of care, specific training on facilitating a conversation on sexual health should be provided to HCPs and counselors. In cases where adequate training had been provided, HCPs

felt a lot more comfortable discussing the sexual health outcomes with FPCS. This finding is supported by a pilot study that demonstrated that brief, targeted training for oncology HCPs positively correlated with HCP frequency and ability to facilitate female sexual health concerns related to cancer.<sup>27</sup> Another barrier to providing sexual healthcare is the limited time allotted for follow-ups with oncologists. A study that explored the different approaches to providing sexual healthcare to survivors across Canada proposed a model of care that involves triaging by specialized sexual health nurses. This model includes several tiers of sexual health services available to survivors, including resources, group interventions, and consultation with sexual health specialists and a triage nurse who assesses individual cases.<sup>28</sup>

Previous qualitative research has focused on either one specific type of cancer, such as cervical cancer,<sup>29</sup> or did not solicit aspects of HCP perspectives.<sup>21,29,30</sup> Osei et al. interviewed 30 cervical cancer patients and explored the impact of cervical cancer on sexual and physical health in Ghana.<sup>29</sup> They found that cervical cancer patients had low libido due to both the cancer itself and impacts of chemotherapy, avoided vaginal sex, and felt impacts in their sex lives with their partners. Another study by Pitcher et al. explored qualitative experiences of women with gynecologic cancer in a follow-up clinic within the gynecology unit in Cape Town, South Africa. Participants explained that sexual functioning was deeply impacted posttreatment in a complex manner, as well as their relationships.<sup>30</sup> They also expressed that more sexual health information from HCPs and resources such as peer support groups would be very beneficial for their sexual functioning posttreatment. In a Turkish study of women who were treated for gynecological cancer,<sup>21</sup> similar results were found, with participants being affected in their body image, sexual functioning, wife and mother roles, fertility, sexual desire and arousal, and changes in intercourse frequency and orgasms. Participants also noted that they wanted more information from HCPs regarding their sexual health as well as opportunities for open conversations.

The findings from this study echo the findings in the literature,<sup>21,29,30</sup> but novel to this study is the information about HCP perspectives, which are important given that they play a large part in the management of the sexual health and function of FPCS. The recommendations from this study take into account the training and education of HCPs, the resources provided to both HCPs and patients, and the overall flow of resources and information from institution to HCP, and HCP to patient. In particular, we found unique experiences specifically among vulvar and vaginal cancer survivors that have only been minimally studied in the past.<sup>13-16</sup>

### Strengths and limitations

A strength of this study is that data were captured from the perspectives of both FPCS and HCPs and showed a holistic picture of the current processes and support for sexual health. This study also demonstrated that vaginal and vulvar survivors are at a heightened risk of sexual health and function issues and are especially prone to issues with mental health and body dysmorphia. One of the limitations of this study was that the experiences of transgender men were not captured, and most of the participants interviewed resided in a large metropolitan city. Future studies should aim to document the experiences of transgender men as well as those who are living in rural areas.

### Conclusion

This study identified several opportunities for improvement of the sexual health and function of FPCS. The sexual health outcomes of female individuals with pelvic cancer can be improved by providing targeted training for HCPs, developing standard resources for sexual health, integrating tiers of support, including group interventions and counselling. Most FPCS expect focused and relevant support to navigate their sexual health functioning after cancer treatment, and highly value this aspect of their lives.

### Author contributions

Conceptualization: L.B.; Methodology: L.B., N.O.; Ethics application and interview design: L.B., N.O.; Recruitment and interviewing: N.O.; Transcribing: N.O.; Data analysis: N.O., Z.K.; Writing - original draft preparation: N.O., Z.K.; Writing - review and editing: L.B., N.O., Z.K.; Funding acquisition: L.B., N.O.; Supervision: L.B..

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*Conflicts of interests.* None.

### Data availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author. Statistical code was not utilized for analysis.

### Ethics approval

This study was approved by the Behavioural Research Ethics Board of the University of British Columbia (H20-02276).

### Consent to participate

Informed consent was obtained from all individual participants included in the study.

### Consent for publication

Informed consent for publication was obtained from all individual participants included in the study.

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