

# The Impact of Cervical Cancer Treatment on Sexual Function and Intimate Relationships: Is Anyone Listening?

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## Abstract

The purpose of this research was to describe women's narrative accounts of the impact of cervical cancer treatment on their sexual function and intimate relationships, and to evaluate what changes in care and education are needed to enhance quality of life and intimacy after treatment. The research approach was a narrative design, using semi-structured, in-depth interviews. Narratives were examined within and across interviews, and thematic content analysis completed. The study was done in a gynecologic oncology clinic at a public hospital in the Midwest United States. The sample consisted of twelve women, ranging in age from 27 to 59, who had completed the cervical cancer treatment with chemo-radiation or radiation and surgery, and were now followed by their gynecologic oncologists. Across narratives, five major themes were identified, including unexpected physical complications, not "getting back to normal," emotional pain and isolation, lack of available information, and inadequate health care provider response to treatment complications and sexual relationship problems. Women's stories reveal that sex and intimacy issues for cervical cancer survivors remain within a culture of silence. In many situations, health professionals did not provide information that realistically prepared women and partners for probable consequences of treatment, did not assess sexual issues before or after treatment, did not recognize various symptoms as being complications of cancer treatment, did not make referrals, and/or recognized complications, but accepted them as "normal" and without solution. Ethical implications for health professionals and the need for education, communication, and the development of new lines of research are discussed.

## Keywords

Cervical Cancer Survivorship, Pelvic Radiotherapy, Sexual Dysfunction, Vaginalstenosis, Patient-Provider Communication

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## 1. Introduction

In the US, standard treatment for women diagnosed with cervical cancer beyond very early stages includes chemotherapy with cisplatin, external beam radiation therapy (RT), and brachytherapy which involves implantation of the radiation source in the vagina, very close to the cervix tumor [1]. Although this treatment has excellent curative potential, it also can cause severe damage to surrounding tissues contributing to significant sexual dysfunction. While sexual and relationship complications arise in many cancer patients, there is substantial documentation that cervical cancer survivors, treated with RT, experience more complications and greater vulnerability to sexual dysfunction than survivors of other cancers [2]-[9].

Radiation destroys the vaginal epithelium, the glands necessary for vaginal lubrication and small blood vessels. Subsequent atrophy causes thinning of the mucosa and loss of lubrication, intensified by radiation-induced menopause. Excessive inflammatory responses involved lead to formation of adhesions and fibrosis, loss of elasticity, stenosis, shortening and possible complete adhesion and closure of the vagina. There may also be severe changes involving inflammation and tissue necrosis with ulceration that can progress to fistula formation. Patients may experience vaginal discharge, bleeding, and vaginal pain (dyspareunia) that contribute to sexual dysfunction and make sexual intercourse difficult or impossible [5] [10]-[18].

Focusing solely on vaginal complications as the cause of sexual dysfunction, however, is an artificial separation from the impact of other tissue damage. This can include uterine complications (perforation, necrosis, infection, abdominal fistulae); bowel (obstruction, rectitis, bloody diarrhea, stricture, recto-vaginal fistulae, perforation); urinary system (cystitis, hematuria, ureteral strictures or stenosis, hydronephrosis, vesicovaginal or bowel fistulas, renal failure); and neuropathic and pelvic pain that are often severe [2] [5] [7] [19] [20]. All of these potential complications can significantly add to the long-term negative impact on psycho-social-sexual functioning and intimate relations, evidenced by significantly lower scores on measures of general health, vitality, mental health, social and emotional well-being, sexual discomfort and gynecologic symptoms than women without cancer or with other cancers [9] [21]-[23].

Although cervical cancer treatment-related vaginal and sexual complications have been described in the literature for over half a century and have been noted in up to 88% of patients, little has changed in incidence or approach to vaginal toxicity and sexual morbidity during that time [8] [10] [24] [25]. Radiation damage to the vagina seems to be considered inevitable and unlike the bowel and bladder, the vagina is often omitted from “organs at risk,” the degree of damage to which influences the determination of maximum doses. Although existing grading systems exist for some treatment complications, a detailed protocol for description and documentation of vaginal morbidity was not published until 2012, in Germany [26]. Although vaginal and sexual changes are reported by patients as one of the most distressing consequences of treatment, this impact is often obscured when quality of life (QOL) is reported as a single overall score [23].

Common post radiation recommendations for cervical cancer patients are limited to 1) resuming sexual function (after variously recommended periods of time post-radiation); 2) vaginal moisturizers and lubricants; 3) vaginal dilation with the aim of maintaining vaginal patency; and 4) (less commonly) topical estrogen treatment. Vaginal dilation recommendations continue, despite a lack of standard protocols, insufficient data to support effectiveness and existing evidence that the practice may be harmful [3] [27]-[29]. Despite evidence showing that topical estrogen promotes partial vaginal epithelial regeneration and decreases dysuria, dyspareunia, and narrowing of the vagina [18]-[30], use of low dose topical estrogen is sporadic [31]-[34].

Although sexual dysfunction is a common consequence of cancer treatment for women, and close to 80% report wanting to discuss sexual matters with their health care provider (HCP), patients often do not bring up sexual issues for fear that it will be considered inappropriate [4]. Providers also have difficulty discussing sexual aspects of treatment, leaving these matters too often overlooked in follow-up and minimally explained during consent for treatment. In a recent observation study [35], HCPs participated in discussion of sexual issues in less than 25% of cancer/RT follow-up visits. Only 15.9% of those discussions were initiated by the HCP.

Most quality of life studies of survivors involve measures and surveys that produce aggregated numeric results, decontextualized from the narrative stories of how treatment complications affect women’s lives and the lives of their intimate partners. Qualitative studies addressing the experience of vaginal damage and sexual function faced within cervical cancer survivorship are rare. A significant gap in the cervical cancer survivorship literature is the voices of the survivors themselves. The purpose of this study was to address that gap by exploring the impact of cervical cancer treatment complications on women’s lives, sexual function and intimate relation-

ships through in-depth interviews with survivors at various points post-treatment. The specific aims of this study were: 1) to obtain patient reports of occurrences of treatment-related complications; 2) to specifically explore the impact of treatment complications on sexual function and intimate relationships; and 3) to evaluate what interventions and educational approaches are desired or perceived by survivors as potentially helpful to enhance QOL and intimacy after treatment for cervical cancer. Permission to conduct the study was obtained from the Institutional Review Boards of the investigator's university and the medical facility. These boards monitor research ethics and protection of human subjects.

## 2. Approach

### 2.1. Research Design

Narrative inquiry, based on a broad definition of “narrative” as peoples’ stories of their experiences, was the methodology used to accomplish the study aims. Telling a story requires making meaning of events in ways that impose order to chaotic experience, contain emotions, and enable connection with others [36] [37]. Illness narratives provide insight into individuals’ reconstruction of identity and self-concept during disruptive events of disease, treatment and complications [38] [39]. In this study, semi-structured interviews were used to explore stories of various aspects of the treatment and survivor experiences. Medical records were also reviewed for demographic, diagnostic, treatment, and follow-up documentation.

### 2.2. Setting and Recruitment

Participants were recruited from a gynecologic oncology clinic at a public hospital in the Midwest United States. Criteria for the purposive sample included women age 18 or over, whose treatment for cervical cancer had included radiation therapy, who were being followed by their gynecologic oncologist after the completion of their treatment and who were physically and mentally able to participate in an interview. Women were accepted for the study at any point post-treatment, as all points provided insight.

From a possible recruitment pool of approximately 80 women (60% Caucasian and 28.5% African American), clinic nurses identified 60 patients likely meeting the study criteria. Letters of invitation to participate in the study were sent by mail to these women. The letters contained information explaining the study and instructions for interested potential participants to contact the investigator. On contact, the study was further explained, and, if the woman agreed to participate, an interview was scheduled.

### 2.3. Sample

Of 14 women who responded to letters of invitation, 12 met inclusion criteria and participated in in-depth interviews. In terms of relationship status, 3 women were married, 4 had live-in partners, 2 were in early long-distance relationships and not sexually active with those partners, 2 women dated occasionally and 1 denied interest in new relationships or sexual activity. The sample included 2 major ethnic groups in close proportion to the recruitment pool, with 8 participants being Caucasian and 4 African American. Of the 12 participants, 11 had received the current standard chemo-radiation treatment [1]. One participant was treated with a combination of surgery and radiation therapy, prior to the implementation of the current standard.

### 2.4. Interview

Interviews were conducted in a small private room within the clinic. At the time of the interview, the study purpose was reviewed and participants signed a consent form as well as written permission for the investigator to review their medical record. Information was collected on all participants (from interviews and medical records) regarding current age, ethnicity, marital/relationship status, number of children, age at diagnosis, stage of cancer at diagnosis, treatment received, response to treatment, and concerns and complications documented during and after treatment. During their interview, the women were invited to ask a current, past, or future intimate partner to participate in a separate interview. Five of the male partners or past partners of the women participated.

Interview questions explored the following areas:

- The participants’ narrative accounts of diagnosis and treatment, information provided during consent, and problems encountered since treatment;

- The nature of communication with health care professionals;
- The existence of intimate partners before, during, and after treatment;
- Relationship/communication patterns with partners before, during, and after treatment;
- Patterns of sex and intimacy before, during, and after treatment;
- Changes in perceptions of “womanhood” or “manhood” and related changes in perception of self (positive or negative) as a result of cancer experience;
- Information, skills, and support desired by the women and partners to promote survival of and satisfaction in relationships; and
- Participants’ responses to the private nature of the interview questions, and suggestions for other questions or topics that the participants felt were relevant.

Upon completion of the interview, participants received a gift card to thank them for their time, as well as transportation reimbursement. Interviews were recorded and transcribed verbatim for individual case and thematic analysis.

## 2.5. Analysis

Narratives can be analyzed in many ways—looking at the narrative as a whole, keeping each story intact, and/or looking across narratives for similarities and differences. Narrative data can be analyzed for common themes within and across interviews; for macro and micro structures of how the stories were told, from repeated words or phrases to detailed linguistic structure; and for performance aspects of the story, considering why the story was told in particular ways to particular audience(s) [36]. Analysis can span a continuum from descriptive to interpretive. The analysis for this initial small study was predominantly descriptive of what the women said, looking at both individual stories and themes that were common across interviews. The stories are very vivid and powerful, speaking volumes by themselves, without further interpretation. The data does, however, lend itself well to future interpretive analyses, such as discourse analysis or analysis through a feminist lens.

Analysis procedures started with the researcher’s multiple readings of interview transcripts and reviews of audio recordings. The data was then organized by interview question and arranged in data displays to map themes and demographic data and to identify possible patterns and relationships among them [40]. Findings were shared in two presentation with participants, and separately, two presentations with hospital physicians, residents and nurses, who provided feedback—both clarifying and affirming—on the identified themes, which contributed to trustworthiness of the data analysis.

## 3. Findings

### 3.1. The Themes

Five major themes were interwoven through the women’s stories. These included unexpected physical complications, not “getting back to normal,” emotional pain and isolation, lack of available information, and inadequate health care provider response to treatment complications and sexual relationship problems. These will be summarized below and also shared within the contextualized stories of women’s lives.

Even within this small sample of 12 women, all of the possible complications previously listed were reported, along with a myriad of emotional and social issues (**Table 1**). Bowel problems included diarrhea, incontinence, fistulas and obstructions. Bladder problems included leakage to severe incontinence, decreased sensitivity or increased pain, fistulas from bladder to vagina or bowel to bladder, and urinary tract infections. Upper urinary tract infections were also involved for some women, as were ureteral obstructions, stents, and renal failure. Nerve damage contributed to back and leg pain, often severe, in 2/3 of the women. Vaginal changes, minimal to severe, included vaginal shrinkage and scarring, vaginal dryness, and significant pain related to intercourse, speculum-aided exams and Paps. Reported sexual changes met criteria for all defined forms of sexual dysfunction related to sexual desire, arousal, orgasm, and pain disorders.

Women were asked what they remembered being told, at the time of diagnosis, about possible complications of treatments that they were to receive. They were then asked to compare their expectations with their actual post treatment experiences. Three story themes were prominent: 1) “If they told me, I didn’t hear it,” 2) “They told me... but I didn’t grasp what that would mean for me,” and 3) “I thought everything was going to go back to normal. All of this was really a surprise for me.”

**Table 1.** Post treatment complications of participants.

TIME POST-TREATMENT	<1 YEAR		1 TO 2 YEARS					2 TO 3 YRS	8 YRS	12 YRS	20 YRS	
PARTICIPANT	C1	C8	C7	C5	A3	C9	C3	C6	A4	A2	C4	A1
Age at interview	31	59	27	53	49	63	54	27	39	42	46	51
Age at diagnosis	30	58	25	51	48	62	51	25	36	34	34	30
Stage	IB2	IIB2	IIA	IB2*	IB2	IIIB	IB2		IIB	IB	IIB	**
Treatment	CRT	CRT	CRT	CRT	CRT	CRT	CRT	CRT	CRT	CRT	CRT	SRT
Relationship status	LIP	D,ND	M	M	R-NS	M	LIP	R-NS	LIP	DO-S	LIP	DO-S
Number of children	3	4	2	3	3	1	2	3	1	2	4	3
Vaginal stenosis	X		X	X	X		X	X	X	X	X	X
Painful intercourse/pap	X		X	X	X			X	X	X	X	X
Bleeding w intercourse/pap			X	X	X		X	X	X	X		
Loss of sexual desire, sensation	X	X	X	X	X			X	X			X
Occasional sexual pleasure	X	X	X				X			X		X
More difficulty achieving orgasm	X	X	X						X			X
Vaginal dryness	X		X	X				X	X	X		
Menopause hot flashes/weight gain	X							X	X	X		
Infertility grief			X					X				
Persistent diarrhea, loose stools		X	X		X							X
Fecal incontinence			X		X							X
Bowel obstruction/diversion												X
Fistula-cystovaginal											X	X
Fistula-rectovaginal												X
Fistula-cystorectal												X
Urinary tract (UT) obstruction											X	
UT diversion/stent											X	
UT infections									X			X
Urinary incontinence		X	X	X	X						X	X
Renal failure/dialysis											X	
Spinal stenosis/bone loss/back pain	X		X			X	X		X	X		X
Neuropathic pain lower extremities	X	X	X			X	X		X	X		X

**Participants:** C = Caucasian, A = African American. (C2 did not meet criteria, not included in data). **Relationship Status:** M = married; D-ND = divorced, not dating; LIP = live in partner; R-NS = in relationship-not yet sexually active; DO-S = dating occasionally-have had some sexual activity. **Stage:** \* All cancers squamous cell carcinomas except C5-endocervical cell carcinoma. \*\* A1 staging unavailable. **Treatment:** CRT = Chemoradiation treatment [1]; SRT = surgery, radiotherapy. All cancer free at time of interview.

Young participants in this study grasped that they would be infertile after treatment and that menstrual periods would stop—but they didn't grasp that that would involve treatment-induced menopausal symptoms.

They were also surprised by the wider social impact of their infertility. It did not relate to how many children they did or did not have, or even if they wanted any more—but rather to their age and what their peers were talking about and desiring. Planning families and wanting babies were big topics in childbearing years. The cervical cancer survivors in this age group didn't feel like they belonged anymore. They were different.

The women interviewed shared the emotional pain related to feeling alone, feeling different from other women, infertility grief, loss of past relationships, frustration in current relationships, fear of new relationships, sex, and disclosure of their physical changes. Women also discussed their intimate partners' frustrations related to their changed sex life. Both partners expected that things should be getting better, rather than worse. When improvement didn't happen, men responded with grief, disappointment, anger and blame. Some men doubted the woman's explanations and questioned if her lack of sexual desire meant that she didn't love him anymore, or that she was seeing someone else. Men either left the relationship, stayed in the relationship which became troubled, or adapted by trying new sexual approaches and focusing more on the friendship and companionship offered by the relationship.

Clearly there was a significant mismatch between what these women and men were experiencing and what they had expected. Many tried seeking information to help them understand what was happening, but the information they could find rarely went beyond the surface of addressing the problems they were experiencing. None of the women knew anyone to talk to who had had cervical cancer, leaving them further isolated. Health care providers rarely asked about sexual problems, and when the patients talked about their problems, more often than not, health care professionals did not respond in helpful ways.

The survivorship stories told by these women were most often told through tears, and most often told for the first time, because no one else had ever asked. Reading about the common themes does not have the same impact as the stories of the women themselves, four of which are shared below. The names used here are not the real women's names to protect confidentiality.

## 3.2. The Stories

### 3.2.1. Janie's Story

Janie is 27 years old and 2 years out from chemo-radiation treatment. She is a single mom of 3 small children, since her husband's mental illness-related suicide 2 years before her diagnosis. She had been studying graphic arts, but gave it up due to the demands of parenting and receiving cancer treatment. She had searched for information, but found little about cervical cancer and less about its treatment complications.

*There was cancer site after cancer site, but all about breast cancer, brain cancer, ovarian cancer.... Cervical cancer is way at the bottom and there is like a sentence or two! It's like cervical cancer is this puny little red-headed step child that no one knows anything about!*

Janie's expectations of getting better after treatment were partly met as she gradually became less fatigued and nauseated after chemotherapy.

*"After the treatment, I thought everything was going to go back to normal—until I went back in [for follow-up]. Exams are SO awful! They are SO painful I cry. There is so much scar tissue. At the cervix it is so narrow that they can't even get the thing up there to get the cells. My body has changed, the tissue is so bad. The doctor said (pause) that I look like a 90-year-old virgin on the inside."*

Asking her doctors what to do didn't prove helpful.

*"The doctor where I get my Paps explained it to me. She said, 'Your vagina down here is fine, it is the same size [as before treatment] but up here by your cervix, it is so narrow I can't even get the thing up there to get the cells.' The dilator they give you doesn't reach up there, so how can that help? I asked her, you know, 'Is there something else that I can use that will help?' and she didn't know. I mean, she looks at cervixes all day! HOW can she not know?"*

Janie, like many, heard and remembered little of what might have been explained before treatment.

*"If they told me, I didn't hear it... They said I had cancer and that's all I heard for awhile. I just thought I was going to die! I was just freaking out!"*

The sudden onset of menopause and increasing sexual dysfunction were surprises.

*"They said it was hot flashes—menopause! It's SO absurd—I'm 27!"*

*"My friends laughed when I told them... They don't know about all the other things. You can't be in a normal*

*relationship. It is not a joke.”*

*“It really sucks to think that after 25 you don’t get to have sex again and you’re already an old lady.”*

Although Janie had three children, she suffered infertility grief.

*“I don’t think I want more children—but...what if someday I am with someone I really love, and we want a baby together?”*

Infertility grief for the women in this study did not relate their existing number of children, but rather to their age and peer group interests. Peers of survivors in this age group were planning babies and the cervical cancer survivors didn’t feel like they belonged anymore. They were different.

Janie had recently rekindled a long distance relationship with a man she had dated prior to her cancer. Her fears of disclosure, pain with intimacy, and rejection were huge.

*“I’m not sure I want it to go anywhere ...I’m afraid of sex. He doesn’t even know I had cancer yet. I haven’t opened up to him. When the time comes for intimacy, I’m afraid. He was with me before and he will judge the difference. I know how much he likes sex, and... I’m afraid he’ll leave.”*

Though she praised her care and caregivers during treatment, there was so much she didn’t know about the “after” part.

*“They say, ‘Yeah, you’re gonna have a little bleeding, you’re gonna have a little soreness.’ They don’t say, ‘Your insides are going to change, you’re not going to have any blood supply, you’re not going to have any lubrication, you’re never going to be able to have sex again like it was before.’ They don’t come to that part.”*

*“Even if they don’t have the answers, the biggest thing is to know what’s coming and that it’s not just you—because all this time, I thought it was just me, and that I was some kind of freak or something, that I must be this weird, mutated person. I feel like I’m broken.”*

### 3.2.2. Laura’s Story

Laura, like Janie, is 2 years out, but 53 years old and in a long term marriage. Her husband has been beside her through diagnosis and treatment. Since completing treatment, she has lost sensation in her bladder, is frequently incontinent, and has frequent diarrhea. She has experienced a loss of sexual feeling and has pain and bleeding with intercourse. The couple’s expectation that things should be getting better adds to the sexual frustration.

*“He gets frustrated—he is thinking the cancer is over with and I should be back to normal. I don’t have the same feelings when we have sex, the feeling is not there. The love for him is, but the physical feeling isn’t.”*

*“Once he tries to go in, it hurts so bad. And every time we have sex, I bleed. I bleed for 24 hours and it is pretty heavy and I don’t know why.”*

*“And the other thing is, when I can’t get to the bathroom in time and urinate all over myself, and he has to help me clean up—I feel so bad for him.”*

*“Half the time I kind of fake it—I don’t want him to feel bad. He doesn’t feel like he is able to make me feel like I want to or like he wants me to, you know. He has actually got to the point now that he will sleep on the couch a lot. And then he will come in to bed after I go to sleep so that it doesn’t bother him and bother me, that awkward feeling.”*

### 3.2.3. LaToya’s Story

LaToya is 42 years old, and 12 years post treatment. She has severe sexual and neuropathic pain. At the time of diagnosis she had a boyfriend who left her due to the excessive vaginal bleeding she was having, and the effect of that on their sex life.

*“Shortly after I got diagnosed, he abandoned me. And I felt really bad. Basically he just said he needed a woman who satisfied his needs and a woman that he could go down on when he got ready and I just wasn’t that girl anymore.”*

Since treatment, she had dated, but found that her sexual problems had worsened.

*“I know that I can’t do everything that I used to, but sex, who thinks that you are never going to be able to have sex again? And you know I CAN have sex, but I am laid up 3 days after because it hurts so bad. It is a pain that, oh my God, it is indescribable. You know, is it really worth it? I have lost a couple of serious relationships because of it.”*

Her neuropathic pain was continual and often severe, despite morphine. Pain had prompted her to attempt suicide twice.

*“I was trying to talk to the resident about it,” and she said, “You know, we don’t treat legs in this clinic.”*

### 3.3.4. Margaret’s Story

Margaret is a divorced, 49-year-old woman who is between 1 - 2 years post treatment. She worked as a special education teacher and hopes to return. She is not married but has had a long term friendship with a man who is also a teacher, a friendship that grew into intimacy. He moved to another state shortly before her diagnosis to take care of his aging mother, but he calls Margaret numerous times a day to check on her. Over a year post-treatment, Margaret is surprised to be dealing with diarrhea and a loss of sexual desire. Like other women in the study, Margaret had difficulty finding information about cervical cancer.

*“Magazines have like information about ovarian cancer, breast cancer, but I never could find anything particularly about the type of cancer that I had. So it made me think, well, maybe this is not very common, but then when I start seeing commercials on TV about the drug that prevents teenagers from getting cervical cancer, it makes me think that maybe it is quite common. So I really didn’t know. I was at a loss for information. Even the cancer packet they give you when you are diagnosed—it has nothing about cervical cancer. Nothing!”*

Margaret has not had sex since her cancer diagnosis and treatment. She uses a dilator as her doctor prescribed, though finds it very painful, as are her Pap tests, which she dreads. She wants to “get through this” before seeing her male friend again, probably in a few months, and despite his supportive attitude, she worries how that might go.

*“You know what, right now, I have not had even the desire to have sex at all. You know, it is just kind of gone. So that is what I was wondering. Is that normal? You know because I used to be very sexually active but now... We [she and her out of town boyfriend] are planning on seeing each other this summer when school is out. He is completely supportive and understanding. He’ll ask me, ‘You think you are up to it?’ I am like, ‘I don’t know. We’ll see what happens when the time comes.’ I am really scared. What if I can’t, you know, what if we get together and I am not able to perform? If I just don’t even have that desire? I am kind of scared of that disappointment.”*

Margaret remembers when she was getting information about her diagnosis and treatment side effects, not understanding everything that was said, and certainly not understanding the real potential impact of what was being said.

*“I would have to go back and say, ‘Now, can you tell me again, what you said and what does that mean for me?’ I think [they told me about] the fatigue and the bowels, the loose bowels... and that I wouldn’t have to worry about being constipated again, but I am thinking that it will just be a casual bowel movement every day. I have like 3 - 4 bowel movements in a day and they are like soft or just like water! If I got to go, I got to go! Otherwise, I’ll use the bathroom on myself. One night me and my daughter had went to the movie and before I could get from the theater to my car, I had a bowel movement on myself! And I am like, ‘Oh my God!’ [If I had known] I would have been more prepared for it. If I would have known how severe it was going to be, it wouldn’t have been, I wouldn’t be—oh my goodness, kind of out in left field about how bad it was going to be! All of this was really a surprise for me. To me, I came out worse than when I started, you know? Now, I got the tiredness, the diarrhea, the leakage, and I am thinking’, “Oh my goodness, I didn’t expect the side effects to be so dramatic!”*

### 3.3. Women’s Recommendations for Improved Care

As women talked, they formulated recommendations for what would make their survivor experience better. Their suggestions fell into two broad categories: 1) informational sessions about what to expect from treatment, provided by a specific member of the health care team; and 2) support groups with others who have had cervical cancer—and partners—to talk about their experiences and possible ways to deal with sexual changes. These are summarized in [Table 2](#).

## 4. Discussion

In 1958, well ahead of their time, Vasicka, Popovich and Brausch [41] published a mixed methods study in which they completed in-depth interviews and pelvic exams with 16 women who had completed radiation treatment for cervical cancer. The rationale for the study was to address a gap in knowledge about the effects of radiation treatment on patients in relation to psychic, sexual, and physical well-being and relationships with husbands, family and friends. Noting that the radiation-induced vaginal damage was familiar to physicians car-

**Table 2.** Participant recommendations for cervical cancer survivorship care.

Recommendation	Supportive Participant Comments
	There should be a designated person on the health team for that kind of counseling.
	I think that before you start your treatment you ought to have a special somebody to talk about these things and then after and then maybe along down the road check in again, as long as you need counseling about it. Plus some pamphlets with detailed information.
<b>Informational Sessions</b>	To understand what is going on with your body—really understanding why and how and what this has done to your body because when I came into this, I didn't know my sex life was going to change. I mean, there was no alternative, we had to do it, but still I didn't know that and that took me by surprise.
	If there is a man involved the staff should be as attentive to him as the woman even though she is the patient. I think he needs to know just what she knows.
	Something that involves both of them, classes for her and classes for him to also know what to expect.
	To talk to somebody who knows what you are talking about—who has been through it and, you know, you could kind of lean on each other.
	Couples groups—so he can see others having same issues—and know that it is not just me not wanting him...
<b>Support Group Sessions</b>	Visual aids, like anatomic models, sex toys you can look at and touch, And I would have someone talking, someone to give their point of view on what happened when you had sex for the first time or what did you do when you didn't have a desire to have sex?
	Or if someone from [a store with sexual aids] or something could come in and say, "OK this is what I have," or "I suggested someone with cervical cancer use this and they did and it worked great for them, etc."
	Separate sessions and couple sessions. I would say all the ladies and then all the partners to see how the partners feel and if it worked out pretty good then bring them together.
	It's important to give "permission"—for us to know that it is OK to please yourself.

ing for cervical cancer patients, the authors puzzled over why the condition had received so little attention in the literature. Sadly, the Vasicka group's interview findings were remarkably similar to the interviews described in this study, done over 50 years later.

Women's narratives in the current study tell us that sex and intimacy issues for cervical cancer survivors remain within a culture of silence. If the sentiments of these 12 women are indicative of those of other survivors, they WANT to talk about sexual issues—in a safe place, with someone who cares to ask and who can respond in knowledgeable and helpful ways. In some aspect of all the women's stories, health professionals 1) did not provide information that realistically prepared women and partners for probable consequences of treatment; 2) did not assess sexual issues before or after treatment; 3) did not recognize various symptoms as being likely complications of cancer treatment; 4) did not make referrals; and/or 5) recognized the symptoms, but accepted the complications as "normal" and without solution. For health professionals, the ethical implications of these behaviors range from inadequate informed consent for treatment to negligence in assessment and treatment of obvious problems, culminating in a degree of patient abandonment and disregard of an oath to do no harm.

Clearly, there is a critical need to move beyond problem identification and beyond silence to development of effective physical, emotional and behavioral interventions for treatment-related vaginal and sexual complications in cervical and other cancers requiring pelvic radiation (bladder, endometrial, anorectal cancers). This area of post radiation vaginal healing and, more broadly, regenerative potential and symptom management for any irradiated tissue will be best served by interdisciplinary investigative teams. Palliative medicine, rehabilitative scar management, urogynecology, pelvic floor therapy, and behavioral science bring together principles and findings that hold particular promise for this area of research and expand on gynecology, oncology and radiology [42]-[51]. Much help can be offered now, however, by breaking the silence around sexuality, providing realistic information (verbal and written), addressing couples as desired, assuring patients that they are not alone, being aware of various dilator sizes and risks of dilation, and making appropriate referrals to resources such as sex therapy, pelvic floor specialists and relaxation training, as examples.

This article and the experiences of these women are written from the perspective of US culture. Complications of cancer and cancer treatment, such as those discussed in this article, can have an even more significant impact on women in some cultures, wherein sexual function and child bearing abilities more strongly define the women's worth, social acceptance, marriage ability and survival. Open discussion of sexuality and the intimacy

within relationships, such as recommended here, will also have different relevance and acceptability in different cultural settings. An estimated 85% of cervical cancer cases occur in less developed world regions, however, so for all our worlds, a deeper understanding of the potential suffering among cervical cancer survivors and development of new research to promote post radiation vaginal healing, are needed.

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