Addressing the Unmet Need of Sexual Health in Oncology Patients



DISCLAIMER: We recognize that all those who identify as women do not have vulvas. We also recognize that not everyone with a vulva identifies as a woman. During this article, we may reference *woman* or *female* and what we are referring to is a cisgender woman. We recognize that there needs to be much more research about how aging, menopause, hormonal changes, and cancer impact sexuality among nonbinary people and transgender individuals.

Introduction

Female sexual dysfunction in oncology patients is a prevalent and well-studied adverse effect of cancer treatment. Over 50% of women treated for breast cancer, 65%-90% of women treated for gynecological cancers, and over 60% of women treated for colorectal cancer report long-term changes in sexual function. However, female sexual dysfunction remains vastly underdiagnosed and undertreated. In fact, patients rank sexual dysfunction as a top unmet need. Left unaddressed, sexual concerns will cause more distress and further impact quality of life.

Sexual health encompasses more than physical dysfunction. It is a complex interplay between psychological, social, and physical function. The early and late effects of cancer treatments can interfere with physiological systems necessary for the sexual response cycle, body image, intimacy, and relationship dynamics. The most common concerns are dyspareunia, reported in 40%-100% of patients, vaginal dryness in 60%-87% of patients, low desire/lack of libido in up to 61% of patients, and lack of orgasm in up to 45% of patients.³ Table 1 outlines the impact that select cancer treatments can have on sexual function. Other impacts of therapy include depression, anxiety, fatigue, scarring, changes in weight, surgical menopause, chronic pain, and infertility.^{1,2}

Providers do not adequately address sexual function before, during, or after treatment. Patients are not being properly educated and warned of the potential for female sexual dysfunction during treatment planning. In a systematic review of 29 studies, 28% of female patients recall that a provider led informed consent of the potential treatment effects on sexual function. Furthermore, only 10% of patients reported being screened or assessed for female sexual dysfunction during follow-up visits, and only 22% were offered treatments.⁴

There have been many studies on the breakdown of communication between providers and patients regarding sexual health. The most notable provider barriers are lack of training, time constraints, and bias. Providers may be reticent to screen for sexual health problems Experts advise that the oncology team should initiate sexual health conversations during treatment planning and at regular intervals during survivorship.

due to insufficient knowledge and expertise in the diagnosis and management of female sexual dysfunction. In a survey of medical oncologists, over 84% of participants self-reported having little or no knowledge of possible sexual adverse effects of cancer drugs and 36% of participants reported avoiding sexual health discussions due to lack of training. There may also be a bias that patients are not sexually active nor interested in sex. Almost 45% of oncologists indicated they do not discuss sexual function if they believe the patient is too ill. Moreover, if the patient is single, there may be an assumption they are not interested in sexual activity. Fortunately, several studies have shown that brief, online-based training for providers improves attitudes, comfort level, and knowledge of sexual health.

Patients also have their own reasons for not disclosing their sexual health concerns. On average, patients ask their providers about their sexual concerns with a prevalence of only 14%.⁷ They may be embarrassed or fear judgment or stigmatization. This is especially true for patients that are not cisgender and who do not engage in heterosexual penetrative intercourse. Patients may also have their own reservations regarding sexual health based on their religion or culture and may be uncomfortable discussing what they consider to be a taboo topic. Worst of all, patients may assume that female sexual dysfunction is unavoidable and irreversible. They wrongly assume there are no treatment options available because none have ever been offered. For all these reasons, most patients prefer their providers to initiate conversations regarding sexual health.

Table 1. Cancer Treatments and Impact on Sexual Function

SURGERY

- Nerve damage
- Negative perception of body image (dysmorphia)
- Loss of sex hormones
- Presence of stoma (an opening on the abdomen)
- Genital deformity

CHEMOTHERAPY

- Fatigue
- Pain
- Alopecia (hair loss)
- Weight gain

RADIATION

- · Vaginal atrophy, stenosis, decrease in tissue elasticity
- Loss of genital sensation
- Loss of bowel or urinary control
- Xerostomia (dry mouth)

HORMONE THERAPY

- Pain with sex
- Low libido
- Difficulty with orgasm
- Vasomotor symptoms

In response to this care landscape, the National Comprehensive Cancer Network developed guidelines for sexual function in cancer survivors. Experts advise that the oncology team should initiate sexual health conversations during treatment planning and at regular intervals during survivorship. It is best practice to use a normalizing sentence and ask the patient directly, for example, "Many women who have gone through similar cancer treatment notice changes in sexual function or vaginal health." Screeners or checklists may be used but may not be as effective in creating a safe environment where the patient feels comfortable discussing these concerns. The guidelines further recommend that once a problem is identified, there should be a medical assessment and then the patient should be referred for appropriate multidisciplinary treatment.

One effective strategy to address sexual dysfunction in cancer patients is to have a clinician seek additional training and become the resident sex expert.² These local experts can increase access to care in their cancer program or practice and create relationships with community providers, such as menopause specialists, psychotherapists, and pelvic floor physical therapists, for referrals. Below, oncology sexual health nurse practitioner, Nicole Dreibelbis, CRNP, WHNP-BC, shares the story of how she created and implemented a sexual health clinic at UPMC Magee Cancer Center.

Recognizing the Need

In early 2022, after working in gynecologic oncology for 7 years, I was inspired by a trusted mentor, medical director Joshua P. Kesterson, MD, MBA, to identify unique services that advanced practice providers (APPs) could offer patients. With the help of a colleague, I soon compiled a list of opportunities for service line growth, including development and implementation of a sexual health clinic. Sexual dysfunction was a prominent issue I noted with patients, but there were no local resources for these patients. Even with 4 large health systems in the region (all within a 1-hour drive) that cared for patients with cancer, none offered oncology sexual health clinics. (For context, UPMC Magee is part of a large health system headquartered in Pittsburgh; however, the cancer center is located in rural, central Pennsylvania). Because of this significant gap in care, I made it my mission to open a sexual health clinic for oncology patients in the region.

Dr. Kesterson was immediately supportive of the idea, and I began researching how to get started. While my certification is as a women's health nurse practitioner (WHNP), sexual health was not a wellcovered topic in my training. In fact, other than some very brief mention of vaginal dryness associated with menopause, I do not recall any other discussion of sex, intimacy, or overall sexual wellbeing. After reviewing several possibilities for additional training, I identified a few options to further my education in the sexual health specialty, ranging from certificate programs to additional master's degrees. Dr. Kesterson was then able to propose the idea of opening an oncology sexual health clinic to the vice president of operations, who wholeheartedly agreed that this service was something UPMC Magee Cancer Center should be able to offer its patients. I was accepted into the University of Michigan's online Sexual Health Certificate program, which offers hours toward completion of an American Association of Sexuality Educators, Counselors, and Therapists (AASECT) certification. The program offers 3 individual tracks and 2 dual tracks. To better meet our patients' needs, I chose the Sexual Health Educator and Counselor track and completed the 12-month program in March 2024. Topics covered in this program included courses on:

- Gender and Sexual Orientation
- Medical and Developmental Aspects of Sexual Health—A Biopsychosocial Perspective Across the Lifespan
- Theory and Methods of Sex-Related Counseling and Psychotherapy—Couple and Individual Approaches.

These classes broadened my perspective on sexual well-being and provided examples of therapeutic communication. Each course consists of a weekend of learning from some of the top professionals in sexual health education and counseling, including review of case studies with opportunities for discussion and feedback.

Attending conferences and networking with providers who already provide sexual health services to their patients has been an important part of the journey to open the clinic. In 2023, I attended both the conference of the Scientific Network on Female Sexual Health and Cancer and the International Consultation on Sexual Medicine (sponsored by the International Society for the Study of Women's Sexual Health). While I have attended quite a few conferences throughout my 8 years of practice, I was in awe of the passion these conference speakers had for educating others on the importance of sexual wellbeing. These conferences were integral in solidifying my knowledge base and allowing me to network and find mentors within the sexual medicine space.

Getting Started

The first step in preparing to stand up the clinic was developing a needs assessment to identify critical data such as: clinic location, when to offer services to patients, the staffing necessary to operate the clinic, and any extra tools that may be required. After compiling this needs

Figure 1. Sexual Health Clinic Needs List

Location and timing of clinic (all day versus 4 hours, once a month versus once a week, etc)

STAFFING:

- APP
- MA
- · Check in/check out/scheduler

NEW EQUIPMENT:

- · Handheld mirrors (each room)
- Anatomically accurate models (external and internal genitalia)

LOCAL RESOURCES:

- Sex therapist
- Menopause specialist
- Pelvic floor physical therapy (PT)
- Mental health specialist

DEVELOP HANDOUTS:

- Female sexual distress screen (Figure 3)
- Dedicated review of symptoms form (Figure 4)
- Lubricants
- Dilator and vibrator resources
- Sexual position information
- Ohnut (intimate wearable device)
- Resources

assessment, I was then able to develop a Sexual Health Clinic Needs List (Figure 1).

In planning clinic staffing availability, the decision was made to hold the sexual health clinic on a day of the month when another provider had a scheduled administrative day to allow for cross coverage with the medical assistants and to ensure ample space in the clinic. Hand mirrors were purchased from a discount store and placed in each exam room for patients to observe their own anatomy. These have also come in handy when I am describing a lesion or explaining to patients how to apply topical therapies. Because anatomically accurate models were not available for purchase prior to clinic opening, I employ anatomically accurate photos and drawings to share with patients as needed.

After almost a year of running this clinic, what stands out most to me is that every appointment is unique.

Expanding the Network

Developing a relationship with the providers to whom I would be referring patients was extremely important to me. Establishing a rapport and building trust with external providers allowed me to feel confident that my patients would receive the best possible care when they left the clinic. I contacted local sex therapists and met with them in person to review the plan for the sexual health clinic, explain the patient population, and discuss patient care philosophies. A menopause specialist would be an important resource for the clinic, so I contacted a former OBGYN colleague who had become a menopause specialist and had recently opened a dedicated clinic with virtual capabilities to assist patients from her location in Pittsburgh. In addition, while UPMC Magee Cancer Center has an outstanding Women's Behavioral Health Group in its community, like most other mental health services, it is extremely overwhelmed. Accordingly, I identified additional general mental health resources for patients. Finally, there are 2 major physical therapy companies located near UPMC Magee Cancer Center, and both have pelvic floor physical therapy specialists. This has been incredibly important. Because the offices (and services) are nearby, patient adherence to treatment regimens has increased.

It's All in the Details

Developing a dedicated review-of-systems form (Figure 4) was crucial in tailoring this clinic specifically toward the sexual health and wellbeing of patients. I started with a preexisting oncology review-of-systems form and added more detailed symptoms, such as pain at the introitus, pain with deep penetration, history of sexual trauma, and relationship conflict, to name a few. To get a comprehensive understanding of what may be impacting each patient's sexual health in addition to their cancer diagnosis and/or treatment, I included questions about symptoms that (Continued on page 19)

UPMC | MAGEE CANCER CENTER Oncology Sexual Health Clinic

Who can seek care with our office?

Any cancer patient with a vulva or vagina who is in active treatment or in remission and is experiencing sexual dysfunction or distress can be seen in our clinic.

What do we help patients with?

- Vaginal dryness and decreased lubrication
- · Vaginal pain with intercourse
- · Decreased libido and desire
- Sexual dysfunction
- Decreased genital sensation
- Difficulty achieving orgasm

What can I expect at a sexual health visit?

As a new patient to the sexual health practice, the first visit will be approximately 60 minutes in length. There will be a review of systems form and a sexual health distress screening form filled out at the start of each visit. This form will help identify the patient's needs and aid the practitioner in developing individualized recommendations. A pelvic exam may be performed as well, depending on the patient's symptoms. Follow-up appointments are approximately 30 minutes in length and will focus on the continued improvement of the patient's sexual wellbeing. Referrals may be placed to other specialists in order to provide comprehensive care for each patient. Some examples of potential referrals include pelvic floor physical therapy, sex therapy, Urology/Urology Gynecology, UPMC Menopause Specialists, etc.

Appointments available:

The fourth Monday of every month at: 2025 Technology Parkway, Suite 108, Mechanicsburg. Every Friday at 4300 Londonderry Rd., Suite 201, Harrisburg.

To schedule an appointment with our sexual health clinic, call 717-221-5940, option 2, and then option 8.

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may not be immediately obvious as impactful on sexual health, such as neurological, muscular, and respiratory symptoms. I also administered a female sexual distress screening tool (Figure 3) to get a sense of what patients felt were their most pressing difficulties.

While I work in gynecologic oncology, the clinic is meant to aid *all* vulva-owning oncology patients in improving their overall sexual well-being. It was important to me to educate the other oncology service lines so they could refer patients in need (Figure 2). I attended at least 1 staff meeting for each oncology service line to explain exactly what I hoped to accomplish with this clinic, and which patients would be appropriate for referral. These meetings were vital, as they spread the word about the clinic and allowed other medical providers to ask questions. Just as I wanted to know and trust the providers I was referring to; I wanted other oncology providers to know they could trust me with their patients. I also reviewed how to place a referral and emailed all providers a screenshot of the referral within the electronic health record. I also agreed to give presentations to UPMC's central Pennsylvania Breast Oncology team, Breast Cancer Support Group, and joint Gynecology and Breast Oncology Survivorship Conference.

Putting It All Together: A Patient Case Study

JK is a female, aged 41 years, who presented in clinic for a discussion of low libido, vaginal dryness, and dyspareunia (difficult or painful intercourse). The patient has a history of recurrent stage IIIC cervical cancer, and she is currently on pembrolizumab. JK stated that she has not been sexually active since beginning oncology therapy 3 years ago. She stated that she has experienced dyspareunia prior to her diagnosis and was concerned that she may continue to experience this post treatment, so she did not resume sexual activity. JK was given a dilator post radiation therapy, but she has not been using this device. Her most recent exams noted scar tissue at the right vaginal wall/apex. JK stated that prior to her diagnosis, she was able to orgasm with clitoral stimulation and/or oral sex. She stated that right before she was diagnosed, she was often avoiding sex, as she felt pain. She has not attempted to orgasm since her diagnosis. JK reported that she feels herself pulling away from her partner physically because she does not want to send mixed signals or do anything that may lead to sexual contact. She was recently noted to have progression of disease on imaging and will be transitioning to tisotumab vedotintftv in the upcoming weeks.

Results From JK's Sexual Health Distress Screen (See Figure 3)

Sexual Health Function Satisfaction

- Satisfied with sexual function: (P) No
- How long have you been dissatisfied?: (P) 3 years
- Sexual function problems: (P) Little or no interest in sex; decreased vaginal lubrication (dryness); pain during sex
- Most bothersome problem: (P) Little or no interest in sex

Feelings about Sexual Relations

- Distressed about sex life: (P) 4
- Unhappy with sexual relations: (P) 4
- Guilty about sexual difficulties: (P) 4

- Frustrated by sexual problems: (P) 4
- Stressed about sex: (P) 4
- Inferior because of sexual problems: (P) 4
- Worried about sex: (P) 4
- Sexually inadequate: (P) 4
- Regrets about sexuality: (P) 4
- Embarrassed about sexual problems: (P) 4
- Dissatisfied with sex life: (P) 4
- Angry about sex life: (P) 4
- Bothered by low sexual desire: (P) 4

Total Score: (P) 52

Oncology History

- 8/6/2020: Initial diagnosis of malignant neoplasm of exocervix (HCC).
- 10/5/2020–11/24/2020: Treated with radiation with concurrent chemotherapy. VMAT: Received a total dose of 55Gy/25fx. HDR: 30Gy/5fx.
- 10/2022: Confirmed recurrence of cancer.
- 10/24/2022-2/8/2023: Treated with an infused therapy: carboplatin/paclitaxel/bevacizumab/ pembrolizumab ×6 cycles.
- 3/1/2023: JK prescribed current infusion therapy: maintenance IV pembrolizumab, single agent.

Review of Symptoms (See Figure 4)

- Constitutional: Positive for fatigue. Negative for activity change, headaches, and pain.
- Respiratory: Negative.
- Cardiovascular: Negative.
- Gastrointestinal: Positive for nausea and vomiting. Negative for abdominal pain, abdominal distention, blood in stool, constipation, and diarrhea.
- Genitourinary: Positive for difficulty urinating. Negative for pain
 with deep intercourse, vaginal intercourse entrance pain, bleeding
 with intercourse, vaginal penetration difficulty, dysuria (burning,
 stinging, or itching during urination), bladder incontinence, pelvic
 pain, vulvar pain, vulvar itching, vaginal pain, vaginal dryness,
 vaginal bleeding, and vaginal narrowing.
- Musculoskeletal: Positive for muscle weakness. Negative for joint pain, difficulty walking, and muscle pain.
- Skin: Negative.
- Neurological: Positive for numbness and/or tingling. Negative for light-headedness, vertigo, dizziness, and syncope (brief loss of consciousness and muscle strength that occurs when blood flow to the brain decreases).
- Psychiatric: Positive for anxiety. Negative for insomnia and/or difficulty sleeping, body dysmorphia (negative perception of body image), current relationship distress, trauma and/or PTSD, and history of sexual trauma.

Physical Exam

- Vitals reviewed.
- Constitutional: General: JK is not in acute distress.

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Figure 3. UPMC Magee Gynecologic Sexual Health Clinic Sexual Health Distress Screening

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2. How long have you been dissatisfied v	with your sexua	ıl functio	on?				_	
a. The problem(s) with your sexual funct a. Problems with little or no in b. Problems with decreased ge c. Problems with decreased vag d. Problems reaching orgasm e. Problems with pain during s f. Other:	terest in sex enital sensation ginal lubrication	(feeling)						
4. Which problem (in question 3 above)	is the most bot	hersome	e (check)	□a □]b 🗆 c	: □d	□ e	□f
distress during the past 3 months. Circle		for each		nd take care no		any items	5.	
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Figure 4. UPMC Magee Gynecologic Sexual Health Clinic Review of Symptoms

CONSTITUTION:	GENITOURINARY:	NEUROLOGICAL:
☐ Activity change	☐ Difficulty urinating	☐ Light-headedness
☐ Headaches	☐ Pain with intercourse	☐ Vertigo
☐ Pain	☐ Deep	Dizziness
☐ Fatigue	☐ At vaginal entrance	☐ Syncope
	☐ Bleeding with intercourse	☐ Numbness/tingling
	☐ Difficulty with vaginal penetration	
	☐ Pain with urination	
RESPIRATORY:	☐ Incontinence	PSYCHIATRIC:
Shortness of breath	☐ Pelvic pain	
	☐ Vulvar pain/irritation	☐ Anxiety
☐ Wheezing	☐ Vulvar itching	☐ Depression
Shortness of breath lying flat	☐ Vaginal pain	☐ Insomnia/difficulty sleeping
☐ Cough	☐ Vaginal dryness	☐ Body dysmorphia
	☐ Vaginal bleeding	Current relationship distress
	☐ Vaginal narrowing	☐ Trauma/PTSD —
		☐ History of Sexual Trauma
CARDIO VASCULAR:		
☐ Chest pain		
☐ Irregular heartbeat		
☐ Ankle/leg swelling		
GASTRO INTESTINAL:	MUSCULAR:	
☐ Abdominal pain	☐ Joint pain	
☐ Abdominal bloating/swelling	☐ Difficulty walking	
\square Blood in stools	☐ Muscle pain	
☐ Constipation	☐ Muscle weakness	
☐ Diarrhea		
☐ Nausea		
☐ Vomiting		

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- Appearance: Normal appearance. JK is not ill-appearing or toxic-appearing.
- HENT: Head: Normocephalic and atraumatic.
- Pulmonary: Effort: Pulmonary effort is normal. No respiratory distress.
- Musculoskeletal: General: Normal range of motion; Cervical back: Normal range of motion.
- Genitourinary: Pelvic exam deferred (recent exam describes right vaginal apex scar tissue)
- Neurological: General: No focal deficit present; Mental status: JK is alert and oriented to person, place, and time.
- Psychiatric: Mood and Affect: Mood normal; Behavior: Behavior normal; Thought Content: Thought content normal; Judgment: Judgment normal.

Assessment

JK is a very pleasant 41-year-old with a history of stage IIIC cervical cancer with subsequent recurrence who is currently on pembrolizumab with progression of disease. The treatment plan is to change therapy to tisotumab vedotin-tftv in the next few weeks to months. She complains of decreased libido, vaginal dryness, and dyspareunia.

Plan

Issue: Not sexually active for 3 years

Reviewed with the patient that penile penetration is not the goal at this time. Reviewed that being intimate with her partner will be the first step. Encouraged the patient to discuss with her partner and take penetrative intercourse off the table for the time being to remove the pressure she feels is associated with any physical contact. Also reviewed the importance of open communication with her partner regarding her feelings about touch. Patient reports she and her partner have not been sexually intimate at all since her diagnosis. Encouraged nongenital touching (eg, massage, hugging, kissing) with progression to external genital touching as she feels comfortable. Encouraged the patient to use moisturizers and lubricants. Reviewed the importance of also using lubricants externally for clitoral stimulation.

Issue: Vaginal dryness

- Reviewed the importance of vaginal moisturizers in rebuilding and maintaining vaginal moisture. Provided the patient with a list of moisturizers and encouraged use daily for at least 1 week; then switch to use 3 to 5 times per week.
- Explained that vaginal estrogen may be used if moisturizers alone
 are not sufficient. Explained that her cancer is not estrogen-driven
 and, therefore, this is safe for her to consider. JK is not interested
 in vaginal estrogen at this time but may consider it in the future.
- Reviewed with the patient that during a sexual encounter, lubricants are recommended because they work more acutely. Reviewed different types of lubricants and their uses and limitations, including water-based, oil-based, and silicone-based. Explained that moisturizers and lubricants often work together to aid in decreasing vaginal dryness. Encouraged the patient to try silicone or oil-based lubricants and provided a list of options.

Issue: Vaginal stenosis/scar tissue post radiation treatment

- Reviewed that if this is a problem when penetration is initiated, there are penetration bumpers that may aid in preventing full penetration but allow for penetrative intercourse. Will discuss in more detail at future appointments.
- Discussed the possibility of pelvic floor physical therapy as an intervention. The patient would like to readdress this at a future appointment, as she has heightened anxiety related to changing her treatment regimen at this time.

Issue: Decreased genital sensation and problems reaching orgasm

- The patient states that prior to treatment initiation, she was able to reach orgasm with clitoral stimulation and/or oral sex.
- Reviewed that multiple factors contribute to decreased genital sensation including, but not limited to: postmenopausal state, radiation therapy, chemotherapy, and immunotherapy.
- Reviewed options for increasing sensation including topical hormones and possible vibrator use. Encouraged the patient to adjust vibrator settings to gauge what will be effective for her and apply lubricant to clitoris prior to use.

Issue: Decreased libido

- Reviewed potential pharmacologic interventions, including flibanserin and bremelanotide injections and data regarding efficacy.
- Explained to the patient that with certain populations (eg, patients
 who were assigned female at birth), arousal often precedes desire.
 Also explained that with diagnosis and treatment and patient's
 history of dyspareunia and cancer, she has had multiple traumas,
 and a decreased and/or absent libido can be completely normal.
 Will continue to explore this issue in upcoming appointments.

Follow-up: Patient will return to the office in 2 months or PRN (meaning pro re nata, or as needed).

Closing Thoughts

After almost a year of running this clinic, what stands out most to me is that every appointment is unique. I have seen patients in their seventies who are widowed and curious about masturbation, patients in their thirties who have dyspareunia and vaginal dryness from radiation and premature menopause, and patients who have avoided penetrative intercourse for years because of how painful it became after cancer treatment. It is of utmost importance that these patients thrive in survivorship, and it is my belief that sexual health is a vital part of the discussion.

Jessie Dorne, PA-C, is a gynecology oncology physician assistant at Baystate Medical Center, Baystate Regional Cancer Program in Springfield, Massachusetts. Nicole Dreibelbis, CRNP, WHNP-BC, is a gynecologic oncology nurse practitioner at UPMC Magee with locations in Harrisburg, Mechanicsburg, Newport, and York, Pennsylvania.

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