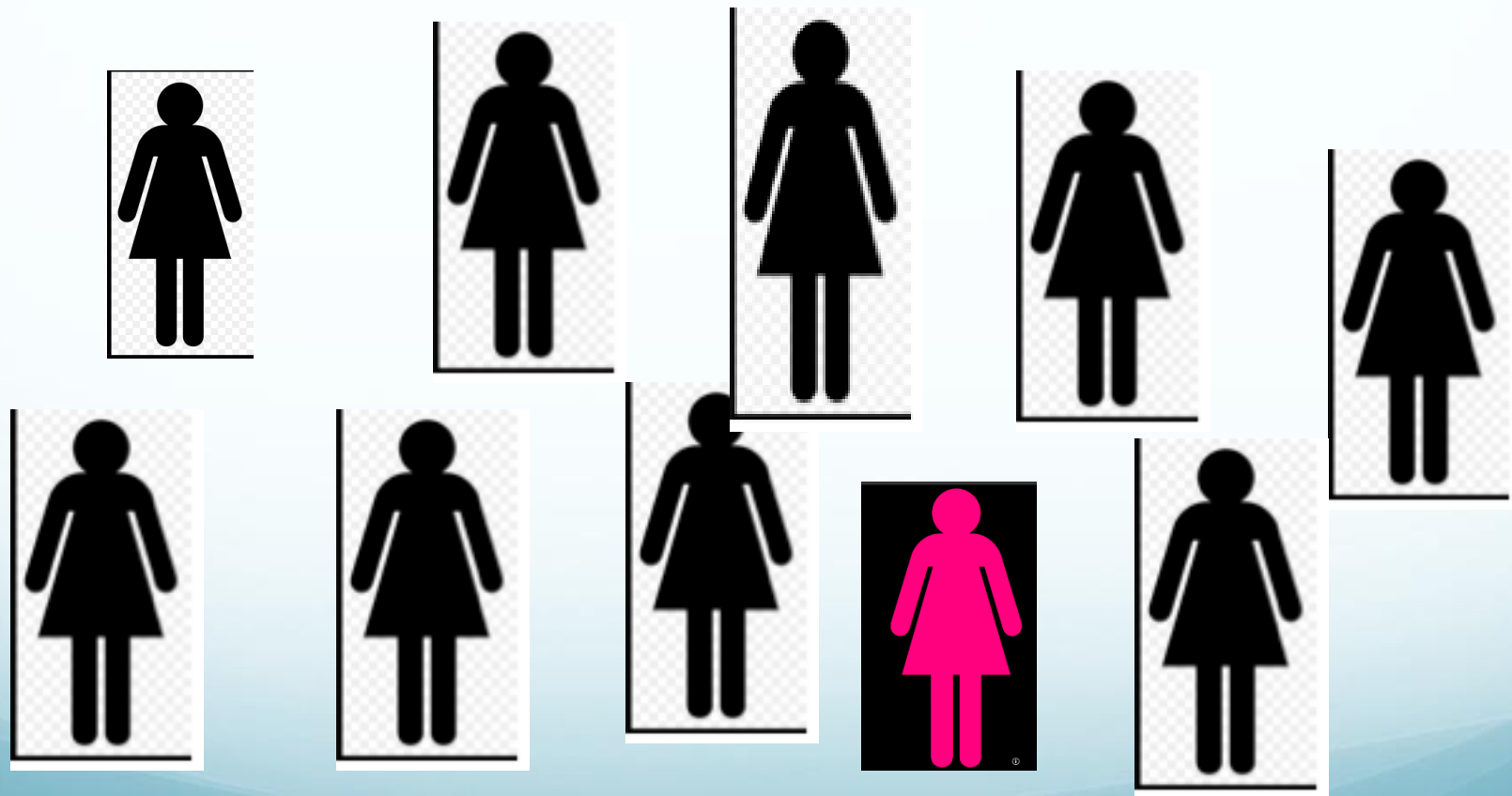


# **Sex and Intimacy After Cancer**

**Overview of survivorship Issues and  
Sexual Health Concerns**

Patricia Handler, APRN  
September 2024

# Up to 90 Percent of Cancer Patients Experience Sexual Side Effects



# Psychological Impact of Cancer

## Fears and concerns

Fear of damaging something

Fear of contamination

Worries about fertility

Feelings of guilt

Mourning

Anxiety about recurrence.

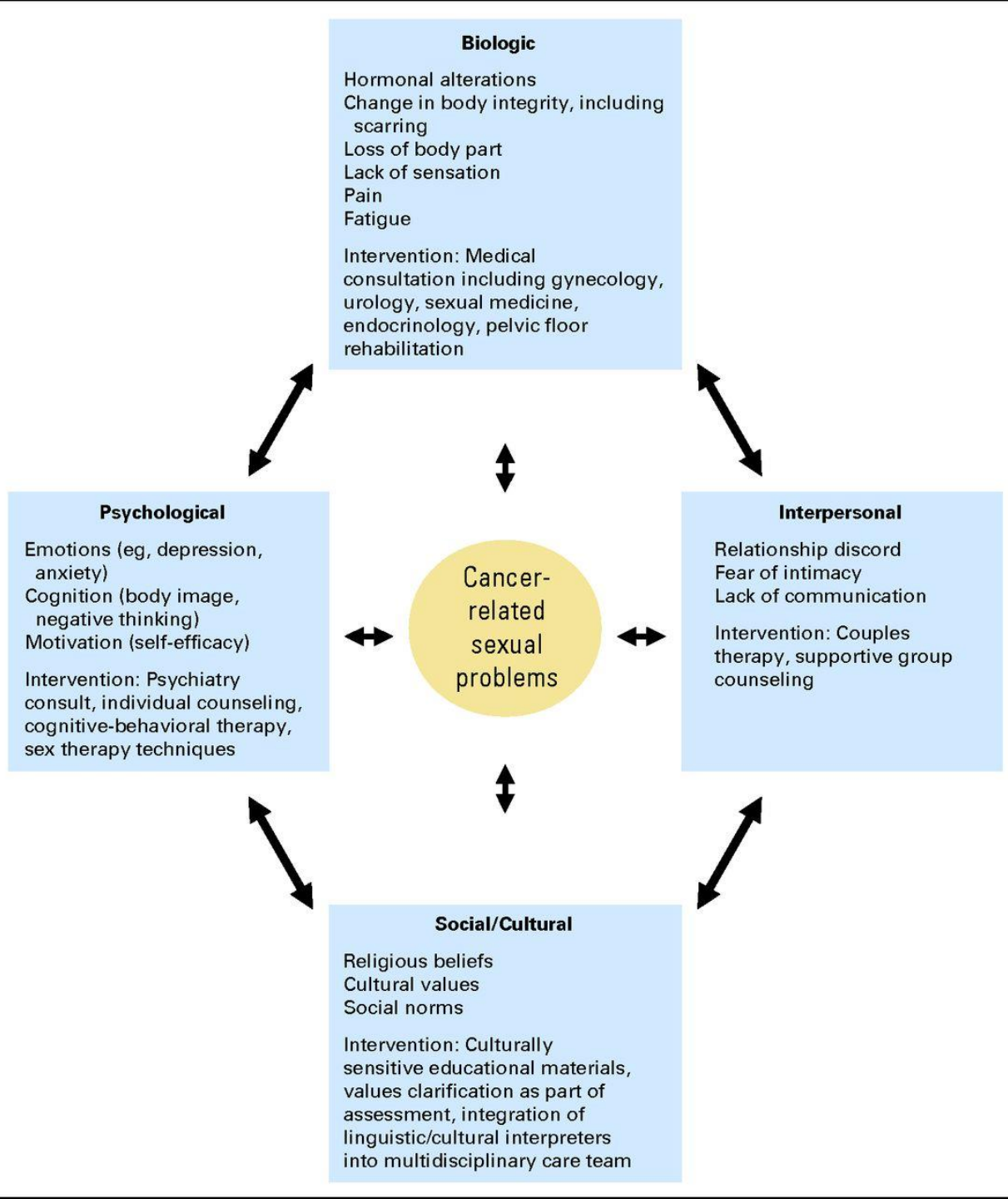




# Resuming Sexual Activity Post-Cancer

*“We're all intimate beings. It's about listening to the patient and figuring out what their needs are.”*

— Stanton Honig, MD, a professor of clinical urology at Yale Medicine



# Common sexual side effects of cancer treatment

**Desire decreased**

**Arousal decreased**

**The ability to achieve orgasm or ejaculate**

**Pain**



# Cancer Consequences that Affect Sexual Health

- **Body Image Concerns**
  - Hair Loss (Public and private)
  - Weight Changes
  - Surgical Scars
  - Ostomy
- **Hormonal Changes (Transient or permanent)**
- **Treatment Consequences**
  - Radiation
  - Chemotherapy
  - Surgical
- **Depression and Anti-depressants**
- **Anxiety**
- **Family Distress**
- **Other medical conditions**

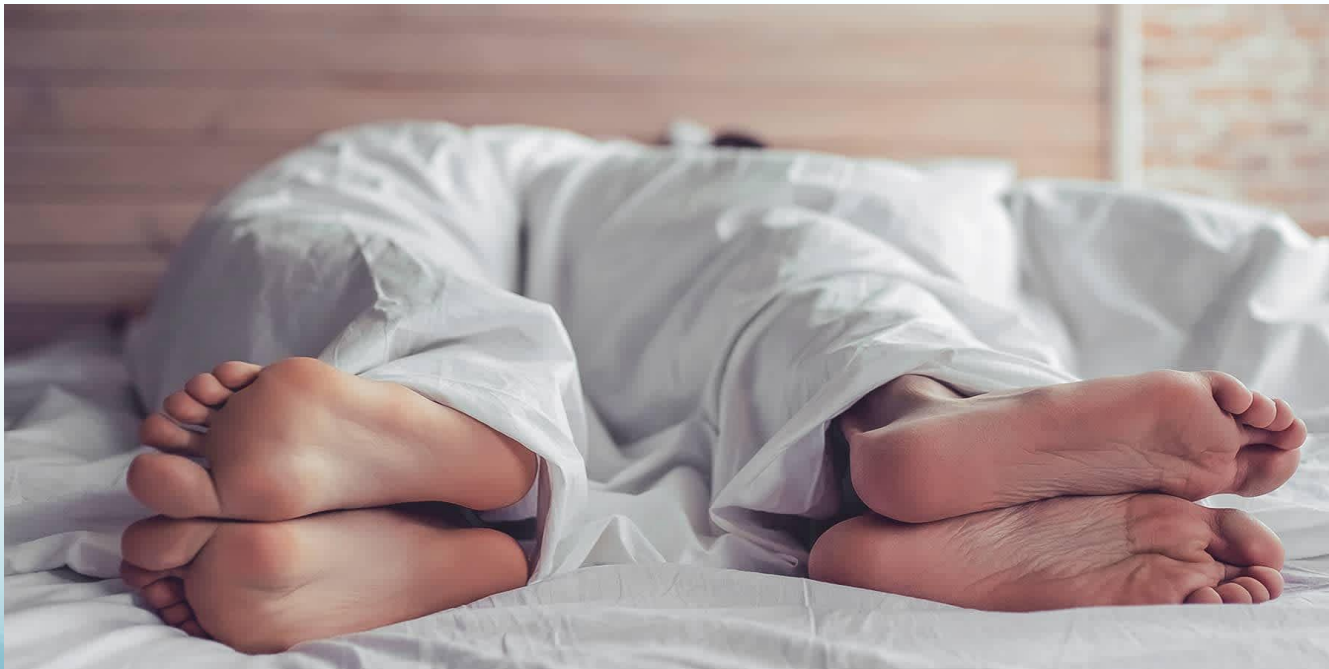


# Chemotherapy

- **Ovarian Failure (may be transient)**
- **Neurologic Changes**
- **Mucous Membrane Irritation**
  - **Vaginal Mucosal Sores, burning, dryness, inflammation**
- **Immunosuppression**
  - **vulvovaginitis**
  - **HSV**
- **Alopecia (public and private)**
- **Fatigue**



**Sexual desire or libido is defined as the broad interest in sexual objects or experiences, while sexual arousal is both a subjective (i.e., feeling sexually excited) and a physiological (i.e., genital vasocongestion) term.**

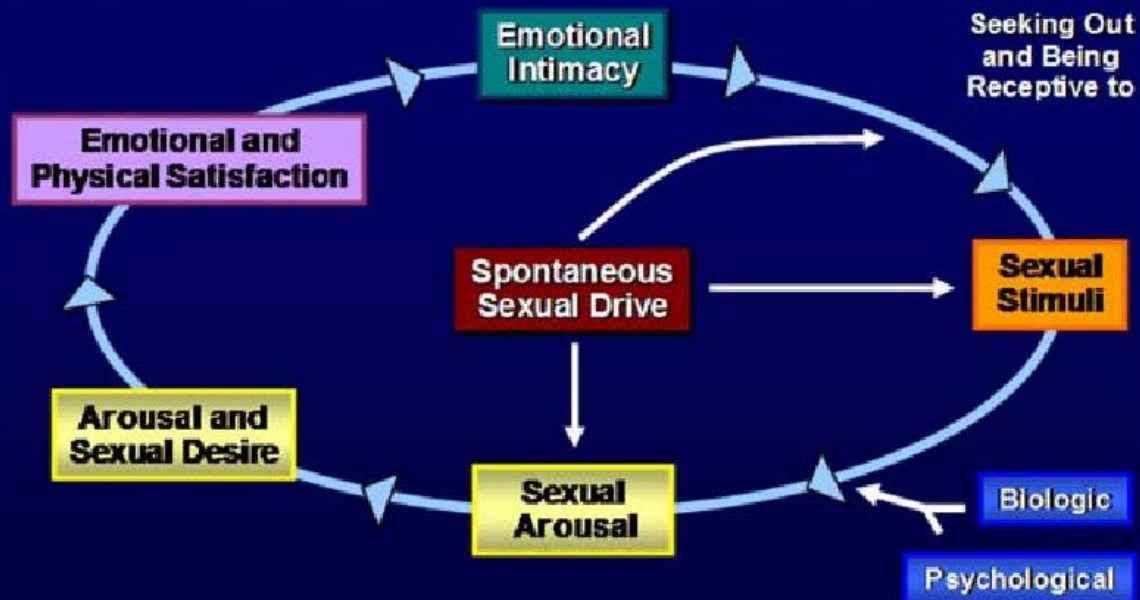


**Pain**  
**Numbness**  
**Decreased sensation**



“Sandpaper Sex”

# Female Sexual Response Cycle



Basson R. *Med Aspects Hum Sex.* 2001;1:41-42.

# Fatigue



- **Treatment**
- **Pain**
- **Inflammation**
- **Depression**
- **Anemia**
- **Anxiety**
- **Insomnia**
- **Hot Flashes**

# **Oncologist's Perception of Sexual Intimacy Issues**

Abstract: NAMS 2019: Larkin L, Portman D etal

- **70 web-based telephone interviews**
- **Board certified oncologists**
- **60 min**
- **Most surveyed largely dismissed importance of sexual function and vaginal dryness, particularly in older patients or in palliative stage**
- **Most felt ill-equipped to treat such complaints**

# Oncologists' Perception of Sexual Intimacy Issues in Metastatic Breast Cancer

## An opportunity to Address Patients' Concerns and Improve Quality of Life



### Oncologists' Perception of Sexual Intimacy Issues in Metastatic Breast Cancer: An Opportunity to Address Patients' Concerns and Improve Quality of Life

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#### INTRODUCTION

Research on women's sexual well-being and partner intimacy issues in breast cancer has been documented and characterized especially in the breast cancer survivorship and adjuvant setting in patients with early stage disease. Sexual dysfunction is a prevalent and frequently reported distressing treatment side effect for many breast cancer survivors as, to date, all endocrine treatment options for women with HR+ HER2- breast cancer result in an increase in vulvovaginal atrophy (VVA) regardless of the patient's menopausal status prior to treatment. It has been documented that this treatment side effect not only impacts the breast cancer survivors' self-esteem, body image, and quality of life, but also negatively impacts their interpersonal relationships and creates additional psychosocial tolls for them that can negatively impact their health.<sup>1</sup> Guidelines have been issued for addressing these concerns in this survivorship population.<sup>2</sup>

There is limited literature and data, however, focused on these sexual functioning issues in women with advanced breast cancer in the metastatic setting. The widespread and first line use of CDK 4/6 agents in combination with endocrine therapy has resulted in a doubling of progression free survival from 12 months with endocrine therapy alone to over two years with the combination.<sup>3-6</sup> With the onset of precision medicine, gene sequencing, and liquid biopsies to identify biomarkers and progression of metastasis or micro-metastasis, it is anticipated that this overall survival benefit and length of time that these patients will be living in the metastatic setting will continue to increase in the future.

As a function of this extended survival, as well as the human need for intimacy even towards the end of life, more women in the metastatic setting will likely be interested in engaging in sexual activity throughout their journey and may be seeking out support and education to address their questions and concerns about sexual intimacy.

#### OBJECTIVE

In an effort to understand the community medical oncologists' attitudes, knowledge, and perceptions specific to sexual activity concerns and issues and their likelihood of counseling their patients in the metastatic setting, a qualitative survey was conducted by Biovid (located in Princeton, New Jersey).

#### PHYSICIAN SURVEY METHODOLOGY

Seventy 60-minute web-assisted telephone interviews were conducted with medical oncologists as part of a hybrid qualitative/quantitative telephone and web-assisted survey.

Each physician surveyed:

- was pre-screened prior to being interviewed to ensure board certification and practice experience
- worked with patients between two and 35 years
- spent >30% of their time on direct patient care
- managed the treatment of >30 cancer patients per month
- managed the treatment of a minimum of 15 breast cancer patients, including at least five who were stage IV metastatic.

Interviewed physicians' breast cancer patient caseload.



#### RESULTS: PHYSICIAN SURVEY

Efficacy continues to be the primary driver and concern for the oncologists in this survey, with quality of life and management of side effects of treatments such as VVA not featured as prominently important in contrast to the documented patient-focused literature which finds sexual and relationship issues are of widespread concern amongst breast cancer patients even in the metastatic setting.<sup>1</sup>

Physicians in this survey largely dismissed vaginal atrophy and sexual dysfunction as clinically important issues in the metastatic setting, although they do acknowledge that they are relevant in the adjuvant setting.

Responses from physicians ranged from lack of regard or lack of knowledge for the VVA and intimacy issues, to a few physicians reporting that they occasionally heard complaints and provided some solutions. A small portion of physicians believe that sexual intimacy is not important to older patients.

#### INTERVIEWED PHYSICIANS SAID:

- "Vaginal atrophy has never been an issue with my patients, never any complaints." <sup>44</sup> It's not much of an issue as the threshold for patient complaints is a little higher given the nature of the disease." <sup>45</sup>
- "Vaginal discomfort is a concern, but not a horrible side effect; metastatic disease is life threatening so they (women) will put up with side effects in order to survive." <sup>46</sup>
- "Minor nuisance for vaginal dryness, but I find solutions with lubricants for painful intercourse." <sup>47</sup>
- "Vaginal atrophy creates stress on patients and their relationships with their spouses because they cannot engage in intercourse." <sup>48</sup>
- "It's a little bit of a problem, I have had a couple patients about that, so I switch them, otherwise it is not a big deal." <sup>49</sup>



Though only a few physicians independently associated VVA with current treatments, all confirmed its relevance when prompted. However, as evidenced by these quotes, very few physicians place it as a high clinical priority in the metastatic setting.

#### DISCUSSION

Since our survey was focused on oncologists and did not include a patient sample, we looked to the literature for data specific to patients' perspectives. In sharp contrast to our medical oncologist perspectives, we found patient perspectives revealed that sexual concerns were a widespread concern for women and that they felt their concerns were often overlooked by physicians. The patient survey was conducted by McClelland, Holland, and Griggs<sup>1</sup>, and below are a subset of quotes from their semi-structured interviews with 32 women diagnosed with metastatic breast cancer who fell within the ages of 35 to 77 years of age:

#### INTERVIEWED PATIENTS SAID:

- "When we tried to have sex initially it was very difficult and we actually were hurting, both of us, because it was real important to both of us and a big stress relief." <sup>44</sup> <sup>45</sup> general  
mBC 17 years
- "The doctors don't tell you how far you can and cannot go. They don't even discuss what you can and cannot do." <sup>46</sup> <sup>47</sup> general  
mBC 4 years
- "What is the best lubricant to use? And maybe some different ways to work around the fact that I am in pain. Those kinds of questions would be good to have somebody to talk to about that." <sup>48</sup> <sup>49</sup> general  
mBC 1 year
- "I have not had a discussion about sexual health with anyone." <sup>50</sup> <sup>51</sup> single  
mBC 4 years

This survey revealed that patient would like for practitioners to proactively discuss sexual functioning issues and solutions with them and do want to engage in sexual intimacy with their partners, yet the medical oncologists do not appear to be aware of their patients' desire for intimacy and their desire for counseling and education from their provider.

#### CONCLUSIONS

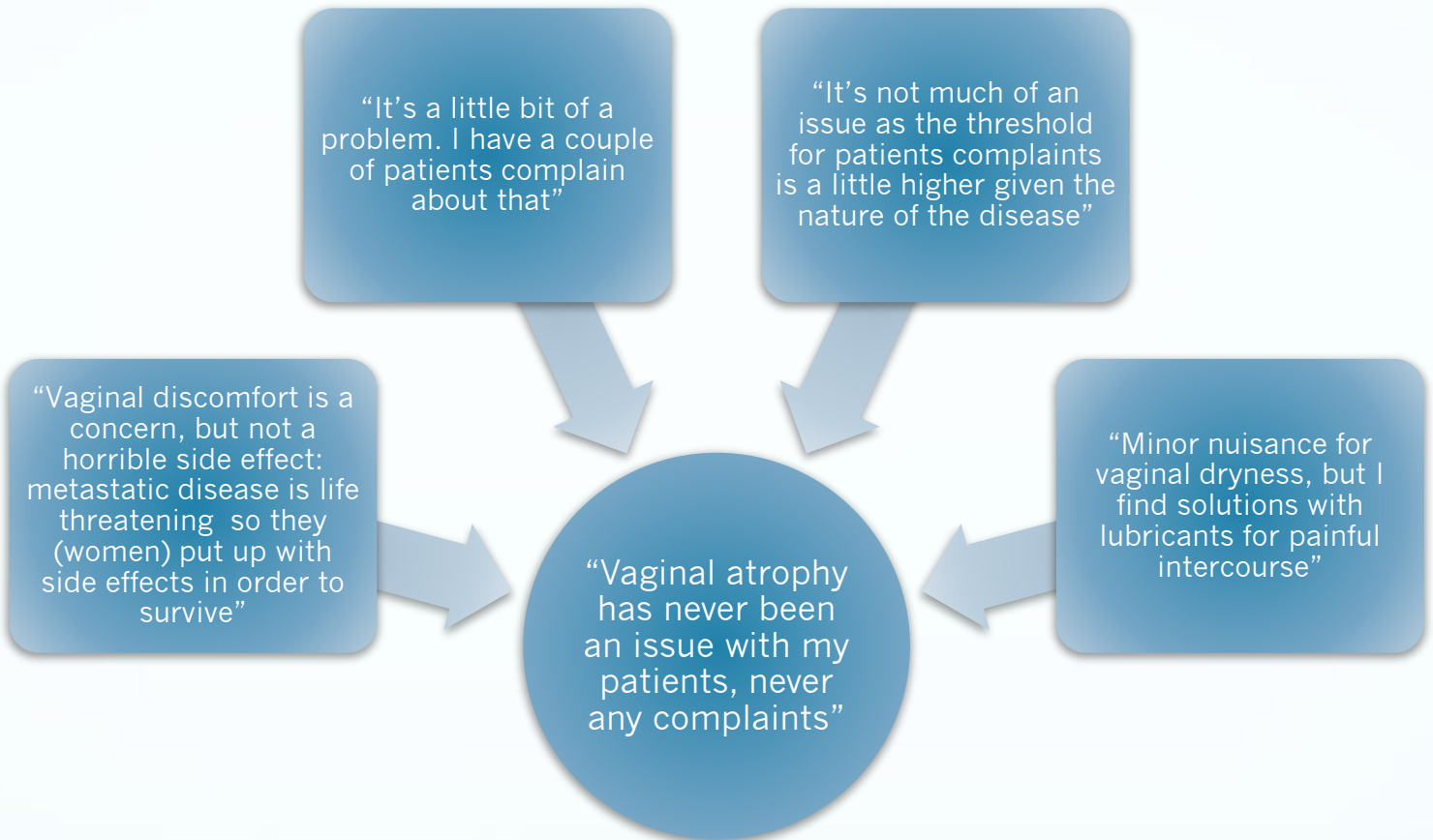
The quotes and findings from these two surveys underscore the magnitude of the disconnect between medical oncologists and patients in the metastatic breast cancer setting as it relates to attitudes and awareness of sexual health.

- Medical providers, particularly oncologists, are often ill-equipped to discuss sexual issues with their patients.
- A study with oncology professionals found that providers made assumptions about which patients would, and would not, want to know about information related to sexuality.<sup>1</sup>
- Often individuals in the palliative stages of cancer were seen as outside the boundaries of sexuality.
- As medical advances continue in the mBC arena and new treatments add years to patients lives, quality of life considerations with respect to sexual intimacy will increase in importance.
- mBC patients' concerns and solutions will be important considerations for health care practitioners to address to ensure that patients are able to enjoy satisfying relationships and the mental and physical benefit that these relationships can provide.

There is need for further research and education to incorporate the appropriate tools and guidelines to bridge from the survivorship population into the metastatic setting so that providers can facilitate discussions with patients to optimize quality of life across the entire breast cancer treatment journey.

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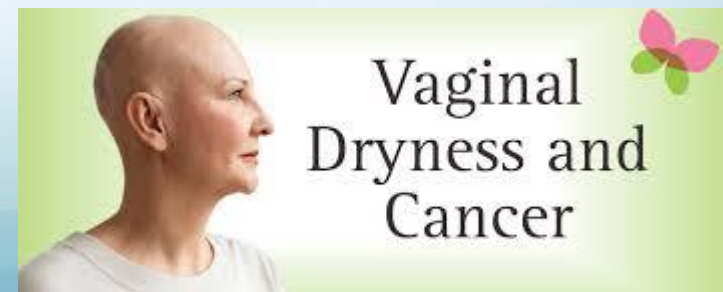
# Barriers to Addressing Sexual Health in Clinical Practice

- Many oncologists and gynecologists feel uncomfortable or untrained to discuss sexual health issues with cancer survivors.
- **Lack of Time:** In busy clinical settings, sexual health concerns are often overlooked.
- **Patient Reluctance:** Women may feel embarrassed or uncomfortable bringing up these issues with their healthcare providers.



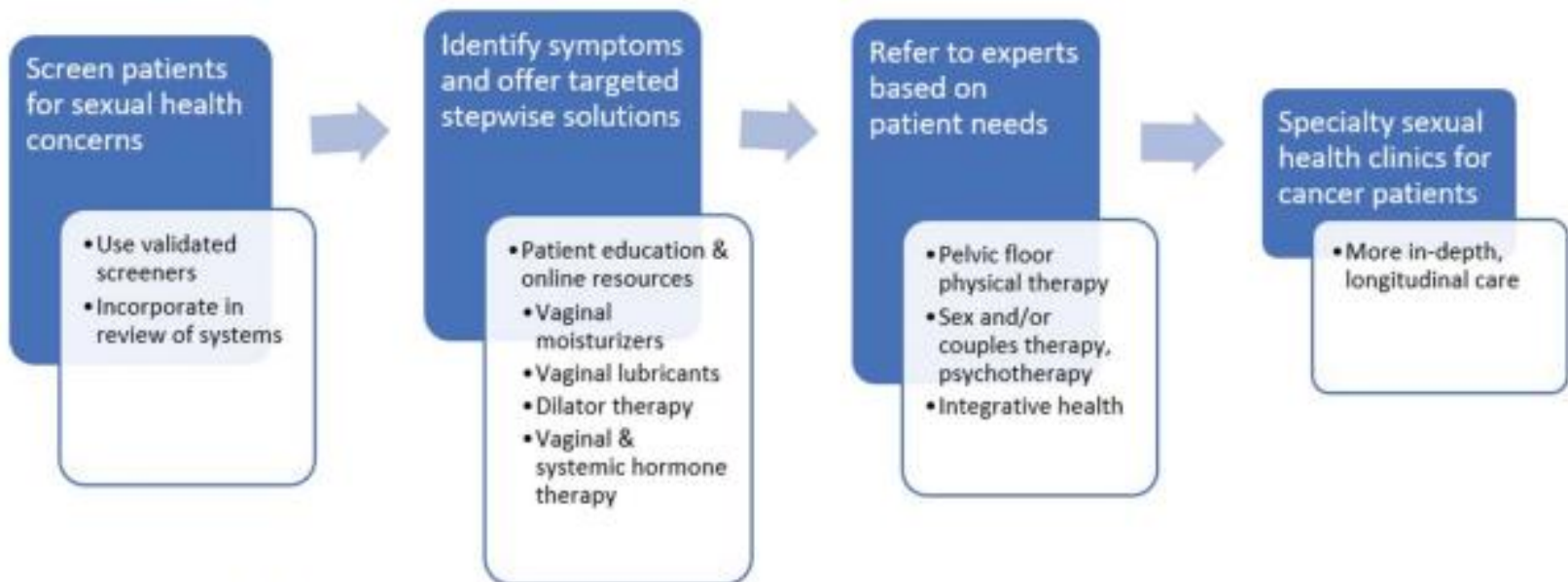
## •Etiology of Sexual Health Issues:

- Sexual health problems in female cancer survivors are caused by a mix of psychological, physiological, and social factors.
- Treatments like chemotherapy, radiation, surgery, and hormonal therapies have significant impacts on sexual health, contributing to issues like decreased sexual desire, decreased arousal painful intercourse, and vaginal dryness.



- **Sexual health is an under-diagnosed and often untreated issue for women who survive cancer.**
- **Survivorship starts at cancer detection and continues beyond treatment, addressing long-term quality-of-life issues such as sexual function.**
- **Many women face sexual dysfunction as a late effect of cancer treatment.**





**Fig. 1.** The approach to sexual health needs among patients with cancer.

*Robison. Sexual Health in Women Affected by Cancer. Obstet Gynecol 2024*

## Approaching Patients Before and After Treatment

**Before Treatment:** Providing anticipatory guidance on sexual health can help patients understand potential issues

**After Treatment:** Routine screening for sexual dysfunction should be part of follow-up care, but this is often missed.



- Cancer affects not only physical health but also emotional and sexual well-being.
- Women undergoing cancer treatment experience significant sexual dysfunction, including pain during intercourse, reduced libido, and changes in sexual identity



- Timing is key to treating depression and psychosexual issues – catching the problem early and counselling patients before it becomes overwhelming or entrenched is important
- It's a bit lonely having cancer, especially afterwards. When you are being treated you've got all those dates on your calendar, but afterwards you are floundering a bit because you are not quite sure what you are supposed to do.



## Effective Treatments for Sexual Dysfunction

- Hormonal Therapies:** Local estrogen therapies can help alleviate vaginal dryness and atrophy, improving sexual comfort.
- Pelvic Floor Physical Therapy:** Helps in rehabilitating muscles that may have been affected by surgery or radiation, reducing pain during intercourse.
- Counseling and Psychological Support:** Sexual health counseling, including cognitive behavioral therapy, can improve sexual function and emotional well-being.
- Lubricants and Moisturizers:** Non-hormonal options are also available to manage vaginal dryness and discomfort.



**Table 2. Patient and Clinician Sexual Health Resources**

Resource	Website
American Cancer Society, How Cancer and Cancer Treatment Can Affect Sexuality	<a href="https://www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/how-cancer-affects-sexuality.html">https://www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/how-cancer-affects-sexuality.html</a>
National Comprehensive Cancer Network, Survivorship: Late Effects/Long-Term Psychosocial and Physical Problems: Sexual Health	<a href="https://www.nccn.org/patients/guidelines/content/PDF/survivorship-crl-patient.pdf">https://www.nccn.org/patients/guidelines/content/PDF/survivorship-crl-patient.pdf</a>
Scientific Network on Female Sexual Health and Cancer	<a href="https://www.cancersexnetwork.org/">https://www.cancersexnetwork.org/</a>
International Society for the Study of Women's Sexual Health	<a href="https://www.isswsh.org/">https://www.isswsh.org/</a>
North American Menopause Society	<a href="https://www.menopause.org/">https://www.menopause.org/</a>
Topic-specific resources	
Pelvic floor physical therapy	
Academy of Pelvic Health Physical Therapy: Find a PT	<a href="https://ptl.womenshealthapta.org/">https://ptl.womenshealthapta.org/</a>
Sex therapy	
American Association of Sexuality Educators, Counselors, and Therapists	<a href="https://www.aasect.org/referral-directory">https://www.aasect.org/referral-directory</a>

## Addressing Sexual Health in Clinical Practice:

Despite the prevalence of sexual health concerns among women who have survived cancer, these issues are rarely addressed in clinical settings.

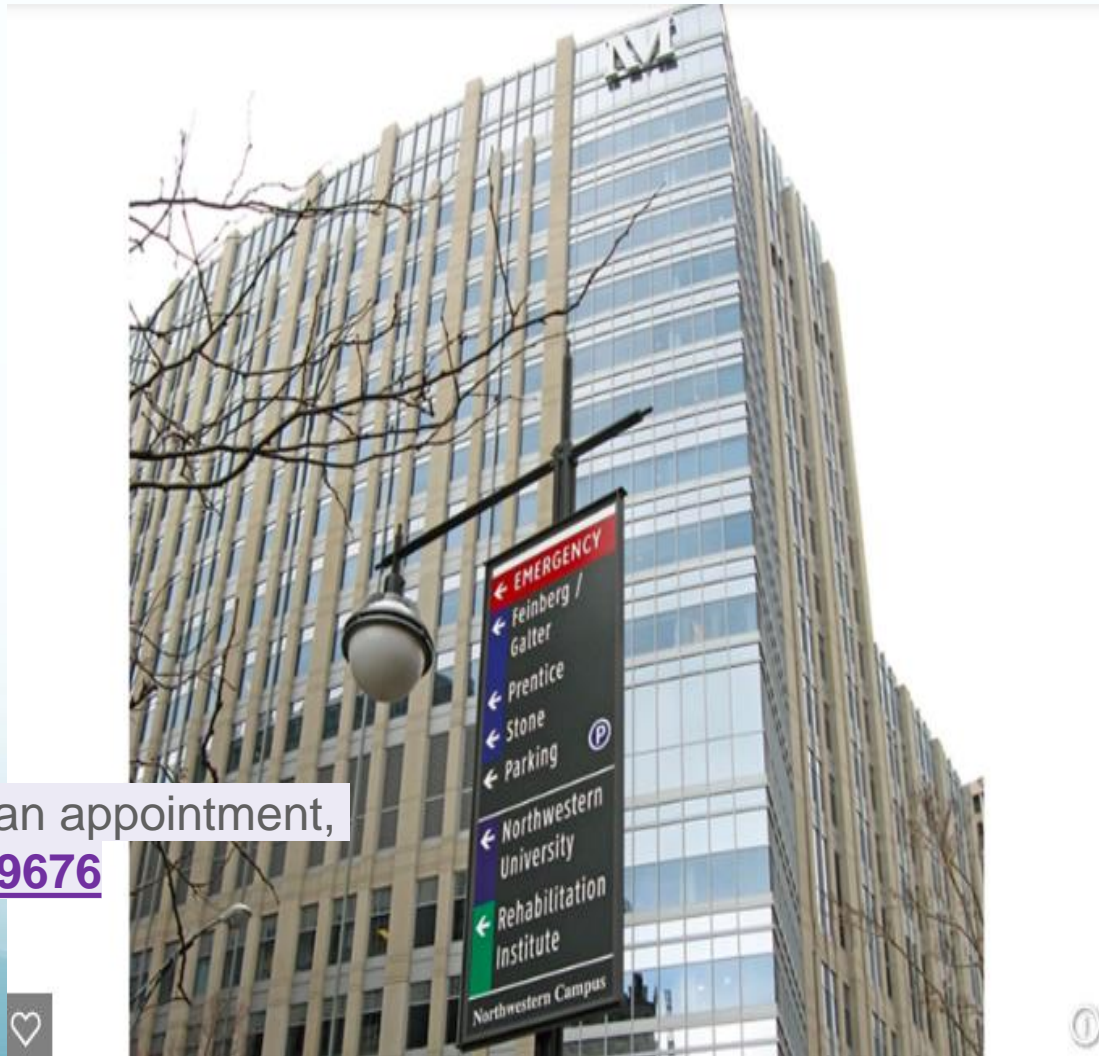
A multimodal approach is required, including open communication, patient education, and treatment strategies that focus on psychological, physical, and relational aspects of sexual health.



•**Conclusions:** Sexual health concerns are common in female cancer survivors but are often overlooked. A comprehensive and multidisciplinary approach, including psychological counseling, physical rehabilitation, and medical interventions, is essential to effectively address these issues and improve the quality of life for cancer survivors.



# Northwestern Medicine Center for Sexual Medicine and Menopause



To schedule an appointment,  
call [312.694.9676](tel:312.694.9676)

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