



Institute for Women's Health Research
Putting Women's Health First

May 2012

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Dear Friends,

Millions of men and women are diagnosed with cancer annually, and the number of women breast cancer survivors alone is nearly equal to the number of Chicago residents-2.6 million and 2.8 million, respectively. A cancer diagnosis and treatment affect one's physical and emotional health and can alter one's quality of life when it comes to sexual health. Sex is an integral component of overall wellbeing for many women. Recently, the [Oncofertility Consortium](#) hosted a lecture by Stacy Tessler Lindau, MD, MAPP, Associate Professor of Obstetrics/Gynecology and Medicine-Geriatrics at the University of Chicago entitled "A Call to Action to Preserve Sexual Function in Women and Girls with Cancer."

We hope that this month's e-newsletter will present new information to consider in light of cancer treatment and how it can affect the body and mind for yourself or someone you love. We have also added a new section to our e-newsletter that highlights the most current activities of the Institute that we would like to share.

Sincerely,

The Institute staff



CANCER AND SEXUAL HEALTH

The Importance of Sexual Health

Sexual health and function are essential components of a healthy life for many people. Sex plays an emotional, physical, and social role, and can influence how we perceive ourselves, what types of relationships we pursue, and how we come to understand what brings us joy and pleasure. People engage in sexual activity at all life stages. In one study, both male and female participants ages 57 to 85 reported engaging in sexual activity well into their mid- to late-eighties (1). For both men and women at all ages, sex can enhance the intimacy of a partnership, provide physical and emotional pleasure, and relieve stress. Sex is also tied to fertility, which is very important for couples or individuals who wish to start a family.

Depending on life stage or circumstance, sex may be more or less of a priority. Stress, illness, medication, or even a major life change such as a new job or the birth of a child can change one's attitudes toward sex, and desire for sexual intimacy may be heightened or dampened. The treatment and healing process of an illness such as cancer can also interrupt interest in being sexual. Physical factors such as pain, tissue damage, and physical changes due to treatment procedures can make sex less desirable or difficult. Psychological factors such as stress, depression, and sense of body image can create barriers to sexual enjoyment and make one feel less sexual or sexually attractive (2).

Before a cancer diagnosis, many women find sex very enjoyable and report that it is an important component of their overall quality of life. Though it may not be the principal focus after a cancer diagnosis or during treatment, many women hope to reintegrate sexual activity into their lives (3). The barriers to sexual functioning after cancer depend on cancer type, method of treatment, preexisting sexual issues, and age. Getting back into a lifestyle routine post-cancer is a significant adjustment in itself, but many find it imperative to reintegrate sex as a part of returning to the familiarity of life before such a diagnosis.

Cancer Effects and Sexual Dysfunction

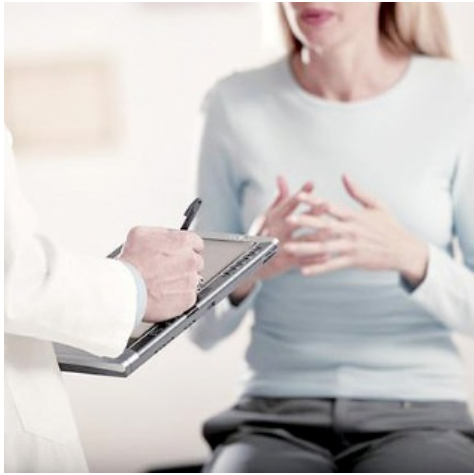
The number of cancer survivors worldwide is increasing, and 64% of

survivors have a diagnosis that directly affects their sexual organs (4). During a lifetime, 1 in 3 women and 1 in 2 men will develop some form of invasive cancer (5). Men have the greatest risk for prostate cancer followed by lung cancer and colorectal cancer, regardless of race or ethnicity (6). Women are most likely to suffer a breast cancer diagnosis (1 in 8 chance), followed by lung and colon cancer. Further, many cancers originate in sexual organs of sexually active people, and therefore it is likely that a cancer diagnosis will affect sexual activity even in a minor way. Sexual dysfunction can manifest in a variety of ways depending on the affected sexual organs, which include the uterus, vagina, cervix, penis, and testis, but also the breasts, prostate, urinary bladder, and the brain. For men, dysfunction may include erectile problems and disruption in the sexual response cycle (desire, excitement, arousal, orgasm and resolution). For women, dyspareunia (painful sexual intercourse due to physical or psychological problems) is common (7), as is a general decrease in sexual desire.



The differing treatment types can impede one's ability to be sexual by decreasing libido, making penetration difficult or impossible, or changing one's attitude toward sex in general (8). A woman might be very sexual prior to a cancer diagnosis but may later find that she has lost interest in sex or that changes in her sexual organs influence her desire for sex. Common treatment such as chemotherapy can lower sexual desire and can often decrease vaginal lubrication, leading to painful intercourse. Further, it may lead to infertility (9). Pelvic radiation for cervical cancer can also lead to infertility, and can significantly reduce the size of the vagina.

Since women are more likely to suffer a breast cancer diagnosis compared to other forms of cancer, sexual dysfunction due to mastectomy (removal of the entire breast) or a lumpectomy (removal of a portion of the breast) is common. Both procedures do not directly affect the vaginal environment but can affect body image and severely inhibit one's ability to experience sexual pleasure. Many women derive pleasure from having their breasts touched during intimacy. The removal of one or both breasts thus presents the risk of changing how a woman feels pleasure, or altering her body image, potentially causing her to feel less attractive or to worry that her partner will perceive her as such. Although treatment for breast cancer does not typically change a woman's ability to physically respond to pleasure through vaginal lubrication or orgasm, it still can cause discomfort with sexual activity.



Cancer can affect an otherwise enjoyable sexual life by changing one's relationships, physical abilities, fertility, and emotional health. Cancer itself alters the body and can make maintaining sexual activity difficult. Many women do not feel like being sexual once diagnosed with cancer, and physical intimacy may move down the list of priorities as they enter treatment. Still, as women move through treatment, they may wish to maintain their sexual activities or reintroduce sex as part of the healing process. Addressing issues of sexual dysfunction can be a difficult and

private manner, but can also be invaluable for the many cancer survivors' well-being.

Barriers to Addressing Issues of Sexual Dysfunction

Although evidence shows that sexual activity continues into advanced age and that those women with cancer care about sex, only 60% of OB/GYNs in a recent study reported routinely asking about a patient's (not specifically those who suffered a cancer diagnosis) sexual activities, and less than 40% reported routinely asking questions related to sexual problems or dysfunction (10). Further, nearly 40% of participating physicians reported that they rarely asked patients about their sexual orientation or identity. These numbers reveal that communication over issues of sex and sexuality is somewhat discordant with the sexual realities of men and women. Women prioritize sexual health, and Dr. Lindau argued that sexual life expectancy—the number of years of sexually active life one has after, for example, a cancer diagnosis—must be considered as an important component of overall quality of life.

Cancer's affect on sexual health is an important topic of discussion for women and healthcare professionals such as Dr. Lindau who, in her clinical work, sees women "who are motivated to come and get help for sexual concerns, even when they don't have a current partner." Still, there are many barriers to open discourse between patients and healthcare providers. In a U.S. public opinion poll of 500 adults, however, 85% of participants responded that they would be willing to talk to their physician about sexual problems, yet 71% did not think the physician would be responsive. Further, 68% reported that they were concerned that the issue of sexual dysfunction may make the physician uncomfortable (11). "One of the barriers to fulfilling ethical care with women is the perception of us raising the topic of sexual functioning and sexuality at the time she's been diagnosed with cancer, it will break her," explained Dr. Lindau in regard to why healthcare professionals may shy away from initiating conversation with cancer patients. She continued, "We haven't found that with men. Men really embrace the opportunity to discuss sexual issues."



Socioeconomic status and age can also act as barriers to discussing sexual dysfunction after cancer. Lower income groups with limited access to healthcare are particularly vulnerable to illness and may not seek or receive adequate treatment due to location, cost, or access to information. Young women and girls who have been diagnosed with cancer might not understand the future implications of cancer treatment as it relates to their sexual health or fertility, and it is often up to parents and guardians to educate them on what to expect. The responsibility of initiating that conversation can be difficult and many adults are unsure how

to even begin or at what age such a conversation would be appropriate. Therefore, the topics of physical and emotional development of young girls and teens through the lens of cancer treatment need special attention.

Despite the robust evidence that women want to discuss issues of sexual activity with their doctors, research is lacking on whether or not broaching the topic with woman diagnosed with cancer will cause additional anxiety or depression. Adequate funding for research on male sexual function post-cancer has allowed for a variety of studies but comparable funding for women's research has yet to allow for thorough exploration of sexual function measures for women. Dr. Lindau suggested future research include educating women on possible sexual side effects of cancer treatment and monitoring potential reactions of heightened stress, anxiety, or depression. Currently, no research confirms or disputes such theories on women's responses to discussion of sexual dysfunction.

Treatment and Resources for Cancer-related Sexual Dysfunction

Tools are available to assess female sexual function that can be used to understand sexual function before a cancer diagnosis. The PROMIS (Patient-Reported Outcome Measurement Information System) is currently used by healthcare professionals to measure sexual function in patients with cancer and in the general population. It includes items related to desire, arousal, lubrication, pain, and satisfaction, and can help researchers acquire information from cancer patients on their sexual life before and after cancer. Clinical trials are needed wherein women with cancer can participate to further develop evidence-based information for physicians and healthcare providers. These will allow researchers to follow patients over time and to assess how their sexual needs and activities change prior to and after treatment.

On the individual level, physical exams for women complaining of sexual dysfunction should include conversation and education by healthcare

providers. Discussing changes and side effects of medications and treatment lets women know what to expect, but patients do not always get the help that they need in addressing their problems. As one patient stated in Dr. Lindau's survey research, "It seems unbelievable to me that a surgeon would remove one's sexual organs and never talk about sex." For patients to make the most informed decisions, physicians must discuss treatment options for sexual dysfunction. Treatment can include estrogentherapy for women who are at low risk for recurring breast cancer, lubricants for women with vaginal dryness, and couples or individual counseling.

Additional attention to resources for underrepresented groups is needed to thoroughly address differences in sexual orientation, sexual identity, and socioeconomic status. A woman without insurance or a job is less likely to receive proactive care for fertility and sexuality than other women. Similarly, both men and women in same-sex partnerships are less likely to seek care or to bring up topics of sexual health with their physicians. Surprisingly, 73 percent of physicians who responded in a recent study failed to ask their patients' sexual orientation at all (12). Future healthcare and health policy should thus include consideration and action on behalf of underserved populations that may have a difficult time getting the information and help that they need. This includes girls and adolescents who often must wait until a physician or guardian chooses to inform them of the physical affects of cancer and cancer treatment on their developing physical and emotional health.

Thanks to researchers and physicians such as Dr. Lindau, progress is being made in the field of sexual health and cancer in women, albeit slowly. With additional funding, cross-disciplinary study, and multi-institutional collaboration, new information will surely emerge that will allow women to receive the information and treatment they need to enhance their overall quality of life and to be active participants in acquiring the care the deserve.

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References

- (1) Lindau ST, et al, *NEJM* 2007
- (2) National Cancer Institute, "Factors Affecting Sexual Function in People with Cancer." 2011
- (3) *US News & World Report*
- (4) *SEER Cancer Statistics 2010*
- (5) *CDC*
- (6) *American Cancer Society*
- (7) Ntekim, A. "Sexual Dysfunction Among Cancer Survivors."
- (8) *American Cancer Society*
- (9) Lindau ST, *Virtual Grand Rounds*. 2012
- (10) Tolman et al., 2003
- (11) Sobecki et al., 2012
- (12.) *Ibid.*

HEALTH TIP

If you are in your reproductive years when you are diagnosed with cancer, be sure to talk to your provider about the impact of your diagnosis and treatment on fertility and what options are available to you to preserve fertility before your treatment begins. The Oncofertility Consortium is an excellent resource on this topic. Visit their website at www.oncofertility.northwestern.edu or call their FERTLINE: 866-708-FERT to talk to the fertility preservation navigator. They can also provide information on fertility preservation in children with cancer.

If you are a cancer survivor and have concerns about your sexual health, visit the [PRISM website](#).

INSTITUTE HAPPENINGS

- Institute Director Teresa K. Woodruff is the newly appointed Vice Chair of Research in the Department of Obstetrics & Gynecology at Northwestern Feinberg School of Medicine.
- The Institute's Women's Health Science Program for High School Girls was invited to participate in the 2nd annual USA Science & Engineering Festival on April 28-29 in Washington DC. Our booth, entitled "Just Bead It", focused on women's health and fertility preservation and how creating alginate beads is helping us make advances in fertility preservation.
- Emma VanZale, a 7th grader from Chicago, was the first recipient of the new Teresa K Woodruff Middle School Science Fair Award for her project "How Consistent is SPF30?" Her project included a sophisticated analysis of 3 different SPF30 sunscreens and found significant difference in the degree that each brand blocked UV rays.
- Sharon Green, Institute Executive Director, will be receiving the 2012 Medical Activist Award from the Women's Health Foundation in June.
- Over 250 health professionals and consumers attended the second annual National Women's Health Week event sponsored by the Institute, the Northwestern Women's Center, the Women's Faculty Organization and the NU chapter of the American Medical Women's Association. Over 40 posters featured current women's health research projects and 22 exhibitors

promoted their women centric clinical services. Dr. Molly Carnes from the U of Wisconsin discussed the role of women in academic medicine at the noon forum.

- Teresa Woodruff, PhD will be a featured speaker at a TEDxNorthwesternU event on June 19 focusing on the *Complex World of Fertility*. Other speakers include Brian Uzzi, PhD, the co-director of the Northwestern Institute of Complex Systems, and Thomas O'Halloran, Director of the Chemistry of Life Sciences Processes at NU. TEDx is a program of local, self-organized events that bring people together to share a TED-like experience. These local, self-organized events are branded TEDx, where x = independently organized TED event. For more information visit the TEDxNU [website](#).
- The Oncofertility Consortium sponsored a webcast featuring Stacy Tessler Lindau, MD, Director of the Program in Integrative Sexual Medicine (PRISM) at the University of Chicago. The lecture can be viewed [here](#).
- Special thanks to our April Forum speaker Bethanee Schlosser, PhD, MD, who spoke on Estrogen and the Skin: Friend or Foe. Notes available [here](#).

UPCOMING EVENTS

June 6, 2012 | 9:00 AM - 12:30 PM | Northwestern Thorne Auditorium, 375 E. Chicago Ave. Chicago

[Why is Healthful Living so Difficult to Achieve? Integrating Research, Programs, Practice](#)

June 7, 2012 (All day) - June 9, 2012 (All day) | Baltimore, MD

[Joint Meeting of the Organization for the Study of Sex Differences and the International Society for Gender Medicine](#)

July 17, 2012 (All day) - July 19, 2012 (All day) | San Diego Marriott Marquis and Varina

[5th National Conference on Behavioral Health for Women and Girls](#)

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