

A manifesto on the preservation of sexual function in women and girls with cancer

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Malignancies that affect females who survive cancer commonly originate in, invade, and/or metastasize to the sexual organs, including the ovaries, uterine corpus, uterine cervix, vagina, vulva, fallopian tubes, anus, rectum, breast(s), and brain. Females comprise most of the population (in number and proportion) with cancers that directly affect the sexual organs. Most females in the age groups most commonly affected by cancer are sexually active in the year before diagnosis, which includes most menopausal women who have a partner. Among female cancer survivors, the vast majority have cancers that are treated with local or systemic therapies that result in removal, compromise, or destruction of the sexual organs. Additionally, female cancer survivors often experience abrupt or premature onset of menopause, either directly with surgery, radiation, or other treatments or indirectly through disruption of female sex hormone or other neuroendocrine physiology. For many female patients, cancer treatment has short-term and long-lasting effects on other aspects of physical, psychological, and social functioning that can interfere with normal sexual function; these effects include pain, depression, and anxiety; fatigue and sleep disruption; changes in weight and body image; scars, loss of normal skin sensation, and other skin changes; changes in bodily odors; ostomies and loss of normal bowel and bladder function; lymphedema, and strained intimate partnerships and other changes in social roles. In spite of these facts, female patients who are treated for cancer receive insufficient counseling, support, or treatment to preserve or regain sexual function after cancer treatment.

Key words: cancer, female sexual function, sexual outcome, survivor

and satisfying sexual activity are experienced by people with cancer as indicators of and important for overall well-being, vitality, and relationship quality.¹ Conversely, loss or lack of sexual drive, impaired sexual function, and sexual activity with pain or without satisfaction can cause individual and relational distress³ and may indicate or cause worry about cancer recurrence or other conditions.⁴ Impaired sexuality is common among women and men who undergo treatment for cancer⁵⁻⁷ and is highly prevalent among cancer survivors.^{2,8} Patient education materials for men reliably address issues that are related to sexual function after treatment for prostate cancer.⁹⁻¹² In contrast to men with cancer, the vast majority of women and girls who are treated for cancer receive no pretreatment information or intervention to preserve or regain sexual function after cancer treatment.^{13,14}

The Interactive Biopsychosocial Model (IBM) is a theoretic framework that was developed by physicians and sociologists for the study of sexuality in the context of aging and illness.¹⁵ This

Sexuality, which includes sexual activity, sexual function, and sexual and gender identity, is an essential element of life for people with cancer, even those without a current partner.^{1,2} Sexual drive, function, attractiveness,

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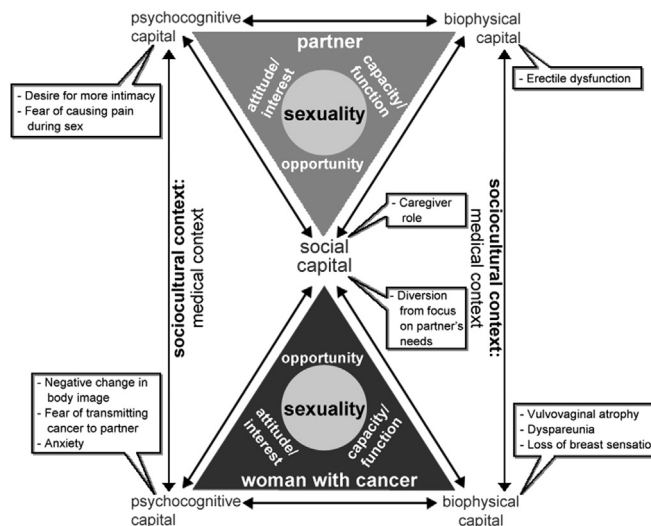
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model builds on psychiatrist George Engel's¹⁶ biopsychosocial model and social capital theory from sociologists Sandefur and Laumann¹⁷ (Figure). This model theorizes a bidirectional relationship between health and sexuality across the life course. For example, aromatase inhibitor therapy for breast cancer can cause severe vulvovaginal atrophy that results in secondary dyspareunia.¹⁸⁻²⁰ Conversely, sexual activity with a partner who has human papillomavirus elevates a woman's risk for the development of cervical cancer.²¹ The IBM proposes a dyadic approach to the study of sexuality that recognizes that most sexual activity occurs with a partner and that each partner's overall health and sexual function contribute to an individual's sexual experience and function. In examples from our clinical practice, a woman with ovarian cancer stops having sex with her husband because she fears she could transmit cancer to him. In another example, a woman with breast cancer complains of painful intercourse that began after her husband experienced erectile difficulties because of prostate cancer treatment. Thorough evaluation of the patient with a sexual concern requires assessment of the physical, psychocognitive, and social dimensions of her and, to the degree possible, her partner's health.

In the IBM, the term *sexuality* is used to encompass 3 main attributes of individual sexual expression. *Sexual opportunity* is defined in the theoretic model as the social possibility for partnership. Women and girls with cancer or cancer history may be disadvantaged in terms of future sexual opportunity. It is not uncommon for a patient to avoid new relationships because of stigma that is related to physical changes like mastectomy, vaginal stenosis, or colostomy or a fear of disclosing infertility or genetic risk that could be passed to offspring.²² Sexual capacity includes sexual activity (types and frequency of partnered or unpartnered physical behaviors such as intercourse, kissing, oral sex, and masturbation) and sexual function. Sexual function includes the physical and physiologic capacity for

FIGURE
Interactive biopsychosocial model of sexuality



Interactive Biopsychosocial Model of sexuality in the context of cancer, with examples in each domain that influence sexuality.

Adapted from Lindau et al.¹⁵

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sex, including desire, arousal, and orgasm as described by the stages of the human sexual response cycle.^{23,24} Head and neck cancer can interfere with the ability to kiss or engage in oral sex. For a woman who has had a mastectomy to treat breast cancer, the sensation of hugging is altered, and the act of hugging can be painful. Pelvic radiation and/or vulvovaginal surgery for genital cancers can interfere with the capacity for vaginal intercourse and reduce genital sensation and clitoral function.

Sexual attitudes include subjective measures of interest, beliefs, preferences, distress or bother, and satisfaction. Changes in body image, relationship roles, grief, and worry about cancer recurrence can alter sexual attitudes and interfere with sexual satisfaction. The general model hypothesizes that the sociocultural context influences the relationship between sexuality and health. Much of the research underlying this manifesto focuses very specifically on the influence of the medical context (Figure), which includes the effects of patient-physician communication about patient sexual concerns, sexual outcomes after procedures, or side-effects of

treatment. Although sexuality is related empirically and meaningfully to overall quality of life and well-being,^{25,26} the ability to function sexually is also understood as a basic component of human physical function that recognizes that there is individual variation in importance attributed to this aspect of physical function (35% of women and 13% of men 57-85 years old in the United States rate sex as "not at all important").²

This manifesto calls for gynecologists and other clinicians who provide gynecologic care to preserve sexual function and eliminate unnecessary suffering because of sexual problems in women and girls with cancer. For evidence, we draw on the published, peer-review literature, the clinical and research expertise of the Program in Integrative Sexual Medicine for Women and Girls with Cancer at the University of Chicago,²⁷ and the shared expertise of the international Scientific Network on Female Sexual Health and Cancer.^{28,29} The term *manifesto* derives etymologically from the Latin words *manifestus*, which translated to *obvious* and, later, *manifesto*, which meant "to make public" (pg 262).³⁰ The purpose of this clinical

opinion is to declare publicly 9 domains of evidence underlying the obvious assertion that ethical and humane care of women and girls who are affected by cancer should optimize the preservation of capacity for sexual function and sexual life. This document was written as a practical tool to be used by clinicians, patient advocates, and others who are motivated to respond to this call to action with an effective argument about the importance of practice change in this domain of women and girls' health and cancer care.

Manifesto on the preservation of sexual function in women and girls with cancer

Most women and girls with cancer have a cancer that directly affects the sexual organs

Most cancers that affect women who survive cancer originate in, invade, metastasize to, and can be associated with an increased risk for primary cancer that originates in other female sex organs. These cancer types, and the number of women and girls with each type based on 2011 prevalence data from Surveillance, Epidemiology, and End Results (SEER) data, include breast (2,899,726), uterine corpus (610,804), colon and rectum (586,969), uterine cervix (249,632), ovary (188,867), brain (68,715), and anus (26,298).³¹ Other cancer types, such as, but not limited to, leukemia and lymphoma,³² head and neck cancers,^{33,34} lung cancer,³⁵ and cancers that affect a woman's partner such as prostate cancer,³⁶ have been shown also to affect female sexual function through physiologic mechanisms.

Women comprise the majority of the population (in number and proportion) that is diagnosed with cancers that directly affect the sex organs.³¹

The vast majority of women in the age groups that are affected by gynecologic and breast cancers are sexually active in the year before diagnosis, which includes the majority of menopausal women and women in the 6th, 7th, and 8th decades who have a partner.²

Girls and teens have sexual thoughts, engage in masturbation, and develop sexual and gender identity even if menarche

and/or puberty are disrupted by cancer or if they were never sexually active with a partner before their cancer diagnosis.³⁷⁻⁴⁰

Cancer and cancer treatment can impair female sexuality

Among female cancer survivors, the vast majority have cancers that are treated with local or systemic therapies that result in removal, compromise, or destruction of the sexual organs.⁴¹⁻⁴⁵ Additionally, female cancer survivors often experience abrupt or premature onset of menopause, either directly because of surgery, radiation, or other treatments or indirectly because of disruption of female sex hormone or other neuroendocrine physiology.^{46,47}

For many women and girls, cancer treatment has short-term and long-lasting effects on other aspects of physical, psychologic, and social functioning that can interfere with normal sexual development and function. These effects include pubertal⁴⁸ and menstrual disruption⁴⁹⁻⁵¹; premature menopause^{46,47}; pain, depression, and anxiety⁵²⁻⁵⁷; fatigue and sleep disruption^{49,54-56,58}; change in weight and body image^{49,52-55}; scars⁵⁸; loss of normal skin sensation and other skin changes because of surgery and/or radiation^{47,50}; changes in bodily odors/scents and sounds; ostomies and loss of normal bowel and bladder function^{53,54}; lymphedema⁵⁹; changes in social roles⁵⁹; and reliance on medical therapies to treat these conditions.^{58,60}

Women and girls with cancer value their sexuality

The vast majority of women who are diagnosed with cancer value their ability (current or future) to function sexually, to experience sexual feelings, and to be sexually attractive to others. This majority includes women who are older, menopausal, or without a current partner.¹

Girls with cancer, especially gynecologic cancer, and/or their caregivers have thoughts, hopes and questions about girls' sexual development, future fertility,^{61,62} future sexual function,⁶³ sexual and gender identity,³⁷ and intimate relationships formation.⁶⁴ These questions commonly go unaddressed

in the clinical care of girls with cancer. The American Academy of Pediatrics publishes guidelines, based on age and developmental stage, for talking to children and adolescents about sexuality.⁶⁵ These guidelines should inform the approach to discussion about sexuality with girls with cancer and their parent(s)/caregiver(s).

Loss of sexual function has negative health consequences for women and girls with cancer and their partners

Women who have or have had cancer and experience loss of current or future sexual function endure physical and psychologic pain and suffering that can erode overall function and quality of life. These effects can extend to a woman's current and future partners.

A woman's ability to function sexually is material to her ability to enter long-lasting life partnerships, marry, and/or enjoy other kinds of sexual and intimate relationships, as well as her ability to sustain these relationships.⁶⁶

A woman's inability to function sexually can result in relationship strain,⁸ infidelity (by the patient or her partner), and dissolution or abandonment of marriage or long-lasting life partnerships.⁶⁷ The consequences of relationship strain also affect the current and future socioeconomic and psychosocial well-being for both the woman with sexual dysfunction and her children.⁶⁶

A woman of lower socioeconomic status is particularly vulnerable to abuse and/or expulsion from a relationship, home, or family if she is unable to perform sexually.⁶⁶

Marital and intimate life partnerships are the most important social relationships for an individual's current and future health, especially as one ages. These relationships have been shown to buffer against disease and be associated with better cancer outcomes via biophysiological mechanisms.⁶⁸ A woman's spouse or life partner may be called on to make critical end-of-life decisions when a woman is no longer able to do this on her own. In a 2004 US survey of 2750 married couples, 30% of respondents (mean age: wives, 62 years;

husbands, 67 years) named their spouse as durable power of attorney for health care.⁶⁹ In a study of 1083 hospitalized older adults, the spouse was the patient's surrogate decision-maker in 21% of cases.⁷⁰

On average, middle aged and older couples have sex 2-3 times a month.² Younger couples have sex once or twice a week.⁷¹ Based on data from the general US population, future sexually active life expectancy for a 50-year-old woman is, on average, 15 years.⁷² Loss of sexual function because of cancer or its treatment can result in hundreds of lost episodes of sexual activity for the patient and her partner.⁷²

Patients want to preserve their sexuality but rarely ask for help

Concerns about loss of sexual function influence patient decision-making about, and adherence to, cancer treatment and cancer risk-reduction recommendations, yet patients rarely voice these concerns.

Women presenting with cancer want their physicians to counsel them about the implications of their cancer, cancer treatment, and cancer risk-reduction therapies for their short- and long-term sexual function because they regard this information as material to coping with, and decision-making about, these treatments, but women and girls with cancer rarely receive this counseling.^{1,13,73}

Women with cancer want to receive care for sexual concerns in the context of considering, receiving, or recovering from cancer diagnosis, treatment, and risk reduction therapies, but rarely receive this care.^{13,74}

When physicians fail to initiate a discussion about sexual outcomes that are related to cancer and its treatment, this signals to patients that sexual outcomes are not relevant, appropriate, or welcome in the context of cancer care and/or that sexual problems in this context are a rare occurrence.^{46,47}

Women who experience, but have not been counseled about, sexual function problems in the context of cancer care commonly believe they are alone, feel ashamed, experience guilt,⁸ and

mistakenly assume that iatrogenic and/or physiologic sexual function problems are "in my head" or because of "not trying hard enough."

Women who experience, but have not been counseled about, sexual function problems in the context of cancer care often feel hopeless, "broken," and/or a loss of femininity.^{8,60,75}

Better evidence is needed to optimize sexual outcomes in women and girls with cancer

Ample evidence, which has been accumulated over decades, establishes the prevalence and types of female sexual function problems in the context of a broad range of cancers, but high-quality evidence about incidence, pathophysiologic process, course and effective prevention, and treatment of these problems remains very limited.

This knowledge has been produced and effectively applied to improve outcomes for male populations with cancer, especially prostate cancer,⁹ at a much more rapid pace than in female populations; attention to the preservation of sexual function and related sexual outcomes is now standard of care for men with prostate cancer.⁷⁶

Reliable, valid, and efficient tools to assess female sexual function before, during, and after cancer treatment are available and applicable to the general population and to women with cancer.⁷⁷⁻⁸³

These tools are slowly being adopted into the care of the general adult female population and in women who have survived cancer but have only scarcely been adopted in the baseline (pretreatment) assessment of women diagnosed newly with, suspected to have, or at increased risk for cancer.⁸⁴

Women with a new or suspected cancer diagnosis are willing to disclose information about sexual activity and problems, and they exhibit a high prevalence of problems at baseline. In one recent study, 98% of women who were evaluated for initial gynecology oncology assessment answered at least 1 question that pertained to sexual function on a new patient intake form.

Of these, 52% indicated at least 1 sexual problem or concern.⁸⁴

No such tools have been published specifically for use in pediatric or adolescent-age girls in the context of cancer or cancer risk-reduction treatment.

To accelerate discovery in this field, providers across disciplines (especially gynecology, physical therapy, and sex therapy) must harmonize and standardize measures and methods to assess female sexual function, symptoms, and outcomes.

Research is needed to establish effectiveness of treatments for female sexual problems in the context of cancer

Treatments that include patient-provider communication, psychotherapy (eg, sex therapy, couples/marital therapy), physical therapy, nonhormonal and hormonal therapy are being used to address and to a lesser degree prevent, sexual problems in women with cancer.^{46,74} Recent, thorough reviews of treatments for female sexual dysfunction in the context of cancer have been published.^{47,85-88}

There is very little evidence that these treatments are being applied in or developed for pediatric or adolescent-age girls beyond fertility preservation.

Many of these treatments lack rigorous evidence to establish effectiveness and safety.^{46,89}

Many treatments are applied without specialized training in the area of female function and/or sexual therapy, despite evidence that general training of physicians (which includes gynecologists, oncologists, psychologists and other mental health professionals) includes very little information or transmission of skills in this area.^{46,50,74}

Many women are treated without physical examination to evaluate the female genitalia (including the breasts) by the provider or a collaborating member of the provider's team, despite evidence that sexual function problems in women are often physical or physiologic in origin and accompanied by physical findings.⁷⁴ Common physical

TABLE 1
Patient and provider resources for addressing sexual concerns related to cancer

Resource	Description
For patients	
American Association of Sex Educators, Counselors and Therapists (AASECT)	A resource list of certified sex therapists by specialty and geographic location; available at: aasect.org
American Physical Therapy Association (APTA)	A resource list of women's health certified pelvic physical therapists and education about pelvic physical therapy; available at: apta.org
The International Society for the Study of Women's Sexual Health (ISSWSH)	A resource list of sexual health fellows practicing in the field; available at: isswsh.org
The Scientific Network on Female Sexual Health and Cancer (The Network)	A resource list compiled and curated by an interdisciplinary group of international experts on cancer and female sexuality; available at: cancersexnetwork.org
The Society for Sex Therapy and Research (SSTAR)	A therapist directory that allows patients to search for certified sex therapists in their area; available at: sstar.org
For providers	
Institute for Sexual Medicine (Irwin Goldstein, MD, President and Director)	Provides training for professionals in basic science research and clinical care in the field of sexual medicine; available at: theinstituteforsexualmedicine.com
The International Society for the Study of Women's Sexual Health (ISSWSH)	Offers a special interest group and provider trainings focused on female sexual health and cancer
The Scientific Network on Female Sexual Health and Cancer (The Network)	Offers membership to professionals with an interest in evidence-based approaches to the prevention and management of female sexual problems in the context of cancer
The Society for Sex Therapy and Research (SSTAR)	Offers member benefits that include access to resources in the field and continuing education credits at SSTAR meetings
University of Chicago's Program in Integrative Sexual Medicine (Stacy Tessler Lindau, MD, MAPP, Director)	Offers on-site consultation, education, and clinical site visits for professionals who seek to create a regional clinical and research program, including a multisite research registry; available at: www.uchospitals.edu/specialties/obgyn/prism.html (contact slindau@uchicago.edu)

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findings that are related to sexual function concerns include the absence or decreased sensation of the breasts, vulvovaginal atrophy, contact dermatitis, and vulvar fissuring, especially at the posterior fourchette. Many women will have a normal physical examination and are reassured by this finding. Physical examination should be a

routine element of evaluation of a woman with cancer and sexual function concerns,^{25,88} following age-based guidelines for appropriate gynecologic examination.²⁵

Reporting an absence of abnormal physical findings and/or educating women about their genital anatomy during physical examination, which

includes an assessment with a vaginal dilator,⁹⁰ can ease fear that is associated with sexual activity and/or alleviate the perception that they have lost physical capacity for sexual activity.⁹¹ Recent evidence shows that women and girls tend to underestimate their vaginal capacity after cancer treatment.⁹²

Special effort should be made to include women and girls of sexual minority groups

Special concern and effort, because of established history of stigma and poorer health and cancer outcomes, is warranted to ensure equitable care for lesbian, bisexual, and other women and girls with cancer and sexual function concerns.⁹³ For example, physicians should not assume that lesbian women are not interested in preserving a capacity for vaginal penetration. Even if penetrative sexual intercourse is not desired, vaginal patency is important for future gynecologic examination and, if possible, fertility.

Sexuality is an essential component of female health

Adapted from former Surgeon General David Satcher's 2001 report on sexual health,⁹⁴ the current and future capacity of a woman or girl with cancer to maintain full agency over her ability to function sexually is essential to her health, quality of life, femininity, and/or personhood, regardless of her age, marital/partner status, sexual identity and orientation, race/ethnicity, socioeconomic or cancer status and includes, but is not limited to, her ability to reproduce.

What can the practicing obstetrician-gynecologist do to elevate the quality of care and preserve sexual outcomes for women and girls with cancer?

Routinely elicit patient sexual function

Improved care for a woman's sexual concerns after cancer can happen only if the patient's concerns are elicited. Include this simple, validated, routine screening item to assess sexual function at least on an annual basis: "Do you have any sexual problems or concerns?"⁹⁵

TABLE 2

Patient resources for obtaining products or services to address sexual concerns or problems

Concern	Product or service	Resources
Individual or couple distress related to sexual concerns	Psychotherapy, sex therapy, couples or marital therapy, mindfulness therapy, group support	See www.aasect.org or www.sstar.org to find trained, local therapists; community-based cancer support or wellness centers; the Cancer Support Community's Cancer Support Helpline (888-793-9355; available at: www.cancersupportcommunity.org)
Pelvic floor dysfunction, including urinary and fecal incontinence	Pelvic physical therapy	American Physical Therapy Association website to find a local, specialized women's health physical therapist: available at: http://www.womenshealthapta.org/pt-locator
Vaginal dryness	Lubricants, moisturizers	Purchase over-the-counter at a drug store or online equivalent or grocery store for food-grade products (eg, oils)
Vaginal stenosis or vaginismus	Vaginal dilators, vibrators, or dildos	Obtaining medical-grade vaginal dilators requires a physician prescription; other products can be purchased over-the-counter at drug stores, pharmacies, sexual product stores, or online equivalents ^a
Male sexual dysfunction	Medical evaluation and treatment	Most urology practices offer treatment for male sexual dysfunction; www.urologyhealth.org provides patient-focused tools to locate a local urologist from among American Urological Association members

^a Information on vaginal dilators can be found online by the use of a combination of the following search terms: *medical grade, silicone, vaginal dilator, and vaginismus*.

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Inclusion of this brief item will signal to your patient that sexual function is within bounds of obstetrics/gynecology care, will normalize sexual function concerns ("my doctor didn't ask, so I assumed I was the only one with this problem...") and will convey that you regard her as a complete human being. In a study of new patients being evaluated for gynecologic oncology care, 52% indicated that they had a problem, but the problem was recognized and addressed only for 14%.⁸⁴ Eliciting a patient's concern only works if the physician reviews and acts on her response.

Provide anticipatory guidance

If a patient indicates no sexual function concerns, say "You indicate that your sexual function is good. It's not uncommon to experience some changes in sexual function during or after cancer treatment and with age. Let me know if anything comes up."

Normalize the patient's concerns and arrange a time to focus specifically on them

If a patient indicates sexual function concerns, say "I see you have some difficulty with your sexual function. As many as 40-50% of women report changes or problems with sexual function during or after cancer. These problems are usually manageable and should improve over time." If you have time (it can take 30 minutes for a therapeutic discussion), ask if she can tell you more about what she's experiencing. If you don't have time, ask if she would be willing to come back for a focused meeting just about her sexual concerns. Invite her to bring her partner.

Provide resources

Offer your patient resources (Table 1) with which she can obtain products or services you recommend to preserve or improve her sexual function (Table 2).

Develop expertise to fill this need for care in your community

Enroll in a course or specialized training (Table 1) to learn more about the treatment and prevention of sexual problems in women with cancer. Promote your skills to providers who are involved in the care of women and girls with cancer (eg, adult and pediatric oncologists, reconstructive surgeons, psychologists, general obstetrician gynecologists, internists, family physicians, physical therapists, nurses). Join the Scientific Network on Female Sexual Health and Cancer at www.cancersexnetwork.org. Create educational materials (website, brochures, posters) that communicate openness to all women and girls (we include the Rainbow Flag symbol) regardless of sexual identity or orientation and age.

Call to action

For the evidence-based reasons stipulated here, this manifesto asserts that all

women and girls of all ages who are affected by cancer, especially with cancer or cancer treatment that directly affects the female sex organs (including, but not limited to, the breasts), be provided with evidence-based care to optimize preservation of current and future capacity for sexual function and sexual life. This manifesto further stipulates that the treatment of women and girls with cancer risk—reducing strategies should include an evidence-based approach to prevention and management of sexual problems or dysfunction that might result from surgical or chemopreventive or other strategies to reduce future risk of cancer.

Women and girls with cancer and the people who love them should be informed fully about the putative and known effects of cancer and cancer treatments on their capacity for future sexual function and life. Gynecologists, gynecologic oncologists, and other providers who render gynecologic care are particularly well-positioned to set the standard for the ethical and humane treatment of all women and girls with cancer, which includes the preservation of female sexual function. The slow pace of change from the medical profession in the adoption of practices that help women and girls with cancer preserve their sexual function is likely, at least in part, due to limited options for effective treatment of female sexual problems. The voices of patient advocates must be heard to motivate medical practice change and the pace of development of effective therapies. Obstetrician gynecologists and patient advocates who wish to effect change beyond their own practice or experience can use the evidence-based arguments outlined in this manifesto to inform and activate policymakers, advocacy groups, and health care professionals about this important gap in care. ■

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