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A National Network to Advance the Field of Cancer and Female Sexuality

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Abstract

Introduction—Understanding sexual health issues in cancer patients is integral to care for the continuously growing cancer survivor population.

Aim—To create a national network of active clinicians and researchers focusing on the prevention and treatment of sexual problems in woman and girls with cancer.

Methods—Interdisciplinary teams from the University of Chicago and Memorial Sloan-Kettering Cancer Center jointly developed the mission for a national conference to convene clinicians and researchers in the field of cancer and female sexuality. The invitee list was developed by both institutions and further iterated through suggestions from invitees. The conference agenda focused on three high-priority topics under the guidance of a professional facilitator. Breakout groups were led by attendees recognized by collaborators as experts in those topics. Conference costs were shared by both institutions.

Main Outcome Measure—Development of Scientific Working Groups (SWGs)

Results—One hundred two clinicians and researchers were invited to attend the 1st National Conference on Cancer and Female Sexuality. Forty-three individuals from 20 different institutions across 14 states attended, including representation from eight NCI-funded cancer centers. Attendees included PhD researchers (n=19), physicians (n=16), and other health care professionals (n=8). Breakout groups included: 1) Defining Key Life Course Sexuality Issues; 2) Building a

Registry; and 3) Implementing Sexual Health Assessment. Breakout group summaries incorporated group consensus on key points and priorities. These generated six SWGs with volunteer leaders to accelerate future research and discovery: 1) Technology-Based Interventions; 2) Basic Science; 3) Clinical Trials; 4) Registries; 5) Measurement; and 6) Secondary Data Analysis. Most attendees volunteered for at least one SWG (n=35), and many volunteered for two (n=21).

Conclusion—This 1st National Conference demonstrated high motivation and broad participation to address research on cancer and female sexuality. Areas of need were identified and SWGs established to help promote research in this field.

Introduction

As more men and women live longer after cancer diagnosis and treatment, attention to symptoms and quality of life is of increasing importance both during treatment and throughout survivorship.[1] There are more than 12.5 million cancer survivors in the United States, and women comprise 54% of this group.[2,3] The most prevalent cancer types seen in female survivors are breast cancer (41%), gynecologic cancers (cervical, endometrial, ovarian, fallopian tube, vulvar and vaginal) (15%), and colorectal cancer (9%).[3] The treatment of most cancers requires a multi-modality approach. Common cancer treatments including surgery, chemotherapy, radiation, and endocrine therapy can have extensive sexual side effects. Female sexual outcomes after cancer diagnosis and treatment of cancer are poorly understood and infrequently addressed.

Knowledge and understanding of survivorship issues are integral for the care of the continuously growing cancer survivor population. In 2010, clinician-scientists at Memorial Sloan-Kettering Cancer Center performed a survey of breast and gynecologic cancer patients, which revealed a high prevalence (70%) of sexual function concerns and a large (66%) unmet need for consultation with a sexual health expert.[4] Similarly, clinician-scientists at the University of Chicago found in a clinical survey of women with breast and/or gynecologic cancers that 42% were interested in receiving care to address sexual issues, yet only 7% had actually received care.[5] The Chicago findings corroborated those from an earlier mail and clinic-based survey of a more diverse cancer patient population at MD Anderson Cancer Center.[6] In 2010, the LIVESTRONG Foundation published findings from an internet-based study of male and female cancer survivors (at least 6 months since last treatment); 43% of volunteer respondents had a sexual concern.[7] In this population, sexual concerns were the third most prevalent physical concern among these survivors. Unfortunately, sexual complications from cancer are often unaddressed, yet they can profoundly affect the lives of women and their partners.

Effectively addressing sexual concerns can be difficult considering the varied etiologies and multifactorial nature of sexual function. Understanding prediagnosis sexual function, counseling and making medical and surgical treatment choices that decrease morbidity, all help to mitigate the negative effects of cancer and cancer treatment on sexual function.[8] Medical and surgical strategies to preserve sexual function in men with prostate and testicular cancers[9-11] are more advanced than for women with breast and gynecologic cancers. For women who do seek help, few evidence-based treatments are available to treat sexual problems during and following cancer treatment. Sexual health in women with cancer is understudied, and the association of sexual dysfunction with specific cancer treatments is not clear. Research on the topic of female sexuality and cancer over the last three decades has been largely descriptive with scientists working in silos.[12] Lack of a coordinated, collaborative approach may be contributing to the slim evidence base for prevention and treatment.

The accumulation of evidence from prior studies[4-7, 13-15] highlighted the need and interest for treatment strategies to address sexual concerns in cancer survivors and was an important impetus for the formation of a collaboration between the University of Chicago and Memorial Sloan-Kettering Cancer Center to convene the broader community of experts. In August 2010, interdisciplinary teams from both institutions jointly developed the aims for a national conference to convene active clinicians and researchers in the field of cancer and female sexual health. The goal was to assemble clinicians and researchers working to support the evidence-base on the prevention and treatment of sexual problems in women and girls with cancer to evaluate the state of the field and determine what could be accomplished by working together. The purpose of this paper is to describe the development and proceedings of the first national conference.

Methods for Conference Development

The invitee list for the first conference on cancer and female sexuality was developed by teams from the University of Chicago and Memorial Sloan-Kettering Cancer Center, using the published literature and scientific conference presentations as important sources for identifying experts in the field. The list was further iterated using a snowball method through suggestions from invitees. The conference took place on November 18-19th, 2010 at the University of Chicago's Gleacher Center in Chicago, Illinois. The conference agenda focused on three high-priority topics defined by gaps in practice and in the peer-review literature. Conference costs were shared by both the University of Chicago and Memorial Sloan-Kettering Cancer Center. All conference attendees paid for their own accommodations.

The meeting structure included a dinner session with a patient advocate to facilitate introductions, discussions and networking. The following day, the conference continued with three plenary sessions to frame the priority issues and breakout groups to identify action items. The meeting was planned with and facilitated by Leslie Freeman, PhD, a professional facilitator, and was designed to maximize engagement of a diversity of scientists across disciplines and institutions.

Results from Conference Proceedings

One hundred two clinicians and researchers were invited to attend the 1st National Conference on Cancer and Female Sexuality. Forty-three individuals from 20 institutions across 14 states attended, including representation from eight NCI-funded cancer centers. Attendees included PhD researchers (n=19), physicians (n=16), and other health care professionals, which included physical therapists, physician assistants, nurse practitioners, and social workers (n=8). (Table 1). A myriad of disciplines were represented at the meeting, including gynecology, medical oncology, surgical oncology, radiation oncology, psychology, and behavioral science.

Patient advocate and Peabody Award-winning documentary film artist, Judith Helfand, was the keynote speaker during the dinner. She shared a clip from her film “A Healthy Baby Girl,” which highlighted her experience seeking help from her oncologist about sexual and reproductive concerns following treatment for DES-related clear cell cervical cancer. The showing also included a segment of Ms. Helfand's interaction with her parents about sexual and fertility matters. Ms. Helfand's presentation became an important reference point and thread throughout the remainder of the conference activities, reinforcing the value of engaging cancer survivors and patient advocates in the scientific process.

Plenary session presentations focused on three main topics: 1) Conceptualizing sexuality in females with cancer: a life course view (Barbara L. Andersen, PhD); 2) Building a cooperative registry to accelerate research and discovery (Stacy Lindau, MD, MAPP); and 3) Strategies for implementing sexual health assessment and developing best practices (David Cella, PhD). Barbara L. Andersen brought a historical perspective, reminding the group of work led by Jimmie Holland, MD and colleagues in the mid to late 1980s to raise awareness about the topic of sexual outcomes for females affected by cancer.[12] Dr. Andersen's talk also focused on key stages of female sexual development and function throughout the lifecourse.

Stacy Lindau spoke of the principles and applications of multisite collaborative clinical research registries, using the University of Chicago Program in Integrative Sexual Medicine for Women and Girls with Cancer (PRISM) Registry as an example. This led to discussion about the feasibility of a multi-site registry for accelerating sexual outcomes research in females with cancer and the need for harmonized clinical data collection and patient evaluation protocols.

David Cella's talk updated the group on the Patient Reported Outcomes Measurement Information System (PROMIS)[16] and work to validate sexual function measures for the female cancer patient population.[17] Several participants added detail on the progress of the work, since they had consulted with or contributed to the PROMIS project. These presentations created important background and a shared knowledge-base upon which breakout sessions were built.

The plenary session was followed by three breakout sessions led by attendees recognized as experts in the following topics: 1) Defining key life course sexuality issues; 2) Building a registry; and 3) Implementing sexual health assessment.

The first breakout group, facilitated by Maura Dickler, MD, and Diane Yamada, MD, discussed key sexual health issues experienced by females who develop cancer at each stage of life: pre-puberty, adolescence, childbearing/reproductive years, menopause, post-menopause, and geriatric years (Table 2). Participants were asked: What issues are most common, and which issues or groups are overlooked? Which issues should we prioritize? The group agreed that a major impact of cancer on sexual function is pain, including dyspareunia and effects of cancer related pain and fatigue on sexual functioning. A priority was to target women who had a positive sexual life pre-cancer, since these women often experience traumatic loss when there are abrupt and drastic changes in this previously fulfilling aspect of their lives. A specific emphasis was placed on the quality of the sexual interactions rather than the quantity.[18] The group hoped to expand boundaries to underserved populations (women without partners, women at risk after risk-reducing surgery, racial and ethnic minorities, women of sexual minority groups, and economically underserved patients) and to raise cross-discipline awareness through education, advocacy, and communication. The group identified education as a need for providers, patients, partners, parents, and siblings. The importance of anticipatory guidance regarding the impact of treatment on sexual function was stressed. Long term goals of the group were for health care providers to advocate for patient rights with respect to health policy surrounding fertility preservation and to discuss the effects of cancer on sexuality regardless of stage of life.

The second breakout group, facilitated by Shari Goldfarb, MD, and Stacy Lindau, MD, MAPP, focused on determining challenges in establishing a multi-center sexual health registry. The group discussed the following questions: Which population of female cancer patients should be the focus of a sexual health registry? What questions are best addressed using a multicenter registry approach? Are there funding mechanisms to support a multicenter effort? The second breakout group also discussed standardization and simplification of data collection, including patient-completed forms and clinical assessment tools, to create a universal registry in existing clinics that treat women with cancer and sexual health concerns. Patient literacy and familiarity with sexual terms were raised as important considerations. A second focus of the group was forming mutually beneficial relationships with important national cancer cooperative groups in order to foster collaborative, multisite research.

The group identified cancer subpopulations with little or no data about female sexual outcomes, such as females with colorectal cancer,[19] women status post breast reconstruction, and girls and adolescents with cancer. Another important potential research topic discussed was compliance with medications that affect sexual functioning. The group also discussed what hypotheses could be tested with registry-based research versus clinical trial research and the value of a registry population to identify potential participants for future clinical trials. The group was interested in initiating clinical trials to evaluate preventive and therapeutic sexual health interventions to improve sexual outcomes. The lack of data and research in this area is evident. The group stressed the fact that evidence about sexual effects of cancer treatments is needed to appropriately counsel patients about the relative morbidity of cancer treatment strategies. Additionally, safe and effective interventions to ameliorate sexual dysfunction in survivors are essential to improve quality of life and must be studied. There was significant interest in developing a multi-center registry to prospectively collect information about the sexual health of female cancer patients. Registry-based research could contribute to knowledge about the effects of various cancer types and treatments on female sexual outcomes, which could be translated into cancer treatment planning and care.

The third breakout group was led by Jeanne Carter, PhD, and David Cella, PhD, and discussed how to implement routine sexual health assessment for women and girls with cancer. What questions need to be explored in the area of measurement? What are important assessment time points (e.g., baseline) and possible challenges? What, if any, assessment or measurement model might we emulate or create? The third breakout group discussion focused on defining a finite set of questions that health care providers can use to efficiently screen patients for sexual function or dysfunction (similar to the widely-adopted CAGE questions for alcohol dependency).[20] The questions should focus on desire, arousal, orgasm, pain, and satisfaction. The group decided that sexual health screening should occur early and often with cancer treatment planning and throughout survivorship. Established barriers to sexual health screening were discussed, including time, patient and provider comfort, presence of family and other support people during pre-treatment counseling, and worry about overwhelming the patient in the pre-treatment period.[21-23] The group deliberated whether to add sexual function as the "7th Vital Sign" to be assessed upon patient intake and considered the implications of assessing sexual activity or function as routinely as are other vital signs.[24] Priorities of the group were to standardize screening questions, looking to the PROMIS effort as an important potential source of screening items, and to encourage providers to initiate sexual function conversations in order to convey openness on the subject. It was suggested that sexual health training be provided for physicians and other health care professionals through Continuing Medical Education (CME) and Continuing Education (CE) programming through organizations like the International Society for the Study of Women's Sexual Health (ISSWSH; www.isswsh.org) and the Society for Sex Therapy and Research (SSTAR; www.sstarnet.org).

The breakout groups generated six Scientific Working Groups with volunteer leaders to accelerate future research and discovery: 1) Technology-Based Interventions; 2) Basic Science; 3) Clinical Trials; 4) Registry Research; 5) Measurement; and 6) Secondary Data

Analysis. Most attendees volunteered for at least one Scientific Working Groups (n=35), and many volunteered for two (n=21).

A final visioning session was conducted to conclude the conference. Broader topics of rotating grand rounds across institutions on female sexuality in the context of cancer, sharing materials, and mentorship were discussed as well as the importance of advocacy for preservation of sexual function in women with cancer. As the closing section came to an end, several questions were posed about whether the group would create a formal independent operating structure (such as a new foundation or 501c3 organization), the mission and vision of the group, the group's name, and the leadership structure. These issues were not decided at this convening, but the planning group was encouraged to continue its work. Many individuals indicated a strong willingness to remain in contact with the group and an interest in its future direction.

Conclusion

The 1st National Conference on Cancer and Female Sexuality demonstrated high motivation, commitment and broad participation across disciplines and institutions to advance research on cancer and female sexuality. A need for collaborative research to improve prevention, diagnosis, and treatment of sexual concerns in women throughout the course of cancer treatment and survivorship was established. Areas of need were identified, and working groups were developed to promote collaborative research in this field. The network is intended to be a catalyst and resource for clinicians and researchers interested in improving sexual health outcomes in the context of cancer.

The goal of the group is to advance the field of cancer and female sexuality by performing research and promoting evidence based practice. The long term plan is to provide all women and girls affected by cancer with access to sexual health information and care to optimize sexual well being. The initial conference provided a foundation for multi-institution collaborative research. Sexual function has been identified as an important dimension of physical, emotional, and social functioning after cancer. The scientific subgroups are working towards advancing the field of cancer and female sexuality through focused efforts toward identified gaps in knowledge. A series of conference calls are underway to further develop multi-institutional research projects. A plan for subsequent meetings was made. The group is currently writing a mission, vision, and charter to further define and establish financial sustainability of the network. A diverse cadre of clinicians and researchers are actively working at the interface of cancer and female sexuality with a limited evidence base for treatment and limited resources for funding. This conference demonstrated high motivation to work collaboratively to accelerate knowledge and care in this domain.

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Table 1

Conference Participants

Name	Institution
Emily Abramsohn, MPH	University of Chicago
Barbara Andersen, Ph.D	The Ohio State University
Shirley Baron, PhD	Northwestern University
Sharon Bober PhD	Dana Farber Cancer Center
Andrea Bradford, PhD	MD Anderson Cancer Center
Kristen Carpenter, PhD	The Ohio State University
Jeanne Carter, PhD	Memorial Sloan-Kettering Cancer Center
David Cella, PhD	Northwestern University
Elise Cook, MD	MD Anderson Cancer Center
Maura Dickler, MD	Memorial Sloan-Kettering Cancer Center
Don Dizon, MD	Brown University
Paige Dorn, MD	University of Chicago
Sandy Falk, MD	Dana Farber Cancer Center
Alessandro Fichera, MD FACS	University of Chicago
Judith Florendo, DPT	Florendo PT
Kathryn Flynn, PhD	Duke
Sallie Foley, MSW, LMSW, ACSW	University of Michigan
Leslie Freeman, PhD	Memorial Sloan-Kettering Cancer Center
Jennifer Gass, MD, FACS	Women and Infants, Rhode Island
Katy Githens	University of Chicago
Amy Goetzinger, PhD	Duke
Shari Goldfarb, MD	Memorial Sloan-Kettering Cancer Center
Hope K. Haefner, M.D.	University of Michigan
Julia Heiman, PhD	Kinsey Institute
Diana Jeffery, PhD	TRICARE Management Activity
Lisa Katona, LCSW	Howard Brown Health Center
Mukta Krane, MD	University of Chicago
Michelle M. Le Beau, PhD, MS	University of Chicago
Stacy Tessler Lindau, MD, MAPP	University of Chicago
Jen Makelarski, PhD, MPH	University of Chicago
Patricia Mumby, PhD	Loyola University Hospital
Nikki Neubauer, MD	Northwestern
Jennifer Reese, PhD	Johns Hopkins University
Leslie Schover, PhD	MD Anderson Cancer Center
Lori Seaborne, PA-C	University of Wisconsin
Amy K. Siston, PhD	University of Chicago
Margaret Straub, PA-C	University of Wisconsin

Name	Institution
Lauren Streicher, MD	Northwestern
Janice Swanson, PsyD	Mayo Clinic
Karen Syrjala, PhD	Fred Hutchinson Cancer Center
Jacqueline Thielen, MD	Mayo Clinic
Kate Timmerman, PhD	Northwestern
Lari Wenzel, PhD	University of California, Irvine
Diane Yamada, MD	University of Chicago

Table 2

Key Life Course Sexual Health Issues Discussed in Conference Working Groups

Stage of Life	Sexual Health Issues
Pre-puberty	Impact on psychological well-being and capacity for future sexual function. Body image concerns. Parental concerns.
Adolescence	Body image and sexual identity, self-esteem and guilt, delayed puberty, disfigurement, impact on relationships (dating, when to share), future fertility. Parental concerns.
Childbearing/reproductive years	Fertility preservation, cultural issues and cost; access to infertility treatment/assisted reproductive technologies. Body image concerns and problems with sexual function, including pain with sexual activity.
Menopause	Menopause (early or transient, leading to decreased fertility), known impact vs. unknown and how to counsel patients. Body image concerns and problems with sexual function, including pain with sexual activity.
Post-menopause/Geriatric	Reestablishment of a satisfying sexual life; impact of cancer on sexuality when there is no partner; the influence of ageism on patient-physician communication about sex; partner health and partner sexual function considerations.