Climacteric

ISSN: 1369-7137 (Print) 1473-0804 (Online) Journal homepage: https://www.tandfonline.com/loi/icmt20

Sexual quality of life in men and women after cancer

L. R. Schover

To cite this article: L. R. Schover (2019) Sexual quality of life in men and women after cancer, Climacteric, 22:6, 553-557, DOI: 10.1080/13697137.2018.1526893

To link to this article: https://doi.org/10.1080/13697137.2018.1526893

Published online: 31 Oct 2018.

CLIMACTERIC
2019, VOL. 22, NO. 6, 553–557
https://doi.org/10.1080/13697137.2018.1526893

Taylor & Francis
Taylor & Francis Group

REVIEW

Sexual quality of life in men and women after cancer

L. R. Schover

Will2Love, LLC, Houston, TX, USA

ABSTRACT

More than 60% of people treated for cancer have long-term sexual dysfunction. However, fewer than 25% of those with sexual problems get help from a health professional. Although cancer-related sexual problems usually begin with physiological damage from cancer treatment, a patient's coping skills and the quality of the sexual relationship are crucial in sexual rehabilitation. Barriers to care for people treated for cancer include a lack of discussion with the oncology team. In repeated surveys, fewer than half of patients recall discussing sex or fertility with their care providers, even during informed consent. Practice guidelines on sexuality and cancer were published in 2017 by the American Society for Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN). Both agree the following:

- The oncology team should initiate discussions of sexuality and cancer during treatment planning and at follow-up visits.
- Psychosocial and medical assessment should take place when a concern or problem is identified.
- Referrals should be offered for multidisciplinary treatment, since sexual problems frequently have both psychosocial and physiological causes.

This article describes a system of care that can meet the guidelines while providing sustainable revenue.

ARTICLE HISTORY
Received 27 August 2018
Accepted 16 September 2018
Published online 30 October 2018

KEYWORDS
Oncology; sexual dysfunction; erectile dysfunction; sexual desire disorder; dyspareunia; genitourinary syndrome of menopause

Prevalence and types of sexual dysfunction after cancer treatment

Sexual problems are common, severe, and persistent side-effects of cancer therapy[1,2]. Their prevalence varies with cancer site and treatment, but averages 50–60%[1–3]. Damaged sexual function is almost universal among high-risk groups, including men treated for prostate cancer[4,5], premenopausal women who become amenorrheic after breast cancer therapy[6], or women treated for breast cancer with aromatase inhibitors[7]. Rates approach 33% in men and women who survive childhood or adolescent malignancies[8,9] or who have hematologic cancers[10].

Although cancer-related sexual problems often remain unidentified, patients rank them among their top unmet needs[1]. In a survey of cancer survivors with an average age of 48 years, only 26% of those with sexual problems received care[3]. In general, fewer than 25% of adults over age 40 years with sexual problems in the United States get professional help[11,12]. In a survey of 253 patients treated at a major cancer center, 24% of men and 21% of women wanted help for a sexual problem in the next year[13]. Sexuality was the third most common concern among patients in a survivorship program, reported by 27%[14].

Most cancer-related sexual dysfunction results from damage to the physiological systems that are necessary for a healthy sexual response: the reproductive hormone feedback cycles, autonomic nerves that direct blood flow to the genital area during sexual arousal, the pelvic vascular beds themselves, or, less commonly, the sensory nerves that mediate erotic sensation. Tables 1 and 2 summarize the most common sexual problems seen in men and women, the cancer treatments that increase risk for these dysfunctions, and the physiologic mechanisms responsible for the damage.

Psychosocial factors also play a role in causing sexual problems, however, notably inflexible sexual attitudes, poor sexual communication skills, impaired body image, feeling stigmatized by having cancer, and conflict and dissatisfaction in the patient's intimate relationship[1,2,15].

Barriers to providing optimal care for cancer-related sexual problems

A review of 29 studies from 10 different countries on communication about sexuality and cancer in oncology care settings found that only 60% of men and 28% of women recalled being informed about potential sexual side-effects of their cancer treatment[16]. Only 22% of men and 17% of women reported that treatment had been offered to them for a sexual problem. Yet research on sexual rehabilitation after cancer suggests that not only can sexual function and satisfaction be improved, but corresponding enhancement of general quality of life and depression are also common outcomes of successful interventions[12,17–20].

Factors that interfere with identifying and treating sexual problems after cancer include patients' reluctance to bring up a personal and potentially stigmatized topic during a

CONTACT L. R. Schover schover@will2love.com Will2Love, LLC, 1333 Old Spanish Trail, Suite G, #134, Houston, TX 77054, USA

Table 1. Cancer treatments and risk for sexual dysfunction in women.

Sexual problem	*Cancer treatments that increase risk*	*Mechanism*
Loss of desire for sex and trouble feeling aroused	• High-dose chemotherapy • Aromatase inhibitors • Immunotherapy	• Possible damage to brain centers • Possible loss of estrogen in brain • Secondary endocrine changes • Chronic fatigue, chronic pain syndromes, nausea, distress, damaged body image
Genitourinary atrophy, dryness, and pain	• Abrupt, premature ovarian failure (chemotherapy, pelvic X-ray therapy, gonadotropin-releasing hormone agonist or antagonist, bilateral oophorectomy) • Exacerbation of normal menopause (aromatase inhibitors) • Pelvic radiation therapy • Genital graft vs. host syndrome	• Severe estrogen deprivation and genitourinary atrophy • Direct scarring, loss of elasticity, and loss of blood supply to genitals • Scar tissue from pelvic surgery • Inflammation and adhesions from graft vs. host syndrome
Difficulty experiencing pleasure and reaching orgasm	• Damage to spinal cord from tumor, surgery or radiation • Loss of erotic breast sensation	• Loss of physiologic sensation • Secondary effects of low desire/arousal and pain
Urinary or bowel incontinence	• Creation of ostomy • Pelvic radiation therapy • Surgery for pelvic cancer	• Trouble managing ostomy during sex • Scarring and contraction of organs • Changed anatomy

Table 2. Cancer treatments and risk for sexual dysfunction in men.

Sexual problem	*Cancer treatments that increase risk*	*Mechanism*
Loss of desire for sex and trouble feeling aroused	• High-dose chemotherapy • Cranial irradiation • Immunotherapy	• Possible damage to brain centers • Possible hypogonadism • Secondary endocrine changes • Chronic fatigue, chronic pain syndromes, nausea, distress, damaged body image
Erectile dysfunction	• Damage to pelvic autonomic nerve bundles (neurotoxic chemotherapy, pelvic surgery) • Pelvic radiation therapy or total body irradiation	• Nerve damage limits blood flow during erections • Venous leakage during erection • Direct loss of blood supply to penis • Penile curvature and scarring
Difficulty experiencing pleasure and reaching orgasm	• Damage to spinal cord from tumor, surgery or radiation • Genital graft vs. host syndrome	• Loss of physiologic sensation • Secondary effects of low desire/arousal and pain
Urinary or bowel incontinence	• Creation of ostomy • Pelvic radiation therapy • Surgery for pelvic cancer	• Trouble managing ostomy during sex • Scarring and contraction of organs • Changed anatomy

medical appointment[12,16], lack of specific training of oncology professionals on how to discuss and manage sexual dysfunction related to cancer treatment, and concern in hospital settings that time spent on impromptu sexual counseling will derail overburdened clinic schedules without being billable to insurers.

Patient education materials are also lacking. Most information on the Internet is superficial and repetitive, offering few practical suggestions for preventing or overcoming problems. Self-help books tend to focus on just one cancer site, such as breast or prostate cancer, and present many patient anecdotes but few strategies to try as an individual or a couple.

Patients want help with a broad range of issues related to sexuality, including feeling attractive, safety of having sex during and after cancer treatment, and how to cope with damaged sexual function[12,16]. Health professionals, however, tend to view their role narrowly as informing patients of potential sexual problems that could interfere with accomplishing heterosexual penetrative intercourse[21,22]. Furthermore, many clinicians, including primary care physicians, gynecologists, oncologists, and psychologists, view discussing sexual issues as the job of some other health-care profession[21,23–25]. Clinicians are even more reluctant to provide information and advice on sexuality to patients who are not conventionally heterosexual[26] or who come from different cultures or nationalities[27]. Sexuality becomes the 'hot potato' of clinician–patient communication in oncology.

The role of new practice guidelines on sexuality and cancer

In 2013, the NCCN issued survivorship practice guidelines, including one for sexuality[28]. The guideline was well intentioned but impractical, advocating assessment by oral questionnaire that could take 5–20 min. An identified problem would trigger immediate sexual history-taking and a set of laboratory tests and clinical examinations that could easily add 30–45 min to the visit. No guidance was provided on how to train clinicians, allocate staff time, or get insurance reimbursement for these services, offered during a routine oncology clinic visit.

A 2017 NCCN update[29] and a sexuality and cancer guideline from the ASCO[30] were both published in late 2017. The ASCO document was modified from recommendations by Cancer Care Ontario. The two practice guidelines overlap considerably. Both agree that the oncology team should initiate a discussion of sexuality and cancer during treatment

planning and periodically at follow-up visits; that further psychosocial and medical assessment should occur when a concern or problem is identified; and that appropriate referrals should be offered for multidisciplinary treatment, since sexual problems frequently have both psychosocial and physiological causes.

The ASCO guideline suggests that initial discussion takes place with the patient alone, including a partner only at the patient's discretion. The guidelines only differ slightly on treatment recommendations for sexual problems. Both guidelines also agree that the evidence base is limited for both psychosocial and medical treatments for cancer-related sexual dysfunctions.

A system to meet practice guidelines and optimize care for sexual problems

The challenge for institutions in meeting new practice guidelines is how to structure a program that will be sustainable. In the United States in particular, this includes making sure that services provided to patients will for the most part be reimbursed by a variety of public and private insurers in order to justify the allocation of time from physicians and allied health professionals. Many clinicians regard sexuality as purely an issue related to survivorship, but that is an inaccurate view. Not only the guidelines, but also the nature of oncology care, require that problems with sexual function be assessed at multiple points in the treatment trajectory starting during treatment planning and continuing during and after active therapy:

- Concern about damage to sexual function leads some patients to choose less effective cancer treatments, so the topic needs to be addressed early.
- Some physiologic damage may be prevented by penile or vaginal 'rehabilitation' starting during or just after cancer treatment. Making an effort to get sexually aroused or to use sexual aids such as penile injection therapy, vacuum erection devices, vibrators, or vaginal dilators may prevent some atrophy of the vascular system in the penis or vaginal walls and vulva[31,32].
- Since cancer treatment is often provided at tertiary care centers, some patients live beyond commuting distance. Clinicians may need to provide a large amount of patient counseling in one session and rely on telehealth follow-ups by telephone or videoconferencing.
- Many patients have problems that are only identified by health professionals years after cancer diagnosis and treatment. Although they could have been spared much suffering by earlier assessment, it may not be too late to treat the sexual dysfunction successfully.

Identifying sexual concerns and problems

Many oncology practice settings only assess potential sexual issues by including one or several questions on a checklist given to each patient to identify various problems affecting daily quality of life. Unfortunately, this method greatly underestimates problems[33]. Many older men and women are embarrassed about asking help for a sexual concern related to cancer[34,35]. The clinician responsible for reviewing the checklist may also skip over the questions about sexuality out of discomfort or minimization of the topic. A better option is for the oncologist or oncology nurse to ask a verbal question, putting it into context with a normalizing statement and giving permission to patients to bring up a sexual concern; that is, 'Many people worry that cancer treatment will damage their sex life or fertility. Do you have a question or concern?'

Rather than having this frontline clinician spend unplanned time trying to delineate the problem and provide counseling, each oncology practice setting should train a 'sex expert' who can be available for a follow-up assessment visit. If the patient lives far away, some same-day appointment slots can be kept available. This assessing clinician should be familiar with the sexual side-effects of the cancer types and treatments common in the clinic. Training could be provided through online resources, such as those available on Will2Love.com[36], through grant-supported training programs[37], or by attending continuing educational programs sponsored by professional societies such as the Scientific Network on Female Sex and Cancer[38]. It is always helpful to include clinical supervision from an experienced clinician as part of the learning experience. The assessing clinician could be an advanced practitioner (advanced practice nurse or physician assistant), which may be optimal for insurance reimbursement since the visit can be billed and may include not only a detailed history-taking, but also a physical examination and ordering of relevant laboratory tests. A physician would certainly also be an ideal, but more costly, option. Other possibilities include a clinical or health psychologist or a nurse navigator.

Outcome of the assessment visit

The assessment visit should lead to a multidisciplinary treatment plan. Some brief counseling on specific treatments for a sexual problem should be provided to the patient (and sometimes partner if the initial assessment visit includes the couple). It is very helpful to give a patient educational materials to use at home that include cancer site-specific information on sexual problems, step-by-step instructions on issues such as resuming sex after a time of abstinence due to illness, coping with changes in body image, sexual communication skills, ways to enhance sexual desire, use of vaginal moisturizers and lubricants, medical treatments for erectile dysfunction, and techniques to cope with incontinence or an ostomy. For patients who have access to the Internet and a basic level of health literacy, an optimal way to provide such education without excessive staff time or expense may be a web-based intervention[17–19]. Printed handouts[20] or a structured telephone-based program[39] are other alternatives.

Most patients also need professional help beyond the assessment visit. Some may want to utilize self-help programs, but to also schedule a follow-up visit to make sure problems are resolving. Others can benefit from male or

female sexual medicine assessment and treatment of sexual problems[28,29,40], including hormonal replacement therapy; oral, injectable, or surgical treatment of erectile dysfunction; treatment of genital pain that interferes with sexual pleasure; or diagnosis and treatment of genital damage such as urethral or vaginal stenosis or scarring and irritation from genital graft versus host syndrome[41,42]. Incorporating a new medical treatment into a couple's sexual routine often also requires some help from an expert mental health professional with sexual communication, body image concerns, and relationship conflict[17–20,39].

Developing a referral network to treat cancer-related sexual problems

Large hospital systems or comprehensive cancer centers may have expert clinicians on staff who can provide medical, surgical, and mental health treatment of cancer-related sexual problems. If specialists are available within a large healthcare system, downstream revenue from increased referrals is an incentive to have a reproductive health and oncology program, particularly in the United States where hospital revenue is a crucial issue.

It is often necessary, however, to create referral networks with specialists in the surrounding community. This can be difficult if the oncology practice is located far from an urban area. In that case, it may be necessary to meet with local specialists, such as gynecologists, urologists, or mental health professionals, and encourage them to get extra training in managing sexual problems related to cancer, with the advantage of getting more patient referrals.

Specialists who should optimally be available in a local referral network include:

- Mental health professionals trained in both psycho-oncology and sex therapy;
- Gynecologists trained to treat menopause symptoms and pelvic pain;
- Urologists or andrologists trained to treat male sexual problems; and
- Pelvic rehabilitation certified physical therapists.

Conclusions

Oncology care has all too often ignored the importance of sexual health as an element of quality of life for patients and partners. New practice guidelines seek to optimize the identification and treatment of cancer-related sexual dysfunction. If oncology professionals make the effort to rapidly identify problems and to have a trained 'sex expert' clinician available to assess them, appropriate treatment plans can be created. Multidisciplinary treatment may include prescribing detailed patient self-help programs, providing follow-up counseling to monitor progress, and referring patients or couples as needed for sex therapy by a trained mental health professional and/or medical evaluation and treatment of sexual dysfunction by a gynecologist, urologist, andrologist, or pelvic rehabilitation certified physical therapist.

Conflict of interest No potential conflict of interest was reported by the author.

Source of funding Nil.

ORCID

L. R. Schover http://orcid.org/0000-0001-7225-987X

References

1. Schover LR, van der Kaaij M, van Dorst E, *et al.* Sexual dysfunction and infertility as late effects of cancer treatment. *Eur J Cancer Suppl* 2014;12:41–53
2. Goldfarb S, Mulhall J, Nelson C, *et al.* Sexual and reproductive health in cancer survivors. *Semin Oncol* 2013;40:726–44
3. Beckjord EB, Reynolds KA, van Londen GJ, *et al.* Population-level trends in posttreatment cancer survivors' concerns and associated receipt of care: results from the 2006 and 2010 LIVESTRONG surveys. *J Psychosoc Oncol* 2014;32:125–51
4. Resnick MJ, Koyama T, Fan KH, *et al.* Long-term functional outcomes after treatment for localized prostate cancer. *N Engl J Med* 2013;368:436–45
5. Adam S, Feller A, Rohrmann S, *et al.* Health-related quality of life among long-term (≥5 years) prostate cancer survivors by primary intervention: a systematic review. *Health Qual Life Outcomes* 2018;16:22
6. Shoshana M, Rosenberg, Rulla M, *et al.* Treatment-related amenorrhea and sexual functioning in young breast cancer survivors. *Cancer* 2014;120:2264–71
7. Streicher L, Simon JA. Sexual function post-breast cancer. *Cancer Treat Res* 2018;173:167–89
8. Ford JS, Kawashima T, Whitton J, *et al.* Psychosexual functioning among adult female survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol* 2014;32:3126–36
9. Kenney LB, Cohen LE, Shnorhavorian M, *et al.* Male reproductive health after childhood, adolescent, and young adult cancers: a report from the Children's Oncology Group. *J Clin Oncol* 2012;30:3408–16
10. Behringer K, Müller H, Görgen H, *et al.* Sexual quality of life in Hodgkin lymphoma: a longitudinal analysis by the German Hodgkin Study Group. *Br J Cancer* 2013;108:49–57
11. Laumann EO, Glasser DB, Neves RC, GSSAB Investigators' Group, *et al.* A population-based survey of sexual activity, sexual problems and associated help-seeking behavior patterns in mature adults in the United States of America. *Int J Impot Res* 2009;21:171–8
12. Flynn KE, Lin L, Bruner DW, *et al.* Sexual satisfaction and the importance of sexual health to quality of life throughout the life course of U.S. adults. *J Sex Med* 2016;13:1642–50
13. Huyghe E, Sui D, Odensky E, *et al.* Needs assessment survey to justify establishing a reproductive health clinic at a comprehensive cancer center. *J Sex Med* 2009;6:149–63
14. Rosales AR, Byrne D, Burnham C, *et al.* Comprehensive survivorship care with cost and revenue analysis. *J Oncol Pract* 2014;10:E81–E85
15. Flynn KE, Reese JB, Jeffery DD, *et al.* Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology* 2012;21:594–601
16. Reese JB, Sorice K, Beach MC, *et al.* Patient-provider communication about sexual concerns in cancer: a systematic review. *J Cancer Surviv* 2017;11:175–88
17. Schover LR, Canada AL, Yuan Y, *et al.* A randomized trial of internet-based versus traditional sexual counseling for couples after localized prostate cancer treatment. *Cancer* 2012;118:500–9

18. Schover LR, Yuan Y, Fellman BM, *et al.* Efficacy trial of an internet-based intervention for cancer-related female sexual dysfunction. *J Natl Compr Canc Netw* 2013;11:1389–97
19. Hummel SB, van Lankveld JJDM, Oldenburg HSA, *et al.* Internet-based cognitive behavioral therapy realizes long-term improvement in the sexual functioning and body image of breast cancer survivors. *J Sex Marital Ther* 2018 Jan 3: 1–12. Epub ahead of print
20. El-Jawahri A, Fishman SR, Vanderklish J, *et al.* Pilot study of a multimodal intervention to enhance sexual function in survivors of hematopoietic stem cell transplantation. *Cancer* 2018;124: 2438–46
21. Ussher JM, Perz J, Gilbert E, *et al.* Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. *Psychol Health* 2013;28: 1370–90
22. Julien JO, Thom B, Kling NE. Identification of barriers to sexual health assessment in oncology nursing practice. *Oncol Nursing Forum* 2010;37:E186–E190
23. Abdolrasulnia M, Shewchuk RM, Roepke N, *et al.* Management of female sexual problems: perceived barriers, practice patterns, and confidence among primary care physicians and gynecologists. *J Sex Med* 2010;7:2499–508
24. Miller SA, Byers ES. Practicing psychologists' sexual intervention self-efficacy and willingness to treat sexual issues. *Arch Sex Behav* 2012;41:1041–50
25. Sobecki JN, Curlin FA, Rasinski KA, *et al.* What we don't talk about when we don't talk about sex: results of a national survey of U.S. obstetrician/gynecologists. *J Sex Med* 2012;9:1285–94
26. Tamargo CL, Quinn GP, Sanchez JA, *et al.* Cancer and the LGBTQ population: Quantitative and qualitative results from an oncology providers' survey on knowledge, attitudes, and practice behaviors. *J Clin Med* 2017;6:E93
27. Wray A, Ussher JM, Perz J. Constructions and experiences of sexual health among young, heterosexual, unmarried Muslim women immigrants in Australia. *Cult Health Sex* 2014;16:76–89
28. Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. *J Natl Compr Canc Netw* 2013;11:640–4
29. Denlinger CS, Baker KS, Baxi S, *et al.* Survivorship Version 2.2017. *J Natl Compr Cancer Netw* 2017;15:1140–63
30. Carter J, Lacchetti C, Andersen BL, *et al.* Interventions to address sexual problems in people with cancer: American Society of Clinical Oncology Clinical Practice Guideline Adaptation of Cancer Care Ontario Guideline. *J Clin Oncol* 2018;36:492–511
31. Jo JK, Jeong SJ, Oh JJ, *et al.* Effect of starting penile rehabilitation with sildenafil immediately after robot-assisted laparoscopic radical prostatectomy on erectile function recovery: A prospective randomized trial. *J Urol* 2018;199:1600–6
32. Gandhi J, Chen A, Dagur G, *et al.* Genitourinary syndrome of menopause: an overview of clinical manifestations, pathophysiology, etiology, evaluation, and management. *Am J Obstet Gynecol* 2016;215:704–11
33. Bradford A, Fellman B, Urbauer D, *et al.* Effect of routine screening for sexual problems in a breast cancer survivorship clinic. *Psychooncology* 2016;25:1375–8
34. Shaffer KM, Nelson CJ, DuHamel KN. Barriers to participation in a sexual health intervention for men following treatment for rectal and anal cancer. *Psychooncology* 2018;27:1082–5
35. Jennings S, Philip EJ, Nelson C, *et al.* Barriers to recruitment in psycho-oncology: unique challenges in conducting research focusing on sexual health in female survivorship. *Psychooncology* 2014; 23:1192–5
36. Will2Love For Health Professionals [Internet]. Houston (TX): Will2Love, LLC. [Cited 2018 Aug 27]. Available from: https://www.will2love.com/personalized-services/health-professionals.dot
37. Vadaparampil ST, Gwede CK, Meade C, Enrich Research Group, *et al.* ENRICH: A promising oncology nurse training program to implement ASCO clinical practice guidelines on fertility for AYA cancer patients. *Patient Educ Couns* 2016;99:1907–10
38. Scientific Network on Female Sexual Health and Cancer [Internet]. [Cited 2018 Aug 27]. Available from: http://www.cancersexnetwork.org/
39. Reese JB, Porter LS, Somers TJ, *et al.* Pilot feasibility study of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *J Sex Marital Ther* 2012;38: 402–17
40. Simon JA, Davis SR, Althof SE, *et al.* Sexual well-being after menopause: An International Menopause Society White Paper. *Climacteric* 2018;21:415–27
41. Kornik RI, Rustagi AS. Vulvovaginal graft-versus-host disease. *Obstet Gynecol Clin North Am* 2017;44:475–92
42. Hamilton BK, Goje O, Savani BN, *et al.* Clinical management of genital chronic GvHD. *Bone Marrow Transplant* 2017;52:803–10