2019
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SUPPORTIVE CARE MAKES EXCELLENT CANCER CARE POSSIBLE

Sexual Dysfunction in Adolescent and Young Adult Patients and Survivors

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MASCC/ISOO
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ISOO International Society of Oral Oncology
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Conflict of Interest Disclosure

Leslie R. Schover, PhD

Ownership Interest (stocks, stock options or other ownership interest excluding diversified mutual funds): Will2Love, LLC

- A digital health company offering software licensing and consulting to cancer centers to optimize care for reproductive health consequences of cancer treatment

What do we know about sexual dysfunction in survivors of childhood and adolescent cancer?

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Authors	Year	Number Surveyed	Response Rate	Age range	Questionnaire
Zebrack et al.	2010	599 men & women	65%	18-39	MOS Sex Function Scale
Sundberg et al.	2011	224 men & women (273 controls)	69% (51%)	---	Custom questionnaire
Ford et al.	2014	2,178 women (408 sisters) (Young breast survivors)	47% (38%)	18-51	Sexual Function Questionnaire; Sex Self-Schema
Rosenberg et al.	2014	461 breast CA <age 40	62%	M=36	CARES Sex Interest & Dysfunction
Bober et al.	2013	291 men & women	---	---	Sex Subscale of Swedish HRQL Survey
Haavisto et al.	2016	52 men after ALL (56 controls)	65%	25-38	Derogatis Interview
Wettergren et al.	2017	365 men & women	89%	15-39	Life Impact Checklist 1 item
Acquati et al.	2018	95 men & women	77%	18-39	MOS Sex Function Scale
Chan et al.	2018	529 BRCA carriers after S&O	60%	---	Female Sexual Function Index
Olssen et al.	2018	285 men & women (255 controls)	74%	19-35	5-items on sex custom for study
Van Lersel et al.	2018	1,021 men	---	18-62	International Index of Erectile Function

Limitations of Methodology

- Most studies did have a good sample size, however:
- Only 3 studies used standard questionnaires with enough items to show reliable differences between groups (SFQ, IIEF, and FSFI)
- A number of studies just included 1-5 items about sex, (custom items, CARES or MOS sexual subscale) often as part of a larger periodic survey of AYA populations
- Only 4 studies compared survivors to age-matched healthy controls
- Wide range of current ages, ages at diagnosis, cancer sites and treatments

Do Survivors of AYA Cancer Have Poorer Sexual Satisfaction?

Yes, all 4 studies comparing survivors to age-matched controls found survivors had lower satisfaction with their sex lives

Low satisfaction is more common in cancer patients than actual sexual dysfunction

- Low sexual satisfaction is often correlated with emotional distress, or feeling unattractive or stigmatized
- Low satisfaction is much easier to improve with intervention than overcoming actual sexual dysfunction

(Sundberg et al. 2011, Ford et al. 2014, Haavisto et al. 2016, and Olssen et al. 2018)

Do Survivors of AYA Cancer Have Worse Sexual Function than Controls?

Yes, all 4 studies comparing survivors to controls found some significant differences:

- Lower desire for sex (2 in men, 1 in women)
- Less sexual activity (1 study)
- Less frequent orgasms (1 in men, 1 in women)

(Sundberg et al. 2011, Ford et al. 2014, Haavisto et al. 2016, and Olssen et al. 2018)

Rates of Specific Sexual Problems

Sexual Problem	Rate in Men	Rate in Women
Low sexual desire	10%	10%-19%
Erectile dysfunction	10%-29%	---
Vaginal dryness/painful sex	---	16%-25%
Problems with orgasm	15%	25%-33%
Sexually inactive	---	28%
At least one sexual problem	29%-54%	29%-77%

Correlates of Sexual Problems

Factor	In Men	In Women
Older age	+ + + +	+ + +
Lower educational attainment	+	+
Negative body image/stigma	+ + +	+ + +
Emotional distress/depression	+ + + + +	+ + + + +
Poor physical health status/fatigue	+ +	+ + +
Premature ovarian failure	---	+ + +
Hypogonadism in men	+ +	---
CNS tumors	+ +	---

2017 ASCO and NCCN practice guidelines for cancer-related sexual problems agree:

The oncology team should initiate a discussion of sexuality and cancer during treatment planning and periodically at follow-up visits

Further psychosocial and medical assessment should take place when a concern or problem is identified

Referrals should be offered for multidisciplinary care, since sexual problems often have psychosocial and physiological causes

ASCO sex and cancer guideline: https://www.asco.org/practice-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/28976
NCCN Updated guideline: Journal of the National Comprehensive Cancer Network 2017 Sep;15(9):1140-1163

Need for Intervention Research

Only 2 studies have evaluated interventions for AYA sexual problems, feasibility studies:

- Canada et al., 21 patients aged 15-25, 3 sessions + workbook; improved sexual knowledge, body image, relationship anxiety, decreased distress at 3-mo FU
- Wiklander et al. web intervention, 15 out of 23 completed ≥ 4 of 6 modules

(Wiklander et al., 2017; Canada et al., 2007)

Elements of Promising Interventions

- Websites or apps allow personalization through customized navigation
- This age group is used to online programs
- Trained interventionists could do videoconferencing to increase geographic reach (barriers of state licensure in USA)
- Unclear whether peer interaction would be beneficial

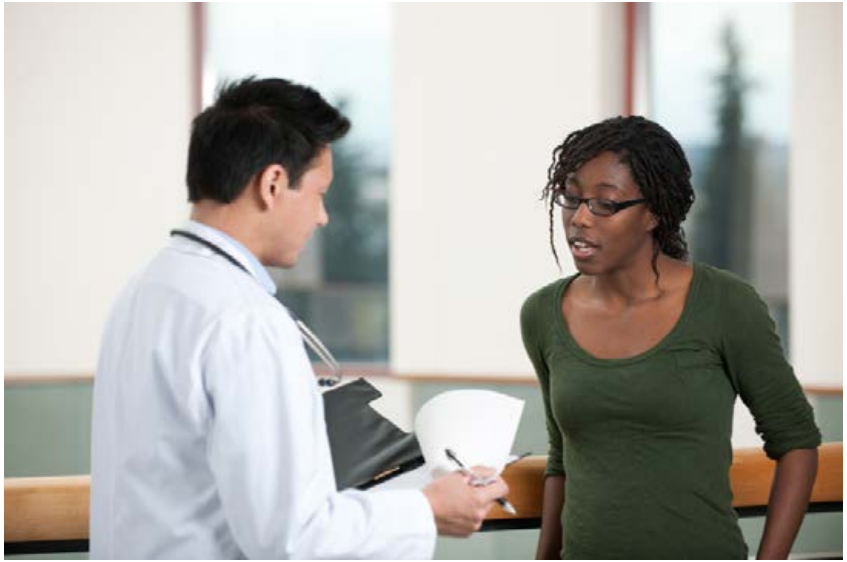
Barriers to AYA-Specific Sexual Interventions

- Developing online interventions is very expensive: average cost for app is $400,000; Will2Love 5 million in NCI grants plus $650,000 over 3 years
- Very difficult to get grants funded that focus on sexual dysfunction (few expert reviewers on panels, topic regarded as frivolous)
- Most AYA programs are underfunded and depend on philanthropy
- Hospitals reluctant to pay for site license

Identifying concerns: Why checklists are not enough

- Patients often skip items out of embarrassment or poor comprehension
- Staff often fail to review or discuss patient’s questionnaire
- Result: Added patient frustration

Step 1: Routinely identify problems and concerns



Ask one question at each visit, prefaced by a normalizing statement: **Many people worry that cancer treatment will damage their sex life or fertility. Do you have a question or concern?**

Step 2: Provide expert assessment and brief counseling

1. Offer patient education materials, preferably interactive online interventions
2. Ask if patient would like an assessment visit with trained clinician
3. Training through Moffitt ECHO program or Will2Love PRO Portal

Step 3: Schedule assessment visit with clinic “sex expert”

- Learns about the sex and fertility problems common in clinical population
- Gets advanced training and clinical supervision
- Can “prescribe” online self-help programs (navigators help with lower literacy patients)
- Can conduct assessment visit (billable with E & M codes if advanced practitioner)
- Makes appropriate referrals for specialty care

Step 4. Make appropriate specialty referrals

- Mental health professionals trained in both psycho-oncology and sex therapy
- Gynecologists trained to treat menopause symptoms and pelvic pain
- Urologists trained to treat male sexual problems
- Pelvic rehabilitation specialty physical therapists
- When specialty clinics are available within a large health care system, revenue from increased referrals helps sustain the program

In Summary

- Survivors of childhood or AYA cancer are at high risk for late endocrine effects and sexual dysfunction/dissatisfaction
- It may not be so crucial to characterize the sexual problems in a large and diverse sample
- Instead, we need to understand factors related to specific cancer sites and treatments associated with problems
- Even more important, we need to help survivors and partners prevent and overcome problems
- Sexuality interventions need to be developed, evaluated, and implemented with practical workflows and professional training

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