Sexual Dysfunction in Adolescent and Young Adult Patients and Survivors

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

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)

# Rates of Specific Sexual Problems

<table>
<thead>
<tr>
<th>Sexual Problem</th>
<th>Rate in Men</th>
<th>Rate in Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low sexual desire</td>
<td>10%</td>
<td>10%-19%</td>
</tr>
<tr>
<td>Erectile dysfunction</td>
<td>10%-29%</td>
<td>---</td>
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<tr>
<td>Vaginal dryness/painful sex</td>
<td>---</td>
<td>16%-25%</td>
</tr>
<tr>
<td>Problems with orgasm</td>
<td>15%</td>
<td>25%-33%</td>
</tr>
<tr>
<td>Sexually inactive</td>
<td>---</td>
<td>28%</td>
</tr>
<tr>
<td>At least one sexual problem</td>
<td>29%-54%</td>
<td>29%-77%</td>
</tr>
</tbody>
</table>
## Correlates of Sexual Problems

<table>
<thead>
<tr>
<th>Factor</th>
<th>In Men</th>
<th>In Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older age</td>
<td>++++</td>
<td>+++</td>
</tr>
<tr>
<td>Lower educational attainment</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Negative body image/stigma</td>
<td>+++</td>
<td>+++</td>
</tr>
<tr>
<td>Emotional distress/depression</td>
<td>++++</td>
<td>++++</td>
</tr>
<tr>
<td>Poor physical health status/fatigue</td>
<td>++</td>
<td>+++</td>
</tr>
<tr>
<td>Premature ovarian failure</td>
<td>---</td>
<td>+++</td>
</tr>
<tr>
<td>Hypogonadism in men</td>
<td>++</td>
<td>---</td>
</tr>
<tr>
<td>CNS tumors</td>
<td>++</td>
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</tr>
</tbody>
</table>
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.

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
For a copy of slides email me: Schover@will2love.com