Sexual Dysfunction in Women with Breast Cancer: An Internet-Based Intervention

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SEXUAL PROBLEMS RANK HIGH AMONG UNMET NEEDS OF SURVIVORS
SEXUAL PROBLEMS ARE SEVERE AND PERSISTENT AFTER BREAST CANCER

- Loss of desire and pleasure, vaginal dryness/pain, trouble reaching orgasm
- Rarely go away without treatment
RISK FACTORS FOR SEXUAL DYSFUNCTION

- Premature ovarian failure in premenopausal women
- Aromatase inhibitors in postmenopausal women
- Type of localized breast treatment is not predictive of staying sexually active or functional
BARRIERS TO GETTING HELP

- Oncologists and nurses often fail to ask about sex or make referrals
- Few gynecologists have interest or expertise
- Insurance coverage is very poor for mental health services related to sexual dysfunction
- Few mental health professionals are cross-trained in cancer and sex therapy
WHY AN INTERNET-BASED INTERVENTION?

• People are very comfortable with sexual material on the internet
• Can tailor information to a person’s type of cancer and treatment
• Women who would not discuss sex in a support group or see a psychologist may be willing to use a web site
• Can supplement with email, phone, video, or in-person counseling
I've looked for 3 years and I can sum up what I've found as: wear a camisole, use a lubricant, speak to your partner, and some day you'll find a "new normal." Gee, that was SO helpful – not!
Tendrils: Sexual Renewal and Motherhood after Cancer

- Randomized trial completed, JNCCN 2013
- Beta version part of AI prevention trial
- Usability testing done, revision in progress
- Hope to have commercial version available in late 2014
- Business model still unclear
GOALS OF THE PROGRAM

• Help people understand how cancer treatment can damage their sex lives
• Teach self-help strategies for specific problems like loss of desire, vaginal atrophy, pain with sex, changes in orgasm, incontinence
• Guide women in finding expert medical help
• Give partners ways to participate in making sex better
**TENDRILS: Sexual Renewal and Motherhood for Women after Cancer**
an Education and Counseling Program

Click on a topic to get started

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Prevention</th>
<th>Solutions to Problems</th>
<th>Family and Friends</th>
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</thead>
<tbody>
<tr>
<td>How will cancer change my sex life?</td>
<td>I want to avoid getting a sexual problem.</td>
<td>I want to feel more desire for sex.</td>
<td>I want to help my partner enjoy sex after cancer.</td>
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<tr>
<td>How will cancer change my ability to have children?</td>
<td>I want to keep an active sex life during and after cancer.</td>
<td>I want to stop having vaginal dryness and pain during sex.</td>
<td>I want to work with my partner to become parents.</td>
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<tr>
<td>I want to know more about my body and sexual response.</td>
<td>I want better sexual communication with my partner.</td>
<td>I want to reach orgasm more easily.</td>
<td>I want to help my daughter who has had cancer.</td>
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<tr>
<td>What will menopause do to my sex life?</td>
<td>I want to keep my relationship healthy during cancer.</td>
<td>I want to find professional help for a sexual problem.</td>
<td>I want to help a friend who has had cancer.</td>
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<tr>
<td>How do religion and culture influence women’s feelings about sex?</td>
<td>I want to preserve my fertility before starting cancer treatment.</td>
<td>I want to cope better with urine or bowel leakage during sex.</td>
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<td>I want to hear other women’s stories.</td>
<td>I want to avoid getting pregnant or getting an infection from sex.</td>
<td>I want to feel more attractive.</td>
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<td></td>
<td>I want to feel comfortable with dating.</td>
<td>I want to find out if I can get pregnant.</td>
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<td></td>
<td>I want to be able to talk more openly about sex and fertility with my health care team.</td>
<td>I want to explore ways of becoming a mother after cancer.</td>
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</tbody>
</table>
I want to know more about my body and sexual response.

These sections of Tendril will help you learn about how women's bodies work for sex and having children. Click on a section to start.

“Down There”: Getting Comfortable with Your Private Parts
Vulvacious! (Create a self-portrait of your vulva, including pleasure and pain mapping)
What is “Normal” Sex for Women?
Fertility and Pregnancy: The Basic System
VULVACIOUS!
SHARING STORIES

• Most “survivor stories” on the internet do not explicitly discuss sexual issues

• We include video interviews with variety of cancer patients (and partners)

• Also fictional cases, with video vignettes played by actors to show people coping with common problems

• Variety of ethnic groups and storylines
Select a woman below to listen to her responses to a series of questions related to cancer and its affects on her sexuality:

Emily
Diagnosed at 7
Now 19
Acute Leukemia
Intensive Chemotherapy

Hear my responses

Yvonne
Diagnosed at 14
Now 23
Ewing’s Sarcoma
Two stem cell transplants

Hear my responses

Wilma
Diagnosed at 21
Now 29
Breast cancer, Bilateral mastectomy, radiation
Breast reconstruction, Chemotherapy, tamoxifen

Hear my responses

Diana
Diagnosed at 27
Now 30
Breast cancer, Bilateral mastectomy,
Chemotherapy, tamoxifen

Hear my responses

Steffany
Diagnosed at 30
Now 33
Breast Cancer, Stage IV Mastectomy, Breast Reconstruction,

Cabrini
Diagnosed at 39
Now 43
Breast cancer
Intraoperative radiation therapy,
DESIGN OF Tendrils STUDY

- Eligible participants: Treated for breast or GYN cancer, NED, off active cancer treatment except hormone therapy, sexually dysfunctional by questionnaire, have sex partner for ≥ 6 months
- Assigned to treatment group by adaptive randomization to balance age, breast vs. GYN cancer, menopausal status
- Tendrils as self-help for 12 weeks, or Tendrils + 3 hours of individual face-to-face counseling
OUTCOME MEASURES

- Assessment questionnaires completed on website at baseline, end of 12-week treatment period, and at 3- and 6-month follow-ups
- Measured sexual function and satisfaction (FSFI and MSIQ), emotional distress (BSI-18), and quality of life as cancer survivors (QLACS)
- At 12 weeks rated program on 12 Likert scales
- Web site usage was electronically recorded
ATTRITION: 117 screened, 22 (19%) declined and 23 (20%) ineligible

36 assigned to self-help
- 31 completed baseline
- 24 (77%) completed post-TX
- 21 (68%) completed 3-mo FU
- 22 (71%) completed 6-mo FU

36 assigned to counseling
- 27 completed baseline
- 22 (81%) completed counseling
- 18 (67%) completed post-TX
- 16 (59%) completed 3-mo FU
- 16 (59%) completed 6-mo FU
DEMOGRAPHIC CHARACTERISTICS

• 58 completed baseline, 78% completed treatment, 66% provided 6-mo follow-up
• No significant differences between treatment groups in medical or demographic factors
• Mean age 53 ± 9, 89% married
• 79% Anglo, 9% AA, 10% Hispanic, 2% other
• 12% < HS, 29% some college, 59% ≥ college
• 81% breast cancer, 19% GYN cancer
• 97% in menopause, 9% on estrogen, 4% testosterone
Counseled group improved significantly more than self-help group on FSFI ($P=0.024$) and MSIQ ($P=0.011$)

Gains remained significant from post-treatment to 6-month follow-up except for MSIQ in counseled group
FSFI by Group and Time

Self-Help
Counseled

Baseline | Post-TX | 3-mo FU | 6-mo FU
---|---|---|---

Self-Help
Counseled
MSIQ by Group and Time

![Graph showing MSIQ by Group and Time with data points at Baseline, Post-TX, 3-mo FU, and 6-mo FU for Self-Help and Counseled groups.](image-url)
BSI-18 by Group and Time

Baseline Post-TX 3-mo FU 6-mo FU

Self-Help
Counseled
QLACS Total by Group and Time

- Baseline
- Post-TX
- 3-mo FU
- 6-mo FU

Self-Help
Counseled
TIME SPENT ON WEB SITE

- Time spent on web site (excluding completion of questionnaires) electronically recorded
- Average was about 2.5 hours, highly variable
- Total usage time related to change in MSIQ at 6 months (P=0.06)

<table>
<thead>
<tr>
<th>Group</th>
<th>Minutes during 12-week treatment</th>
<th>Minutes after 12-week treatment*</th>
<th>Total minutes</th>
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</thead>
<tbody>
<tr>
<td>Self-Help</td>
<td>108.6 ± 141.9</td>
<td>38.6 ± 60.9</td>
<td>147.2 ± 174.5</td>
</tr>
<tr>
<td>Counseled</td>
<td>143.4 ± 134.8</td>
<td>7.6 ± 17.7</td>
<td>151.1 ± 137.7</td>
</tr>
</tbody>
</table>

*P<.001 between groups
PROMISING EFFICACY TRIAL

- *Tendrils* improves sexual function/satisfaction, particularly with supplemental counseling, but not to “normal” range, decreases emotional distress, improves cancer-related quality of life
- Women like and value the program
- Accrual disappointing and too much attrition
- Women disliked questionnaires and coming to cancer center for counseling
- Usability testing showed need for better navigation, shorter text sections, less clipart
- Plan to add goal-setting, tracking progress, and relapse prevention
CHALLENGES

• What is the optimal human supplement to the web site?
• How can we reach people with low health literacy?
• Can we find elements that fit well with smartphone technologies? (Summary from start of each section, lists of questions for your doctor, CBT exercises)
FUNDING AND PARTNERSHIPS

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• *Tendrils*: R42 CA123932

• Partnership with Paul Martinetti, MD, principal, Digital Science Technologies, LLC

• Video production: UTTV