Sexual Health Clinic

Pilot Research Project

Funded by BC Cancer Foundation, Southern Interior

Myrna Tracy, MSW, RSW – PI
Dr. Susan Holtzman, Co-Investigator
Dr. Lori Brotto, Consultant
The idea began…

Time Line

- Oct/08 – Idea
- Apr/09 – Donated Funds app’n submitted
- Jan/10 – Funding approved
- Apr/10 – Hired RA
- Aug/10 – Team solidified
- Nov/10 – Ethics submission
- Jan/11 – Ethics’ approval
- Apr/11 – 1st 4 referrals received
The Team

-Nurse, Maureen Ryan
-Gynecologist, Dr. Roberto Leon
-Urologist, Dr. Ziad Jaklis
-Psychiatrist, Dr. Lidia Schuster

Dr. Ziad Jaklis
Dr. Lidia Schuster
The Clinic

- Offered one afternoon per month
- Clinic was at BCCA in Kelowna in ACU
- Patients had appointments at BCCA except for patients seeing gynecologist
- Did exercise appointment flexibility for patient’s benefit
Principal Research Objective

To determine the feasibility and effectiveness of offering a Sexual Health Clinic in the Cancer Centre at Kelowna, BC using an education and referral format.
Participants

- 43 survivors agreed to participate
- Only 21 of those provided complete data
- Sample consisted of 10 women (mean age 56.5) and 11 men (mean age 66.6)
- 95.2% were of Euro-Canadian ancestry and 4.8% identified as South Asian
Sample Demographics

• 85% had some post-secondary education
• One individual identified as bisexual, all others identified as heterosexual.
• All but two individuals reported being in a committed relationship.
• 25% reported not feeling satisfied within their personal relationship.
• Most females (70%) had iatrogenic/surgical menopause, 20% had natural menopause, and one woman was currently perimenopausal.
• Most participants had received surgical (90.5%) or radiation (90.5%) cancer treatment with less than half receiving chemotherapy (42.9%).
Sample Demographics

• 47.6% of participants had previously sought treatment for a sexual concern.

• Participants by cancer type:
  – Prostate – 8
  – Colo-rectal/anal – 2
  – Breast – 7
  – Endometrial – 2
  – Lung – 1
  – Lymphoma - 1
How the project worked

Consent

Questionnaires (Q1)

RN Intervention

Questionnaires (Q2)

Face-to-Face Interview

Questionnaires (Q3)

Baseline

Post-tx

2 months

6 months
Questionnaires Used

- The international Index of Erectile Function Questionnaire (IIEF; Rosen et al., 1997)
- The Female Sexual Function Index (FSFI)
- Global Measure of Sexual Satisfaction (GMSEX; Lawrance & Byers, 1998)
- Relationship functioning was assessed with the Dyadic Assessment Scale (DAS; Spanier, 1979)
Questionnaires cont’d

• Mood was assessed with the Beck Depression Inventory (BDI; Beck & Beamesderfer, 1974).

• A global measure of perceived stress was also included, the Perceived Stress Scale (PSS-10; Cohen, Kamarck, & Mermelstein, 1983)

• Quantitative Analysis was conducted but the sample size was too small to reveal significant information
Results from Interviews

• **Reason for Attending SHC:**
  
  – The majority were seeking solutions for problematic changes to their sexual health as a result of their cancer and/or cancer treatment.
  
  – They were seeking information about or a resolution of the issues that they faced.
  
  – One participant identified attending the clinic as a step towards returning to normalcy.
  
  – Two people participated in the study as an effort to advocate for the existence of a future clinic.
"...I was having some difficulty in my relationship with sexuality and ... so I just thought it might be a good place to come to, to be able to find out about myself and the effects of cancer on my sexuality and my relationship."
Issues identified

- loss of personhood
- vaginal dryness
- erectile dysfunction
- loss of libido
- painful intercourse
- decrease in sex life
- changes in sex life affecting their relationship
- sexual side effects of medications
- urinary tract infections
- the need for a SHC in Kelowna
- the psychological effects of cancer diagnosis and/or treatment.
• **Impact on QoL**
  – Most participants reported significant changes in their sexual life due to having cancer and cancer treatment.
  – These changes were associated with a loss of some type.
  – The degree of loss identified ranged from complete loss (i.e. no more sexual life) to changes in frequency of intimacy, loss of enjoyment or pleasure, performance issues, loss of spontaneity, a need to explore different techniques and/or use other products and dissatisfaction with the outcome, and an inability to achieve orgasm.
“So I’m, I’m thinking, and I’m researching and [I was] very upset that this is the way that I was going to be forever, that my life would be forever changed, and so that was very difficult and then ... my husband felt bad because he felt that he couldn’t satisfy me and it was ... a difficult road.”
3 areas where QoL were effected

• **Psychological** issues: loss of self or identity as a sexual being; anxiety; increased stress and depression due to changes in sexual life, and; ambivalence toward sexual life.

• **Physical** issues identified were: fatigue, erectile dysfunction, vaginal dryness, pain or discomfort during sexual intercourse, and; a desire to return to previous level of functioning prior to diagnosis and treatment.

• **Relationship** issues arose when changes in a couple's sexual life put stress on their relationship. The most severe impact on relationship was noted as complete relationship break down. For one participant not in a relationship, anxiety was experienced at the thought of starting a new relationship.
"You know ... its affected my marriage greatly. ...We had a very close marriage before, and now ... we are quite distant. So, it’s affected us a lot - ... it changed my marriage totally. ... I feel like I don’t even want to bother trying anything, and my husband is a very normal healthy man, and ... we are only in our early 50’s so its very difficult for him, its been a long time, its been since 2004, so ... obviously he’s got a lot of patience, but... there have been times that I have wanted to tell him to move on, find someone else."
• **Discussing sexual health with health care practitioners**

- People were open to being asked about sexuality by health care practitioners or within the context of the SHC.
- Patients want health care practitioners to introduce the topic of sexual health. (NOTE: this concern usually comes up ~ one year post-treatment)
- Patients are unlikely to raise the topic of sexual health with a health care practitioner for a variety of reasons.
"... it's easier to talk to somebody who’s from the sexual health clinic rather than somebody else. I don’t think I, I don’t know if I would have approached my family doctor or not. I’d probably think it’s just a trivial matter. Yeah I’d think it was, it would be a waste of a trip and a waste of her time. People have more important things; do you know what I mean?"
**Impact of SHC**

- Referrals to other resources included:
  10 - urologist, 5 - gynecologist, 1 - plastic surgeon, 2 - psychiatrist, 1 - psychologist, 2 - education materials and 1 - community counselling resources.

- **16 participants experienced an overall improvement** in their wellbeing and/or sexual life after contact with the SHC.

- Some also noted that they experienced an increased comfort level when speaking with their partner about their sexual life and the changes or improvements they wanted to happen.

- **3 felt that nothing had really changed** or they were disappointed that they didn't get what they had hoped for from their involvement.

- **2 people found aspects helpful and other aspects not helpful.**
“I am going to ... chat with my husband a little bit more about some things that I would like to see changed or improved upon ... I’ve got a good head start and he’s going to be open to it, and I feel more comfortable talking to him about these kinds of things.”
Most helpful aspects of SHC

- **safe environment** to talk to a professional about issues they were experiencing;
- appreciation for having **access to medical professionals** that they needed in a timely manner;
- **confidence** that the professionals that they were seeing would be non-judgemental and sensitive to participants' discomfort with the topic, and;
- **confidence** that it was **acceptable to speak** to these professionals specifically about sexual health concerns.
Hope

• Increase in hopefulness was a positive outcome and a recurring theme

• Conversely, having their hopes unfulfilled was disappointing

• Reassured that they were not alone
Need for SHC in the future

Participants identified the need to:
- have professionals available who are skilled and experienced in dealing with the sensitive topic of sexual health, and
- to have service available in one place
- BCCA needs to address the mental and emotional effects of cancer and cancer treatment in a holistic manner as wellbeing in one area affects wellbeing in other areas.
"I was desperate, for something, and had been asking, I think that’s why the nurse kind of pulled me aside and said there is this [Sexual Health Clinic]. You know, so what would I have done [if the Sexual Health Clinic had not existed?] Probably just tried to just pull away from my partner."
• **Issues affecting access to service**

- **Travel** was identified as being expensive, time consuming, exhausting and inconvenient. It is worth considering whether any of these services could be offered using telehealth technology.

- Some participants also experienced **financial barriers** to getting the help they needed. Some drugs and non-covered professional fees (e.g. physiotherapy, psychology) were not available to some individuals due to financial constraints.
Other recommendations…

- a library of resource materials available for loan,
- a support group for this issue,
- an online call centre,
- brochures and materials around the cancer clinic.
- Post-tx involvement by professionals and continuity of care providers to address survivorship issues.
- have sexual health services always available
- other supports available (e.g. massage therapy)
- Physicians have ongoing PD in sexual health
- HCP be sensitive, non-judgmental & knowledgeable about sexual health
Clinician Questionnaires

- Ten (of 21) questionnaires were completed.
- Eight of the clinicians felt that their patients’ concerns were addressed, while the other two clinicians were unsure.
- Patient outcomes for those that attended the SHC were noted as: better assessment, conversations about sexual issues aiding in the normalization of the experience, improved quality of life, increased support, and an opportunity to address sexual concerns in more detail.
Clinician Suggestions

• Have counselling service available for sexual issues
• Have online forums/ “post a question”
• Useful to have a place to refer patients and
• Important to have gynecologist & urologist available.
Thank you:
- Participants
- BCCF
- Research Team
- Esp. Lori Brotto!
- Clinicians

Contact:
Myrna Tracy, MSW, RSW
mtracy@bccancer.bc.ca
250.712.3973