My body my self: Body image and sexuality in women with cancer

by Anne Katz

Abstract

Women undergoing treatment for cancer report ongoing issues related to sexuality and sexual functioning. In my work as a sexuality counsellor at a large ambulatory care centre, I have spent many hours talking with and counselling these women and their partners. A common theme is the centrality of the experience of alterations to body image. Body image problems are associated with mastectomy, hair loss from chemotherapy, alterations in weight, low self-esteem, and the partner having difficulty understanding the feelings of the woman and her partner. This is something that can be addressed by nurses at all stages of the cancer trajectory. While alterations to body image can occur with any type of cancer, the most frequently reported complaints occur in women treated for breast and gynecological cancer. This article describes the problems encountered by women and suggests some nursing interventions that may be helpful.

Women undergoing treatment for cancer report ongoing issues related to sexuality and sexual functioning (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005; Stead, 2003). In my work as sexuality counsellor at a larger ambulatory care centre, I have spent many hours talking with and counselling these women and their partners. A common theme is the centrality of the experience of alterations to body image. Body image problems are associated with mastectomy, hair loss from chemotherapy, alterations in weight, low self-esteem, and the partner having difficulty understanding the feelings of the woman (Fobair et al., 2006). This is something that can be addressed by nurses at all stages of the cancer trajectory. While alterations to body image can occur with any type of cancer, the most frequently reported complaints occur in women treated for breast and gynecological cancer.

Breast cancer

The sequelae of breast cancer treatment have a profound effect on body image for many women. These women describe their breasts as being medicalized during the various stages of treatment. Breasts, however, are gendered organs; they denote femininity to some and are a central aspect of female body image. Breasts are also sexual organs (Langellier & Sullivan, 1998). During radiation therapy, the daily exposure of the breasts to radiation therapists and other staff can cause women to become dissociated from their breasts as sexual organs. Women describe actively shutting off their thoughts from what is happening and taking their mind to a different place. This

dissociation may be an effective coping mechanism, but may also be the source of problems in the future when the woman tries to reconnect with her breasts as sexual organs. Some women joke that if a health care provider wearing a white coat enters the room, the first action is to expose their breasts for examination. This contrasts with the notion of breasts as a private part of a woman's body usually used for the nourishment of babies or as part of sexual play.

While mastectomy or lumpectomy does not have a direct effect on the sexual response cycle, the resultant scarring, deformity or absence of the breast can have emotional consequences that are related to body image for both the woman and her partner. Some women may avoid sexual activity due to fear that their partner will reject their new, cancer-scarred body.

Lumpectomy, which is regarded as a breast-conserving intervention, may leave one breast looking and feeling different from the other. Alteration in sensation at the site of the scar is common, and while these sensations may change over time, numbness and loss of sensation may persist in the long term. This may have sexual consequences for both the woman and her partner. Some men are reluctant to touch the affected breast for fear of causing pain. This reluctance may be interpreted by the woman as rejection.

Women who had a mastectomy report negative body image more than those who had a lumpectomy. Reconstruction leads to some satisfaction in terms of body image (Al-Ghazal, Fallowfield, & Blamey, 2000) and this, in turn, relates to sexual attractiveness for some women. Some women who have had breast reconstruction after mastectomy report that while the reconstructed breast is aesthetically pleasing, the lack of sensation of that breast affects sexual pleasure (Wilmoth & Ross, 1997a). Other women report altered sensation in the reconstructed breast (pins and needles, numbness), and the appearance of the scarring is something that persists and does not go away (Rowland et al., 2000). Even with reconstruction, women report that the new breast looks and feels different (Nissen, Swenson, & Kind, 2002) and may be caressed less by her sexual partner (Schover et al., 1995).

Body image after breast conservation surgery or reconstruction surgery may be more positive (Bukovic et al., 2005). Women report that they are more comfortable appearing naked in front of sexual partners and are more satisfied with sex, but this does not apply to all women. Some younger women have described feeling ashamed of their bodies (Bloom, Stewart, Chang, & Banks, 2004). This may be reflective of unrealistic expectations on the woman's part related to what the reconstructed breast looks and feels like.

But body image changes are not only related to the presence of a scar. Some women experience lymphedema in the arm and/or shoulder following lymph node dissection or sentinel lymph node biopsy (Morrell et al., 2005). The lymphedema may cause the woman to feel unattractive and some women experience restricted movement and flexibility of that arm, which can also impact on sexual activity.

Many women will have radiation therapy as part of the treatment for breast cancer. Body image may be affected by skin discoloration on the chest wall due to radiation damage that may be both painful

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and disfiguring (Wilmoth & Botchway, 1999). The tattoo marks placed for accuracy of the treatment can be a constant reminder of the cancer that may have long-lasting emotional and sexual side effects as well.

Gynecological cancer

Body image changes are common after treatment for gynecologic cancer (Lagana, McGarvey, Classen, & Koopman, 2001). Body image plays an important role for many women in maintenance of sexual self-image. Scarring, edema or weight gain may impact this self-image and have long-lasting effects on the woman's sexual confidence and in her intimate relationship. The presence of a surgical scar can be a reminder of both the cancer and its treatment. The loss of ability to bear children may also impact on how women see themselves (Wilmoth & Spinelli, 2000).

After treatment, women also report a sense of violation after the invasive diagnostic and treatment procedures that have been endured. Like women treated for breast cancer, these women may distance themselves from their bodies in an attempt to cope and maintain a sense of bodily integrity. Unfortunately, this interferes with the woman's ability to experience her body as a source of pleasure. Women also experience relationship stresses following treatment, fearing that lack of sexual activity may cause problems in the relationship (Sun et al., 2005). Women may also have a perception of their genitalia that is inaccurate. They may envisage their vagina as being really small after surgery or radiation and this may cause tension with sexual touch and may lead to vaginismus, a condition where muscle spasms occur, precluding insertion of anything into the vagina. This has obvious profound effects on sexual activity, but can also cause difficulty when the woman needs a pelvic examination.

Alopecia and body image

Hair loss commonly experienced as a side effect of chemotherapy can have a profound impact on sexual self-image (Fitch, 2003). Loss of pubic hair will occur as a result of treatment and this can have a significant impact on the woman's perception of herself as a sexual being. This loss of pubic hair specifically is often not discussed and many women are shocked when this occurs. They were prepared for the loss of head hair, eyebrows, etc., but pubic hair was not mentioned. Many women are embarrassed by this loss and report that it is a barrier to feeling and acting like an adult

sexual partner. They report that without pubic hair they feel like "little girls", and little girls are not supposed to be sexual and so sexual touching raises bad feelings for the woman.

Challenges for single women

Women who are not in a relationship at the time of diagnosis and during treatment may have special needs. Questions concerning when and how to disclose their cancer history with prospective sexual partners are common and these women often feel shame, and say that they have experienced a loss of dignity as well as difficulty looking at their own bodies (Holmberg, Scott, Alexy, & Fife, 2001). Unpartnered women with breast cancer may suffer significant distress about their body image. Women who are not confident about their physical attractiveness may have received negative messages about their bodies in previous relationships; they may be anxious that this might happen in any future relationship, particularly now that they have scars, reconstructed breasts or two breasts that do not look exactly alike.

Body image and depression

Difficulties with body image may lead to depression and younger women experience more depression, greater distress and difficulty adjusting to the diagnosis and lower quality of life (Sammarco, 2001; Wong-Kim & Bloom, 2005). Depression is well recognized in women with breast cancer and may result in alterations in sexual functioning including lack of desire, difficulty with arousal and ability to achieve orgasm (Clayton, 2001). Depression is commonly treated with selective serotonin reuptake inhibitors (SSRIs) and this class of drugs has been shown to affect sexuality. About half of those who take these drugs experience a decrease in libido, difficulty becoming aroused, less vaginal lubrication, and difficulty reaching orgasm (Ferguson, 2001).

Return to sexual activity

Women tend to return to sexual activity in spite of sexual difficulties and fatigue. Some women fear abandonment if they are not sexual with their partners. They may even endure physical pain

Figure One: PLISSIT Model (Annon, 1974)

Permission:

All nurses should be able to function at this level.
An example of this level would be to include a general statement that normalizes the topic.

Limited Information:

Most nurses should be able to give this kind of information.
In the case of a couple where one person has had surgery, the nurse should be able to give general information about resuming intercourse following the surgery.

Specific Suggestion:

This level of the model requires a deeper level of expertise on the part of the nurse. Information at this level includes anticipatory guidance related to possible sexual consequences of medications and other treatments.

Intensive Therapy:

This level of the model usually requires a referral to a sex therapist or specially trained counsellor. Nurses should know where to refer patients when problems or issues are disclosed that are beyond the scope of practice or expertise of the nurse.

Figure Two: BETTER Model (Mick, Hughes, & Cohen, 2003)

Bringing up the topic:

Nurses are encouraged to raise the issue of sexuality with patients.

Explaining that sex is a part of quality of life

This helps to normalize the discussion and may help the patient to feel less embarrassed or alone in having a problem.

Telling the patient that resources will be found to address their concerns

This step suggests to the patient that even if the nurse does not have the immediate solution to the problem or question, there are others who can help.

Timing of intervention

Patients may not be ready to deal with sexual issues at the time a problem is identified, however patients can ask for information at any time in the future.

Education about sexual side effects of treatment

Educating patients about potential side effects from treatments does not mean that they will occur. However, informing the patient about sexual side effects is as important as informing them about any other side effects.

Recording

It is not necessary to describe in detail what was discussed, however, a brief notation that a discussion about sexuality or sexual side effects occurred is important.

with intercourse (Anllo, 2000). Others may resume sexual activity as a means of expressing affection in the relationship despite problems or lack of interest. Sex, once a source of comfort, may become a source of physical and emotional pain (Davis, Zinkand, & Fitch, 2000) and finding solutions that work can be challenging. The ability of the woman to return to a healthy view of her sexual self is partially dependent on a woman's ability to engage in pleasurable activities, comfort with her body, and the reaction of her sexual partner (Wilmoth & Ross, 1997b).

Implications for oncology nurses

Nurses are often the most consistent care provider for the woman during the disease trajectory. Nurses assess wound healing, give advice about skin care during radiation therapy, and assess for side

effects during chemotherapy. Nurses also see women in follow-up. We are the health care provider most likely to consistently address psychosocial issues such as coping, anxiety, and adaptation. Nurses are thus ideally situated to inquire about body image issues and to identify problems or concerns. Suggestions for opening the conversation about this topic are presented in Figures One and Two using two well-known models. Additional suggestions and a more detailed discussion of the issues facing women with breast and gynecologic cancer can be found in Katz's (Katz, 2007) text for health care providers.

If the woman identifies concerns about her scar(s), she can be reminded that with time the scars will fade. But the reassurance from her sexual partner of her attractiveness and desirability will likely be of greater importance. However, some women find it difficult to even hear and believe those words from the partner and a referral to a sexuality counsellor or social worker may be helpful. Reality checking is sometimes helpful. Ask the woman if her partner still looks the same as he/she did 10 or more years ago and if this has affected her feelings for him/her. Most women laugh and comment that he/she has gained some weight, lost some hair, and developed wrinkles. She will also state that she loves him/her just as much, if not more. This may help her to see that it is possible for her partner to love and desire her despite the physical changes that are so bothersome to her.

If the woman states that she is suffering the consequences of repeated exposure during diagnostic tests and treatment, talking about it can help. Talking about their feelings can help them to express their grief and loss over what has happened and may be the first stage of healing. Referral to a social worker can be very useful for this. Encouraging women to experience the body as a source of pleasure and not just pain is another important step in the healing process. A manicure or pedicure is non-threatening to most women and does not involve exposure of the body and can be the first step in her relearning that touch can be pleasurable. Spending time in a warm bath with soft music playing can also assist in this process. It is important that she use hypoallergenic bath products and lotions to avoid irritation or allergic reactions. She can learn from her own touch what feels pleasurable to her. A therapeutic massage by a trained therapist may be helpful too, but only when she feels ready for another person to touch her.

An intervention that is used by sex therapists and counsellors is sensate focus exercises (see Figure Three). These help the woman to reconnect with her body as a source of pleasure, but also allow the partner to participate in providing pleasure and to receive in return. This may allow for the resumption of sexual activity between the couple, but it may take considerable time for the woman to be ready for intercourse. However, some women are not comfortable with this and may not find sexual touching to be pleasurable. The couple may then need to find alternative ways of expressing their sexual feelings and a referral to a sexuality counsellor or therapist is warranted. Sensate focus exercises do not require the couple to complete all stages. The couple may prefer to not proceed beyond the first one or two stages.

Conclusion

All of these interventions are within the scope of practice of oncology nurses working in collaboration with the multidisciplinary team. The first step—assessment of body image issues—is the most important one. Allowing women to express their feelings about body changes will often elicit both a flood of emotions, as well as gratitude for being able to talk freely. This is also the first step in helping these women resolve their issues and is an important part of becoming a cancer survivor.

Figure Three: SENSATE FOCUS EXERCISES

These exercises can be helpful in increasing communication and closeness between two people when touch is either painful or not pleasurable.

In these exercises, partners take turns touching each other following the steps described below. In the following descriptions, it is assumed that the one doing the touching is a man and the one being touched is a woman. Both homosexual, as well as heterosexual couples can do these exercises.

It is necessary to establish some basic rules:

- Decide who will be the first giver.
- Establish whether clothing will be worn—this is optional and many women prefer to remain clothed.
- A location needs to be found where both will be comfortable, preferably not the bed.
- The lights may be dimmed and soft music can be played.
- The use of pillows or a comforter can increase comfort.
- Baby oil, lotions, or powder can be used.
- The woman needs to communicate what feels good and what does not.

The couple should begin with facial caressing. The giver usually sits and the receiver lies flat on her back with her head resting on the partner's thighs. With the hands well lubricated, the giver begins by stroking the chin, then the cheeks, the forehead, and temples.

It is then time for the couple to reverse roles and the woman then touches her partner's face.

Then the rest of the body can be tenderly massaged with reversal of roles periodically.

The exercises are divided into four progressive stages. Each stage should be done in order before moving to the next, and all stages should be repeated each time the couple performs these exercises.

First stage: Limit touching and stroking to the areas of the body that are not sexually stimulating; breasts and genitals should not be touched.

Second stage: The entire body including breasts and genitals can be touched without intent to cause arousal (erection or vaginal lubrication).

Third stage: The prior stages are repeated. Both the penis and clitoris are stroked and the vaginal opening can be gently probed with a finger.

Fourth stage: The first three stages are repeated. Using a lubricant can be helpful, especially for the genitals of the woman. When the man's erection is firm enough to attempt penetration, the couple may want to insert the penis in the vagina.

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