Sexuality and Breast Cancer- Addressing the taboo subject

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Abstract

Despite the integral role sexuality plays throughout the continuum of breast cancer, sexual needs of a woman with breast cancer are very rarely addressed in the clinical setting. Health professionals frequently express an uncertainty about 'not knowing where to begin' or, they presume that post-menopausal women are no longer sexually active. The Cancer Information and Support Service (CISS) have addressed this gap in service through the development of workshops *"Sexuality and Cancer- Addressing the taboo subject"* for both health professionals and patients. The effect of breast cancer and treatment on self-image and sexuality is addressed, together with strategies for communication at whatever stage of disease, regarding changes with regard to sexual functioning. Evaluations of the workshops and resulting changes in practice are also presented.

Key Words:

Sexuality—cancer—communication—aging—sensuality—intimacy—health-professionals—education.

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Sexuality and Breast Cancer- Addressing the taboo subject

Doreen Akkerman &Amanda Hordern.

A diagnosis of breast cancer can affect the way a woman views herself, her sexuality and intimacy throughout her entire life span. Despite the integral role sexuality plays throughout the continuum of breast cancer, the sexual needs of a woman with breast cancer are very rarely addressed in the clinical setting. Health professionals frequently express an uncertainty about 'not knowing where to begin' or, presume that post-menopausal women are no longer sexually active (Hordern, 1999). Another barrier to successful communication is that many health professionals equate sexuality only with sexual intercourse. Yet human sexuality is more than sexual function. It is an ever changing, lived experience affecting the manner in which we view ourselves and our bodies (Hordern, 1999). It has been shown that women who received chemotherapy are especially susceptible to adverse changes in their current sexual functioning. Indeed, "… all current treatments for breast cancer can result in serious sexual impairments" (Young-McCaughan, 1996: 1). To make things worse, "… adjuvant chemotherapy and hormone treatments, which represent a promising new advance in breast cancer management, often impair female sexuality on a physical basis".(Singer Kaplan, 1999: 3). It is, therefore, the responsibility of the clinician to provide accurate and up to date information about the possible impact of breast cancer treatment on a woman's sexuality in order to enable her to make fully informed decisions.

Communicating openly and honestly about sexuality

One of the most fundamental aspects of successful communication about sexuality in the clinical setting is for the health professional to recognise personal barriers to discussing sexuality. If these are not recognised, health professionals may 'professionally distance' themselves from patients at a time when patients often feel isolated and vulnerable (Wilkinson, 1991). This may occur when the health professional feels unable to respond to

difficult questions relating to sexuality or feels so uncomfortable that s/he makes it awkward for the patient to ask sexual questions. It is not surprising to read that " … patients rarely ask for information about the influence the illness could have on their sexual activity, and doctors avoid the subject, assuming that the absence of questions indicates satisfactory adaptation to the situation." (Barni & Mondin, 1997 p. 149). Distancing tactics only compound the feelings of isolation and the lack of control a woman may experience as a result of a breast cancer diagnosis (Evans, 1995; Lavery & Clarke, 1996; McGee, 1993).

Barriers to successful communication about sexuality in the clinical setting

Recognising personal barriers to open communication

Cultural values and beliefs:

In today's multicultural society, long held values and beliefs often result in barriers which influence the way that doctors and patients communicate about sexuality. For example, in some cultures fertility is more important than sexual satisfaction for the woman and it is also not deemed appropriate for a woman to discuss such things with a male doctor. Doctors and patients need to be aware and sensitive to these types of situations.

Issues of survival overshadow sexuality

The issue of survival in the early days of a breast cancer diagnosis may overshadow everything else, however, once the crisis subsides, most women hope to resume their previous lifestyles. Expressions of sexuality can remain an intimate form of communication which relieves suffering throughout both the aging and cancer process (Shell & Smith, 1994). Health professionals may adopt the societal belief that *survival overshadows sexuality* -this implies that women should be grateful to be alive and should not trouble health professionals with questions regarding sexuality. (Meyerowitz, Desmond, Rowland, Wyatt & Ganz, 1999).

Presumption that only the young are sexy

Ageing is often linked with physical and emotional life-style changes - as is a breast cancer diagnosis. These changes may include isolation, depression, pre-existing disease, physical and

sensory changes, loss of control or self-esteem. Society tends to associate sexuality with youth, older women therefore face additional emotional distress as they are adjusting to surgical disfigurement or contemplating reconstructive surgery (Shell & Smith, 1994). It is important for health professionals to feel comfortable discussing sexuality in order to openly and routinely communicate about the impact a diagnosis and subsequential breast cancer treatment may have on a woman with breast cancer. When addressing these issues, particularly with postmenopausal women, there is often an assumption that the elderly have lost interest in sex .

It is disappointing to read that, at a time when elderly people require physical and psychological support, the quality of communication between patients and physicians may also deteriorate with age (Silliman, Troyan, Guadagnoli, Kaplan & Greenfield, 1997, p. 1327). Additionally, when a health professional says that a patient needs rehabilitation, the inference is usually that the person will be rehabilitated back to what they could do before the diagnosis - yet there is rarely any reference made to their sexuality (Murkies, 1996). Sexual function for a person at any age depends on his/her physical and psychological well being and customary sexual activity.

Belief that same sex partnerships are less valid than heterosexual relationships

A diagnosis of breast cancer is a shock to any woman, but if one adds the fear of discrimination or judgement, then it greatly increases the sense of vulnerability a woman experiences. (Batho & King, 1995). Being in a homosexual relationship often compounds the enormity of the physical adjustments of aging and breast cancer treatments, where a lesbian woman with breast cancer faces further isolation and loneliness in a health system that presumes universal heterosexuality.

Society often views same sex relationships as less valid and more superficial than heterosexual relationships and so the general community often perceives people attracted to the same sex as ‘abnormal’ (Phelps, 1993). Partners in same sex relationships often face their own mortality as a result of a lover’s cancer diagnosis where each woman in Australia has a one in 11 lifetime risk of experiencing a breast cancer diagnosis (NBCC, 1999).

As health professionals, we must provide a vital link in the healthcare system to ensure that all people, irrespective of sexual orientation, receive the information and support that they deserve.

Identifying gaps in service and educating health professionals to communicate about sexuality

The Anti-Cancer Council of Victoria Cancer Information and Support Service (CISS) responds to over 36,000 calls per year. In 1999, approximately 20, 000 calls concerned breast cancer and 796 calls sexuality. CISS identified that consumers were not being provided with information or support about the impact of cancer treatments on sexuality. Identifying this CISS also noted that health professionals were often at a loss as to how to address sexuality in a practical, helpful way to ensure that women, whether autonomously or with a partner, could explore and resume their usual sexual function.

In 1997 CISS developed a highly interactive and patient-centred workshop for health professionals and consumers titled *"Sexuality and breast cancer – addressing the taboo subject"*. These were initially conducted in Melbourne and were expanded, upon demand to rural, interstate and international settings. These workshops provide accurate information about the physical and psychological changes a woman with breast cancer may experience as a result of cancer treatment or aging, and ways of addressing the issues in a non-judgemental, helpful manner.

Providing relevant education to assist the open communication process

Applicants are requested to submit their 'most challenging case study' related to communicating about sexuality in the clinical setting. This data is collated in an anonymous way and integrated into the workshop.

Surmounting barriers to assist health professionals to openly communicate about sexuality in the clinical setting.

Both professionals and consumers state the greatest barriers to addressing sexuality in the clinical setting are lack of privacy, lack of time and knowledge. Providing accurate and up-to-date information about the physiological impact of breast cancer treatment on a woman's sexuality is an important part of the workshop. Participants are provided with a researched based educational segment which addresses all areas of breast cancer treatment and sexuality. Literature about the sexual problems arising from breast cancer treatment and management has been outlined in great detail (Hordern, 1999 & 2000; Meyerowitz 1999; Schover, 1997; Topping 1996) and an extensive reading list and resource pack is provided.

The importance of sensuality and intimacy

Re-focussing on sensuality as an important part of exploring one's sexual experience is discussed. Information is provided regarding ways of improving a woman's self-esteem and acceptance of her 'changed self' (Akkerman 1999). Adapting to change takes time and the workshop participants are given information on ways of offering information and reassurance at any stage during treatment or afterwards.

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Coping with emotional changes:

Sensate focus shifting is one of the methods which may be used so that if a woman has lost the breast which used to be an important part of foreplay for her she can pick another spot which can become her *'erotic trigger'*.

Setting the scene for sensual play is suggested, with dimming of the lights, perfume on the light bulbs, perfumed candles, sensuous baths, dressing up, music and the use of fantasy-all contribute to ways of feeling good about oneself. Good touch in the form of a foot or hand massage is a wonderful way of receiving and giving pleasure. All of this activity may be indulged in alone or with a partner.

Coping with physical changes

For women reluctant to be seen by a partner without clothing, wearing a pretty camisole or a lacy bra with a prosthesis in place, is suggested, until she feels comfortable. The main point of any sensual activity is for a woman to feel good about herself and to find out what still gives

her pleasure. If she explores this herself, she can then communicate with a partner and can re-establish the beneficial sexual side of her life. Plenty of water based lubrication is essential if a woman is experiencing a dry vagina either through the effects of treatment or aging.

Focusing on the communication process

Basic skills in communication are explored to ensure a base line understanding of the setting and style of communication conducive to open and honest discussions about sexuality in the clinical setting. At this point in the workshop, tips in setting the scene for effective communication, creating a sense of privacy, and building a fast rapport with the patient are all explored. Participants are given case studies to incorporate into role-play. This activity is provided with the purpose of observing effective and disruptive communication processes which are likely to result in barriers to effective communication

Initiating a conversation about sexuality in the clinical setting

Feedback from workshop participants has constantly revealed that initiating a conversation about sexuality is one of the greatest challenges to many health professionals. Hence, an important part of the role-play activity is to encourage health professionals to use phrases such as:

- *How has this treatment affected you sexually?*
- *How has this experience affected your relationship with your partner or your self?*
- *Have you found that your vagina is drier since taking tamoxifen? How has this affected you sexually?*
- *Many women feel different about themselves and their bodies after this kind of surgery. How do you feel about yourself after the operation?*

Evaluation of the sexuality and breast cancer – addressing the taboo subject workshops

Responses to the *Sexuality and breast cancer- addressing the taboo subject* workshops have been overwhelmingly positive. Participants have indicated that they were provided with previously unknown basic knowledge about changes to sexuality as a result of breast cancer treatments. They also received encouragement and skills to recognise that it is part of their professional duty of care to initiate the topic of sexuality as a routine part of a health assessment.

Further evaluations of the workshops have also revealed that:

"With this knowledge, I feel I can initiate the conversation about sexuality with my patients and know what I am talking about."

"I think it was great to be able to have the opportunity to 'try out' strategies that would be useful when communicating with patients and to be able to get immediate feedback from other health professionals which ultimately helped me to evaluate my practices." (Hordern, 1998).

The authors suggest that the workshop is just the beginning of a learning curve regarding sexuality and breast cancer. It is a starting point for research and further instruction as it provides an overview and a comfortable place to explore one's feelings and skills in communicating about this taboo subject. We also state the importance of referring to another member of the multi-disciplinary team if one finds that one can never be comfortable with discussing sexuality so patient's concerns are addressed.

The importance of sensuality and intimacy is rarely addressed in the literature. We believe that when a person becomes more aware of the definition and importance of acknowledging sensuality, that the focus of sexual function in sexuality can be expanded upon to assist women to live more fulfilling lives. The following discussion will explore the definition of sensuality and intimacy in breast cancer.

Sexual desire and intimacy

Because the loss of sexual desire after cancer often results from more than one cause, restoring libido typically takes more than one simple treatment (Schover , 1997). Sometimes the desire for sex remains strong, but cancer treatment interferes with some aspect of sexual performance or pleasure. Breasts are equated with desirability in our society, so it is not surprising that scarring or the loss of any part of her breast should cause a woman emotional distress and sap her self confidence. (Akkerman, 1999)

It is important for a woman to recognise that she is loved for her personal qualities not for the sum of her body parts. Strains in communication may adversely affect a relationship with the partner feeling reluctant to touch the woman for fear of hurting her or even the thought of

losing the woman they love may affect their ability to be sexual. Many women state that their partners are a significant source of comfort and support and a major asset to their coping mechanisms, however, because of a desire to protect their partner some may feel unable to share their innermost thoughts and fears relating to their disease.

Communication is an essential part of an intimate relationship and the health professional may assist the woman and her partner to not only regain the intimate relationship they once had, but to expand and add to it through their experience of living through breast cancer.

Conclusion

Sexuality remains a taboo subject for health professionals and consumers, however, the authors have found that participants in the workshops have enthusiastically taken part in role-play and have left the workshops with the desire to improve their practice. Several have telephoned or written stating their surprise at how easy it became once they consciously included the discussion of sexuality in the clinical setting and how guilty they then felt about not having done so for so many years. Just as adapting to change takes time for the woman experiencing breast cancer, so changing the medical culture takes time, but it can be achieved. We ask you the reader to include the sentence *"Have you found that the treatment has affected you sexually"* when appropriate in future consultations with women with breast cancer. You will find that the women will appreciate your concern for their whole life experience and are then more likely to be empowered to truly live their lives.

Reference List

Akkerman, D. (1999): *Breast Cancer, Sexuality and Self-Esteem* .ACCCIS database. Anti-Cancer Council of Victoria.

Anike L (1995): Older women, relationships and sexuality. In: Sorger R (ed): *Age cannot wither her: Older women's sexuality*. Australia: Healthsharing Women's Health Resource, pp.18-22.

Barni S & Mondin R (1997): Sexual dysfunction in treated breast cancer patients. *Annals of Oncology. 8*: 149-153.

Batho, Wendie & King, Petrea (ed) (1995): *Women who love women*: Spirited Women-Journeys with Breast Cancer, chap.9: 220-235

Cave D (1993): Gay and lesbian bereavement. In: Dickenson D and Johnson M (eds.): *Death Dying and Bereavement*. London: Sage Publications Ltd., Chapter 58.

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Evans , B. (1995). The experiences and needs of patients attending a cancer support group. *International Journal of Palliative Nursing.* 1(4): 189-194.

Hordern, A. (1998). Feathers and Fun: communicating about sexuality. Breast Cancxer Support Service Newsletter, Anti-Cancer Council of Victoria, December: 7.

Hordern, A. (1999). Sexuality in palliative care: addressing the taboo subject. In: Aranda & O'Connor (eds.), *Palliative Care Nursing: A guide to practice*. Melbourne, Australia: Ausmed Publications: 197-211.

Hordern, A. (2000). Intimacy and sexuality for the woman with breast cancer. *Cancer Nursing,* 23(1), in print.

Horsley P (1995): Older lesbians and sexuality. In: Sorger R (ed): *Age cannot wither her: Older women's sexuality*. Australia: Healthsharing Women's Health Resource Service, pp. 26-28.

Lavery J & Clarke V. (1996). Causal attributions, coping strategies, and adjustment to breast cancer. *Cancer Nursing*. 19(1): 20-28.

McGee R F., (1993). Overview: Psychological Aspects of Cancer. In S. Groenwald, M. Hansen Frogge, M. Goodman & C. Henke Yarbro. (Eds.). *Cancer Nursing: Principles and Practice.* London: Jones and Bartlett Publishers Inc: 437-449.

Meyerowitz, B., Desmond, K., Rowland, J., Wyatt, G., & Ganz, P. (1999). Sexuality following breast cancer. *Journal of Sex & Marital Therapy*. 25: 237-250.

Murkies A (1996): Sex and the post menopausal woman. *Australian Family Physician* 25: 509-517.

Phelps K (1993): *Sex: Confronting sexuality. The essential guide for today's individuals.* Australia: Harper Collins Publishers.

Schover L.R. (1997). Enhancing Sexual Desire after Cancer. In*: Sexuality and Fertility After Cancer.* USA: Wiley and Sons, Chap. 9: 71-78.

Shell J A & Smith C K (1994): Sexuality and the older person with cancer. *Oncology Nursing Forum* 21(3): 553-558.

Silliman R, Troyan S, Guadagnoli E, Kaplan S, & Greenfield S (1997): The impact of age, marital status, and physician-patient interactions on the care of older women with breast carcinoma. *Cancer*, 80 (7): 1326-1334.

Singer Kaplan, H. (1992). A neglected issue: the sexual side effects of current treatments for breast cancer: *Journal of Sex and Marital Therapy*, 18 (1): 3-19.

Topping A (1996): Sexuality and breast cancer. In: Denton S(ed): *Breast Cancer Nursing* London: Chapman & Hall, pp. 216-233.

Young-McCaughan, Stacey (1996) Sexual functioning in women with breast cancer after treatment with adjuvant therapy: *Cancer Nursing*, Vol.19 (4): 308-319.

Wilkinson S. (1991). Factors which influence how nurses communicate with cancer patients. *Journal of Advanced Nursing.* 16: 677-688.