

SEXUAL REHABILITATION OF BREAST CANCER PATIENTS  
AND THEIR PARTNERS

Jill Taylor-Brown

A practicum report presented in partial fulfillment  
of the requirements of the degree of  
Master of Social Work in the School of Social Work,  
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BY

JILL TAYLOR-BROWN

A practicum submitted to the Faculty of Graduate Studies  
of the University of Manitoba in partial fulfillment of the  
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MASTER OF SOCIAL WORK

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Introduction

As medicine has advanced in its ability to prolong life, the tide has turned to living with cancer as a chronic illness rather than dying from it, and efforts have been directed at helping cancer patients cope with the psychosocial aspects of disease and treatment. Although the health care system has begun to respond to the emotional and social impact of breast cancer on women and their families, sexual issues have not been attended to in the same way.

This practicum represents an attempt to address the issue of the sexual rehabilitation of breast cancer patients and their partners and to demonstrate the need for the inclusion of sexuality in the psychosocial rehabilitation of patients:

My educational objectives were to become knowledgeable about the effects of breast cancer and adjuvant chemotherapy on sexual functioning, to become well informed about sexual dysfunction, and to develop my clinical skills in the assessment and treatment of psychosexual distress.

I intervened with 15 breast cancer patients who had previously had a mastectomy or lumpectomy, almost half of whom were currently being treated with adjuvant chemotherapy.



The goal of my intervention was the sexual rehabilitation of these clients and, where applicable, their partners.

Sexual rehabilitation was defined as the enhancement of, or the return to, the individual's/ couple's pre-illness level of functioning, or a level of functioning that was satisfactory to them. Sexual functioning was defined as "the ability of the individual to engage in and experience pleasure from sexual activities" (Woods, 1984, p. 342).

Within the framework of Annon's (1977) PLISSIT model, I developed a two-stage intervention model. The first stage was a short term, time-limited structured intervention. It involved creating an atmosphere of trust in which to discuss sexual concerns, and providing limited information to the clients as was appropriate and relevant.

Second Stage Intensive Therapy was to be offered to those clients whose sexual rehabilitation needs extended beyond this short term intervention, using a cognitive and behavioral approach to treatment. However, none of the clients proceeded to Stage II Intervention.

The following Literature Review describes the impact of breast cancer on sexuality and the

receptiveness of breast cancer patients to sexual rehabilitation interventions. As I had difficulty recruiting clients for Stage II Intervention, a section of the Literature Review addresses the factors which might be an influence on whether or not breast cancer patients would seek and follow through with sexual counseling. Literature is also reviewed on the causes and implications of treatment of sexual difficulties of breast cancer patients. An assessment and intervention model is developed.

The Practicum section describes the setting and my experience in recruiting clients. Interventions with the 15 clients, including case presentations and common themes and elements are explored. Evaluation was comprised of a Client Feedback Form and the results of this questionnaire and their implications are described.

In the Conclusion, I extrapolated issues for the sexual rehabilitation of breast cancer patients which arose from the Practicum and have made recommendations for the future. Finally, I have described my own personal learning and skill development from this experience.

Literature Review

### Literature Review

In this Literature Review, I will report on the current state of knowledge on the relationship between sexual functioning and breast cancer. I will demonstrate that breast cancer patients are concerned about sexual issues, that a significant number appear to develop sexual difficulties, that patients report they would like the opportunity to discuss these issues, and that sexual counseling of cancer patients has not been routinely provided by health care staff.

I will discuss the causes and implications for treatment of psychosexual distress and sexual dysfunction in breast cancer patients. Assessment and intervention strategies for the sexual rehabilitation of breast cancer patients and their partners will be explored, with particular attention to a description of the PLISSIT model and its application to this population.

### Breast Cancer and Sexual Functioning

It has been estimated that 7% of all North American women will develop breast cancer at some time in their life (Gunn, 1984). Current statistics on breast cancer victims indicate that 50% will survive 10 years or more, and 40% will survive 20 years (Bransfield, 1982).

Obviously many cancer patients do die from their disease but it is becoming more common for the terminal stages of the disease to be significantly delayed as the disease is managed through surgery, chemotherapy or radiotherapy.

As medicine has advanced in its ability to prolong life, and at times to cure cancer, attention has turned to the psychosocial impact of the disease and its treatment with an increasing focus on living with cancer and the implications of cancer treatment (Cohen, Cullen & Martin, 1982; Feinstein, 1983; Gunn, 1984; Sobel, Worden & Weisman, 1982; Watson, Greer, Blake & Shrapnell, 1984; Weisman, Worden & Sobel, 1980).

The most frequently utilized treatments for breast cancer patients are surgery, chemotherapy and radiotherapy, or some combination of these.

Previously, adjuvant chemotherapy following surgery was recommended to those women with nodal

involvement, or advanced stages of the disease. As knowledge and understanding has increased about cancer and how it behaves, more and more patients are being treated with chemotherapeutic drugs to control and arrest the disease. Adjuvant chemotherapy for breast cancer patients is increasingly recommended, even for those patients with minimal disease in order to prevent recurrence and metastases. Chemotherapy protocols vary according to the stage of the disease, in terms of the drugs used, in the intervals and frequencies of administration, and in the method of administration, that is, orally or intravenously.

Until very recently, breast cancer was synonymous with mastectomy. Although the majority of breast cancer patients in my clinical experience have had a mastectomy, women today diagnosed with breast cancer are becoming more consumer-aware, and are recognizing that they may have choices. Lumpectomy, with adjuvant irradiation and/or chemotherapy is an option for some patients, as is breast reconstruction either at the time of the mastectomy or at a later date.

It is not within the scope of this practicum to make comparisons between the sexual functioning of breast cancer patients undergoing different specific treatment modalities. However, I contend that no

matter which treatment regime is used, when treated with chemotherapy following mastectomy or lumpectomy, the breast cancer patient and/or partner may be at risk of psychosexual distress.

Steinberg, Juliano and Wise (1985) compared the psychological outcome of 46 mastectomy patients with 21 patients who had a lumpectomy and radiation. Among other findings, they reported that the lumpectomy patients were more open about their sexual feelings after surgery and unlike the mastectomy patients "they saw their spouses sexuality as enhanced after surgery" (p. 34). Sixteen percent of the mastectomy patients and 6% of the lumpectomy patients were described as having severe sexual dysfunction after surgery.

However, Schain et al. (1983) reported that aside from body image concerns, there were no psychosocial differences in a prospective randomized clinical trial between 28 patients treated with mastectomy and 18 patients treated with excision biopsy and radiation.

There are few studies in the literature that have focused exclusively on sexual functioning and breast cancer. Most have reported on the psychological sequelae of breast cancer, including sexuality, or have studied sexuality in the general cancer population.

An exception is Witkin who in 1978 reported on a pilot research study conducted at a New York hospital to examine the utility of psychosexual counseling and the "centrality of the sexual relationship" for the mastectomee.

Forty-one women returning to an outpatient clinic for a checkup or chemotherapy were asked if they would like to speak to a psychological counselor specializing in sex therapy. It is significant that all 41 women said "yes". A structured interview was conducted focusing on the sexual history of the women and her partner before and after mastectomy, with a goal of ascertaining "their general emotional attitude as it centered around the mastectomy experience" (Witkin, 1978, p. 22).

She found that "practically without exception, the sexual role and functioning of the women were experienced by her not merely as being important but as central issues in her psychological recovery. Woman after woman mentioned that she was not afraid to die but what really troubled her was the possible loss of affection and sexual responsiveness of the man or men in her life." (Witkin, 1978, p. 22)

Frank, Dornbush, Webster and Kolodny (1978) reported on a retrospective study of 60 mastectomy



patients. They found that the women had a temporary decrease in orgasm and that 19% had no intercourse in the first 3 months postoperatively. Breast stimulation as part of sexual foreplay was found to have reduced from 79% to 44% postoperatively. They recommended that sexual counseling be routinely presented to the mastectomy patient and her partner.

Reporting on the psychological impact of breast cancer, Maguire in Watson and Morris (1983) stated:

There is good agreement about the incidence of sexual problems. Maguire et al. (1978) found that 33% of those who had an active and satisfactory love life before surgery avoided lovemaking completely or found it much less satisfying 12 months later. Far fewer (8%) of their control subjects had noted such deterioration. (p. 78)

Morris, Greer and White (1977) studied 69 mastectomy patients and 91 benign breast disease controls and compared their psychological and social adjustment, including sexual adjustment over a two year period. At the two year mark, approximately 30% of the subjects in both groups reported sexual dissatisfaction. However, at three months the researchers found statistically significant greater deterioration in sexual satisfaction for the cancer patients; 18% of the cancer patients reported dissatisfaction as opposed to 6% of the benign group.

Jamison, Wellisch and Pasnau (1978) administered a questionnaire to 41 women post-mastectomy, with a mean of 22 months and a median of 10 months since surgery to study the psychological aspects of mastectomy. These researchers were the first to include the man's perspective in their inquiry, administering questionnaires to 31 men whose partners had had a mastectomy. As part of the psychological impact of mastectomy, they were interested in the perceived effects of mastectomy on sexual adjustment.

Sixty-three percent of the women reported no change in "sexual satisfaction in relationship", 24.2% "worse", and, interestingly, 12.1% "better". Frequency of intercourse was reported as follows: 75.8% no change, 21.2% less often and 3.0% more often.

Although like the women, the majority of men reported that the mastectomy had no influence on their sexual relationship satisfaction, 14.3% of the men when asked about the influence of their wife's mastectomy on their sexual relationship rated it as "bad" and 21.4% as "somewhat bad". A significant negative correlation was found between the man's satisfaction with the general relationship and the negative influence of the mastectomy. This study must be viewed with caution as the sample was largely Caucasian and had only a 15%

response rate. Silberfarb, Maurer, and Crouthamel (1980) studied the psychological impact of three different treatment regimens of breast cancer. One hundred and forty-six patients were divided into three categories according to treatment strategies: primary, that is, curative (mastectomy, plus adjuvant chemotherapy or radiotherapy), recurrent (first recurrence of disease with all forms of treatment other than chemotherapy), and palliative (recurrent disease at any time in the past with palliative chemotherapy).

The researchers found that "physical disability did not necessarily relate to an increase in emotional disturbance" (p. 450).

The most common disturbance in each of the three categories of breast cancer patients was in what they termed "mate role functioning". Furthermore, they reported that "the responses that indicated disturbances in mate role were virtually all confined to questions indicating lack of sexual desire and decreased amount of coitus for all three treatment categories, regardless of age" (p. 452).

The researchers admitted that sexual distress was significantly correlated with increased physical debilitation but contend that the psychological factors

related to the impact of breast cancer and its treatment were major contributors.

Gerard (1982) studied the effects of mastectomy on sexual functioning by comparing the physiological and emotional reactions of 13 women who had had a mastectomy with 11 matched controls. There were no significant differences reported on most measures between the two groups other than the control group showing significant positive correlations between the physiological and subjective indices of sexual arousal. Gerard postulated that anxiety in the experimental group may have accounted for the discrepancy between physiological cues and cognitive labeling of the cues.

Heinrich, Schag and Ganz (1984) have developed an instrument, The Cancer Inventory of Problem Situations (CIPS), and administered it to 84 cancer patients as a preliminary evaluation of their instrument. Among other psychosocial and physical implications of cancer and cancer treatment this instrument attempted to identify was the area of interpersonal interactions. It included three problem categories relevant to this practicum: sexuality with spouse, affection with spouse, and sexuality for singles. Although the study was not specific to breast cancer patients, the results appear to support the hypothesis that breast cancer

patients are at risk of psychosexual distress. The researchers found that 16% of the subjects reported severe problems in affection with spouse, 20% somewhat and 64% no problem. In the sexuality with spouse category the results were 56% severe, 35% somewhat and 10% no problem. Sixty-one percent of the applicable subjects reported severe problems under the sexuality for single category, 30% somewhat and 9% no problem. Thus, it appears that sexuality is significantly disrupted for both the cancer patients with regular partners and those who describe themselves as single.

Anderson and Jochimsen (1985) compared the sexual functioning of breast cancer patients, gynecological cancer patients and healthy women. Sixteen Stage II breast cancer patients treated with mastectomy and on adjuvant chemotherapy, 16 Stage I and Stage II gynecological cancer patients previously treated with surgery and radiotherapy, and 16 women receiving routine gynecological care were administered questionnaires and interviewed on a variety of scales intended to measure sexual behavior, sexual responses, body image and marital adjustment. All subjects in both the experimental and control groups were statistically significantly matched on relevant variables. To be included in the study subjects had to

have been sexually active, defined as intercourse or equivalent heterosexual activity at least once a month. For the cancer population sexual activity related to the 6 months prior to diagnosis and treatment. It is noteworthy that the researchers had only a 6% refusal rate for the breast cancer sample, 4% for the gynecological cancer sample, and 15% for the healthy women.

Anderson and Jochimsen found that there was a significant lower level of sexual behavior activity at the .05 level for women with cancer as compared to healthy women. In comparing the scores of the two cancer groups no significant differences were found other than for frequency of kissing which was significantly lower for the breast cancer population over the gynecological cancer population.

In terms of the sexual response cycle, no significant differences were reported between women with cancer and healthy women nor between the two cancer groups. However, differences on the scale for sexual excitement reached significance between the healthy women and the cancer patients, but not between breast cancer and gynecological cancer patients.

The researchers also found that the subjects' current marital adjustment did not affect their current

sexual life. It is interesting to note however that 82% of the gynecological cancer subjects reported poorer body image evaluations whereas only 31% of the breast cancer patients and 38% of the healthy women reported this. Although it is commonly believed that breast cancer patients experience body image disruption, empirical testing of this hypothesis seems to indicate that this may not be the case.

In summary, Anderson and Jochimsen found that women with breast cancer and gynecological cancer differed from the healthy women in the frequency of sexual behaviors and the level of sexual arousal. The researchers suggested that the difference in kissing frequency between the two cancer groups may be due to the possible reluctance among women who have had a mastectomy for close body contact. Alternatively, their partner may avoid close contact for fear of injury to the partner's surgical site.

One study described the psychosocial implications of adjuvant chemotherapy after surgery for Stage II breast cancer patients. Meyerowitz, Sparks and Spears (1979) interviewed 50 subjects and reported that all experienced adverse changes. Of interest to this practicum is that of the 37 women who were sexually active prior to diagnosis, 40% reported behavioral

disruption, and 29% emotional distress in their sexual relationships.

Todres and Wojtiuk (1979) studied the impact of chemotherapy from the patient's viewpoint on life style. Fifty of the 67 subjects interviewed were breast cancer patients. They reported, among other findings, that 28% of the subjects "indicated that their sex lives had been negatively affected after having received chemotherapy" (p. 285).

Zemore and Shepel (1987) recently reported that 301 women with mastectomy after early diagnosis were no more maladjusted emotionally or socially than 100 women without cancer. This study is particularly interesting because it is Canadian and the subjects were women from the Prairie Provinces. Although the researchers did not examine sexuality specifically, it is significant that they found the breast cancer patients reported they had more opportunities to discuss their feelings and concerns with significant others, and that these relationships therefore seemed to be strengthened.

These findings contradict the classic studies I have described above and it is important to remember the breast cancer patients had only Stage I or Stage II disease and none had received chemotherapy. It does suggest, however, that the health care system may have



become more responsive to patient's psychosocial needs, that there may be differences in Canadian women, and, as always, that different research designs, methodology, and testing procedures can produce different results.

Bransfield (1982) undertook a literature review from 1953 - 1981 of sexual functioning and breast cancer. Reviewing in depth much of the research reported above, Bransfield concluded that "although there is much evidence to suggest that women with breast cancer are at risk for developing sexual difficulties as a result of their illness and subsequent treatment . . . the study of breast cancer and sexual functioning is in its infancy" (p. 197). One of her main criticisms was that most of the research has not addressed the complexity of variables which may affect the sexual functioning of these patients. She has divided the variables into biological, psychological, and sociocultural factors and partner and health care provider variables.

She identified the biological factors as age, stage of the disease, effects of varying treatments, symptoms associated with hormonal depletions frequent in breast cancer patients because of the nature of the disease, physical status, and alcohol and drug use.

Body image, self-esteem, sexual identity and patient mood fluctuations were identified as possible psychological factors. Bransfield noted that although many researchers have mentioned these factors, few appear to have tested hypotheses about their relationship to sexual functioning and she could find no replications of those studies which had tested them.

In terms of sociocultural factors, Bransfield points out that most of the research in this area has been confined to married women, virtually ignoring the percentage of the female population that is single, separated, widowed or divorced. The assumption that single women may have more difficulty with sexual adjustment after breast cancer exists without definitive study in the area. She noted that only one researcher in her review footnoted that breast cancer is not confined to heterosexual women.

She also spoke to the issue of marital adjustment or marital satisfaction influences on sexual functioning and found that the research has not addressed these variables in much depth and has tended not to include relationship communication patterns.

Research in this area has frequently not offered definitions of "psychosexual distress", "dysfunction", "problems" or "difficulties" and as they are not

consistent, cross-study comparisons cannot be conclusive.

Bransfield also noted that patient's sexual adjustment tended to be measured by pre and postillness frequency of intercourse. Sexual functioning involves much more than coitus and further studies need to include past history of sexual functioning, communication of sexual needs, definitions of "satisfactory" sexual relationship and information on the patient's sexual attitudes and knowledge base. Cultural and religious based sexual attitudes will affect the behavior of the patient and therefore need attention.

Another variable identified was time, and Bransfield reported that no studies have used identical time frames in assessing sexual functioning of these patients.

Finally, Bransfield stated that very little exploration has been done of two obviously important components to the breast cancer patient's sexual rehabilitation: her partner and her health care provider.

Bransfield could find only two studies to date that researched the male's psychosexual response to his partner's breast cancer treatment, Wellisch et al.

(1978) as described above and Leiber, Plumb, Gerstenzang, and Holland (1976). Leiber et al. found that 25% of the partners had a decreased desire for intercourse postillness and 44% wanted more nonsexual physical closeness.

Other questions not yet tested involve the partner's own fears of mortality and mutilation precipitated by his mate's cancer and the effect of the woman's physical appearance and the absence of a breast on his sexual arousal.

Bransfield pointed out that almost all of the variables identified for the patient, also need to be explored in the partner, such as his interpretation and understanding of breast cancer and its treatment, his sexual knowledge, attitudes, beliefs, and previous functioning. She concluded that "assessment of psychosexual functioning after breast cancer needs to treat the patient's partner as just that: a partner who has the capability of greatly affecting their sexual rehabilitation" (p. 209).

The ambiguity of the term "health care provider" reflects the indecision and controversy about who, if anybody, or all, of the health care team is responsible for the sexual rehabilitation of the cancer patient. Bransfield found that physicians, surgeons, social

workers, nurses, psychologists, psychiatrists and volunteers "have all been discussed as possible candidates for this role. No research has been conducted on which professionals on the health care team is best suited to broach the topic of sexuality with the patient with breast cancer" (p 209).

The skill, ability, experience, attitudes, values and level of knowledge of the health care professional, and the willingness to discuss sexual concerns, will all affect the sexual rehabilitation process of the patient and partner. Again, Bransfield found that no research to date has specifically studied the effects of these important health care provider variables.

Anderson (1985) reviewed the available data and looked at some of the methodological issues involved in researching sexual dysfunction in cancer patients. She pointed out that "17-25% of all hospitalized cancer patients could be diagnosed as clinically depressed" (p. 1835). Therefore sexual difficulties may be secondary to clinical anxiety or depression.

Furthermore, due to the nature of the illness and its treatment, other factors such as fatigue, shortness of breath, pain, somatization, and poor prognosis leading to repriorization of life issues, may adversely influence sexual functioning.

Anderson concluded that the etiology of sexual difficulties for cancer patients is multiply determined. She highlighted a series of questions, as yet unanswered by the current research, which need to be considered when studying sexuality and cancer, and in particular in determining intervention strategies.

What disease or treatment context will negatively influence sexuality for cancer patients?

What sexual difficulties or dysfunctions develop for cancer patients?

What are the characteristics of cancer patients who are at risk for developing sexual difficulties?

When will sexual problems develop in cancer patients?

What factors contribute to the etiology of sexual dysfunction among cancer patients?

(Anderson, 1985, p. 1839-1840)

Although these questions were addressed to the general cancer population, they are extremely relevant to the study of sexuality and breast cancer patients and to the development of models of intervention for the sexual rehabilitation of these women and their partners.

This section of the Literature Review has attempted to show that breast cancer patients are indeed at risk of developing psychosexual distress. Although not every woman who is diagnosed with breast

cancer will develop problems in sexual functioning, it would appear that between 20-30% of these patients will develop sexual difficulties. It also seems likely from the evidence presented that the partners of breast cancer patients are at similar risk and that both the patient and, where applicable, her partner, could benefit from a social work intervention of sexual rehabilitation either individually or conjointly.

Receptiveness of Breast Cancer Patients to Sexual  
Rehabilitation Interventions

Having determined in the previous section that psychosexual distress exists in breast cancer patients, the following is a review of the literature addressing the fact that sexual issues are rarely discussed with cancer patients in the health care system, that cancer specific sexual rehabilitation is rarely offered to this population, and that these patients would welcome the opportunity to discuss their sexual concerns with a member of the health care team.

It is not surprising that sexual concerns have not been routinely discussed with cancer patients. The very word cancer strikes fear and horror in most of us, conjuring up images of cachectic, pain-ridden victims who ultimately die a slow and agonizing death. In contrast, sexuality evokes images of health, wholeness, vitality, intimacy and life. It is only relatively recently, since the advances of medical technology have extended longevity, that the psychosocial impact of living with cancer and its treatments have been studied. Interventions and treatments have been developed not only to cure and control the disease but also to enhance the quality of life of cancer patients



and their families. It is even more recently that sexuality has been included in this holistic approach.

As Schain (1982) stated "the concept of physical pleasuring or recreational sex, as aspects of healthful pursuits, did not gain popular acceptance in the public domain (much less in the medical world) until past the middle of the 20th century" (p. 279).

It would seem that more myths and taboos exist in both sex and cancer than in any other human conditions. Many people seem to have difficulty discussing sexual concerns under the best of circumstances. It seems reasonable to assume that communicating their needs for sexual counseling will be that much more difficult for cancer patients who are facing a life-threatening illness and at times debilitating treatments.

There seems to be an assumption in the general public that discussions of sexuality are initiated by the physicians and surgeons of women who have breast cancer. I have been surprised by the relatively little research that has been done in this area, and to learn through clinical experience that the vast majority of medical professionals do not routinely address sexual concerns of cancer patients.

Lief (1978) was astonished to discover that of the surgeons he surveyed who performed mastectomies, only

10% stated that they routinely discussed sexual concerns with their patients.

Frank et al. (1978) found that out of a sample of 60 women who had had mastectomies, only 5 had discussed sexual concerns with a member of the health care team, and 5 with their partners. The other 50 reported they had not discussed their concerns with anyone.

Two-thirds of the women stated they would have welcomed discussion of these concerns with their doctors.

Witkin (1978) found it very significant that all 41 women approached in her pilot study agreed to talk to a psychological counsellor specializing in sex therapy. She stated "most 'normal' people have inhibitions about psychological counseling especially when sex is involved, and it is very unlikely that everyone of 41 people approached would agree to see a counsellor. That these women did implies very strongly that their anxiety and their perceived need for help were sufficient to overcome their inhibitions and that the traumatic effect of the mastectomy is more severe than the patient may reveal" (p. 21).

She also reported that she had to change the design of her original study because of the lack of co-operation of the surgeons in three major hospitals in allowing post-operative interviews. This is

particularly significant given the reputation and high quality of therapists involved in this study.

Reporting on sexual counseling for gynecological patients, Capone and Good (1980) noted a recent study of women with cervical cancer. Seventy percent reported that they received no sex information from their doctors before, during, or after treatment. Of these, 79% wanted more information but revealed that they would not ask for it.

Wasow (1982) reported that health care personnel and hospital administrators were extremely reluctant to allow her access, and often blocked access to cancer patients when she was trying to collect voluntary data on their sexual concerns. However, when access was granted, she consistently found patients wanted to have the opportunity to discuss these concerns.

Wasow promoted the concept that routine sexual assessment should be carried out by physicians in the same way that they routinely assess other systems of the body and that all patients should be offered the option to discuss these concerns. She astutely added that the objective is to open the door for the option to discuss sexual issues, and that cancer patients should not be pushed into discussions or made to feel abnormal if they do not have such concerns.

Woody and Tombrink (1983) reviewed several studies and found that patients' needs for information and discussion of their sexual concerns were not being met. In one of the studies reviewed, the majority of mastectomy patients wanted more sexual counseling than is usually offered. Another found that although 40% of the patients had been able to talk to their physician about their sexual concerns, "only 7% felt that they had received helpful advice from any source" (p. 47).

Bullard (1980) also reported on a number of studies of this issue. In addition to most of the research discussed above, he reported on a study of 26 men and women diagnosed with cancer within the previous 3 years, most of whom were on active treatment. Although not specific to breast cancer, 63% of the subjects responded that they would have liked more information on the effects of cancer on sexuality. They were asked to identify with which member of the health care team they would feel most comfortable discussing their sexual and social concerns. Fifty-four percent "indicated their physician, 54 percent indicated a counsellor whose specialty is human sexuality, and less than 25 percent indicated a psychologist, nurse, friend, social worker or psychiatrist" (Bullard, 1980, p. 69). This has some

implications for this practicum and indicates that I may need to present myself as a counsellor specializing in sexuality with cancer patients in order to recruit clients.

Having reviewed most of the literature in this area, I concur with the following conclusions drawn by Bullard, and have taken these issues into consideration in the design of this practicum:

1. Many cancer patients and their partners have sexual concerns that they wish to discuss with their physicians or other members of the health care team.
2. These same patients may not discuss sexual concerns unless their physician or other medical personnel first bring up the question of sexuality.
3. In part because of their having investment of time and energy in the treatment of the cancer, such persons may be less likely to seek help at a "sex counseling clinic" even when they are having sexual problems - only so much energy can be expended by persons in establishing new therapeutic relationships.
4. Staff tend to be very protective of patients with cancer, so any sexual health services that are afforded must be thoroughly explained to staff who are in the position to make referrals. (p. 70)

Factors Influencing Whether Breast Cancer Patients Seek  
Sexual Counseling

Hawton (1985) suggested that there are three factors likely to affect the demand for treatment of sexual problems in the general population:

First, the frequency with which sexual problems exist in the general population; secondly, the extent to which people wish for help; and thirdly, the extent to which such people are detected or seek help themselves and when appropriate are referred to a specialized service. (p. 45)

These same factors, which may influence the general population, will also impact on the breast cancer patient population.

Hawton identified a number of methodological difficulties in surveying the prevalence of sexual dysfunction in the general population including sample selection, response rate, how questions are asked (by questionnaire or in person), validity of responses, resistance to surveys, and definitions of sexual problems.

Hawton reviewed the available literature on the frequency of sexual problems in the general population and concluded that sexual problems are not rare and appear to be more common among women than men, or, women more often admit sexual difficulties. The "prevalence of sexual dysfunction in women is probably

between 35 and 60 percent with impaired sexual interest and arousability being the most common" (p. 49). The incidence of sexual dysfunction in men is much less clear, as men have rarely been surveyed. The suggested figure is in the region of 40 percent.

Jehu (1979) stated that "sexual failure of varying severity is probably experienced by most people at some time in their lives" (p. 69). However, not every failure is viewed by the couple or individual as a dysfunction or a problem.

There are no absolute standards for sexual satisfaction and competence and certainly it is unrealistic to expect to be completely satisfied every time. How then does one define sexual dysfunction?

Jehu suggested to regard it as that behavior "judged to be inadequate by the client or other people" (p. 70). This subjective judgment is influenced by a number of factors and is an extremely complex process.

The nature of the sexual behavior (e.g., lack of desire, erection or ejaculation difficulties, orgasm difficulties), although not sufficient on its own to define sexual dysfunction, is obviously relevant.

The context of the behavior also provides a number of criteria for judging its adequacy including amount of sexual stimulation, partner variables, persistence

of the difficulty over time, frequency of the difficulty and environmental influences.

The consequences of the sexual behavior will also influence whether it is perceived by the clients as a problem or dysfunction. For example, if physical pain or strong feelings of guilt, anger, anxiety, humiliation, or lowered self-esteem are evoked, the client is likely to judge the behavior as problematic.

Finally, Jehu suggested that sexual behavior that apparently deviates from normative standards is likely to be perceived as problematic.

Personal characteristics of the client such as age and sex and characteristics of judges, that is, spouses, friends, physicians, and so forth, may influence judgments of inadequacy.

A historical perspective of the role of cultural attitudes and the mass media in shaping popular and therapeutic views of male/female roles and "normal" sexual behavior was discussed by Lo Piccolo and Heiman (1977).

It was only 100 years ago that sex became an acceptable topic for discussion in scientific circles. By 1920, sex was more openly discussed although "permission to be sexual . . . was still enjoyed more by men than women" (Lo Piccolo & Heiman, 1977, p. 171).



After 1940, sex became acceptable for both men and women, but the emphasis turned to performance ability. Currently, the mass media, equally as much as the sex researcher, generates cultural definitions of sexual function and dysfunction. The media creates a problem for women by depicting mixed messages about beauty, sexuality, and virginity and for men by developing a role model for the "real man" as one who is sexually aggressive, assertive, competent, and free of sexual concerns.

Lo Piccolo and Heiman concluded that:

Our culture has found it difficult to accept a view of sexuality as simply an expression of basic human need for pleasure, closeness, love, sharing and play, but continues to portray sex in the media and elsewhere as a powerful force which must be controlled at society's peril . . . . Over the centuries, religious, therapeutic and media-generated norms for sexuality have constricted and confined people into roles and behaviors that have not allowed them the full range of their sexual and emotional potential. (p. 182)

A satisfactory sex life is obviously not an "all or nothing" phenomenon--there are different degrees of satisfaction as well as different types of problems and it is extremely difficult to establish a true incidence of any aspect of sexual behavior in the general population (Bancroft, 1983). However, it would appear, according to Bancroft (1983), that "sexual dissatisfaction and sexual dysfunctions occur with a

frequency that would overwhelm the health services if they are presented for help" (p. 203).

Of interest is that Bancroft estimated an annual referral rate on a sexual problem clinic in Oxford to be 64 referrals per 100,000 adult population, that is, only .064% of the available population.

Equal numbers of men and women presented and the mean age was 38 years for the men and 29 years for the women. Jehu (1979) also made reference to age as a factor in individuals seeing themselves as having a problem.

It is possible that younger people are more prone to consider any less than perfect sexual behavior to amount to a dysfunction. Their elders may tend to have greater experience and understanding of the variable nature of the sexual response and the level of sexual performance may not feature so prominently in their evaluation of a person's overall adjustment to life. (p. 74)

This has particular relevance to the breast cancer patient population. Of the 627 breast cancer patients diagnosed in Manitoba in 1985, 408 or 65% fell between the ages of 50 - 79 years, with the greatest number falling in the 60 - 69 age bracket. Only 45 patients (7%) were 39 years old or younger. Age distribution for 1983 and 1984 was similar (Manitoba Cancer Treatment and Research Foundation, 1985).

An interesting and relevant study was reported by Frank, Anderson and Rubinstein (1978). They examined

the prevalence of sexual dysfunction in couples not seeking sexual treatment for sexual problems. They gave 100 couples, who defined themselves as having marriages that were working, a questionnaire that covered most aspects of marriage and looked at three separate aspects of the sexual relationship: sexual dysfunctions, sexual difficulties, and a global measurement of overall sexual dissatisfaction.

They found that:

Although 80 percent of the couples reported that their marital and sexual relationships were happy and satisfying, 40 percent of the men reported erectile or ejaculatory dysfunction and 63 percent of the women reported arousal or orgasmic dysfunction. In addition, 50 percent of the men and 77 percent of the women reported difficulty that was not dysfunction in nature (e.g., lack of interest or inability to relax). (Frank, Anderson & Rubinstein, 1978, p. 111)

Sexual "difficulties" rather than sexual dysfunctions were much more consistently and highly correlated with overall sexual dissatisfaction. This indicates that aspects other than dysfunction may be more important in causing dissatisfaction and thus lead to seeking counseling.

One of the surprising findings in this study was the high incidence of sexual difficulties reported particularly since the sample was not representative of North American marriages. "That is, compared with a

population representing a broader range of marital satisfaction levels, this more satisfied population would be expected to report a lower frequency of sexual problems than would be predicted in the general population" (Frank, Anderson & Rubinstein, 1978, p. 114).

The fact that the wives seemed to have greater reported sexual complaints may be a reflection of their greater willingness to admit a problem.

Wives accurately perceived their husbands' dysfunction, although the men tended to underestimate the occurrence of sexual dysfunction in their wives. The authors interpreted this underestimation as consistent with the typical North American pattern of sexual interaction where the husband assumes everything is fine as long as the wife does not refuse to have intercourse and does not complain. Frank, Anderson and Rubinstein (1978) concluded:

All this material leads one to the conclusion that it is not the quality of sexual performance but the affective tone of the marriage that determines how most couples perceive the quality of their sexual relations. (p. 115)

Two studies have attempted to give profiles of those couples who have actually sought sexual counseling. One study compared couples who have sought

sex therapy with couples who have not (Chesney, Blakeney, Cole & Chan, 1981), and the other compared couples seeking sex therapy with couples seeking marital therapy (Frank, Anderson & Kupfer, 1976).

Chesney et al. compared 53 couples who attended a sex therapy workshop with 48 volunteer couples who had not sought sexual counseling during their current relationship. Among the women in the comparison group, 41.7% reported at least one sexual problem, while 70% of the women in the sex therapy workshop were labeled symptomatic by the therapists. Among the nonworkshop men, 35.4% reported at least one sexual problem and 58.5% of the workshop group were labeled symptomatic. Using multivariable analysis the authors concluded that communication problems were the primary difference between the sex workshop group and the comparison group. In the comparison group, a communication process existed which allowed for constructive problem-solving whether the problems were sexual or not. Conversely, those couples seeking sex therapy were those who could not problem-solve their sexual difficulties on their own.

Frank, Anderson and Kupfer (1976) compared 29 couples seeking marital therapy with 25 seeking sexual therapy at the same institution. They found both

groups were demographically similar and both had a young modal age of 31.5 years. The overall frequency of sexual difficulties was quite similar for both groups and both groups appeared to be experiencing considerable marital discord.

Clearly the two groups did not separate in a way that would have been expected, that is, the sex therapy couples experiencing significantly more sexual complaints and the marital therapy couples experiencing significantly more marital difficulties.

Although the two groups were very similar demographically, the authors derived the following major differences between them:

1. Sex therapy couples were more thoughtful in their approach to life and less conservative.
2. More of the sex therapy couples' wives worked outside the home.
3. Sex therapy clients were more mature and less impulsive.
4. Sex therapy couples allowed each other more independence and privacy.

Segraves, Schoenberg, Zairns, Knopf and Camic (1982) were interested in the referral pattern to a sexual dysfunction clinic for impotent men, recognizing that one might expect difficulties with this process

because of the sensitive nature of the problem. They found that referral to a sexual dysfunction clinic was rarely successful. Seventy-six patients who were seen by the urologist for erectile dysfunction and underwent physical examination, penile blood pressure monitoring, psychological testing, and a psychiatric assessment were referred to psychiatry for further evaluation. Referrals were made on patients suspected to have organic causes for their dysfunctions as well as those presumed to have psychogenic causes.

The authors found that only 62% of the referred patients actually made appointments. Of those seen and for whom sex therapy was recommended, only 32% accepted the recommendation. And finally, for those who initially entered into the recommended treatment program, 57% terminated before treatment was completed and against medical advice.

Segraves et al. offered some possible explanations for their failure to successfully refer and engage impotent men in sex therapy. The only difference they could find between the group of men who were more likely to make at least initial appointments was that the complaints of these men were more long-standing. One of the most frequent reasons given by the men for declining therapy was their reluctance to involve their

wives or sexual partners in the therapy as was required by this particular sexual dysfunction clinic.

Another explanation postulated by the authors was the sociocultural attitudes against patients in psychiatry, and it does appear that the majority of the patients "preferred to view their problems as organic and preferred treatment from a non-psychiatric physician" (Segraves et al., 1982, p. 527).

A study by France, Weddington & Houpt (1978) supports the difficulties cited above. These researchers were interested in the referral process between primary care physicians and a community mental health clinic. They found that only 10% of referred patients who had no previous contact with the mental health centre completed the referral.

From the above literature review on the general population, it can be seen that a greater number of couples experience sexual dysfunctions and difficulties, but do not seek help in this area. One study indicated that although individuals may have a sexual dysfunction, they do not consider themselves to be dissatisfied with their sexual relationships overall. It would appear that how most couples perceive their sexual relations is based on the quality of the relationship rather than on sexual performance.



There is also some suggestion that satisfaction with sexual relationships and acceptance of difficulties appear to increase with age. Furthermore, for those clients who in some way identify themselves as having a sexual problem or difficulty, very few follow through on recommendation for counseling in this area. There is no question that sexuality is a very sensitive subject in our culture. "The decision to seek professional advice for a sexual problem is a difficult one for the majority of people. The attitude of the professional to whom they first speak is probably crucial" (Bancroft, 1983, p. 198).

All these factors, that may influence seeking sexual counseling in the general population, may also influence the breast cancer patient population.

As mentioned earlier, Bransfield (1982) undertook a literature review from 1953 - 1981 of sexual functioning and breast cancer. She noted that most of the research has not addressed the complexity of variables which may affect sexual functioning. Some of the variables Bransfield discussed might also be relevant in terms of factors that might affect breast cancer patients seeking sexual counseling, in particular, age. Whether age on its own has an effect on sexual adjustment in the breast cancer patient is

unknown. However, Bransfield reported on a review by Meyerowitz (1980) who found that the loss of a breast seemed less upsetting to older women. Jamison, Wellisch and Pasnau (1978) reported:

We found that the younger women did rate their postmastectomy adjustment as significantly poorer . . . that a higher percentage of this group sought professional help for psychological problems secondary to mastectomy . . . and that more of these women perceived the mastectomy as having had a negative influence on their sexual relationships . . . . (p. 434)

Another difficulty interpreting the research in this area is that:

To date, the definition of sexual "difficulties", "problems", or "dysfunction" has not been offered in the literature on psychosocial aspects of breast cancer. Therefore, one cannot ascertain if the definitions proposed by Masters and Johnson (1970) or those set forth by Kaplan (1974) have been used, or if any complaint regarding a sexual functioning is labeled as "dysfunction". Some operational definitions are needed in future studies to facilitate cross-study comparison. (Bransfield, 1982, p. 207)

Bransfield also astutely noted that the patient's sexual attitudes and knowledge base need to be taken into account as the patient's interpretation of sexual satisfaction will vary enormously and will affect whether they seek out sexual counseling.

It is obvious from the literature reviewed that the question of what factors might influence whether

breast cancer patients seek sexual counseling is very complex and that due to these factors I may have difficulty recruiting clients for my practicum.

Psychosexual Distress and Sexual Dysfunction of Breast Cancer Patients: Causes and Implication for Treatment

In this section of the Literature Review, theories of causation and implications for treatment of the breast cancer patient experiencing psychosexual distress and/or sexual dysfunction will be explored.

Terms such as "psychosexual distress", "sexual problems", "sexual concerns", "sexual difficulties", and "sexual dysfunction" have all been used in the literature, seemingly with the assumption that each term is basically defining the same phenomena.

Jehu (1979) defined sexual dysfunctions as "responses to sexual stimulation that the clients and/or their partners consider to be inadequate. The responses involved might be in sexual interest, arousal, intromission, orgasm or pleasure" (p. 3). Specific sexual dysfunctions are comprised of "erectile dysfunctions, premature ejaculation, retarded or absent ejaculation and retrograde ejaculation in the male; vasocongestive dysfunction, vaginismus, and orgasmic dysfunction in the female, and inadequate sexual pleasure and dyspareunia in both sexes" (p. 3).

For the purposes of this practicum the above definition of sexual dysfunction will be adopted. However, the term psychosexual distress will go beyond

this definition to include any difficulties perceived by the client and/or partner in pleasuring and intimacy behavior such as kissing, cuddling, or hugging, not necessarily for the purpose of sexual arousal. It will also encompass difficulties in sexual self-image.

The rationale behind this is explained by von Eschenbach and Schover (1984b):

Sexuality is not only the way we ensure our genetic posterity and the survival of our species, but also is the most intimate and precious way we have of sharing ourselves with others. It is a source of great pleasure and satisfaction both emotionally and physically. (p. 2662)

I was hesitant to focus my practicum on sexual dysfunction alone. The term dysfunction implies an abnormality. It is my opinion that distress in the area of sexuality may not be an abnormal response to breast cancer and breast cancer treatment. The crisis of the diagnosis and its subsequent treatment has an impact on all levels of the individual's psychological and social functioning, including sexuality. To feel distress about any or all aspects of one's sexuality at this life crisis may not necessarily mean that one is experiencing a sexual dysfunction.

On the other hand, sexual dysfunction may develop in the breast cancer patient and/or her partner as has

been shown in the first section of the Literature Review, or may have existed prior to diagnosis.

Von Eschenbach and Schover (1984a) stated that cancer affects sexuality because it diminishes self-worth.

A patient with cancer may endure the loss of freedom, productivity, sense of well-being, the loss of bodily function or part and even the ultimate loss of life itself. With each of these losses there may be a progressive lessening of self-esteem and withdrawal into a shell of loneliness. The cancer patient's isolation is exacerbated by the fears of the healthy. Lovers, family and friends may become alienated by fear of contagion, revulsion over physical changes, anxiety, uncertainty, insecurity and the pervasive frustration of being helpless . . . . Few of us have the serenity to recognize our inherent self-worth and inner beauty. We, as well as significant others, measure our value not so much by who we are but rather how we appear and what we achieve. Therefore, we are highly vulnerable to the depredations of cancer. (p. 155-156)

Sexual difficulties are most often due to the interaction between the physiologic and psychologic consequences of the disease and its treatment (von Eschenbach & Schover, 1984a, 1984b). Therefore, assessment of both the psychological and physical components of breast cancer and sexuality is needed.

Psychosocial consequences of breast cancer on  
sexuality.

Jehu (1979) stated that "sexual behavior can be impaired by the negative emotional reactions that tend to accompany all forms of stress and which include depression, anger, guilt and especially anxiety" (p. 45). All of these are possible emotional responses to a diagnosis of breast cancer in oneself or one's partner.

Changed body image, as a result of mastectomy, lumpectomy or breast skin changes after radiation may be another psychologic effect of breast cancer on sexuality. Emaciation and alopecia from chemotherapy, although temporary, may also lead to decreased self-esteem (von Eschenbach & Schover, 1984a, 1984b).

Although breast cancer is no longer synonymous with mastectomy, Witkin's (1982) discussion of the psychological consequences of mastectomy continues to be relevant.

Witkin states that the primary concern of the patient is the possible loss of sexual responsiveness and affection by her partner or partners. She often sees herself as incomplete, may fear that her partner will view her as physically repulsive and, because of this fear of rejection, may be less likely to initiate

sexual activity. On the other hand the partner fears that if he initiates sex "too soon" he will appear unfeeling or demanding or will do something harmful or hurtful. Further, neither wants to burden the other with their fears or feelings. This results in a spiral that Witkin termed the "mastectomy bind". As each hesitates in approaching the other, their greatest fears appear to be true. A self-fulfilling prophecy results whereby the woman's fears of her sexual unattractiveness and the man's fears of his partner's fragility are confirmed.

For those patients without partners, Witkin proposed that the fears and subsequent avoidance of potential sexual contacts are even greater. Without a regular partner, the woman does not have the opportunity to quickly resume sexual activity and prove her fears unfounded.

For the women with a regular partner, the response of the men, according to Witkin (1982), is most often helpful and for most couples their communication and coping skills facilitate their sexual rehabilitation.

For those couples unable to work through the "mastectomy bind", sexual dysfunction in either partner or both may occur.



Kolodny, Masters and Johnson (1979) proposed that the psychologic responses to the diagnosis of cancer are compounded by the psychologic responses to the treatments employed. Cancer treatments can be paradoxically lifesaving and life-threatening at the same time. The patient fears pain, fatigue and weight loss from both the disease and the treatments.

Grinker (1976) confirmed that the psychological impact of the disease and its treatment affects sexuality. He stated:

The dread of exposing oneself to one's spouse as crippled, damaged, incomplete or dying may cause sexual inhibition or abstinence. Intimacy and sexual bodily functions may be affected by shame and embarrassment. Mutilation (e.g., mastectomy) may make exposure and nudity extremely painful . . . . Lack of self-esteem and a relative feeling of emotional poverty in survivors may prevent the resumption of their previous relationships. (p. 131)

The psychological consequences of diagnosis and treatment, particularly anxiety and depression can affect libido. Although most often this results in decreased libido, Wise (1978) pointed out that certain depressed men and women have increased wishes for physical closeness, although not necessarily intercourse.

Breasts in our culture are generally regarded as objects of sexual desire and symbols of femininity and

attractiveness. Breasts also play a role in mothering, for food and for bonding. Stimulation of the breasts may be a source of sexual arousal for both the man and the woman. Thus, any assault on the breast, whether it is surgery, amputation, or radiation may create problems in psychological and sexual adaptation (Kolodny et al., 1979).

Self-esteem for many women is based on their rating of their body-image and this begins at a very early age (Schain, in press). Schain stated that at diagnosis the breast cancer patient may be obsessed with fear of death, and simultaneously or sequentially fear of what will happen to her breast. The patient may use one or other of these obsessions to avoid facing the crisis.

Women who have a greater investment in their breasts in terms of self-worth will be at greater risk for developing psychosexual distress, as will women whose partners have difficulty accepting the body alteration or cannot cope with the risk of the patient dying. The intact breast is often ignored either by the partner or the patient because it may be a reminder of vulnerability or viewed as a possible source of further cancer (Schain, in press).

Schain (in press), acknowledged that some women experience a period of hypersexuality and seek out partners who will respond to them sexually and "prove" that they are lovable and attractive. In order to avoid dealing with her fears and anxieties some women may become overinvested in sex as a defence mechanism.

The partner of the breast cancer patient is also at risk for developing sexual dysfunctions as a result of the psychological impact of the disease and treatment. According to Witkin (1982) "the response of the men is usually favorable" (p. 54).

However, the strength and maturity of the relationship prior to diagnosis affects post-illness responses. This crisis may be the "first nodal point in the natural history of emotional disruption . . . men with a negative view of the relationship before the procedure tended to become more negative after mastectomy" (Wellisch, Jamison & Pasnau, 1978, p. 546).

Male sexual dysfunctions of inadequate sexual interest, erectile dysfunction, ejaculatory problems, and inadequate sexual pleasure may all be caused by psychological factors and stresses. They may be precipitated by real or perceived dysfunctions in the female partner (Jehu, 1979), or the psychological

impact of one's wife or lover being diagnosed with breast cancer, and all that it implies.

Physiological consequences of breast cancer and sexuality

Witkin (1982) stated that fatigue was the sole physiologic consequence of mastectomy that could affect sexual functioning and therefore any difficulties in this area must be presumed to be psychologic. This may be so for the "cured" breast cancer patient who has early stage disease, no metastases, no recurrence and no other treatment.

However, even with mastectomy alone, the type of operation performed may place physical limitations on rehabilitation. Approximately 10% of these patients develop persistent lymphedema (Kolodny, Masters & Johnson, 1979). Changes in the arm and hand, changes in range of motion in the affected arm and shoulder, numbness or pulling in the incision area with healing, decreased sensation in pectoral and inner aspect of arm and phantom breast sensation are all possible physiological consequences of modified radical mastectomy that may affect sexual functioning (Schwarz-Appelbaum, Dedrick, Jusenius & Kirchner, 1984).

Although it is not within the scope of this practicum to examine each and every possible treatment or combination of treatments for breast cancer and their specific side effects on sexuality, the following is an examination of the possible physiologic affects of breast cancer on sexuality for those patients treated with radiotherapy and/or chemotherapy. Although chemotherapy literally means drug therapy, it is commonly accepted and used here to denote treatment with anti-cancer drugs.

For some women, lumpectomy with beam radiation or iridium implantation is a viable option to modified radical mastectomy.

Side effects that may be caused by radiotherapy include change in skin colour, altered consistency or texture, change in size of the irradiated breast and possible diminished sensation or tingling, which may affect the patient or partner's ability to involve the breast in foreplay. Fatigue is a very common effect of radiotherapy which may also affect sexual functioning.

It has been estimated that one-third of all breast cancer patients today receive adjuvant chemotherapy in addition to breast surgery (Schain, in press). In fact as many as 90% of all breast cancer patients referred to the St. Boniface Hospital Oncology Clinic are placed

on National Surgical Adjuvant Breast and Bowel Protocols (NSABP), which are chemotherapy protocols and include Stage I and Stage II breast cancer (E. Bebchuk, personal communication, September 18, 1985). Some of the most common chemotherapeutic agents used in these protocols are tamoxifen, methotrexate, doxorubicin, cyclophosphamide, and fluorouracil.

Premenopausal breast cancer patients are at risk of permanent or temporary ovarian failure and reduced hormone levels from some chemotherapeutic agents. Hormonal replacement therapy for controlling premature menopause symptoms in these women is not recommended because of the associated risk of recurrence of breast cancer with this treatment (Dr. B. Weinerman, personal communication, June, 1985). "The effects of ovarian failure and reduced hormone levels on female sexual desire are controversial, but this change certainly may contribute to the decreased desire seen after chemotherapy . . ." (von Eschenbach & Schover, 1984a, p. 2664).

Women treated by androgen administration may experience virilization and increased libido and may be upset by the increased desire they experience (von Eschenbach & Schover, 1984a).

The side effects of various chemotherapy drugs differ from each other and individuals do not necessarily experience the same side effect from the same drug. However, the above-mentioned agents generally produce a variety of side effects namely, alopecia, loss of weight due to anorexia, nausea, vomiting, diarrhea, fatigue, cutaneous manifestations, such as hyperpigmentation, hyperkeratosis, ulceration, and radiation recall skin reactions. All of these may contribute to a decreased level of sexual excitement and desire. Other side effects such as dryness of vaginal mucosa due to decreased estrogen levels and inflammation and ulceration of the vaginal mucosa due to cellular destruction may result in sexual dysfunction.

In addition to the above iatrogenic consequences of chemotherapy, bone marrow depletion is also common, with resulting infections. "Leukopenia could restrict the individual's ability to participate in intercourse based on the risk of overwhelming infection" (Woods, 1984). Mouth pain associated with stomatitis may limit the individual's expression of affection and sexuality through kissing or oral sex. Anal intercourse is not recommended due to the risk of infection, tissue damage or bleeding due to low platelet counts.

Pain, either from the disease itself or from the effects of the treatments, can be a powerful deterrent to sexual activity. It seems reasonable that fear of pain in the patient or fear of inflicting pain by the partner, if not controlled with appropriate medications, could lead to a variety of sexual dysfunctions.

Other drugs in addition to those employed directly to control or cure the cancer are often prescribed to control symptoms and side effects of treatment. "Any drug that is generally debilitating or incapacitating or which specifically affects the neural, endocrine or vascular mechanisms concerned may contribute to sexual dysfunction" (Jehu, 1979, p. 28).

The side effects of drugs on the sexual functioning of women have not been methodically studied and little information exists. With this in mind, specific drugs that may be used to control symptoms and side effects in breast cancer patients and their probable effects on sexual functioning are listed below:

<u>Drug Category</u>	<u>Probable Effects</u>
Antihypertensives	Peripheral blockage of neural innervation of the sexual organs



Antidepressants	Central depression, peripheral blockage of nervous innervation of sex glands
Antihistamines	Blockage of parasympathetic nervous innervation of sex glands
Antispasmodics	Ganglionic blockade of nervous innervation of sex glands
Sedatives and Tranquilizers	Central sedation; blockage of autonomic innervation of sex gland; suppression of hypothalamic and pituitary function (may also be of benefit as produces tranquilization and relaxation)
Narcotics	Central depression; decreased libido (may also be of benefit due to pain control, relaxation and release of inhibitions)  (Woods, 1984, p. 450-451).

The causes of psychosexual distress and sexual dysfunction in the physically healthy population are

varied and complex (Hawton, 1985; Jehu, 1979; Kaplan, 1983; Kilmann & Mills, 1983). These are compounded in the breast cancer population. These women have been diagnosed with an extremely complex and not fully understood disease and are subjected to invasive treatments that while life-sustaining have enormous implications for their psychosocial health, including their sexual health.

The next section of the Literature Review will address assessment and intervention strategies for the sexual rehabilitation of the breast cancer patient.

## Sexual Rehabilitation of Breast Cancer Patients:

### Assessment and Intervention

Sexual rehabilitation reaches beyond restoring penis-in-vagina intercourse or the ability to reach orgasm. To achieve sexual rehabilitation we must address the entire spectrum of human sexuality, from recognizing the cancer patient as attractive and worthy of love in spite of the devastation of disease to supporting the spouse in taking the risk of being close in the face of the constant reminder that he or she may be left alive in a world made barren by death. (von Eschenbach & Schover, 1984b, p. 157)

Prognosis, treatment, age, marital status, or religious beliefs do not preclude sexual rehabilitation for any cancer patient. It must be based on the specific needs and desires of each individual.

I recognize that not every breast cancer patient has been or wants to be sexually active. Furthermore, not all patients want to have a partner, and not all partners are of the opposite sex. However, as the focus of this practicum will be interventions with breast cancer patients who have been sexually active in heterosexual relationships prior to diagnosis, the following discussion of assessment and intervention strategies is directed at this population.

Assessment is an ongoing process and is imperative to problem definition and specification of client goals and objectives. The possible influences of breast cancer and its treatment on sexual functioning are

endless. Cancer and sex are both extremely complex phenomena, and their complexity is compounded by their interaction.

Wasow (1982) suggested the following components of a sexual assessment in the rehabilitation of cancer patients: age, socio economic class, ethnic background, degree of religiosity, sexuality values, sexual development, preillness sexual practices and the sexual limitations of the specific illness and treatment. She also advocated including both the patient's and partner's present concerns, fears and expectations in the assessment.

In addition to information about premarital sexual activity, it is also important to ask about the satisfaction or responsiveness of sexual relations, both for the patient and the partner (Schain, 1982).

Darty and Potter (1984) discussed the fact that traditional sex role socialization may affect the woman's response to breast cancer. They stressed the importance of including an assessment of how much a woman's value system may follow the stereotype of believing "male approval is necessary to validate [her] existence and self-esteem" (p. 90).

As sharing intimate sexual information is difficult for many, and rarely initiated by patients,

both Schain (1982) and Wasow (1982) have suggested ways of gathering sexual assessment material.

Universalizing sexual concerns, creating an atmosphere of relaxation and trust and a constant flow of information back and forth between interviewer and interviewee all help in eliciting sensitive material. The assessment process is not stagnant, and intervention begins immediately. Establishing that sexual concerns are normal and that they can be discussed openly can then lead to specifying the particular problems of each individual case (Wasow, 1982).

It is important to ask specific, but open-ended questions in order to glean specific information. Schain (1982) suggested utilizing the medical model for sexual assessment, that is, asking about "onset, precipitating events, current efforts to improve the situation, and information dissemination about alternative behaviors . . ." (p. 284).

Wise (1981) divided the components of assessment of sexual concerns in cancer patients into four factors:

1. the stage of the disease and the concrete limitations of the illness,
2. the patient's past sexual history,
3. past and present psychological status,

4. the reaction of the sexual partner. (p. 64)

He included treatments and their side effects in his assessment of the physical limitations of the disease. Preillness psychiatric disorders and the presence of clinical depression or anxiety states are included in the assessment of psychological status.

The reaction of the sexual partner needs to be assessed both from the patient's perception of this reaction, and through interviewing the partner. The sexual significance of the breast to the woman and to her partner, and the relative importance of breast stimulation in the couple's sexual repertoire are important factors to be considered.

Walbroehl (1985) pointed out that a couple may be at risk for developing problems if the partner has a need for an attractive mate and the woman fails to meet that need, either through breast surgery, or loss of hair and other body changes from chemotherapy.

Assessment should also include an exploration of any myths or misunderstandings the couple may have about the disease itself. Some people fear that the illness is just punishment for past sexual "transgression" or "promiscuity". Discussion of these

myths will help to understand the dynamics involved in the sexual difficulties the couple may be experiencing.

Schain (1982) stated that the degree to which body image and sexual activity determine a patient's self-esteem and overall sense of adequacy and well-being is crucial to evaluating the extent to which sexual functioning will be affected by cancer.

She developed a model of conceptualizing self-esteem, using the metaphor of a commercial banking system. The four compartments of self-esteem she identified are:

1. the body-self - which has a functional (what I can do) and an aesthetic (what do I look like) part;
2. the interpersonal self - which is comprised of both social and acquaintance relations as well as intimate sexual interactions;
3. the achieving self - which contains elements of work or competitive efforts such as career or school behaviours;
4. the identification self - which is made up of those attitudes and behaviors that are related to spiritual, ethical or ethnic concerns. (p. 283)

Patients may need to "borrow" from one of the compartments at a time of crisis. Different compartments may have more "investments" than others and this would form part of the assessment. Part of the treatment intervention might include explaining

this "banking" model of ego-strength to the client and helping the client recognize accessibility to several areas of "potential revenue". "This economic paradigm permits analogies which view patients as capable of establishing assets, recording debits and negotiating for projects in their own psychological balance sheet" (Schain, 1982, p. 283).

Schain (in press) has also identified characteristics of patients at high risk of developing difficulties in sexual rehabilitation after breast cancer treatment. Included are those patients who are highly invested in or displeased with their breasts, particularly those who have had augmentations, have negative self-image or a negative view of their own femininity, have been sexually abused, lack an available support system, are uncomfortable disclosing feelings and sexual practices, are apprehensive about finding a new sexual partner, and/or experience serious physical difficulties associated with the disease or treatment.

I found only two studies in the literature which have described specific counseling strategies and attempted to evaluate the outcomes of these interventions in the sexual rehabilitation of breast cancer patients.



The first is described by Witkin (1978) who interviewed 41 women who had had a mastectomy and were attending an outpatient clinic for chemotherapy or checkups. The counseling involved one structured interview lasting 45 minutes to one hour. The author/interviewer explored the sexual history of the woman and her partner before and after mastectomy using a "specially constructed instrument" (p. 21), assessed subjectively the woman's psychological status, and provided counseling on specific topics that emerged during the interview.

She reported three areas where further counseling was conducted. The first, issues around sexual intercourse, such as when to resume, frequency, and/or positions. The second area was in concerns around the partner, such as fears of rejection or unattractiveness. In these two areas the therapist employed techniques of information-giving, reassurance, and universalization.

The third area was in what Witkin termed sexual dissatisfaction and involved women who had no partners or who had preexisting sexual problems with their regular partners. The therapist suggested masturbation, gave information on the benefits of

masturbation and alleviated guilty feelings about its use.

Witkin reported all 41 women without exception volunteered that they found the counseling interview positive and believed it would be helpful. Twenty-five percent of the women independently sought out Witkin at a later date to share positive results.

Although no definite conclusions can be drawn because of the exploratory design of the study, it is important as it appears to be the first study to attempt to evaluate the efficacy of counseling this population and because of the suggested 100% success rate.

Christensen (1983) developed and tested a structured treatment protocol for postmastectomy couples. Although his intervention was aimed at reducing the broader psychosocial discomfort following mastectomy, he included measurements of sexual satisfaction in addition to measurements of marital happiness, depression, self-esteem, helplessness, anxiety, alienation and emotional discomfort.

The subjects consisted of 20 mastectomy patients and their husbands with a mean age of 39 years, with nonmetastatic disease in remission, and who had had surgery within the previous two or three months. The

couples were obtained through referrals from health care staff. Each couple was randomly assigned to a control (no treatment) or experimental group and received a pretest and a posttest on the variety of measures mentioned above.

The treatment consisted of four structured conjoint sessions based on Witkin's work and traditional problem-solving. Christensen incorporated bibliotherapy by having the couple read Witkin's (1979) "Psychosexual Myths and Realities of Mastectomy". He also used an expressive technique involving the making of collage posters by both the men and women as a method of exploring self-image.

Results showed that both husbands and wives who received this treatment had statistically significantly higher mean scores on sexual satisfaction than did the control group. Reduction of depression in the woman, and reduced emotional discomfort in both patients and partners was also found.

This study is of particular importance as it was the first to involve both the mastectomy patient and her partner in a controlled study. Also, the treatment protocol is easily reproducible and took place in only four weeks.

The PLISSIT model (Annon, 1977) has been suggested by many in the literature as an appropriate theoretical framework for the sexual rehabilitation of cancer patients (Schain, in press; von Eschenbach & Schover, 1984a, 1984b; Woods, 1984).

Four levels of intervention are proposed for dealing with sexual problems: Permission (P), Limited Information (LI), Specific Suggestions (SS) and Intensive Therapy (IT). As not every breast cancer patient or partner experiences the same degree of difficulty in sexual rehabilitation, and as not every client or couple needs intensive intervention, PLISSIT is an attractive model. Each stage of intervention is progressively more complex and includes the preceding stage or stages. For example, if the social worker uses Specific Suggestions with a couple, Permission and Limited Information will also be included in the intervention strategies. If one stage of the intervention fails to resolve the concern or difficulty, the social worker would consider proceeding to the next level of intervention.

The following is a brief discussion of the four stages of the PLISSIT model, as applied to a breast cancer patient and her partner.

Permission (P).

At this level, all that may be necessary to restore or enhance the sexual functioning of the couple, is the permission to talk about the changes that have occurred, their feelings about the changes and their fears. To learn that their feelings and fears are normal and expected, and shared by others may be sufficient. Thoughts and dreams as well as feelings can be explored and "universalized", thereby reassuring the patient and partner.

Permission may involve acknowledging that sexual desire and behaviors do not have to stop because of the illness or treatment.

Although permission giving will not solve all sexual problems, it will resolve some and most importantly can be viewed as a preventative technique to deal with distress and concerns which might otherwise develop into major problems or dysfunctions.

Limited information (LI).

Limited Information involves providing the patient and partner with very specific factual information, in this case, directly related to the effects of breast cancer and its treatment on sexuality. This might include information such as the fact that a certain chemotherapeutic agent may cause vaginal dryness and

the recommendation to use a water-soluble lubricant such as KY jelly. The couple might be given material to read such as Witkin's (1979) "Psychosexual Myths and Realities of Mastectomy" or the chapter on sexuality in Dunlop's (1985) book "Understanding Cancer".

Discussion about their thoughts, feelings and experiences in relation to the readings would be facilitated at the next session, again using techniques of universalization to help the couple recognize that others in the same situation share their concerns. Misunderstandings and misinformation would be clarified.

At this stage, the intervention might include exploring with the couple some of the concerns that breast cancer patients commonly have to determine whether the individual or couple are experiencing a specific difficulty. Limited information would then be given related specifically to the particular concern of the client or couple. The side effects of the patient's particular treatment or combination of treatments and the implications for sexual activity would be explained. Information about breast prostheses and breast reconstruction might also be appropriate at this level.

Specific suggestions (SS).

At the previous two levels of intervention, no contract has been established between the client and social worker for the clients to take active steps to change their behavior.

The Specific Suggestions level of intervention involves giving specific suggestions within a framework of time-limited brief therapy in order to help the clients change their behavior and reach their stated goals. Recommendations are intended to "change or add new behaviors to the existing repertoire" (Schain, 1982, p. 289).

It is crucial at this level to have obtained all the pertinent background information about the presenting problem and to specify both the problem and outcome goals with the clients. Annon (1977) talked about the need at this level for a "sexual problem history" as opposed to a "sexual history". He distinguished between the two, suggesting the latter is relevant only to intensive therapy.

A sexual problem history will include eliciting from the clients a description of the current problem, its onset and course, their concept of cause and maintenance, past treatment attempts, and current expectations and goals of treatment.

The specific suggestions given at this level of intervention will be based on the assessment of the clients and their sexual problem history. Included might be suggestions about varying intercourse positions, other modes of sexual expression, taking pain medication one-half hour prior to sexual activity, relaxation techniques, and so forth. One suggestion that both Schain (1982) and Witkin (1982) recommended is that mastectomy patients and their partners not adopt the female superior position initially. It is the most strenuous for the woman, whose strength may be compromised up to six months post-surgery, and the male is visually confronted with the absent breast and surgical scar.

Specific suggestions about the inclusion of the partner in the sessions is also appropriate. "It is always risky in working with one person on a problem that involves two people in such an intimate situation, and the clinician should definitely attempt to see both people involved if at all possible" (Annon, 1977, p. 80).

There is some controversy in the literature about specific suggestions as to when to recommend resumption of intercourse after breast surgery. Witkin (1982) advocated recommending to the couple that they resume



intercourse as soon as the woman is physically able, even the day she is discharged from hospital. She contended that this reduces the opportunity for the woman to view herself as "impaired" and is reassurance that she continues to be sexually attractive to her partner.

Although this seems reasonable, I agree with Kolodny et al. (1979) who suggested that although physically able to resume sexual activity on discharge from hospital, each patient and where possible partner must be carefully assessed to determine their psychological readiness, rather than giving blanket instructions that may result in psychological distress for the couple. The coping abilities of the couple, their previous sexual life, and the strength of their relationship, among other variables, might all affect their readiness to resume intercourse immediately after breast surgery.

#### Intensive therapy (IT).

Cancer does not discriminate on the basis of income, age, or marital and sexual satisfaction. Any woman may develop breast cancer and require treatment.

Although the minority, there will be clients who have had chronic marital or relationship problems, or chronic sexual dysfunctions that are further

exacerbated by the diagnosis and treatment of breast cancer either in themselves or their partners.

For those clients who have not responded to the previous three levels of intervention, Intensive Therapy would be initiated at this stage.

This might include relationship or marital counseling, or intensive adjustment therapy for those clients who have been unable to come to terms with their own or their partner's diagnosis of cancer. Indepth individual and couple assessment, including a sexual history, is essential to developing an appropriate intervention strategy.

It is extremely important at all levels of the PLISSIT model, in particular this level, that physiological causes, including drugs, be explored as possible reasons or contributing factors to the dysfunction. If surgery or drug manipulations could alter the dysfunction, referral would be made to the appropriate medical professional.

It is not within the scope of this Literature Review to discuss all possible sexual dysfunctions, their causes and treatment. At this point, it is suffice to say that any breast cancer patient and/or partner could present with sexual dysfunction that existed prior to this life crisis. An indepth

assessment would be carried out and treatment would follow the behavioral approaches to sex therapy described by Jehu (1979) and Hawton (1985). The literature indicates good results with this type of focused behavioral sex therapy for psychologically caused erectile dysfunction, orgasmic difficulty, vaginismus, and lack of sexual desire or arousal (Hawton, 1985; Jehu, 1979; Kilmann & Mills, 1983; von Eschenbach & Schover, 1984a, 1984b).

### Conclusion

The literature reviewed in the previous chapters suggested that breast cancer patients and their partners were at risk for developing psychosexual distress and sexual dysfunction, and that services addressing their sexual concerns were not routinely provided by the health care system.

The following Practicum for the sexual rehabilitation of breast cancer patients and their partners was developed from the knowledge base presented in this Literature Review.

The Practicum

## The Practicum

### Setting

The setting of my practicum was the St. Boniface Hospital Oncology Unit, which is a joint program that combines the expertise and staff of the St. Boniface Hospital and the Manitoba Cancer Treatment and Research Foundation.

The unit is divided into three specialties-- Radiotherapy, Chemotherapy and Gynecological Oncology. Clients for this practicum were recruited from the Chemotherapy Clinic.

Staffed by four oncologists, six full and part-time nurses, and support services including home care, social work and pastoral care, the Clinic provides outpatient chemotherapy treatments and follow-up services. Each month, there are between 500 and 800 patient visits to the Clinic and between 30 and 50 new patients.

It had been estimated that just over half of the patients attending the Chemotherapy Clinic are breast cancer patients (E. Bebchuk, personal communication, September 18, 1985).

The staff of the Oncology Unit are dedicated not only to the physical care of the patient, but also to the psychosocial care of the patient and family.

### Rationale

The findings of the literature reviewed in the previous chapters suggested that breast cancer patients and their partners are at risk for developing psychosexual distress. The literature also indicated that health caregivers do not routinely inquire about the sexual issues of cancer patients. This was consistent with my experience in the Clinic.

As the social worker in this unit, I had been in the unique position of participating in the development of the psychosocial component of patient care over the past six years, and had seen the unit grow and become very responsive to the patients' and families' psychosocial needs.

At the time of my practicum proposal, however, sexuality had been identified as an area of neglect.

Physicians and nursing staff routinely inquired about patients' and families' emotional response to the disease and offered appropriate resources for those having difficulty coping. Clinic staff were comfortable talking about issues of fertility and generally their patients routinely received accurate and consistent information.

However, unless a patient requested information, or indicated a problem, issues around sexuality were

not routinely assessed, explored, or discussed by either the physicians or nurses.

Clinic staff cited several reasons for the lack of systematic assessment of sexual concerns. Some staff admitted that they did not feel comfortable initiating discussions around sex, and found themselves embarrassed, especially when the patient is of the opposite sex and/or much younger or older.

Some staff, recognizing they have only so much time and energy for each patient, believed that concerns around sexuality are much less of a priority to patients than other issues around the disease and treatment, both physical and psychosocial.

A fear that opening up the subject may "open a can of worms" was the most pervasive reason among staff for not broaching the subject. They were concerned because they felt inadequate in their own level of knowledge and skill, and because they felt there were no backup resources available in the Clinic to provide expert and quality sexual rehabilitation of cancer patients.

This practicum was a beginning attempt to fill this gap. By demonstrating knowledge and clinical skill in this area with a number of breast cancer patients, I hoped to lay the foundation for developing a comprehensive multidisciplinary sexual rehabilitation



program for all cancer patients of St. Boniface  
Hospital Oncology Unit.

### Client Recruitment

Clients were recruited from the breast cancer patient population who were attending the Chemotherapy Clinic. Selection criteria was initially established as follows:

1. Patient's breast surgery will have been completed not less than three months prior to recruitment.
2. Patients will have been sexually active in a heterosexual relationship prior to diagnosis.
3. Patients will be receiving any form of adjuvant chemotherapy.

I decided that clients should be approached at least three months after surgery because my experience has been that in the initial period of diagnosis, surgery and beginning chemotherapy, patients are overwhelmed and have difficulty assimilating all the information and experiences with which they are faced. I felt that it may take this period for the woman to deal with personal issues of mortality before allowing herself to look at how her disease and treatment are affecting her sexuality and interpersonal relationships. I also believed that the couples would need some time to experience a sexual difficulty before they would define it as problematic.

Conjoint counseling was offered, but did not preclude intervention with individuals who were not willing to involve their partner.

From the literature reviewed, I anticipated I would have some difficulty recruiting clients. Therefore, in addition to notifying and requesting referrals from all the oncology nurses and physicians, I also enlisted the support and cooperation of the Nurse Practitioner in the Clinic. She interviews most of the new breast cancer patients who are to be placed on chemotherapy protocols, and has regular follow-up with these patients. Part of her role is to provide patient education, and to explore issues with patients that might require referral to support services such as home care and social work.

Beginning at the end of October 1985, the Nurse Practitioner offered sexual rehabilitation services to all the breast cancer patients she saw who met the selection criteria. She made a statement, similar to the following, which we had agreed upon in advance:

We, at the Clinic, are aware that many breast cancer patients have concerns about their sex life and their sexuality. We are developing a sexual rehabilitation program at the Clinic to meet these needs, and wonder if you would like to talk to a counsellor who is specializing in this area.

It was hoped that this nonthreatening, nonproblem directed approach would result in six to ten referrals within four to six weeks.

By mid-January 1986 I had seen five clients who met the selection criteria and were willing to participate in my practicum. However, none saw themselves in need of sexual rehabilitation counseling.

As I had been unable to connect with the group of patients identified in the literature as having sexual difficulties, I tried other methods to recruit clients. I met again with the Nurse Practitioner to encourage her to be diligent in her recruitment of clients. I also asked her to keep track of those clients who were approached but declined to participate. I also spoke again to the medical and nursing staff in the Clinic, reminding them of my practicum and the availability of sexual rehabilitation services.

With the permission and approval of the Director of Oncology, I also wrote an open letter which explained the service and invited breast cancer patients to contact me directly (Appendix A). These letters were left on the coffee tables and end tables in the three oncology waiting rooms, and at the Chemotherapy Clinic reception desk from February 1986 to December 1986. Although over 150 letters eventually

disappeared over the months, I did not receive any calls from distribution of this letter.

In early February 1986 I contacted both the social worker and the head nurse at the Chemotherapy Clinic of the Manitoba Cancer Treatment and Research Foundation located on the Health Sciences Centre grounds and asked their assistance in recruiting clients who had identified a sexual concern.

I also sought clients through the Winnipeg Social Work Oncology Interest Group of which I am a member. This group consists of social workers from each of the Winnipeg hospitals that treat cancer patients. I had also informed the other social workers in the St. Boniface Hospital Department of Social Work who regularly saw breast cancer patients of the availability of sexual rehabilitation services.

I did not receive any referrals from the Manitoba Cancer Treatment and Research Foundation or from any other social workers either from St. Boniface Hospital or from any other hospital in Winnipeg.

By the end of May 1986 I had only seen six women and one couple. None had been seen for more than one session. After a five month maternity leave, still unable to connect with the clients identified in the literature in psychosexual distress, I decided to try

another alternative. With the permission and support of the attending oncologist, I spent one morning a week for three weeks in his clinic and personally approached every breast cancer patient who was attending that clinic, who was known to be in a heterosexual relationship, and who had had breast cancer surgery at least three months previously. I decided to drop the third selection criteria of "currently receiving adjuvant therapy" due to the difficulty I was experiencing recruiting clients. Although I did not connect with any clients who were dissatisfied with their current sexual functioning, in October and November 1986, I interviewed an additional seven women around their experience of breast cancer and sexuality.

In January 1987, I saw another woman who was referred by the Nurse Practitioner. Although she had not identified any sexual concerns, she had indicated she was willing to participate in the practicum. She was currently on chemotherapy treatments, but had had her mastectomy only six weeks prior to my session with her.

In summary, from October 1985 to January 1987, 15 breast cancer patients were seen, one together with her husband, but none for more than one session.

Although I had recognized that I would have difficulty recruiting clients, I did not anticipate that I would not be able to connect and work with anyone who had sexual concerns and wanted further intervention.

As described earlier in the Literature Review, there are many factors which might influence whether breast cancer patients will respond to an offer of sexual rehabilitation services.

Age was identified as a possible factor and as most breast cancer patients are over 50, this may mitigate against seeking sexual counseling.

Also to be considered is the fact that studies cited, both in general population and with breast cancer patients, were conducted primarily in the U.S.A. and to a lesser extent in England and Europe. Although purely speculative, I wonder whether there are any sociocultural variables that are peculiar to Canadians that may make them even less likely to seek sexual counseling or more hesitant to see themselves as sexually dissatisfied. There may even be regional differences between one part of the country and another or urban versus rural areas.

As the reader will see from my findings described in the following sections, the quality of the

relationship appears to be a strong determining factor in how sexual functioning is perceived. If the relationship appeared to be strong and stable, even in those situations where there were sexual concerns, the women were confident of rectifying the situation without outside help. If the relationship was viewed as poor, the breast cancer patient did not feel sexual rehabilitation counseling was a priority or worth the time, energy and commitment involved.

It is also worth noting that my selection criteria excluded separated, divorced, and single women without partners and I therefore cannot comment on whether breast cancer and sexual functioning influenced partnership breakdown.

The most common response of those breast cancer patients approached by the Nurse Practitioner or by me was that although they themselves did not have any sexual concerns, they were willing, in fact eager, to share their experiences as part of my practicum. The experience in the Clinic is that cancer patients are very willing to participate in any kind of study or research. They want to contribute to the knowledge and understanding of the disease and its physical and psychosocial affect on people, and they want to "give back" to others what they perceive as the care and



concern given to them. This is particularly true for cancer survivors who sometimes suffer survivor guilt and feel duty bound to cooperate in any way. Those patients who still view themselves in need of treatment from the Clinic because of on-going disease also tend to cooperate with studies so as not to "rock the boat" or offend the caregiver.

### Intervention

My intervention was based on the PLISSIT (Annon, 1977) model of sexual counseling as described in the preceding Literature Review.

The goal of sexual rehabilitation was the enhancement of, or the return to, the individual/ couples' preillness level of sexual functioning or level of functioning that was defined satisfactory for them. Sexual functioning was defined as "the ability of the individual to engage in and experience pleasure from sexual activities" (Woods, 1984, p. 342).

The intervention can be viewed as a two-stage model. The first stage was to have been those clients whose needs were met by giving them permission to discuss and explore their feelings and providing them with limited information, as described in the Permission and Limited Information states of the PLISSIT model. No behavioral changes were expected of the clients and therefore no contracting around setting specific behavioral outcome goals occurred between myself and the clients.

If at any time during or after this brief intervention, it became clear that the clients needed more intense therapy, or identified a specific concern or problem they were willing to work on in terms of

behavior change, I had planned to proceed with the Specific Suggestions and Intensive Therapy interventions of the PLISSIT model, that is, Stage II Intervention. A more intense and thorough assessment would take place including the use of pretreatment questionnaires and measurements, the involvement of the partner in the intervention would be more strongly encouraged, and if a particular sexual dysfunction was identified, I would have followed a cognitive and behavioral approach to sex therapy as described by Jehu (1979) and Hawton (1985).

Of 19 clients recruited, 15 were seen for one session only. Of these, two clients also received follow-up telephone contacts. None of the 15 clients proceeded to Stage II Intervention.

Four women, who had initially agreed to participate in the practicum were never actually interviewed by me. One moved out of province after her husband was suddenly transferred and said she was too busy selling her house and moving to come in and discuss her situation with me. Another told the Nurse Practitioner that she would prefer to call me herself directly, but I never heard from her.

It is of interest that the other two women who did not come in for an interview had both indicated to the

Nurse Practitioner that they had sexual concerns. One woman made two appointments with me, but did not show for either one. In discussing this with her in a follow-up telephone call, I suggested to her that perhaps she was not ready at this time to begin to explore this area. She agreed and I encouraged her to call in the future should she feel differently. I have not heard from her to date.

Similarly, the second woman, who had initially indicated that sexual functioning was a concern, was reluctant when contacted to make an appointment. After two telephone calls, I again decided to leave the decision of an appointment up to the client. I have had no further contact to date.

In the eight cases who were referred by the Nurse Practitioner, I began by telephoning them to arrange for an interview. I asked each of them to consider inviting their partners to attend the session with them, but explained that this was not a prerequisite to meeting. Only one woman came with her husband. The others primarily cited "time", "too busy", and because they had "no problem" as the reasons their spouses chose not to attend. I interviewed one woman, who had just undergone reconstructive surgery in hospital. The

others were seen by appointment in my office in the Oncology Unit.

The remaining seven clients were seen in the Chemotherapy Clinic at the time of their appointments. Of the three women who had their husbands with them in the waiting room, all chose to be seen on their own.

Each session began with an introduction of myself and a rationale for the practicum. I explained that I wanted to explore with them their experience of breast cancer and sexuality and that I was also available to assist them with any concerns or difficulties they might be having in this area.

Demographic data was gathered and I then began to examine the client's understanding of her disease, treatment and prognosis. As a way of establishing trust, I moved from less threatening to more threatening material. I generally followed the assessment form I had developed as a basic guideline, that is, the Initial Assessment Form, items 1 to 27 as found in Appendix B. In all cases, at least half of the session was spent on exploring how the cancer was detected, how decisions were made around surgery and treatment, feelings about the surgery and treatment particularly as they related to self-image and self-

esteem, and reactions of the partner and other family to the diagnosis, surgery, and treatment.

Specific questions around sexual functioning were generally not asked until I had dealt with more general psychosocial aspects of the disease and until I felt some rapport had been established. Preillness and current sexual activity and levels of satisfaction were explored. Myths and misconceptions were rectified as they arose in our discussion and I concentrated on normalizing and universalizing their experiences and feelings. Their perspective of how their breast cancer affected their self-image and sexuality was elicited, as well as their perceptions of how their partner's sexuality had been affected. In three cases, specific suggestions were given around particular issues that arose during the discussion. The issue of reconstructive surgery was explored with approximately half of the women.

At the end of the interview, each client was offered the opportunity for further sessions. When it was established there would be no follow-up sessions, I explained I would be mailing them a Client Feedback Form (Appendix C), with a self-addressed stamped envelope and asked that they complete it as soon as possible. Each also received my card with my name and

number should they wish to contact me in the future. All but one Client Feedback Forms were returned.

The women I interviewed ranged in age from 29 to 64, with a mean age of 55. At first glance, this seems consistent with the age distribution of breast cancer patients. However, as shown in Table 1, the 15 patients I saw tended to be younger than the general breast cancer population. This is consistent with the literature which suggested the younger patient is more likely to be concerned about their sexual functioning, or at least more likely to seek help. It might also be a function of my selection criteria which required the women to be sexually active in a heterosexual relationship. It may be that many of the older women were excluded from the practicum because they were widowed.

All the women were married, only one for the second time. The length of the relationships ranged from 7 to 45 years, with a mean of 20, and an average of 2.7 children. Nine of the women were off treatment at the time of my contact and six were currently on some form of chemotherapy. Two had had lumpectomies, one had had bilateral mastectomies, and the remainder had modified radical mastectomies. At the time of my contact, three of the women had active disease with

Table 1

Age Distribution of Breast Cancer Patients

	Practicum Group		Total Diagnosed in Manitoba - 1985	
Under 39	(4)	17%	(45)	7%
40 - 59	(7)	46%	(212)	34%
60 - 69	(4)	27%	(153)	24%
70 and over	<u>--</u>	<u>--</u>	<u>(217)</u>	<u>35%</u>
Total	15	100%	627	100%
	==	====	===	====



metastases, two were on treatment and presumed to be in remission and the remainder were known to be in remission.

The last client I saw, who had been referred by the Nurse Practitioner had had her surgery only six weeks prior to my contact with her. For the others, the range was from 7 months to 120 months, with a mean of 42 months.

Table 2 is a summary of the client's demographic data, including age, years in relationship, number of children, type of surgery, length of time since surgery and whether they were on treatment at the time of my contact and known to be in remission or not.

Eleven of the clients tended to fall into one of three categories:

1. those who had had no difficulty quickly returning to their previous satisfactory pattern of sexual functioning;
2. those who initially had some difficulties around their sexual functioning, but who had resolved these concerns to their satisfaction by working them out within the relationship with their partner;
3. those who were still experiencing some difficulties, but who were confident they could work

Table 2

Demographic Data

Age	Years in Relation- ship	Child- ren	On/Off Treatment	Type of Surgery*	Months Since Surgery	A = Active Disease or R = Remission
55	34	6	Off	M	13	R
36	15	2	On	L	20	N/A
42	26	2	On	M	10	R
64	45	6	Off	L	120	A
52	31	3	On	M	7	R
36	12	3	On	M	1 1/2	N/A
34	8	1	Off	M	24	R
53	20	3	On	M	84	A
43	22	2	On	M	12	A
61	17	1	Off	M	48	R
55	26	2	Off	M	120	R
62	25	0	Off	M	27	R
29	7	4	Off	DM	27	R
48	26	2	Off	M	60	R
63	44	4	Off	M	60	R

\* L - lumpectomy

M - mastectomy

DM - double mastectomy

them out directly with their partner, without outside help.

The remaining four clients each presented somewhat differently. Hannah, the most recently diagnosed client, denied any sexual concerns, but was distressed and focused on the life-threatening aspect of her illness and the effects on her young children.

Emma admitted to long-term relationship problems. Although the frequency of her sexual activity was reduced since her diagnosis, she was content with it within this relationship.

Kathy, the youngest woman in the sample, who had had bilateral mastectomies, reconstructive surgery to one breast, and an extremely difficult course of chemotherapy, stated emphatically that throughout all of this, sex was the one area of her life that was unaffected, although she did admit to feelings of jealousy.

One client, Heather, described a specific sexual difficulty that had occurred since her surgery and which she initially indicated she wanted to work on. She lived over five hours drive from Winnipeg, worked full-time and helped her husband with their farm. She told me in a follow-up telephone call that after she had spoken to her husband about how she felt, things

had improved. She had thought it over and decided she was comfortable with how things were at present. However, I believe she would have come in for further sessions if she had lived in the city and if the practical concerns of time, travel, finances and work were not issues.

The following are assessments and outcomes of each of the cases. I have grouped them according to the categories indicated above and I have included the completed Client Feedback Form at the end of each assessment.

Following the case descriptions, I will summarize common themes and elements that surfaced during our sessions.

Nicole, Janet, The Lands, Rita and Marilyn:  
Indicated No Sexual Difficulties

Nicole

Referred by: Nurse Practitioner

Month Seen: January, 1986

Description of client.

Nicole is a 55 year old woman who was diagnosed with breast cancer in September, 1984. She had a left modified radical mastectomy in November, 1984 and one month later, began a course of chemotherapy treatment. This chemotherapy protocol involved months of heavy chemotherapy drugs which resulted in hair loss, nausea, vomiting, and fatigue. It consisted of one treatment every three weeks for a period of three months, then a six month break, and then four months of further chemotherapy treatments.

Nicole is Roman Catholic and very involved in her church. She and her husband have been married 34 years. She has been working for the past six years as an aid at a local school. They have six children, four daughters and two sons, with the youngest being the only child left at home.

Situation as seen by client.

Nicole stated that she and her husband have a very good marriage and that they have had physically and emotionally satisfying sexual relations both prior to her surgery and after her surgery.

She and her husband commenced intercourse within the first two weeks of her discharge from hospital. Any problems in terms of her sexuality have been in the area of hot flushes and dryness in the vagina which she attributed to her early menopause which occurred over 10 years ago. She and her husband have used KY jelly to resolve this problem.

Nicole found the chemotherapy treatment extremely difficult and stated to me that she was not sure if she would take it again if needed. She particularly found the nausea/vomiting and fatigue difficult.

She denied any feelings of unattractiveness. She said that she felt she had a very positive approach because of her previous positive experience with friends and relatives who have had breast cancer.

Nicole also talked about reconstructive surgery. However, she was very cautious and stated that she wanted to know "all the facts" before proceeding.

Diagnostic impressions.

Nicole and her husband appeared to be a well-adjusted couple with a strong faith and good family supports. They have coped well with Nicole's surgery and this has not seemed to interfere with their sexual functioning.

According to Nicole, her husband is an extremely supportive man and the fact that he showed affection and caring for her following her surgery and during her very difficult chemotherapy treatments has meant a great deal to her.

Plan/recommendations.

No further intervention is indicated at this time. At present, Nicole and her husband have a positive outlook and are not unduly distressed about her missing breast or the possibility of recurrence.

Outcome.

Nicole was sent a Client Feedback Form which she completed and returned. She did not see herself in need of sexual rehabilitation counseling, although she was willing to share her experience of her breast cancer and sexuality with me.

On the Client Feedback Form, she indicated that she never initiated discussion of her sexual concerns, and no health caregiver had ever inquired about this area of her functioning. Although she said she found the social worker easy to talk to, she did not know whether sexual rehabilitation should be offered to all cancer patients.

Nicole stated that she heard about the sexual rehabilitation service from a doctor. I believe she



thought the Nurse Practitioner, who wears a white lab coat, was a doctor.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
other (please specify) N/A

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no

6. If yes, who did you talk to?

doctor nurse social worker/psychologist  
partner/spouse friend relative clergy  
other (please specify) N/A

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor nurse other staff nobody

8. If this service had not been provided, would you have asked for such help?

N/A  
definitely probably maybe probably definitely  
yes . not no

9. How helpful did you find the sessions?

N/A  
very helpful not a little not at all  
helpful sure helpful helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to?

very easy easy in-between hard very hard

11. Did you have enough sessions with the social worker?  
The number of session should have been:

much more more the same fewer much fewer  
N/A

12. Did the counselling you receive result in a change in your sexual activity? *N/A*

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session? *N/A*

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer? *N/A*

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No      *DONT Know*

16. Other comments or suggestions: \_\_\_\_\_

*Since I did not require counselling I have answered most questions with N/A as above.*

Janet

Referred by: Nurse Practitioner

Month Seen: December, 1985

Description of client.

Janet was diagnosed with breast cancer in March 1984, with Stage II disease. She had a lumpectomy followed by 25 sessions of radiotherapy and has been on the two year protocol of chemotherapy involving 5 FU and malfalan. She was due to finish her chemotherapy treatments in April of 1986.

I had one interview with Janet in December in my office. She presented as an attractive 36 year old woman who was articulate, able to express her feelings easily and readily, and good rapport was quickly established. She is a school teacher, has been married for 15 years and has two daughters aged 14 and 9.

Janet has an excellent understanding of her disease, treatment and prognosis.

Situation as seen by client.

Janet admitted that when she was first diagnosed, she and her husband were very distressed. They spent some time discussing the options of treatment and as breasts played an important part in their sexual repertoire and in Janet's feelings of self-esteem, they chose to have a lumpectomy. The decision was mutual

and both of their feelings were discussed. She stated that both she and her husband are very pleased with the results of the lumpectomy.

Janet related to me that her husband expressed much love and affection for her and that the crisis of her cancer has drawn them closer. She stated that there has been no change in their sexual relations since her diagnosis and that they resumed sexual intercourse on the day of discharge from hospital. She said that sexual activity was regular and satisfactory to both her and her husband. However, frequency was somewhat reduced which she attributed to her age and lifestyle, rather than to fatigue from her chemotherapy or from any connection with her cancer or surgery.

Janet did admit that the length of time that she has been on chemotherapy has been very draining and that she finds it difficult to cope with the fatigue. Although she denied this having any affect on her sexual relations or sexual feelings, she said that it interfered with other aspects of her life.

She stated that she feels as sexually attractive as she did prior to her surgery and attributed this to her decision to have a lumpectomy.

One concern that she did express was that she sometimes felt that her colleagues at work may not

realize that she is continuing on her chemotherapy. She feared that her colleagues may attribute her lack of participation in extracurricular activities to her being "lazy".

Diagnostic impressions.

Janet and her husband appeared to have a supportive, stable relationship. I believe it is particularly significant that they were able to discuss treatment alternatives, including surgical options prior to any procedures taking place. It is also significant that breasts played an important part in their sexual repertoire and that this was one of the main reasons that she and her husband, in consultation with the medical staff, decided on the lumpectomy.

Although there are times that Janet feels irritable and fatigued from her chemotherapy and resents the tie to the hospital, she appeared to be coping well under the circumstances, with the support of her friends and extended family as well as her husband.

Plan/recommendations.

As Janet had indicated there were times that she felt "down" during her chemotherapy treatments, particularly prior to her treatments, I offered to see her again around this difficulty. She agreed to call

me if needed. In terms of sexual rehabilitation, I believe there is no need for further intervention.

Outcome.

I had no further contact with Janet. She has returned the Client Feedback Form.

Janet indicated that no one had enquired about the sexual aspects of her life since her diagnosis and that she would not have requested sexual rehabilitation services. Although she might recommend sexual rehabilitation to a friend or relative with breast cancer, she indicated that she thought all breast cancer patients should be offered this service.



CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no



12. Did the counselling you receive result in a change in your sexual activity? N/A

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session? N/A

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes

Maybe

No

16. Other comments or suggestions: \_\_\_\_\_

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Mr. and Mrs. Land

Referred by: Nurse Practitioner

Month Seen: February, 1986

Description of client.

I had one interview with Mr. and Mrs. Land together. Although the Lands had told the Nurse Practitioner that they did not have a problem in the area of sexuality, they were willing to speak with me about their experience. The Lands have been married 26 years and have two children, a daughter age 16 and a son age 13.

Mrs. Land was diagnosed with breast cancer in March, 1985 and had a modified radical at that time. She then began chemotherapy treatments and is on a protocol of three months of heavy chemotherapy treatments, then a six month break, and is now nearing the finish of another four months of chemotherapy treatment. Specific side effects of treatment for Mrs. Land were hair loss including pubic hair, fatigue and hot flushes.

Situation as seen by clients.

Mr. Land readily admitted that he missed his wife's breast and stated, "I wouldn't be a man if I didn't miss it." However, he quickly added that this did not affect his sexual satisfaction. Both Mr. and

Mrs. Land stated that their sexual activity has continued with equal satisfaction to that prior to her illness and that they have not found the surgery nor the chemotherapy treatment to have interfered with this. They estimated that they participated in some form of sexual activity on a weekly basis but that they are physically affectionate with one another on a daily basis.

Both Mr. and Mrs. Land are of the Mennonite faith and said they found that their church and their faith have been extremely important in helping them through this crisis.

Diagnostic impressions.

Mr. and Mrs. Land appeared to be well-informed about Mrs. Land's diagnosis, her treatment and her prognosis. They presented an attitude of being "in this together" and the strength and warmth of their relationship was apparent during our session.

Mr. Land is 9 years older than his wife and they were married when she was 17 years old. Although they did not have the support of their family at the time of their marriage, they seem to have developed a mature and satisfying relationship which has earned them the respect and support of their family and church. This relationship includes a satisfying sexual component,

which continued for both of them after Mrs. Land's surgery.

Plan/recommendation.

As they appear to be coping well with their sexuality, and had identified no problem areas, no further intervention is indicated.

Outcome.

Although the Lands did not see themselves in need of sexual rehabilitation counseling, they were willing to share the experience of how breast cancer had affected them.

It was evident that although her diagnosis, surgery and treatment had made them fearful and caused them emotional pain, the strength of their relationship had helped them cope. Their sexual functioning had returned to a preillness level which was satisfying to them both.

Mr. and Mrs. Land both completed Client Feedback Forms and had identical responses to the questions. They said they found the session a little helpful, but that it would be most helpful if it was introduced immediately after diagnosis or within three months of surgery.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3  
months

3-6  
months

6-12  
months

12-24  
months

over 2  
years

2. How did you find out about the availability of sexual rehabilitation services?

doctor

nurse

social worker

partner/spouse

friend

other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes

no

4. If yes, who have you spoken to?

doctor

nurse

social worker/psychologist

partner/spouse

friend

relative

clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes

no

6. If yes, who did you talk to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy

other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor      nurse      other staff      nobody

8. If this service had not been provided, would you have asked for such help?

definitely      probably      maybe      probably      definitely  
yes                  not

9. How helpful did you find the sessions?

very      helpful      not      a little      not at all  
helpful      sure      helpful      helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to?

very easy      easy      in-between      hard      very hard

11. Did you have enough sessions with the social worker?  
The number of session should have been:

much more      more      the same      fewer      much fewer

ns  
ed



12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: Counselling

would be very helpful if started  
right after being diagnosed.

HUSBAND

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3  
months

3-6  
months

6-12  
months

12-24  
months

over 2  
years

2. How did you find out about the availability of sexual rehabilitation services?

doctor

nurse

social worker

partner/spouse

friend

other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes

no

4. If yes, who have you spoken to?

doctor

nurse

social worker/psychologist

partner/spouse

friend

relative

clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes

no

6. If yes, who did you talk to?

doctor nurse social worker/psychologist  
partner/spouse friend relative clergy  
other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor nurse other staff nobody

8. If this service had not been provided, would you have asked for such help?

definitely probably maybe probably not definitely  
yes no

9. How helpful did you find the sessions?

very helpful not sure a little helpful not at all helpful  
helpful helpful sure helpful helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to?

very easy easy in-between hard very hard

11. Did you have enough sessions with the social worker?  
The number of session should have been:

much more more the same fewer much fewer

12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: The Counselling  
would be more helpful if started  
within 3 months of being diagnosed.

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Rita

Referred by: directly contacted in Clinic

Month seen: October, 1986

Description of client.

Rita is a 64 year old woman who has been married for 45 years, has six children and nine grandchildren. She was diagnosed with breast cancer in 1976 and currently has metastatic disease in her spine. She had received radiotherapy for two weeks and chemotherapy for one year and although she did not have a mastectomy, she had a large lumpectomy of her left breast, which meant most of her left breast was missing. She had no hair loss nor fatigue from her treatments.

Situation as seen by client.

Rita described herself as a woman whose faith is extremely important to her. She has a fair understanding of her disease and treatment and despite her poor prognosis has a very positive attitude about her chances of survival.

Rita told me that she believed that an experience she had a few years back of a nun's "laying of the hands" answered her prayers for survival. She told me that she believed God is watching over her and is protecting her.

When I asked about her previous patterns and frequency of sexual activity prior to her cancer diagnosis, she told me that she and her husband had intercourse once or twice a week and that she was very satisfied with their sexual relationship. She said that she never had any reason to believe that her husband felt any differently about her after her illness. Since her diagnosis of cancer she stated that her current pattern of sexual activity continues to be intercourse once or twice a week, and that she is very satisfied with this.

In discussing her feelings and her perception of her husband's feelings, Rita stated to me "it never entered my mind that he would love me less or find me less attractive because of my illness or because of my surgery". In fact, she said that her sex life "may be even got better after my cancer" because she and her husband seemed to grow closer emotionally.

Diagnostic impressions.

Rita presented as a woman who is well supported by her family, her husband and her faith. She had a strong sense of self and self-esteem and did not appear to be experiencing any difficulties in relation to her sexuality. She believes in "God's will" and because

she believes she has had a loving and fruitful life, she views any more years as a "bonus".

Plan/recommendations.

I had only one session with Rita. It was evident that there were no problems in this situation and that her cancer has not interfered with her sexual activity. No further contact indicated.

Outcome.

Rita was sent a Client Feedback Form and when it was not returned about two months later I sent a letter and another questionnaire. Unfortunately, it also has not been returned to me.

Marilyn

Referred by: Nurse Practitioner

Month Seen: November, 1985

Description of client.

Marilyn is a 52 year old woman, married, with two daughters aged 25 and 24 and a son aged 21 still at home. She is a nurse and she and her husband have been together for 31 years.

Marilyn was diagnosed with breast cancer in April, 1985. She had a modified radical mastectomy and was placed on the tamoxifen trial.

She presented as an attractive woman looking younger than her stated age and was very articulate. Good rapport established.

Situation as seen by client.

Although Marilyn told the nurse that she had no problems in terms of her own feelings of sexuality or the sexual interaction between herself and her husband, she was willing to share her experience with me.

Marilyn was very well informed about her condition, treatment and prognosis.

She stated that both she and her husband had been satisfied with their previous patterns of sexual activity and continued to be satisfied with their current patterns of activity.



She stated that her husband was a "bum" man and breasts had not played an important part of their sexual repertoire, either prior to her surgery or postsurgery.

Marilyn reported that her husband in many ways, both through physical attention and through verbalization, made her feel that she was sexually attractive to him. She said there had been no change in their sexual repertoire or in the frequency of their sexual activity since her surgery. She did admit, however, that when she looked at her scar in the mirror, she sometimes felt unattractive.

Marilyn stated that she and her husband resumed sexual intercourse within one week of discharge from hospital, even though this was difficult due to pain in her arm and chest.

Diagnostic impressions.

Marilyn and her husband appeared to have adapted well to the crisis of the mastectomy and cancer. They seem to have a stable, very supportive and open relationship, and were able to resume their sexual activity within one week of discharge from hospital. This was obviously important to both of them as Marilyn stated "where there's a will, there's a way". The fact that there has been no change in their sexual

repertoire or in the frequency of their sexual activity indicated they have not allowed the mastectomy or the cancer to interfere with this part of their relationship.

Plan/recommendations.

No further contact is indicated with this client as both she and her husband appear to be coping very well.

Outcome.

Marilyn completed a Client Feedback Form. She indicated she would probably not have asked for help around sexual concerns and note that "everything depends on the attitudes of the different individuals".

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no



12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: Everything depends on the attitudes of the different individuals  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Marie, Sarah, Rebecca and Jackie:  
Had Sexual Difficulties but Resolved on Own

Marie

Referred by: Nurse Practitioner

Month seen: April, 1986

Description of client.

Marie is a 32 year old woman who was diagnosed with Stage I breast cancer two years ago and had a modified radical mastectomy. She received no further chemotherapy or radiotherapy at that time. She is married and has a six year old daughter.

Marie was approached by the Nurse Practitioner about participation in the practicum in regard to discussing her feelings and concerns around her sexuality. We agreed to meet when she was in hospital as she was due to have reconstructive surgery. I had one session with Marie on April 22, 1986 on the ward when she was recovering from her surgery.

She presented as a very attractive tall woman who spoke with a Swedish accent. Good rapport established. Appropriate affect.

Situation as seen by client.

Marie stated that basically her sex life with her husband had continued in a similar fashion as to that prior to her mastectomy. However, when questioning her further about this, it became evident that there had been some changes in their sexual life. She told me

that it took approximately a year before she was willing to remove her nightie during sexual activity. She said that she continued to feel unattractive and this was one of the reasons that she decided to have the reconstruction. She sees herself as a very private person who relies on her husband as her main source of support. She has not shown her scar to her daughter although her husband has seen it. She admitted that frequency of intercourse has been reduced since her mastectomy but she wondered whether this was not also related to their age and the length of time they have been married. She said she felt loved by her husband and believed that he finds her sexually attractive.

Marie is originally from Sweden and feels quite alone here.

Her diagnosis of cancer is still a very real concern to her. When she first heard she had cancer she thought she was definitely dying, as this was her only experience with cancer. She has begun to learn that cancer can mean survival. However, she is very frightened about the possibility of recurrence.

#### Diagnostic impressions.

Marie presented as an intelligent woman who is well supported by her husband. She has few close



friends and does not reveal her feelings easily to others.

She continues to struggle with the meaning her cancer has for her. The loss of her breast has been significant to her and has resulted in her own feelings of unattractiveness, both physically and sexually. She viewed the reconstructive surgery as very successful. She also made some adjustments in her values and feelings about what is important to her in life. She has used the cancer to allow herself to live more in the present and spend more time with her husband and child. She felt very positive about this.

Although Marie indicated there had been some difficulties and changes in their sexual functioning initially, these were sorted out through open communication within the marital relationship.

Plan/recommendations.

As Marie did not see any problem or need of social work intervention at this time, I had no further contact.

Outline.

I sent Marie a Client Feedback Form, which was completed and returned. Marie indicated that she had spoken with her partner/spouse about sexual concerns in

the past and that she was ambivalent about the usefulness of counseling.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

- At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

- How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
 friend      other (please specify) did not know

- Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      ~~no~~

- If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
 other (please specify) \_\_\_\_\_

- Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no

6. If yes, who did you talk to?

doctor nurse social worker/psychologist  
partner/spouse friend relative clergy  
other (please specify) does not apply

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor nurse other staff nobody

8. If this service had not been provided, would you have asked for such help?

definitely probably maybe probably definitely  
yes not no

9. How helpful did you find the sessions?

very helpful not a little not at all  
helpful sure helpful helpful

Please explain: It helps to talk about your  
problems but I am not sure it changes  
anything.

10. Did you find the social worker easy to talk to?

very easy easy in-between hard very hard

11. Did you have enough sessions with the social worker? The number of session should have been:

much more more the same fewer much fewer

12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much enjoyed

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much ups

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: \_\_\_\_\_

*This might be very helpful to some people but it is not for everyone  
I don't think it do anything for me*

Sarah

Referred by: . directly contacted in Clinic

Month seen: October, 1986

Description of client.

Sarah is a 53 year old woman who was diagnosed with breast cancer in 1980 and had a modified radical mastectomy of her left breast. She was diagnosed with recurrence of disease last month and is now on chemotherapy. Sarah has been married for over 20 years and has three grown children.

She presented as a very nervous woman with whom I had difficulty establishing rapport. I found that although she had agreed to speak with me about her experience, she was not open with her information or her feelings.

Situation as seen by client.

Sarah was well-informed about her disease, treatment and prognosis. She told me that in her opinion the "crux of the matter" in terms of sexual rehabilitation was the partner. She stated that having a loving partner made all the difference. She told me that her sexual activity is the same now as it had been before in spite of the fact that she looked quite ill and fatigued when I saw her. She did admit that for approximately one year she undressed with her back

turned from her husband, but that she is now comfortable being naked in front of him.

She believes that her illness has brought them closer together.

Diagnostic impressions.

Sarah presented as a woman who is very soft spoken and who seemed to find it difficult to express herself to me particularly her feelings around her illness and sexuality.

Her relationship with her husband was stable and secure and she viewed him as a tremendous support. However, she looked distressed and worried and I sensed she was preoccupied with her recurrence.

Plan/recommendation.

Sarah was not interested in any further social work intervention. I had offered services to her both in terms of my practicum, as well as in relation to her feelings about her illness.

Outcome.

I sent Sarah a Client Feedback Form which she returned to me. It is interesting to note that she said she found the sessions a little helpful, the social worker easy to talk to, and that she would recommend sexual rehabilitation counseling to friends or relatives diagnosed with breast cancer.

Therefore, it may be that my perception of the lack of rapport between us was not accurate. Sarah reiterated on her Client Feedback Form that "in regards to my own sexual concerns, my husband has been very loving and supportive and this in turn has eased my mind a great deal".



CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no

6. If yes, who did you talk to?

doctor nurse (social worker/psychologist)  
(partner/spouse) friend relative clergy

other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor nurse other staff (nobody)

8. If this service had not been provided, would you have asked for such help?

definitely probably maybe (probably not) definitely  
yes no

9. How helpful did you find the sessions?

very helpful helpful not sure (a little helpful) not at all helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to?

(very easy) easy in-between hard very hard

11. Did you have enough sessions with the social worker? The number of session should have been:

much more more (the same) fewer much fewer

12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: In regards to my

own sexual concerns, my husband has  
been very loving and supportive and this  
in turn has eased my mind a great deal.

Rebecca

Referred by: Nurse Practitioner

Month seen: November, 1986

Description of client.

I had one interview with Rebecca who presented as a slight woman of 61 years. She had been married for 17 years and had one 16 year old daughter. Rebecca described herself as a waitress.

She was diagnosed with breast cancer in April, 1982 and had a modified radical mastectomy at that time. There was no further treatment recommended as there was no nodal spread of the disease.

Situation as seen by client.

When asked about the specific side effects of her surgery, Rebecca stated that she had a stiff arm for almost two years postsurgery and that she felt it was now almost back to normal.

Rebecca described the reaction of her partner to her diagnosis and surgery as "supportive". She said that she and her husband did not discuss much about her cancer or her surgery but that she knew without words that he accepted her "just the way she was".

She found that it was initially difficult to have a "brush with death". However, she said she very quickly learned to see herself as being lucky and that

the experience had "awakened" something in herself. She said that she now enjoyed everything in life to a greater degree than she did before her cancer.

She also said that she felt if she had been younger it would have bothered her more that she had lost her breast. She said she did not want to look at the scar in the first few weeks, but that she felt comfortable with it now.

Rebecca related that in the first few months postsurgery, her husband was extremely nervous and not too affectionate. However, she attributed this to his worry that she was going to die. In time, and since she has had no recurrence, her husband has become affectionate again.

When asked about her previous pattern of sexuality she replied "quite often--three times a week". When I asked her how satisfied she had been with this level of activity she said that she sometimes would have preferred it to be less, mostly because she felt very tired at times. She would not elaborate on any other reasons.

She said that their current pattern of sexual activity is once or twice a week and occasionally three times a week and that she is satisfied with this level

of sexual activity. She believes that her husband is likewise content with this.

Diagnostic impressions.

Rebecca presented as a woman who was somewhat reticent to reveal her feelings. It would seem that neither she nor her husband are particularly verbal in their communication and do not express their feelings verbally to one another.

At the same time, Rebecca gave me a sense of being satisfied and at peace with herself and her marriage.

Plan/recommendations.

No further contact was indicated with this client as she and her husband appeared to be coping well, both with the diagnosis and the surgery. Their sexual practices have returned to their previous level. Rebecca is not unduly concerned about recurrence and sees the doctor for follow-up only.

Outcome.

Rebecca was given a Client Feedback Form which was returned completed. Although she indicated she believed sexual rehabilitation should be offered to all breast cancer patients, she noted she would probably not have asked for such help and would probably not recommend it to a friend or relative with breast cancer.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

- 0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

- doctor      nurse      social worker      partner/spouse
- friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

- yes      no

4. If yes, who have you spoken to?

- doctor      nurse      social worker/psychologist
- partner/spouse      friend      relative      clergy
- other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

- yes      no

6. If yes, who did you talk to?

doctor nurse social worker/psychologist

partner/spouse friend relative clergy

other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor nurse other staff nobody

8. If this service had not been provided, would you have asked for such help?

definitely yes probably maybe probably not definitely no

9. How helpful did you find the sessions?

very helpful not sure "N/A" a little helpful not at all helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to?

very easy easy in-between hard very hard

11. Did you have enough sessions with the social worker? The number of session should have been:

much more more the same "N/A" fewer much fewer



12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

"N/A"

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

"N/A"

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Jackie

Referred by: directly contacted in Clinic

Month seen: November, 1986

Description of client.

Jackie is a 62 year old slim, attractive woman who looked much younger than her stated age. She is married with no children. She had worked in the fashion industry for over 35 years until her diagnosis, at which time she retired.

Jackie was diagnosed with breast cancer in July, 1984 and had a modified radical mastectomy of her right breast. She received no chemotherapy treatments and has been followed approximately every three or four months in the Clinic. She had been offered to go on the tamoxifen study but rejected this as she felt she could not live with the idea of not knowing whether she was taking a placebo or the tamoxifen.

Situation as seen by client.

I explained the purpose of the practicum to Jackie and asked whether she would share her experience of how her breast cancer had affected her sexuality and her sexual relationship with her husband. I explained to her that I would also be available for further counseling in this area.

In discussing how she discovered her cancer, Jackie explained that although she had been looking for lumps, the doctor noticed that her nipple had flattened and this was the deciding factor in sending her for a mammogram. She described the three week wait for the results of this mammogram as one of the worst experiences of her life. At the same time, she said that she was not surprised to find that she did have cancer as she had two aunts who had died young of cancer and her mother had died of leukemia at age 53.

Jackie was well-informed about her condition.

She described her husband as extremely supportive and that his reaction to her illness was "remarkable". She said that it was her husband with whom she shared her feelings and with whom she spoke about her illness and her fears.

She stated that her previous pattern of sexual activity with her husband had been approximately once every two to three weeks, and that both she and her husband had been satisfied with the frequency and quality of their sexual activity.

Jackie related that it had been four or five months postsurgery before she and her husband resumed intercourse. Prior to this, they were affectionate physically with one another and she stated that she was

too tired, and recovering from her surgery to want intercourse prior to that time.

In terms of looking at the mastectomy site, Jackie said that it took her months before she looked at it, although her husband looked at it within the first few days. She said that she does not avoid looking at her scar now, but for the first year she felt "mutilated" and "cut up". She denied any of these feelings at present and said she now felt attractive both to herself and to her husband.

The greatest problem she identified at present was that she missed wearing light lacy bras and had to wear functional unattractive lingerie. Therefore, she does not wear her prosthesis frequently. She told me that in the "company of good friends" she would often simply wear a loose dress, and in summer, she would even wear her bathing suit without the prosthesis.

Specific suggestions.

We discussed the possibility of breast reconstruction. Jackie had wondered what was "wrong" that she did not seem to be pushing for it. She said that before she had had her mastectomy she would have thought anyone would have wanted a reconstruction. Now that she is faced with that decision herself, she finds it disturbing that she does not want to immediately

have one. We discussed this at some length and I helped to universalize her feelings by giving examples of other patients I knew who also did not want to have reconstructive surgery. Jackie's reasons were that she has now adjusted to the loss of her breast and no longer feels unattractive, that she does not feel it has affected her relationship with her husband or her sex life, and finally, that she does not want to go through another surgery. At present, Jackie told me that sexual intercourse has decreased in frequency because of constant pain in her shoulder. We discussed different positions and alternatives in terms of taking pain medication to make her more comfortable prior to sexual activity. She said that she had tried these alternatives but they were not satisfactory. She was at the Clinic to have the shoulder pain investigated further.

Diagnostic impressions.

It would seem that the first year postmastectomy was extremely difficult for Jackie. During that year, a friend of hers in Toronto also had a mastectomy, but died within the year. This affected her greatly and was naturally extremely distressing to her.

It would appear that their sexual activity has returned to previous levels of frequency and

satisfaction. Current difficulties appear to be related to an acute pain episode which is being investigated. Although during the first year Jackie had difficulty around self-image and self-concept, she denied any difficulties in these areas at present.

Plan/recommendations.

I offered further counseling to Jackie if and when needed, which she refused at this time.

Outcome.

I had no further contact with Jackie. She returned the Client Feedback Form, indicating that she did not see herself as a recipient of sexual rehabilitation, that she would not have requested such help and that it maybe appropriate to offer the service to all breast cancer patients.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
 friend      other (please specify) N/A  
DO NOT KNOW OF SERVICE

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
 partner/spouse      friend      relative      clergy  
 other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no

6. If yes, who did you talk to?

doctor      nurse      social worker/psychologist  
partner/spouse      friend      relative      clergy  
other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor      nurse      other staff      nobody

8. If this service had <sup>IT HAS NOT</sup> not been provided, would you have asked for such help?

definitely      probably      maybe      probably      definitely  
yes      -           not      no

9. How helpful did you find the sessions?

very      helpful      not      a little      not at all  
helpful           sure      helpful      helpful

Please explain: \_\_\_\_\_ N/A  
\_\_\_\_\_  
\_\_\_\_\_

10. Did you find the social worker easy to talk to? N/A

very easy      easy      in-between      hard      very hard

11. Did you have enough sessions with the social worker? The number of session should have been: N/A

much more      more      the same      fewer      much fewer



N/A

12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

N/A

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

N/A

N/A

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Mabel and Susan:  
Some Difficulty, but Currently  
Working it out with Partner

Mabel

Referred by: Nurse Practitioner

Month seen: January, 1986

Description of client.

Mabel is a 43 year old woman who is a teacher but had taken a leave from school due to her illness and subsequent cancer treatments. She was diagnosed with breast cancer, Stage II, in February, 1985 and had a modified radical mastectomy. She was on the B15 protocol which is four months of chemotherapy with a six month break, followed by another three months of chemotherapy. Her cancer recurred after the first six weeks of the first stage of this treatment, and she then received radiotherapy in addition. She is receiving her last chemotherapy treatment this month.

I had one interview with Mabel in January, 1986. She presented as a very articulate, bright woman. She has been married for 22 years and has two teenage sons.

Situation as seen by client.

Mabel had been feeling unwell for 2 1/2 years prior to her diagnosis. She said she finds this very distressing and wondered if she had had cancer all that time and whether an earlier diagnosis would have improved her prognosis.

She found the side effects of her chemotherapy treatment particularly distressing. She described a severe burn and swelling, and "three weeks of extreme depression" following the radiotherapy. She believed this depression to be a specific side effect of the radiotherapy rather than a reactive depression to her whole situation.

Her chemotherapy resulted in hair loss over her entire body in the first four months of treatment. Her mother-in-law cooked and cared for her for a period of four to five days after each treatment and she had a great deal of difficulty with vomiting--every 20 minutes, even with stemetil injections.

Mabel and her family are Baptist and she described her faith as very strong and very important to her and her family. She attributes her own and her family's ability to cope with this situation to their strong faith.

In terms of her husband's reaction to her cancer, her surgery and her chemotherapy, Mabel told me that at first he cried frequently and was very bitter and angry. Mabel related that by being open and talking things out, the family has developed the attitude that they will survive even if she died. She felt the whole experience had brought the family closer together.

In terms of their sexual relationship, Mabel felt that she and her husband were completely satisfied with their previous pattern of sexual activity and that it was "darn nigh perfect". In terms of their current patterns of sexual activity, she related that their frequency has been reduced and that for him, this has been a problem and has been a cause of some conflict over the months since her surgery. She also related that the dryness in her vagina from her hysterectomy and the chemotherapy was a problem, as was her fatigue and tiredness. She said that she interpreted her husband's sexual overtures as lack of concern for her feelings. However, she stated that they talked these conflicts out openly and have, over the months, come to terms with this and arrived at a new equilibrium that is satisfactory to them both. There is much cuddling and physical affection in their relationship and this has not changed as a result of her surgery or treatment.

She said that her husband has always said that one or two breasts has made no difference to him and that he finds her "just as sexy". However, she did admit that it took several months before she allowed him to touch the other breast and that she still continues to make love with her nightie on. She said she felt like

"an ugly duckling" with no hair, the missing breast, and weight gain and it made her feel more comfortable to leave her nightie on.

Mabel said that she has always been "well-endowed", had what she considered to be a good figure, and had prided herself in this.

Mabel anticipated being able to make love without a nightie on at some point in the future, but that this would take time just as it did in allowing her husband to touch her intact breast.

In terms of reconstructive surgery, Mabel stated that she has had six surgeries in six years and has no desire to go through another. Furthermore, her missing breast seemed irrelevant to her because she believed she was fighting for her life, especially since the cancer had recurred so quickly.

#### Diagnostic impressions.

Mabel presented as a woman who was working hard and successfully at coming to terms with her feelings around her cancer and her chemotherapy treatments. She recognized her prognosis was compromised due to her recurrence and was attempting to remain positive, but realistic. She and her husband appeared to have the necessary problem-solving and communication skills to resolve the difficulties they have encountered.

The fact that Mabel had taken pride in her figure and her breasts prior to surgery likely contributed to her feelings of poor body image. However, with the support of her husband, I am confident this will gradually improve.

There is no question that this family's faith and spirituality assisted them and that they have used this coping mechanism appropriately in dealing with this crisis.

Plan/recommendations.

Mabel did not see herself in need of any further counseling. I reinforced her feelings of being able to sort out her difficulties on her own, and also indicated she could contact me in the future if she wanted to explore any issue with me further.

Outcome.

Mabel had complained of vaginal dryness postchemotherapy and when I suggested the use of KY jelly, she told me the nurse had already mentioned this to her. She had found this extremely helpful information and stated she would never have known about this had the nurse not given her this information.

I had no further sessions with Mabel. She returned the completed Client Feedback Form, reiterating that the specific suggestion of KY jelly

was very helpful, that she believed all breast cancer patients should be offered sexual rehabilitation counseling, and that she would definitely recommend it to a friend or relative. Unfortunately, the middle page of the Client Feedback Form is missing.



CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse

friend      other (please specify) yourself - Jill - Elaine  
asked whether I wanted to participate in the study

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist

partner/spouse      friend      relative      clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no

12. Did the counselling you receive result in a change in your sexual activity? *Wasn't any real counselling. Elaine just suggested the use of gel. which was helpful*

much more enjoyable    more enjoyable    same    less enjoyable    much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset    less upset    about the same    more upset    much more upset

*doesn't apply*

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes    probably    maybe    probably not    never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes    Maybe    No

16. Other comments or suggestions: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Susan

Referred by: contacted directly in Clinic

Month seen: October, 1986

Description of client.

I had one interview with Susan in the Clinic in October, 1986. She is a 55 year old woman who has been married for 26 years and has two sons, age 28 and 26. She does not work out of the home but has done community volunteer work for several years.

She was diagnosed with cancer of the left breast in 1976 and had a modified radical mastectomy and approximately one year of chemotherapy at that time. In the midst of her chemotherapy treatments, she had a number of complications including hemorrhaging which resulted in a hysterectomy and then a bladder repair posthysterectomy. She describes this period as "the most terrible time of her life". She had no hair loss from her chemotherapy but was extremely nauseated and developed anticipatory nausea.

She did not complete her chemotherapy due to a "misunderstanding". After her recovery from her hysterectomy and bladder repair, she did not return to the Clinic to complete her chemotherapy treatment because "she didn't know she was supposed to". She now sees the oncologist every six months and because of the

mix up with her treatment, she has been very concerned that her cancer may return. However, now that she is ten years postsurgery, she is less concerned about a recurrence.

Situation as seen by client.

When talking about her previous sexual activity, Susan stated that she and her husband had had intercourse approximately twice a week prior to her surgery, and that this frequency had remained constant since her surgery. She described herself as satisfied with her current and her previous sexual activity and stated that she believed her husband felt the same way. She described him as extremely supportive.

It was interesting that she did not speak openly with her children about her cancer during the time that she was going through her treatment. It has only been more recently since they have been viewed by her as "adults" that she has been able to share her feelings with them about her cancer and vice versa.

Susan stated that she could not undress in front of her husband for over a year, although this is no longer a problem. She said that they had had intercourse within a week of returning home from hospital. However, for the first year, she left her nightie on during sexual activity.

Susan did admit to me that her husband never touched with his hands her intact breast, although he does kiss it. She became quite tearful when discussing this with me and described how once her husband had touched her in the kitchen and she had said in a joking manner, "wrong one". Apparently he has not touched her breast since and she has never talked to him about this.

Specific suggestion.

We discussed "misunderstandings", for example, he may believe she does not want him to touch her breast and therefore this may be why he is not touching it. Susan and I discussed a number of alternatives for her to deal with this situation. She thought that she would either talk to him directly about this or when the next opportunity arose she would very gently place his hand on her breast indicating to him nonverbally that this was okay with her. We discussed this issue at some length and she said she would follow through on this.

Diagnostic impressions.

Susan, who is ten years postmastectomy, appeared to have coped well with her cancer and her treatment, although it was clear that her feelings about her mastectomy were just below the surface and could easily

be brought forward. I felt that Susan might benefit from further discussions with me, but she stated that she would like to try out the suggestions with her husband and would call me if she has any further difficulties.

Plan/recommendations.

Although Susan initially stated that there were no difficulties at all in her sexual relationship with her husband, during the course of our discussion she did indicate an area of concern as mentioned above. We discussed this at some length and specific suggestions were made to Susan, as well as an offer for further counseling either on her own or conjointly with her husband. However, she rejected this and said she felt she and her husband would be able to work it out on their own.

Outcome.

I have had no further contact. Susan returned the Client Feedback Form, but unfortunately did not answer all the questions.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3  
months

3-6  
months

6-12  
months

12-24  
months

over 2  
years

2. How did you find out about the availability of sexual rehabilitation services?

doctor

nurse

social worker

partner/spouse

friend

other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes

no

4. If yes, who have you spoken to?

doctor

nurse

social worker/psychologist

partner/spouse

friend

relative

clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes

no





12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable	more enjoyable	about the same	less enjoyable	much less enjoyable
------------------------	-------------------	-------------------	-------------------	------------------------

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset	less upset	about the same	more upset	much more upset
--------------------	------------	-------------------	------------	--------------------

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes	probably	maybe	probably not	never
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15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes	Maybe	No
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16. Other comments or suggestions: \_\_\_\_\_

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Hannah:

No Sexual Difficulties, But  
Concerned Re: Diagnosis and Prognosis

Hannah

Referred by: Nurse Practitioner

Month seen: January, 1987

Description of client.

Hannah is a 36 year old woman who lives in Winnipeg with her husband and their three children aged ten, seven and two. She is a health care professional and had been working full-time prior to her diagnosis of Stage II breast cancer in November, 1986. She is currently receiving chemotherapy, a combination of cisplatinum, cyclophosphomide and 5 FU. She had a modified radical mastectomy in December, 1986, began treatment two weeks postsurgery, and when I interviewed her was halfway through her six month treatment protocol.

Situation as seen by client.

Hannah was very well-informed about her treatment and diagnosis. She was well aware of what a Stage II diagnosis meant, that is, that her prognosis was not as good and found herself, understandably, frequently ruminating on this thought.

Hannah found the side effects of the chemotherapy to be less severe than she had expected. She had some nausea and vomiting, although these were well

controlled by a new protocol of sedatives and antinausea drugs.

Hannah decided not to work during the period of her chemotherapy and stated that she viewed this time off much as she viewed her maternity leaves. In many ways she has found her life easier, that is, to be off work with cancer and having chemotherapy, than she did being a full-time health care professional and full-time homemaker with three children! She described her husband as very supportive and sharing in child care and home duties.

In terms of her sexuality, she denied any feelings of loss of attractiveness to her husband either due to her lack of hair, her lack of breast, or generally feeling unwell. She stated that their regular sexual activity was intercourse approximately once a week, and that this pattern has continued since her surgery. She said that she and her husband had intercourse within the first week of her return home from hospital, and that she is satisfied with the quality and frequency of her sexual activity.

Although Hannah denied that she had any sexual concerns, she did admit that she would not let her husband touch her intact breast. She said it was not that the touching of the breast reminded her of the

absence of her other one, but that she was very angry at her breast to the extent that she wished she had never had breasts. She was feeling it was unfair that she had these relatively useless body parts where cancer could implant itself and possibly cause her demise. She said if she had not had Stage II cancer, she would have requested prophylactic removal of her other breast.

When asked about her husband's response to this, she stated that he was understanding and cooperative but thinks she is a bit "nutty" to have these feelings. She felt that the lack of touching of that breast does not interfere with his or her enjoyment of their sexual intimacy. She stated that breasts had not been a major part of their sexual repertoire prior to illness.

Diagnostic impressions.

Hannah at present is struggling very much with issues around survival. Although she did not see herself dying imminently, she saw her life span drastically reduced.

Hannah denied that her breasts were in any way sexual to her or a means of sexual satisfaction for her. She presented this in a very believable, matter of fact way and I sensed that her fears and concerns around the disease itself and its prognosis far

outweighed at this point any concerns around body image and sexuality. She and her husband appeared to have a solid stable marriage, with an atmosphere of open communication between themselves and their children.

Plan/recommendations.

Sexual rehabilitation was not indicated for Hannah and her husband. However, through the course of our discussion it became evident that she could benefit from some further intervention around her illness, mortality, and the effects of her illness on her children. As she had previously been seen by another worker in our department, and as my contract with her was to discuss her sexuality and her illness, I encouraged her to contact the other worker for follow-up.

Outcome.

Hannah was sent and returned a completed Client Feedback Form. Her comments on the form concurred with my assessment in that she wrote that sexual rehabilitation was not a concern for her although she had other worries.

Hannah continues to be seen by another worker on an "as needed" basis.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3  
months

3-6  
months

6-12  
months

12-24  
months

over 2  
years

2. How did you find out about the availability of sexual rehabilitation services?

doctor

nurse

social worker

partner/spouse

friend

other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes

no

4. If yes, who have you spoken to?

doctor

nurse

social worker/psychologist

partner/spouse

friend

relative

clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes

no





12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: I do not view my

cancer as causing sexual problems. If this study finds there is a problem, it is helpful to discuss it.

I found the social worker very helpful in discussing my concerns for my children and supports available.

Kathy:

No Sexual Difficulties -  
Issues Around Self-Image

Kathy

Referred by: contacted directly in Clinic

Month seen: November, 1986

Description of client.

Kathy is a 29 year old, somewhat obese, woman. She presented as a talkative, young woman who expressed herself easily and openly. She has been married for seven years. This is her second marriage. They have four children, ages 12, 10, 8 and 5. All but the youngest child are from her first marriage. Kathy described herself as a homemaker.

She was diagnosed with breast cancer in her right breast and had a modified radical mastectomy in 1983. She had reconstructive surgery in March, 1984 and had many medical complications postsurgery. In June, 1984, she was found to have breast cancer in her left breast and had a left modified radical mastectomy. At the time of my contact, she said she was scheduled for an implant of her left breast.

She had no radiotherapy, but had chemotherapy from July, 1984 to December, 1984. She was very nauseated, lost her hair, lost weight and was very fatigued while on chemotherapy. She developed anticipatory nausea and vomiting at the thought of chemotherapy. She is currently in remission.

Situation as seen by client.

Kathy told me that both she and her husband looked at the scar immediately after both mastectomies. They resumed sexual intercourse the first week home from hospital. She stated that previously their pattern of sexual activity has been intercourse three to four times per week. She said that this level of sexual activity continued postsurgery. The only time their sexual activity was curtailed was during her chemotherapy treatments when she was so ill from the side effects. However, her husband continued to be very physically affectionate with her during this time which she found helpful.

Kathy stated emphatically that both she and her husband are very satisfied with their sex life. She said that it was one area in their relationship in which they have never had any problems. Kathy attributed this to the fact that they communicate openly about their sexual needs and desires.

When I asked how she accounted for her very enjoyable sex life despite the loss of both breasts and the trauma she had been through as such a young woman, she told me she thought it was because she never really liked her breasts. Breast fondling had never appealed

to her, she said her breasts were "no loss for her", and that they "never turned her on".

The only concern that Kathy could identify at present was a feeling of jealousy when she saw women who, in her opinion, "flashed" their bodies at her husband. If she perceived her husband looking at other women, she found herself very jealous. Kathy was quick to admit that she had always been a very jealous woman, and had felt this way prior to her mastectomies. She did admit that these feelings were amplified since her illness.

In summary, Kathy remarked that the only way she could see that sexual activity would be a problem would be "if you made it a problem". She believes that it is important to have a satisfying sexual relationship in a marriage. According to Kathy, even when she and her husband are angry with each other, they have always had the time and energy for sexual activity which in her opinion helped to sustain their relationship.

Diagnostic impressions.

It would appear that a sexual life is extremely important to this couple, and that they have not allowed the disfiguring surgery to interfere with their sexual relationship.

I had a sense that it was somehow important to Kathy to convince me that she had a wonderful relationship with her husband and had had no difficulty coping with her cancer and mastectomies. However, with some gentle exploration, it was evident that there was some unhappiness lying just below the surface in her. Kathy presented as very well-defended and for whatever reason seemed to need her defences at present.

Plan/recommendations.

Kathy asked me to send a Client Feedback Form to her husband as well as herself. She said she was planning to ask him directly whether he thought her surgeries had changed their sexual functioning and whether he was satisfied with their current patterns. I encouraged her to do this and sent them two Client Feedback Forms.

Outcome.

I received only one Client Feedback Form which appeared to have been completed jointly. Kathy's husband had written a note on it and asked me to call him at work. When I called, he told me that although their sexual relationship in his opinion was fine and satisfying to both of them, he found he has not been able to communicate with Kathy as well as before. He described her as "down on herself", and she has

confessed to him that she does not feel "a full woman" since losing both her breasts.

He told me that he has tried to reassure her by expressing how important she is to him and how "womanly".

When I offered to discuss these issues with them further, he said he would talk to Kathy and get back to me. However, they did not contact me further.

It would likely be helpful to see this couple together to further assess this situation. However, this does not appear to be a priority for them. They seem to be coping and I would think only a crisis would lead to further counseling. Kathy and her husband both work out of the home, they have four children to care for and they live some distance outside Winnipeg. Kathy's husband mentioned that these practical factors would make it difficult for them to follow through on the offer of counseling.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

- 1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months      3-6 months      6-12 months      12-24 months      over 2 years

- 2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse      social worker      partner/spouse  
 friend      other (please specify) didn't have any.

- 3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes      no

- 4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
 partner/spouse      friend      relative      clergy  
 other (please specify) \_\_\_\_\_

- 5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes      no



6. If yes, who did you talk to?

doctor      nurse      social worker/psychologist

partner/spouse      friend      relative      clergy

other (please specify) \_\_\_\_\_

7. Other than learning about this sexual rehabilitation program, since you or your partner have had cancer, has anyone asked you about your sexual concerns?

doctor      nurse      other staff

nobody

8. If this service had not been provided, would you have asked for such help?

definitely      probably      maybe      probably  
yes                  .                  not

definitely  
no

9. How helpful did you find the sessions?

very                  helpful                  not                  a little                  not at all  
helpful                  .                  sure                  helpful                  helpful

Please explain: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

N/A

10. Did you find the social worker easy to talk to?

very easy      easy      in-between N/A      ~~hard~~      very hard

11. Did you have enough sessions with the social worker? The number of session should have been:

much more      more      the same      fewer      much fewer

12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

N/A

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

N/A

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

N/A

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions:

CALL ME AT WORK. I CAN ANSWER SOME QUESTIONS.

NOBODY HAD TIME FOR ME TO TALK ABOUT ANYTHING EXCEPT WHAT MY WIFE WAS GOING THROUGH.

WIZ AS A PARTNER TO THIS MATTER SHOULD BE ABLE TO GET INVOLVED WITH EVERY DETAIL THAT SURROUNDS CANCER BETWEEN MEN & WOMEN.

NOBODY TOLD ME ABOUT SEXUAL COUNSELLING.

L.L.  
MIE IS MORE IT IS HARD TO WAD IN WRITING. WNT SIT & TALK WEL WITH HE GETS A LITTLE T, AS SHE CALLS HERSELF A FULL WOMAN SINCE BREAST HAVE BEEN TAKEN OFF

Emma:

Long-term Relationship Problem

Emma

Referred by: contacted directly in Clinic

Month seen: October, 1986

Description of client.

Emma is a 63 year old woman who has been married for over 40 years and has four children, all married and away from home. She works part-time doing laundry and lives on a farm with her husband.

She was diagnosed with breast cancer in 1982 and had a modified radical mastectomy of the left breast at that time. She received radiotherapy for several weeks and this was followed by one year of chemotherapy every two weeks. She lost her hair and was bedridden for two days following every bi-weekly treatment. Emma was in the Clinic the day I spoke to her for suspected recurrence of her cancer.

History.

I had known Emma and her husband from a previous contact in May 1983 around the time of her first diagnosis. There had been severe relationship difficulties with her husband at that time. Due to the distance of their home from the Clinic, I had arranged for them to be seen by a worker in their district. However, they did not follow through on counseling either as a couple or as individuals.

According to Emma, in 1985 the family doctor spoke directly to her husband and insisted that he stop drinking. He did not follow through and in fact became very depressed. It sounds like he suffered a clinical depression and was hospitalized in a rural mental health hospital. Emma described her husband as having a "nervous breakdown". She said that since that time, their relationship has improved. He helps her more with the house and is not drinking.

Situation as seen by client.

Emma told me that prior to her illness, sexual intercourse took place approximately once or twice a month. She found that she enjoyed sexual activity with her husband much more when she was younger and when he was not drinking. She had not enjoyed sexual activity for some time prior to her illness. She said she could not stand the smell of his drinking and that he was rough with her.

She told me that their current pattern of sexual activity is sexual intercourse about once every three months. She said this is because she feels tired all the time. They no longer share a bedroom and have not since she was first diagnosed and he was drinking.

Emma stated that she is much happier now that

their sexual activity has been reduced. She said she does not miss it.

When I asked her about her mastectomy scar, she told me that she never hid it from her husband, but that he did not want to see it. She told me it took six months or more for him to look at it.

She stated that it really "bothered" him that she had cancer, and that he was initially unable to talk about it. She believes his increased drinking was due to his worry about her illness.

#### Diagnostic impressions.

Emma's marital relationship has never been very satisfying to her and has been fraught with communication problems, financial problems and alcoholism. It appears that her husband has difficulty coping with stress.

Although her sexual functioning has change since her surgery, she is not unhappy that the frequency has been reduced. There appears to be little affection in this relationship and the lack of enjoyment in the sexual relationship appears to be a reflection of their whole relationship.

#### Plan/recommendations.

As Emma may have a recurrence of her cancer, I plan to monitor this situation. Given her husband's

previous difficulties in coping with her first diagnosis, problems may again arise if her disease is progressing.

There is no indication for sexual rehabilitation counseling as Emma is satisfied with their current level of activity. The couple has not followed through on previous attempts at relationship counseling and Emma is not interested in pursuing this.

Outcome.

Emma returned a completed Client Feedback Form and indicated that not only did she find the one session helpful, but that she would have wanted more.

Emma was diagnosed with recurrence of her cancer and began a course of radiotherapy treatments. I saw her for short-term supportive counseling during the two weeks she was in Winnipeg for her treatment. At that time, her husband was coping and remained sober. I have had no further contact.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3 months     
  3-6 months     
  6-12 months     
  12-24 months     
  over 2 years

2. How did you find out about the availability of sexual rehabilitation services?

doctor      nurse       social worker      partner/spouse  
 friend      other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes       no

4. If yes, who have you spoken to?

doctor      nurse      social worker/psychologist  
 partner/spouse      friend      relative      clergy  
 other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes       no





12. Did the counselling you receive result in a change in your sexual activity?

much more  
enjoyable

more  
enjoyable

about the  
same

less  
enjoyable

much less  
enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less  
upset

less upset

about  
the same

more upset

much more  
upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely  
yes

probably

maybe

probably  
not

never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes

Maybe

No

16. Other comments or suggestions: \_\_\_\_\_

---



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Heather:

Sexual Difficulty Identified

Heather

Referred by: Nurse Practitioner

Month seen: March, 1986

Description of client.

Heather is a 48 year old woman who lives five hours drive from Winnipeg. She works full-time in a government office and she and her husband also run a cattle farm. They have two grown children and three grandchildren. Heather had a mastectomy in 1982 and subsequently received two years of chemotherapy. In the spring of 1985 she found another lump in her breast which was biopsied and found to be benign. She was considering reconstructive surgery at the time of my contact with her.

Heather had indicated to the Nurse Practitioner that although she did not have any problems sexually she would be interested in talking to me.

Situation as seen by client.

Heather is very well-informed about her condition, her treatment and her prognosis. She said that she had found the chemotherapy treatments extremely difficult and had lost her hair four times. She described the first day she lost her hair as the worst day of her life. Her treatments were very heavy and she found

herself very fatigued and ill during the period of her chemotherapy, particularly the first six months.

Heather stated that she and her husband had an extremely satisfactory sex life, prior to her mastectomy and had had intercourse about once a week. However, in her opinion, the quality and frequency of their sexual relations has deteriorated since her diagnosis.

She explained that approximately six months after her surgery, while she was still on chemotherapy, there were a couple of incidents where her husband was unable to maintain an erection. This was extremely difficult for him and he and Heather have not talked about it at any length. Occasionally they have joked about it, or teased one another about it. However, since then, rather than weekly intercourse, they have intercourse approximately once a month and Heather described it as a very hurried affair "as if he wanted to finish quickly to reassure himself that he can do it". She said that it left her feeling less sexually attractive to her husband.

Heather had attempted to talk with her husband a few times about this, particularly when she told him she was coming to see me. He was apparently unwilling to discuss their current sex life in any detail.

However, he did say that he mostly remembered her being too ill to have any sexual relations during the time that she was on chemotherapy. She also said that she thought she and her husband did not have enough knowledge and information about sex.

Diagnostic impressions.

Heather was very tearful during our discussion. She was obviously distressed about the deterioration in her sexual life and was unsure how to proceed to improve it. Heather seemed to need information about erectile difficulties and what was "normal" for a man of 50. She had the insight to recognize that the subsequent successful but "hurried" episodes of intercourse and the reduction in frequency were probably related to anxiety around the initial incidents.

Heather was finding it difficult to find a way to talk with her husband about how she was feeling. She was afraid of making him feel worse and thereby risk increasing the problem.

The relationship between Heather and her husband appeared to be strong and stable and Heather believed they had a loving marriage. However, it was evident that there were several other stressors impinging on this couple in addition to cancer. In particular there

were severe financial difficulties in relation to the farm. From Heather's description, her husband appeared to be very worried and fretting over the viability of the farm.

Further assessment was needed in this situation.

Specific suggestions.

I spent some time explaining to Heather that age may affect the sexual response cycle, in that responses tend to be slower than in younger people, that everything is always possible but it may take longer. I also suggested that stress and anxiety were thought to be common causes of sexual difficulties, particularly concerns about performance. I asked Heather to consider whether her husband may be feeling anxious and upset that he was not pleasing her sexually and that she may be feeling upset because she thinks she is not sexually attractive to her husband. Without talking with one another openly about how they are feeling, these assumptions and misunderstandings may be contributing to their difficulty.

I did also mention that if difficulty maintaining an erection persisted, the cause could be due to a medical problem. However, as the incidents were isolated and resolved I said this was unlikely and that communication between them seemed to be the issue.

Plan/recommendations.

Heather and I discussed a number of options with which to deal with her current situation. Alternatives offered to her were further assessment session with her and her husband together, either with me or if this was too impractical due to the travelling, with someone nearer to their home. Heather said she would talk to her husband about what we had discussed and would suggest coming to see me, but she thought he would decline. I encouraged her to discuss it with him. Heather thought her husband would be more comfortable with his family doctor or a doctor in Winnipeg and I supported this as a starting point. She was to get back to me with their decision.

Outcome.

Heather called me about three weeks later and told me that she had talked to her husband about our conversation and that things had improved a bit. She said that she had thought it over and found that she felt comfortable as things were at present and was not interested in further involvement at this time.

She was then sent and returned a completed Client Feedback Form. She indicated that she found the session helpful and that she felt less upset about her sexual activity. She also wrote that it might have



been helpful to have husband and wife present, that patients should be advised that this type of help is available and that perhaps printed material on the subject should also be available.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3  
months

3-6  
months

6-12  
months

12-24  
months

over 2  
years

2. How did you find out about the availability of sexual rehabilitation services?

doctor

nurse

social worker

partner/spouse

friend

other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes

no

4. If yes, who have you spoken to?

doctor

nurse

social worker/psychologist

partner/spouse

friend

relative

clergy

other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

yes

no



12. Did the counselling you receive result in a change in your sexual activity?

much more enjoyable      more enjoyable      about the same      less enjoyable      much less enjoyable

13. Do you feel as upset about your sexual activity as you did before the counselling session?

much less upset      less upset      about the same      more upset      much more upset

14. Would you recommend sexual rehabilitation counselling to a friend or relative who was diagnosed with breast cancer?

definitely yes      probably      maybe      probably not      never

15. Do you believe all cancer patients and their partners should be offered sexual rehabilitation?

Yes      Maybe      No

16. Other comments or suggestions: I feel it would be a good idea if the doctor or nurse at the clinic advises you that this type of help is available. Perhaps printed material should be available also.

### Common Themes and Elements

The relationship between the partners, and the importance of the partner in facilitating uncomplicated sexual readjustment after breast cancer is well illustrated. Eight of the women volunteered that their partner was the most significant variable in terms of their adjustment to their cancer and their surgery, and four of these women spontaneously remarked that they felt the cancer experience had in fact drawn them closer together.

This seems to fit with the literature which suggested that both the quality and affective tone of the relationship seemed to determine how well couples adjusted and how satisfied they were with their sexual activity.

As destructive and devastating cancer can be, my own clinical experience of nine years of working with cancer patients and their families has taught me that many patients can turn this experience into one of personal and interpersonal growth and learning. Marie and Rebecca both remarked that the cancer had changed them in that they now valued life more and saw it in a more positive light.

Four patients said that their faith had also been a tremendous source of support and strength for them.

I believe these comments take on added significance because of the fact that I had not directly asked about these factors.

Other than Heather, none of the women indicated a sexual concern they wanted to work on, although not necessarily because there were no concerns. Two of the women told me they had left their nightgowns on while engaged in sexual activity for the first year postmastectomy. Another, who had had her surgery about one year previously, continued to have intercourse in her nightgown, although she anticipated being able to take it off in the near future. Two others indicated that for about a year they had been unable to undress in front of their husbands or undress only with their backs turned. Jackie told me that she had felt "cut up" and "mutilated" but only for the first year.

It is interesting that all of these women talked about "one year" as being a significant point of adjustment. This has implications for the timing of intervention and suggests that further study is needed to determine if it would be helpful to offer sexual rehabilitation services within the first few months of surgery. It is also relevant to note that these women were not unduly distressed by their inability to be naked with their husbands and all but one had

successfully resolved the issue within a year. Given the problem-solving skills and indicated strength of that relationship, I have no doubt that the couple will also overcome this issue.

Breast stimulation was identified in the literature as significant for women with mastectomy and which Frank, Dornbush, Webster and Kolodny (1978) found to be reduced from 79% to 44% postoperatively. Four of the women I saw had concerns around breast stimulation. One woman was currently distressed because her husband avoided touching her intact breast, one had recently resolved her feelings around not wanting her husband to touch it, and one currently rejected breast stimulation because it brought forward feelings of anger about her diagnosis. Another had chosen a lumpectomy because breasts were significant to both herself and her partner. Two women indicated that breast stimulation was not currently an issue for them because it had never been an important part of their sexual repertoire.

Unfortunately, in hindsight, I did not explore the issue of reconstructive surgery with every woman. Two women had had lumpectomies, and two had had breast reconstructions. One was seriously considering this an option, one was waiting for her second, and two had

thought about it and decided they would definitely not want one, either because the missing breast was not significant to them or because they did not want to go through another surgery. This highlighted for me the variety of responses women have to breast surgery. It is therefore difficult to make generalizations about how women cope, adjust, and function with breast cancer and what is ideal for one woman may not be at all important to another.

Two women admitted to frequency reduction of sexual activity but attribute the reduction to something else other than the breast cancer such as age, lifestyle or fatigue. This is also consistent with the literature which indicated sexual functioning changes in the general population. More importantly, neither woman reported dissatisfaction with the current level of sexual activity.

There were four situations in which there were issues other than sexuality which might have benefitted from further social work intervention. Adjustment therapy of a more general nature related to the cancer experience, rather than focusing on sexual rehabilitation, may have been helpful in these situations.



Table 3 summarizes the common themes expressed by the clients.

Table 3

Frequency of Themes

---

N=15

---

Relationship	8
One year adjustment	6
Faith/religion	4
Breast stimulation	4
Issues other than sex	4
Positive Life Attitude Change	2

---

### Evaluation

In the original design of my practicum, I had planned to use the Client Feedback Form as the outcome measure of Stage I Intervention. For Stage II Intervention, I had planned to use the Golombok Rust Inventory of Sexual Satisfaction (GRISS), the Beck Depression Inventory and the Dyadic Adjustment Scale at assessment and termination to provide pretreatment and posttreatment scores in order to make comparisons and evaluate the efficacy of the intervention. Client self-monitoring records throughout the intervention, and the Client Feedback Forms were also to be used as a further guide to clinical evaluation.

As there were no clients who proceeded to Stage II Intervention, only the Client Feedback Form was used. The focus of the sessions were primarily assessment and not intervention and the form is not a validated measurement instrument. Therefore, I offer the following comments and results of these forms as descriptive material and an indication of what the experience was like for these clients. Extreme caution should be used in extrapolating conclusions and/or generalizations.

The Client Feedback Forms were all mailed within one week of my session with the client and accompanied

by a letter thanking them for the participation and giving instructions for filling in the form. A sample of the letter is found in Appendix D. All but one of the questionnaires were completed and returned.

For me, the most revealing question and response, which paralleled the experience describe in the literature, is Question No. 7 which asked whether anyone had inquired about their sexual concerns since their breast cancer diagnosis. Every respondent replied "NOBODY". One partner wrote on his wife's form a very astute comment "NOBODY had time for me to talk about anything except what my wife was going through. We as a partner to this matter should be able to get involved with every detail that surrounds cancer between men and women. (Nobody Told Me About sexual counseling.)"

When asked whether they would have asked for such help, all but one respondent replied "definitely no" or "probably not". At the same time, six of the clients indicated that sexual rehabilitation should be offered to all cancer patients and their partners and six replied "maybe". No one said it should not be offered.

It would appear, as reflected in the literature, that health care professionals do not routinely enquire about sexual concerns and that patients do not initiate

discussions in this area. However, these women, virtually without exception, eagerly talked to me about how their cancer had affected their sexuality. One might argue that they found it "safe" to talk to me because they did not have any problems. However, close examination of at least half of the situations indicates there were concerns which either had been or continued to be distressing to these clients.

It is interesting that the two women who replied that they wanted more sessions with the social worker were the same two clients who stated they were less upset about their sexual activity after our session. All the other respondents indicated that their sexual activity and the way they felt about it remained the same after our session.

In my search for some reason why no client moved onto Stage II Intervention, I wondered whether it might be because I had failed to connect with these women or establish a level of trust in which they could confide such sensitive material. However, the responses on the Client Feedback Form indicated that of the 12 individuals who answered the question, 11 replied they found the social worker "very easy" to talk to, and 1 responded "easy". I believe this is an indication of

the rapport established between myself and these clients.

Over half of the respondents wrote comments on the questionnaire. One woman reiterated that it was her supportive and loving husband who made the difference for her, and another remarked that "everything depends on the attitudes of the different individuals". A few women said that it was always helpful to talk with someone and one stated that she found it easier talking to a stranger.

Having both partners present, introducing sexual rehabilitation counseling within the first three months of surgery, and having printed material available on the subject were offered as suggestions to improve service.

Table 4 is a summary of the Client Feedback Form responses.

Table 4

Client Feedback Form Results

Client	Question No.							
	1	2	3	4	5	6	7	8
1	over 2	MD	no	--	no	--	nobody	prob not
2	12 - 24	did not know	yes	partner	no	--	nobody	prob not
3	6 - 12	nurse	yes	rela- tive	no	--	--	--
4	0 - 3	nurse	no	--	no	--	nobody	def no
5	over 2	sw	no	--	no	--	--	prob not
6	over 2	nurse	no	--	no	--	nobody	prob not
7	over 2	did not know	no	--	no	--	nobody	def no
8	12 - 24	sw	no	--	yes	part- ner	nobody	def no
9	0 - 3 (recur- rence)	sw	no	--	no	--	nobody	may- be
10	12 - 24	MD	no	--	no	--	nobody	--
11	12 - 24	nurse	no	--	no	--	nobody	def no

(table continues)

Client	Question No.							
	1	2	3	4	5	6	7	8
12	6 - 12	nurse	no	--	no	--	nobody	prob not
13	Over 2	sw	yes	partner	yes	part- ner sw	nobody	prob not
14 wife	6 - 12	MD	no	--	no	--	nobody	prob not
15 husband	6 - 12	MD	no	--	no	--	nobody	prob not

(table continues)



Client	Question No.							
	9	10	11	12	13	14	15	16
1	--	very easy	--	--	--	maybe	yes	--
2	not sure	easy	--	about the same	about the same	maybe	maybe	not for every- one
3	--	--	--	--	--	def yes	yes	--
4	help- ful	very easy	same	same	same	maybe	maybe	cancer caused sex prob.
5	--	very easy	--	--	--	--	--	--
6	help- ful	very easy	more	same	less upset	prob- ably	yes	printed material.
7	--	--	--	--	--	--	maybe	--
8	--	--	--	--	--	--	--	--
9	help- ful	very easy	more	same	less upset	prob- ably	yes	--
10	--	very easy	--	--	--	--	don't know	--
11	--	very easy	--	--	--	maybe	yes	--
12	--	very easy	same	same	same	maybe	yes	--

(table continues)

Client	Question No.							
	9	10	11	12	13	14	15	16
13	a little helpful	very easy	same	same	same	prob- ably	maybe	husband
14	a little helpful	very easy	same	same	same	maybe	maybe	time
15	a little helpful	very easy	same	same	same	maybe	maybe	3 mos.

Conclusion

## Conclusion

### Issues

The fact that I was unable to recruit any clients who proceeded beyond one session was the most striking and most disappointing experience of my practicum. I am left with many more questions than answers as to why this occurred.

It may be that the purpose of the oncology setting as perceived by the patients acted as an inhibitor for those patients who were experiencing sexual difficulties. In other words, did the patients view the Clinic as an inappropriate place to discuss sexual issues? Did the concept of the interdisciplinary team raise issues of confidentiality in patients? Were there feelings of shame or embarrassment, or concerns that the oncology staff would be judgmental if the patient admitted to sexual difficulties?

From my clinical experience, I believe that many patients view their oncologist as their "life-line" and therefore want to be liked and respected by him/her so that the physician will try as hard as possible to save their life. Similarly, some patients have a need to be perceived by clinic staff as "good copers", not only in terms of retaining self-esteem, but also because of the emphasis, particularly in the media, of the

relationship between a good prognosis and a "good" attitude.

Thus, some patients may not have revealed sexual difficulties or concerns for fear that this information might compromise the relationship with their caregiver. It is interesting that although three of the women admitted sexual concerns to me, they had originally told the Nurse Practitioner there were no difficulties.

In regard to these three cases, I wonder whether I should have pursued further intervention more actively. My philosophy has been to respect what the client is saying to me about how they wish to proceed, and that clients will engage in the counseling process only when they feel ready to work on the problem. However, if nothing else, a planned three month follow-up contact would have given me more information and understanding about whether these women did or did not resolve their sexual concerns and may have provided an opportunity to offer further intervention if needed at that time.

Although this was not a research study and I am not drawing any definitive conclusions, it does appear that coping skills and personal and interpersonal resources are factors in sexual rehabilitation rather than prognosis, recurrence, or level of physical discomfort from the disease itself or the treatment.

I also found myself questioning whether my original hypothesis had been accurate, that is, that breast cancer patients are at risk of psychosexual distress, particularly in light of the recent study cited earlier by Zemore and Shepel (1987). They concluded that breast cancer patients were no more socially or emotionally maladjusted than women without cancer. It is important to remember that the women in this study had only localized disease and none had had chemotherapy. Nonetheless, it does suggest that the health care system may have become more responsive to patients psychosocial needs, and that for whatever reasons, these patients seem to have the personal and interpersonal resources to cope effectively with these very difficult issues.

However, I still believe that there are women and their partners who have sexual concerns and difficulties and who could benefit from counseling. The real challenge is both in determining which women and partners are at risk, and in finding ways to connect with this population.

Finally, and in my opinion most significantly, as highlighted in the previous Literature Review, it is clear that health caregivers do not routinely enquire about sexual concerns of breast cancer patients. I

strongly maintain that the sexual functioning of the patient is as important an area to explore and assess as any other psychosocial issue.

There seems to be no contraindications to offering sexual rehabilitation services. None of the women who were approached indicated they felt insulted or personally invaded. In fact, none of the women I approached declined to discuss their sexual experience with breast cancer, and the Nurse Practitioner reported that only one woman she approached declined to participate in the practicum citing "lack of time" as her reason. None of the clients indicated on the Client Feedback Forms that sexual rehabilitation services should not be offered to all cancer patients and their partners.

### Recommendations

In hindsight, I wonder if taking sexual rehabilitation out of the realm of a more general psychosocial rehabilitation made it more difficult to connect with the population in need. In making sexual rehabilitation counseling something "special" and "different" from other counseling, I may have inadvertently given the exact opposite message I had intended. That is, my goal was to have sexual rehabilitation included as an integral part of the Clinic and that sexual issues be assessed, discussed, and resolved as any other psychosocial issue. I wanted to create an atmosphere which viewed sexual consequences of disease and treatment, in the same way other side effects such as hair loss or fatigue are discussed with patients and families, and support provided to deal with them.

In order to achieve this, I would now suggest, rather than setting up a separate sexual rehabilitation program, that each member of the health care team include sexual rehabilitation in their rehabilitative work with cancer patients and their significant others. As enhancement of the quality as well as the quantity of life is a goal of the team, the rehabilitative goals



would include recognizing and preserving sexuality as a fundamental part of being human.

Sexual rehabilitation "calls on all members of the health care team to contribute to whatever degree they feel confident and capable and is tailored to the specific needs and desires of each patient" (von Eschenbach & Schover, 1984b, p. 157). The PLISSIT model of intervention continues to be useful. Permission and Limited Information are appropriate levels of intervention for all Clinic staff and should be included as part of patient education protocols. Staff need to develop a level of comfort and become informed about human sexuality and the effects of surgery, radiation and chemotherapy on sexuality. Those patients and/or partners who indicate a particular problem or concern would then be referred to the oncology social worker who might provide Specific Suggestions or Intensive Therapy directly or make appropriate referrals to community resources as needed.

Social workers who see breast cancer patients would also include Permission and Limited Information in their assessments and interventions, even if the patient was originally seen or referred for reasons other than sexual issues. One of the most important interventions I believed I employed when talking with

these women, was to give them permission to express their feelings about their sexuality, whether positive or negative, and to universalize and normalize their concerns. It is helpful for a woman who has had a mastectomy to know she is not the only one who does not want reconstructive surgery and that this does not mean there is something wrong with her.

It is evident that further work is needed to help caregivers feel more comfortable initiating discussions of sexual issues. I am encouraged that some progress has been made with Clinic staff in this area. When I started my practicum 18 months ago, most of the nurses admitted to feelings of fear and anxiety and felt very uncomfortable bringing up the subject of sexuality. They now state that they feel more comfortable with this subject, and rather than generalized anxiety, can identify certain patient groups with whom they have more difficulty, for example patients of their own age, but of the opposite sex. I believe discussions about my practicum and the individual cases at team conferences have helped this process.

The experience expressed by many of the patients I saw was that they now felt closer to their partners and stressed the importance of the partner in sexual rehabilitation. This parallels the literature which

also identified the partner as a key factor in sexual adjustment. Interventions which include the partner need to be developed. Perhaps, rather than offering service to the partner through the patient, we need to borrow from the obstetrics model, and set up an expectation that the partner be involved from the beginning. As Kathy's husband wrote, nobody had told him about sexual counseling and he felt no one had time for him. We need to develop more creative ways to include the partner in all aspects of treatment.

Breasts mean different things to different women and to their partners and the importance breasts play in the sexual repertoire of couples varies greatly. One of the breast cancer patients described earlier had recognized that her breasts were significant both to herself and her partner. In consultation with her husband and her surgeon, she chose lumpectomy rather than mastectomy and they were both very happy with their decision. Unfortunately, not all patients have the personal resources to explore options and make decisions. Therefore, early assessment of the meaning of breasts to the patient and her partner and early discussion of treatment alternatives, including reconstructive surgery at the time of the mastectomy might be useful in preventing psychosexual distress.

Ideally, preoperative psychosocial assessment, including sexual assessment would be carried out by a social worker at the time of diagnosis. However, as this is not possible due to staffing limitations, it may be a more appropriate role for the oncology social worker to educate other disciplines, particularly nurses, in sensitive, nonjudgmental assessment skills.

In the design of this practicum, I had stipulated that patients be three months postsurgery as part of the selection criteria. Given the number of women who talked about one year as being a significant point of adjustment, I am now inclined to recommend some kind of Permission and Limited Information intervention at time of diagnosis, as a means of hopefully preventing distress. I recently had the opportunity to meet with a patient two weeks prior to surgery and explored sexual concerns with her. She told me it was a relief to be able to share her fears about possible changes in her sexual relationship with her husband, to learn how other women had felt and coped, and to be aware of pitfalls, such as making assumptions and not communicating.

One of the women noted on the Client Feedback Form that written material would be helpful. I think this is an excellent idea, which would increase the

likelihood of every patient receiving information about sexuality and breast cancer. The handouts and pamphlets that are currently being used to describe the side effects of treatment need to be reviewed to ensure that possible sexual side effects are included. Furthermore, it may be helpful to develop a pamphlet for patients and their partners which specifically addresses themes and issues of sexuality and breast cancer to be distributed to every breast cancer patient. As patients are inundated with information at the time of diagnosis, having something to refer to at home would be most beneficial.

It is evident that human sexuality and cancer are both extremely complex phenomena and their interaction is far from being completely understood. Further exploratory, descriptive and empirical research is needed to determine who is at risk for developing sexual difficulties after a diagnosis of breast cancer, what the specific sexual difficulties are that they may develop, when sexual problems are most likely to occur, what intervention techniques are best suited to this population, when is the best time to intervene, how to maximize the probability of breast cancer patients contracting for counseling for sexual difficulties, and

how to effectively involve the partners in assessment  
and intervention.

### Personal Learning and Skill Development

One of my primary goals when I began my practicum was to develop knowledge and skill in the area of sexual counseling. Unfortunately, I was unable to develop skills in sex therapy.

However, through the Literature Review, I did gain knowledge and understanding of human sexuality, and a theoretical knowledge base of the causation, assessment, and behavioral treatment of sexual dysfunction. I also learned about the specific side effects of certain chemotherapy treatments and the extent and results of research done to date on sexuality and breast cancer. I am also familiar and comfortable with the conceptual frameworks on the impact of breast cancer on sexuality and self-image as developed by Witkin (1978, 1978, 1982) and Schain (1976, 1980, 1982).

Most importantly for me personally, I now feel much more confident in initiating discussions around sexual concerns with clients and with the interdisciplinary team. Furthermore, I believe my modelling of learning to be informed and confident in discussing sexual issues has helped to alleviate anxiety and discomfort in some of the oncology Clinic

nurses who are now feeling more comfortable with this material.

Prior to my practicum, I had never used an evaluative tool, either to enhance assessment of a client situation or as an evaluative measure of my interventions. I learned the value of questionnaires, how simple they are to use and the wealth of information that can be obtained. In retrospect, I regret not planning a pre, post, and follow-up test for Stage I Intervention, which would have given me more data on the impact of this brief assessment/intervention. I intend to include measures such as questionnaires and other evaluative instruments as part of my clinical practice in the future.

I also discovered that even with the excellent working relationships I believe I have with the physicians and nurses in the oncology Clinic, trust is still an issue when a sensitive idea such as sexuality is introduced into an existing system. I received no referrals from the physicians and I question to what extent they explored sexual issues with their patients, given that no one had asked the women I saw about their sexual concerns. I wonder if their initial fears of "opening a can of worms" remained throughout the practicum. Nobody interfered or directly discouraged



me in my efforts to recruit clients for my practicum. However, neither do I believe that anyone, other than the Nurse Practitioner, actively sought out clients for possible participation. The implication is that it would be that much more difficult for someone who had not already developed working relationships with the staff to develop a sexual rehabilitation program in an oncology clinic.

Finally, I learned again, as I have over and over in my work with cancer patients and their families, how resourceful and resilient people are in the face of adversity. Although I continue to believe there is a group of women and their partners who are at risk of psychosexual distress, the majority of women when faced with breast cancer seem to be able to gather up their personal and interpersonal resources and cope effectively. We need to find ways to accurately and efficiently determine who is at greatest psychosexual risk, and to develop and test intervention strategies for working with this high risk group.

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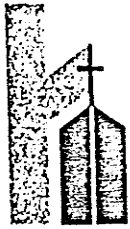
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Appendix A



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February 18, 1986

AN OPEN LETTER TO BREAST CANCER PATIENTS

Dear Patient:

The staff of the Oncology Clinic are aware that many cancer patients and/or their partners, from time to time, have concerns about the sexual aspects of their lives and relationships.

In recognition of these concerns, we are in the beginning stages of developing a sexual rehabilitation program here at the Clinic.

If you would like to speak to a counsellor who is specializing in sexual rehabilitation with breast cancer patients, or would like more information about this project, please contact me at .

Yours sincerely,

Jill Taylor-Brown  
Social Worker  
Oncology Unit

JT/sv



Appendix B  
Initial Assessment Form

## Initial Assessment Form

Stage I and II Intervention

1. Client's Name: \_\_\_\_\_
2. Address: \_\_\_\_\_
3. Phone #: \_\_\_\_\_
4. Age: \_\_\_\_\_
5. Marital Status: \_\_\_\_\_
6. Religion: \_\_\_\_\_
7. Number of Years in Current Relationship \_\_\_\_\_
8. Partner's Name: \_\_\_\_\_
9. Children: \_\_\_\_\_
10. Occupation (specific): \_\_\_\_\_
11. Diagnosis: \_\_\_\_\_
12. Date of Diagnosis: \_\_\_\_\_
13. Stage: \_\_\_\_\_
14. Treatment: \_\_\_\_\_
15. Date Treatment Commenced: \_\_\_\_\_
16. Length of Treatment: \_\_\_\_\_
17. Specific Side Effects of Treatment: \_\_\_\_\_  
\_\_\_\_\_
18. Possible Physiologic Causes of Sexual Problems: \_\_\_\_\_  
\_\_\_\_\_
19. Past Psychological Status: \_\_\_\_\_
20. Present Psychological Status: \_\_\_\_\_
21. Reaction of Partner: \_\_\_\_\_  
\_\_\_\_\_
22. Client's Understanding of Disease, Treatment and Prognosis: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

23. Previous Pattern of Sexual Activity: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
24. Satisfaction with Previous Pattern: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
25. Current Patterns of Sexual Activity: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
26. Satisfaction with Current Pattern: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
27. Presenting Problem (if any): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
28. Tentative Hypotheses about Cause of Presenting Problem: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
29. Goal: \_\_\_\_\_  
Indicator: \_\_\_\_\_
30. Goal: \_\_\_\_\_  
Indicator: \_\_\_\_\_

Stage II Intervention Only

31. Onset of Problem: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

31. Extent of Problem: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

32. Precipitating Events: \_\_\_\_\_

\_\_\_\_\_

33. Previous Efforts to Resolve Problem (and outcome): \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

34. Goal: \_\_\_\_\_

Indicator: \_\_\_\_\_

35. Goal: \_\_\_\_\_

Indicator: \_\_\_\_\_

36. Goal: \_\_\_\_\_

Indicator: \_\_\_\_\_

Appendix C  
Client Feedback Form.

CLIENT FEEDBACK FORM

Your answers to the following questionnaire will help to develop and improve a sexual rehabilitation program for breast cancer patients at St. Boniface Hospital Oncology Clinic. Thank you for your help and co-operation.

Please circle the response that best fits for you.

1. At the time of your contact with the social worker, how long had it been since you or your partner was diagnosed with breast cancer?

0-3            3-6            6-12            12-24            over 2  
months        months        months        months        years

2. How did you find out about the availability of sexual rehabilitation services?

doctor        nurse        social worker        partner/spouse  
friend        other (please specify) \_\_\_\_\_

3. Have you ever initiated discussion of your sexual concerns with anyone at any time in your life?

yes            no

4. If yes, who have you spoken to?

doctor        nurse        social worker/psychologist  
partner/spouse        friend        relative        clergy  
other (please specify) \_\_\_\_\_

5. Have you initiated discussion of your sexual concerns with anyone since you or your partner were diagnosed with cancer?

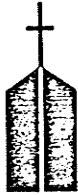
yes            no







Appendix D  
Sample of Letter Accompanying  
Client Feedback Form



Hôpital Général - St. Boniface - General Hospital

409 Tache Avenue,  
WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

DEPARTMENT OF SOCIAL WORK

Dear

Thank you again for your time and participation in the sexual rehabilitation project for breast cancer patients.

I have enclosed the Client Feedback Form I mentioned to you, and would appreciate if you would fill it in and return it to me in the enclosed stamped, self-addressed envelope as soon as possible.

Please try to answer every question and if a question does not apply to you, please indicate this.

Thank you again for taking the time to share your experience with me. If I can be of any further assistance, please do not hesitate to contact me.

Yours sincerely,

Jill Taylor-Brown  
Social Worker  
Oncology Clinic  
ph.

/mb