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SEXUAL ADJUSTMENT FOLLOWING SURGICAL TREATMENT
FOR GYNECOLOGICAL CANCER

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Psychology


by
Sue Ellen Martin-Christian
August 1990

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ABSTRACT

This exploratory study was designed to investigate the nature of post-surgical sexual functioning and adjustment in women with gynecological cancer. Specifically, this study examined the psychosexual effects of cancer treatment on sexual activity, partner relationships, and body image in women who have been treated surgically only or surgically with a combination of chemotherapy and/or radiation.

The sample consisted of 20 patients with the cancer of the ovary (N = 9) endometrium (N = 4) cervix (N = 4) and vulva (N = 2).

A structured 88 question interview designed for this study covering demographic, psychosocial and psychosexual issues was administered individually in clinical interviews that ranged from 1 1/2 to 3 1/2 hours each. Subjects also completed several standardized measures assessing the affective, cognitive and somatic components of their illnesses and/or sexuality.

Premorbid relationships and levels of sexual functioning and satisfaction with partner were found to be the best predictors of post-morbid psychosexual adjustment. The need for further research to define the effects of disease site, treatment modality, and demographic variables is discussed as well as the need for empirically based intervention strategies.

TABLE OF CONTENTS

TITLE PAGE.....	i
SIGNATURE PAGE.....	ii
ABSTRACT.....	iii
INTRODUCTION.....	1
METHOD.....	19
RESULTS.....	30
DISCUSSION.....	41
APPENDIX A: VARIABLES.....	54
APPENDIX B: QUESTIONNAIRES AND SCALES.....	57
REFERENCES.....	93

INTRODUCTION

As more methods and techniques increase life expectancy among cancer patients, the prolonging of life among this population also affects multidimensionally the physiological, psychological and sociocultural domains (Mantell, 1983). Although the pervasive focus for cancer patients is survival, longer life expectancies for these patients necessitate further investigation of ways for maintaining the quality of living along with extending it. Certainly integral to quality of life is the maintenance of positive sexual responsiveness especially for women with gynecological cancer who may undergo physiological and psychological changes (Mantell, 1983).

In exploring the psychology literature one finds little research on sexual functioning and adjustment in women with gynecological cancer who have had surgery or surgery with combined treatment regimens. Moreover, most of these investigations have been with cervical and endometrial patients (Andersen, 1987). Although in one study Andersen (1988) investigated sexual functioning in patients with vulvar cancer, there have been little or no data on sexual adjustment and functioning among ovarian cancer patients (Andersen, 1987). Along with the ubiquitous concern for survival, it is reasonable to assume that the patient's reluctance to discuss the intensely private and personal

nature of one's sexuality may also account for the smaller numbers of investigations among women with gynecological cancer and suffices as a partial explanation for the small number of investigations in this study of primarily ovarian cancer patients.

The types of cancer and the treatments of choice are germane to the cancer patient's lifestyle--particularly when treatment methods affect the appearance and functioning of the body (Mantell, 1983). Moreover, these medical and surgical procedures that produce such bodily alterations evoke psychological responses that may reduce self-esteem and be deleterious to sexual relationships (Mantell, 1983). A woman's sexuality and self-esteem may be diminished by loss of hair, breast removal, or mutilating surgery. For women with gynecological cancer, their perceptions are exacerbated by cultural expectations where emphasis is on sexualizing the female body (Mantell, 1983).

Women who have gynecological cancer are surviving longer. With early detection and what Andersen and Anderson (1986, p.233) describe as "aggressive therapy," two-thirds of these women who have cancers among the primary disease sites (ovarian, endometrial, cervical, and vulvar) will usually survive for a minimum of 5 years or longer. In addition to survival, patients undergoing medical treatment

for cancer have to face debilitating effects that accompany the various methods for treating cancer.

Even prior to treatment effects, physiologically and psychologically negative sexual issues surface with the onset of symptoms (Harris, Good & Pollack, 1982). These researchers postulate that women with gynecological cancer are affected by worries over mutilation, issues of femininity and sexual difficulties. While the literature supports that poor body image occurs in those who have had surgery for both benign and malignant hysterectomies (Daly, Dennerstein, Wood & Burroughs, 1977), when comparing breast cancer patients who have had mastectomies with that of healthy women and gynecological cancer patients who have had surgery, chemotherapy, or radiation, Andersen and Jochimsen (1985, p.30) suggest "that body image disruption may be a more prevalent problem for gynecologic cancer patients... ." While there are no precise data measuring sexual functioning with anxiety and body image, these studies do show the overlapping concerns regarding sexual functioning and body image.

Because of the later onset of gynecological cancer, at the time of diagnosis sexual activity or interest may be waning for the patient and/or her partner or she may be without a sexual partner (Andersen, 1987). Andersen (1987, p. 2126) states "...if a woman is without a sexual partner

at the time of initial treatment and consequently undergoes change to her body and/or her ability to respond during or engage in sexual activity due to cancer treatment, she is likely at risk for a more difficult general adjustment and for not resuming sexual activity." Andersen (1987) suggests that women's anxiousness over mutilation needs to be seen in terms of partner relationships as well as that of concerns for body image. For some women then, the focus of anxiety and concern for adequacy may shift from lower levels of sexual functioning before surgery to body image after surgery because of age and/or lack of partner. Although there are no data as yet in the literature to specifically measure pre-surgical sexual functioning with body image anxiety after surgery, the analytic literature supports the Adlerian notion that when one finds her/himself inadequate in one area s/he compensates in another area (Dinkmeyer, Pew, & Dinkmeyer, 1979). It may be that if levels of sexual activity or interest in sexual activity are waning prior to surgery, women with gynecological cancer may have already sought to compensate for their diminished sexual activity by emphasizing their sensuality in "looking attractive." Therefore, the threat of disfigurement particularly to an area which has already been the focus of their sexuality may actually heighten their anxiety.

PHYSIOLOGICAL OVERVIEW OF GYNECOLOGICAL CANCER SITES

To really understand what women with gynecological cancer face, it is important to look at the physiological implications, namely, sites, symptoms and treatment modalities that can affect their sexual functioning and adjustment.

Endometrial

Endometrial (uterine) cancer is the most common gynecological cancer often affecting women in their fifties or sixties either during or after menopause (Mantell, 1983). As with other gynecological cancers, abnormal vaginal bleeding (menorrhagia) in the premenopausal phase may signal uterine cancer (Mantell, 1983; Harris et al., 1976). Surgery is the standard procedure if the cancer is detected early (Andersen & Anderson, 1986). A total hysterectomy, removal of both ovaries and fallopian tubes (bilateral salpingo-oophorectomy) and radiation with surgery are the medical approaches unless the disease is recurrent. With recurrence, more extensive surgery requires the removal of the vagina and surrounding vaginal areas including the rectum (Mantell, 1983). When the cancer is metastatic, progesterone may be another treatment of choice (Mantell, 1983). External beam radiation or a radioactive implant (brachytherapy) is utilized for women who are at high risk of recurrence or who experience recurring cancer (Mantell, 1983).

Cervical

Cervical cancer previously the most prominent gynecological malignancy, has declined in incidence as a result of pap smears and pre-invasive treatment (Mantell, 1983); Andersen, 1986). Vaginal bleeding and watery bloody discharge often after intercourse are symptoms of cervical cancer (Mantell, 1983). Medical treatment consists of radical hysterectomy which is the removal of the uterus, tubes, ovaries, adjacent lymph nodes on both sides or radiation with surgery (Mantell, 1983). With recurrence, pelvic exenteration is the protocol which may be utilized and necessitates reconstructive surgery of the vagina (Andersen, 1987). With pelvic exenteration, however, Andersen's study (1987) showed that most women do not continue to have vaginal intercourse. According to Andersen, cervical cancer patients with pre-invasive lesions report few or little sexual difficulties following radiation or radical hysterectomies if the treatment for cancer is within the early stages (Andersen, 1987). With later stage cancers, surgery may cause vaginal foreshortening and be problematic for vaginal intercourse (Andersen, 1987). Premenopausal women who have cervical cancer are able to retain ovarian functioning after surgery while premenopausal women who are radiated may produce artificial menopause and experience such menopausal symptoms as hot flashes and mood

swings (Andersen, 1987). Estrogen may be administered to repair healing of the vaginal tissues after radiotherapy (Andersen, 1987). Atrophy and vaginal foreshortening are consistent outcomes of radiation treatment. Patients with invasive carcinoma of the cervix experience decreased libido, intercourse with pain (dyspareunia) and overall less enjoyment of vaginal intercourse because of the vaginal foreshortening from radiation (Mantell, 1983).

Ovarian

Ovarian cancer makes up one-fourth of all the female gynecological cancers diagnosed (Mantell, 1983; Andersen & Anderson, 1986). The onset of ovarian cancer occurs among women in their forties with increasing incidence as women become older (Mantell, 1983; Andersen & Anderson, 1986). An ominous element of this particular malignancy is that it can remain asymptomatic until it is in the advanced stages. Complaints that may mask the symptoms for this cancer present as non-specific abdominal pain, pre-menopausal menstrual irregularities or vague general intestinal problems (Mantell, 1983; Andersen and Anderson, 1986). With later stages of ovarian cancer, a total abdominal hysterectomy or bilateral salpingo-oophorectomy is performed and chemotherapy (cis-platinum) is used to treat the malignancy (Andersen and Anderson, 1986).

Vulvar

Vulvar cancer is quite rare and makes up 3 to 5 % of the gynecological cancers diagnosed (Andersen, 1986). Although the onset of vulvar cancer occurs among women from their late forties on, the most invasive form (squamous cell) of the disease is generally found among women in their seventies and eighties (Mantell, 1983; Andersen, 1986). Protractive itching with a history of conical, wartlike tumors (condyloma acuminata) is symptomatic of vulvar malignancy (Andersen and Anderson, 1986). Treatment for non-invasive cancer is wide local excision--the removal of the entire vulvar skin and replacing it with grafted skin from the groin area (Mantell, 1983; Andersen, 1987). Radical vulvectomy (removal of the clitoris, labia, and bilateral groin lymph nodes) is the medical treatment for invasive vulvar malignancy. Because of the delicacy of the vulvar tissue, radiation is not recommended as treatment of choice (Mantell, 1983; Andersen & Anderson, 1986).

SUMMARY OF TREATMENTS AND THEIR IMPACT ON SEXUALITY

Surgery

As indicated in the literature, different treatment modalities affect the way in which women with gynecological cancer adjust and function sexually. Medical treatment notably affects sexual activity and often after treatment, sexual activity decreases or even ceases to continue. The more radical the treatment the more women are likely to

encounter sexual difficulties (Andersen, Turquist, LaPolla & Turner, 1988; Andersen, 1987; Mantell, 1983). A radical hysterectomy for endometrial and cervical malignancies can disturb both the sensory and autonomic nerves which cause the vagina to lose feeling and elasticity (Mantell, 1983). A total abdominal hysterectomy with pelvic node dissection is another protocol that can interfere with vaginal intercourse because of the vagina's tendency to shrink. Pressure on a tender abdomen can also hinder intercourse (Mantell, 1983).

With the most extreme of surgeries--pelvic exenteration in which mutilation is so extensive--nearly 80-90% of previously sexually active patients do not continue to have sexual intercourse (Andersen, 1987). Women who have undergone radical vulvectomies report pain and body image reasons for no longer having intercourse. Physiologically, the introitus becomes less elastic causing dyspareunia which discourages further intercourse and these women also report adverse feelings by the patient or her partner (Andersen, 1987).

Radiation

Some of the psychological fears which patients express are that of being burned or becoming sterile from the radiation treatment (Andersen, 1987). Bransfield (1984) suggested that sexual problems which arise among women with

gynecological cancer emanate from psychological and menopausal factors as well as from radiation or other medical treatment effects. An earlier study of mainly black women with cervical cancer found that the women who were irradiated had more sexual problems than those who were treated surgically (Seibel, Freeman & Graves, 1979).

Another study among Nigerian women with cancer of the cervix reported similar findings in women who were radiated (Adelusi, 1980). Along with some mixed data, Andersen (1987) cited earlier research suggesting that there are more data showing that radiated patients have more sexual difficulties than those having other forms of treatment. Andersen and Tewfic (1985) in a pre- and post-external radiation study in women with gynecological cancer, found that highly anxious women or women with little preparation prior to treatment remained highly anxious after treatment. Gynecological cancer patients given internal or intracavity radiation (ICR) fared worse with both physical and psychological side effects (Andersen, 1987).

Chemotherapy

The predictable side effects of chemotherapy are hair loss (alopecia), nausea and vomiting. The debilitating effects of this treatment often create a psychological response termed ANV or anticipatory nausea and vomiting (Andersen, 1987). Patients knowing that they are facing a

series of chemical treatments report high levels of stress which often generalize to other areas such as unkept appointments for these treatments (Andersen, 1987).

Chemotherapy in combination with radiation also produces weakness and vomiting which can inhibit the patient's social life extending to the most highly intimate relationships, namely, the sexual relationship (Andersen, 1987).

PSYCHOSOCIAL IMPLICATIONS

A cancer diagnosis has several psychosocial ramifications even though patients are living longer and there is life after cancer. From the time of diagnosis there is major upheaval in the cancer patient's life. Stahly (1988, p.12) described a cancer diagnosis as a "precipitating variable" for family crisis in which marital stress and role shifts upset the family system. Green (1986, p.222) states that "reverberations and spinoffs are felt within the cancer patient's support networks as the diagnosis is confirmed." Those involved with the cancer patient may either overtly or covertly send messages of unacceptability to the cancer patient (Stahly, 1988). From such messages patients may react in a variety of ways beginning with the patient's own sense of denial that "cancer can happen to me." Denying and sublimating feelings can assume different forms such as refusing to comply with medical programs or, conversely, presenting as the "good

patient" who is reticent to ask questions or share her/his feelings. This type of denial is associated with being overwhelmed and helpless (Stahly, 1988).

Role changes usually mean new responsibilities for the family members of the cancer patient. Family members must assume added roles of the cancer patient whereas the cancer patient must cope with the loss of roles, hence often loss of autonomy (Stahly, 1988). Accompanying loss of autonomy, dependency issues emerge. As coping strategies are strained, family members--particularly the spouse--may distance her/himself emotionally and physically from the patient (Stahly, 1988). One pervasive theme in the psychosocial literature on cancer is that of victimization. Cancer patients, not unlike the victims of domestic violence, can be relegated to a stigmatized role (Stahly, 1988). Stahly (1988 p.2) writes that "the derogation of the victim, even a victim who is perceived to be innocent is well established in psychological literature." The cancer patient also may become victimized. Stahly (1988) relates the just world hypothesis (attitude that people usually get what they deserve) to the perception of the unafflicted person who either directly or indirectly stigmatizes the patient for having cancer. "It is based on the profound need of the observers to believe they have some control over their own lives and will be able to somehow prevent tragic

things from happening to themselves" (Stahly, 1988, p.1). Stahly (1988) suggests that the just world theory is not limited to the observer only, but that the cancer patient also searches for the causes or reasons for getting cancer and then proceeds to blame her/himself.

Another stigmatizing factor for the cancer patient is the fear of contagion. Stahly (1988) cited longstanding prejudices toward cancer patients by others who fear contracting cancer from shared restroom facilities or dining situations. Renshaw (1985) along with others noted that spouses may fear contaminating one another. "In the bedroom, cancer may lead to personal and sexual distance between the couple even to sexual dysfunction which may not be due to physical or biological causes but to a couple's fear about 'giving or getting' cancer" (Renshaw, 1985, p.24).

Positively or negatively, the patient's support network appears to affect the outcome of the patient's wellbeing.

Changes in sexual functioning may be particularly difficult for partners in relationships where sexual apathy prevails and there is little affection, intimacy and communication. In contrast, women with warm, loving relationships before the onset of cancer may find their mates to be invaluable sources of support in post-diagnosis and treatment periods hastening the psychosexual adjustment. (Mantell, 1983, p.7)

This observation reflects an earlier study by Weisman and Worden (1975) who showed that terminally ill patients tended

to live longer when receiving positive and supportive emotional input from significant others. The entire spectrum of the social network affects the self image of the cancer patient. The crisis literature well documents the effectiveness of social support availability during the times of acute stress or crisis (Moursand, 1985; Zaro, Barach, Nedelman & Dreiblatt, 1985). Knowledge of how one responded to or previously functioned in crisis situations is a good predictor of current functioning (Zaro et al., 1985). Andersen (1987, p.8) writes that using correlational data of healthy women as a basis for assessing sexual difficulties in gynecologic cancer patients, "variables such as the level of past sexual activity and that immediately prior to diagnosis, age at diagnosis, menopausal status and changes in menopausal status and magnitude of partner dysfunction should be important predictors of posttreatment activity." Therefore, it may be that women who have functioned fairly well sexually and otherwise prior to what Andersen (1987, p.1) views as the "existential plight" (that is, one's instant and following emotional reactions to the cancer diagnosis) will also better adjust and function sexually later. Mantell (1982, p.235) writes, "Although sexual functioning and interest may diminish during acute episodes of illness, many patients are capable of

maintaining their premorbid patterns of sexual behavior when their disease has been stabilized."

Based on the literature, there is little information, support, and assistance in dealing with the stigma and impact that cancer surgery has on women's sexuality. An investigation of issues centering on sexual function and adjustment may later lead to more palliative ways that medical and psychological personnel can enhance the aftercare and the quality of life of these women.

In summary, site and treatment therapies are significant to sexual functioning and adjustment in women with gynecological cancer (Andersen, 1987; Mantell, 1983). Some longitudinal data show that women with gynecological cancer are more likely to develop sexual problems during the early recovery periods (Andersen and Anderson, 1986). Women with gynecological cancer report less sexual activity than that of healthy women (Andersen and Jochimsen, 1985). Partner relationships, body image and menopausal status are other factors suggested as affecting the sexuality of women with gynecological cancer (Stahly, 1988; Andersen, 1987; Andersen & Jochimsen, 1985; Mantell, 1983).

Some of the questions that are posed for this study then are: Who are more likely to report better sexual adjustment? How will perceived partner availability and/or support affect posttreatment sexual functioning? Will women

report more concern for mutilation and survival issues than sexual concerns? Will sexual functioning and adjustment differences be found for women between sites and/or treatment modes?

"Information on sexual functioning following cancer treatment is generally lacking" (Andersen, 1987, p.9).

"Extensive descriptive data on the sexual outcomes following cervix cancer are available. Much less is known about the sexual outcomes for women with other disease sites such as the ovary or vulva, or women receiving radical or combination treatments" (Andersen, 1987).

Because of the paucity of either descriptive or empirical data on women with ovarian cancer and on combined treatments, this retrospective and exploratory study of primarily ovarian cancer patients will look at the effects that surgery and surgery with chemotherapy or radiation will have on these women's sexual functioning. It is expected that:

(1) Women with satisfactory premorbid sexual functioning will be more likely to report good post-surgical outcome of sexual adjustment.

(2a) Post-surgical concerns regarding desirability (body image) will be greater than pre-surgical concerns with desirability (body image).

(2b) Women will report more concerns regarding mutilation and survival than pre-surgical frequency of sexual concerns.

(3) Post-surgical sexual activity will be related to libido. (Libido is defined as reasons for engaging in sex after surgery, and reasons to avoid sex after surgery and the Index of Sexual Satisfaction Scale.)

(4) Post-surgical sexual activity will be related to menopausal status, and non-menopausal women will have more sexual activity.

(5) Post-surgical sexual activity will be related to partner availability.

(6) If levels of sexual functioning are low before surgery, women with gynecological cancer will focus more on body image as their area of desirability and attractiveness. Therefore, post-surgical anxiety and concern for body image will elevate as surgery poses a threat to body alteration.

(7) General mood states will be related to interpersonal (partner) support for cancer patients.

(8) The longer the interval of time following surgery, the more positive reasons will be reported for engaging in sex.

(9a) As age increases, there will be less social support (partner) and social desirability (attractiveness and body image).

(9b) The more partner support reported the better the body image prior to and after surgery.

(10) Women who have combined treatments of chemotherapy or radiation with surgery (excepting pelvic exenteration and radical vulvectomy) will report more sexual difficulties than women who have been treated with surgery only.

METHOD

Subjects

Total subject sample for this exploratory study consisted of 20 female gynecological cancer patients from the obstetrics and gynecological clinic at the Kaiser Hospital, Fontana, California. The sample was comprised mainly of ovarian cancer patients (N = 9) with the distribution among the other three primary cancer sites respectively: cervical (N = 3) endometrial (N = 6) and vulvar (N = 2). The predominantly caucasian, heterosexual participants' ages ranged from 32 to 70 years with a mean age of 50 years.

Demographic characteristics of this sample can be seen on Table 1 and Table 2. These tables show the frequency of site of cancer by marital status and by income.

Measures

A questionnaire specifically designed for this study was used. It contained 88 questions consisting of both closed and open-ended queries (See Appendix B). The first part of the questionnaire asked general information such as age, gender, marital status, familial, occupational, and religious affiliation. The second part inquired about the subject's lifestyle such as nutrition, exercise, eating, drinking and smoking habits. The third division asked about significant life events including those relevant to the

subject's illness. The remaining questions centered on subjects' feelings about self image, body image and sexuality. In addition to this questionnaire, the following scales were used:

(1) The Beck Depression Inventory (Beck, Ward, Mendelson, Mock and Erbaugh, 1961). The complete 21-item BDI scale was used to assess depression in which the respondents indicate both the presence and severity of each symptom on a scale of 0 through 3. The item scores are then summed with a range from 0 to 63 on the long form with the higher scores indicating the greater severity of depression. Split-half reliabilities range from .78 to .93 showing good internal consistency. (2) The Center for Epidemiologic Studies--Depressed Mood Scale (Radloff, 1977) was also used to assess depressive symptoms. The CES-D consists of 20 items selected from items drawn from previously validated depression scales and factor analytic studies. Scores are produced by reversing the scores on items 4, 8, 12, and 16 and then summing the scores on all items that result in a range of 0 to 60 with the higher scores showing greater depression. Split-half and Spearman-Brown reliability coefficients ranged from .77 to .92 indicating good internal consistency. (3) The Cognitive-Somatic Anxiety Questionnaire (Swartz, Davidson & Goleman, 1978) is a 14-item scale used to measure both the cognitive and somatic

aspects of anxiety. The CSAQ is a trait measure of anxiety and scored by computing the cognitive (items 1, 3, 6, 8, 9, 10, 13) and randomly ordered somatic items by scoring the sums of the scores on each item. The range for each of 7 to 35 for both the cognitive and somatic scales are computed separately. CSAQ correlates significantly with the State-Trait Anxiety Inventory showing good concurrent validity. No data are reported on the reliability of the CSAQ scale.

(4) The Profile of Mood States (McNair, Lorr & Droppleman, 1971) is 65 5-point adjective rating scale derived by factor analysis. A Total Mood Disturbance Score was obtained by summing the scores (Vigor scale scored negatively) on the six primary mood factors. Norms and validity data are not presented for the Total Mood Disturbance score but is considered to be highly reliable because of the intercorrelations of the POMS factors. (5) The Illness Behavior Questionnaire (Pilowsky and Spence, 1983) consists of a 62-item measure derived from factor analysis to assess illness related ideas, attitudes, affects and what attributes the respondents believe contribute to their illnesses. The IBQ has seven subscales to assess general hypochondriasis, disease conviction, psychological versus somatic perceptions, affective inhibition, affective disturbance, denial and irritability. The "correct" answers and the items of the subscales are in the right hand column

of the questionnaire and then these items are summed to obtain the subscale scores. Although the IBQ has good content and face validity there are no data on internal consistency. (6) Index of Sexual Satisfaction (Hudson, 1982) was used to measure sexual satisfaction relative to behaviors, attitudes, events, affect and sexual preferences. The ISS is a 25-item scale to assess the degree of severity of the sexual relationship and is scored by first reversing the items listed at the bottom of the scale (1, 2, 3, 9, 10, 12, 16, 17, 19, 21, 22, 23,). By summing these and subtracting 25 shows a range of 0 to 100. The higher the scores indicate the greater the respondent's sexual dissatisfaction. The ISS has excellent internal consistency with a mean alpha of .92. (7) The Clinical Anxiety Scale (Thyer, Papsdorf, Himle & Bray, 1981). The CAS is a 25-item scale to assess the severity of clinical anxiety. The items for the CAS were derived from a large pool of items based on the DSM-III. To score the CAS, first reverse the items 1, 6, 7, 9, 13, and items 15-17. Combine these totaled scores with the scores on the other items and subtract 25. The possible range of scores are from 0 - 100. The CAS has good internal consistency with a coefficient alpha of .94.

Variables (See Appendix A)

The following variables were used in the statistical analysis to test the main hypotheses.

Pre-surgical satisfaction saliency versus post-surgical adjustment

These factors were measured by a total of 31 items assessing the following: post-surgical global attitude for responding to sex, post-surgical number of reasons for engaging in sexual activity, and for avoiding physical sexual activity. Two representative items are: My interest in physical sexual activity was because of loving my partner; My lack of interest in physical sexual activity was because of tiredness. Scores ranged from 0 - 31. Eighteen items from 0 - 18 assessed specific pre- and post sexual behaviors (e.g. Prior to my diagnosis my sexual activities consisted of vaginal intercourse; After surgery my sexual activities consisted of affectionate fondling). Seven items scoring from 0 - 7 assessed sexual concerns (e.g. I believed that it (surgery) would not change my sexual desires in any way.) and 12 items assessed patient/partner concerns affecting physical sexual activity. One representative item is: Partner's fear of contagion. Scores ranged from 0 - 12. Scores ranging from 0 - 21 measured compatibility and relationship issues. An example from this 21-item assessment is: I would describe my partner's and my relationship to be emotionally sexually compatible.

Perceived desirability (body image) after surgery
versus perceived desirability (body image) prior
to surgery

Two items were used to measure how the patient felt about her body prior to surgery and after surgery (e.g. When I thought about my body before surgery I felt: a) positive b) somewhat positive c) neutral d) somewhat negative e) negative. When I think of my body after surgery I feel: a) positive b) somewhat positive c) neutral d) somewhat negative e) negative.

Post-surgical sexual functioning versus libido

The following factors comprised these variables: 31 items on reasons for engaging in sexual activity or avoiding sexual activity (e.g. My interest in physical sexual activity is because of sexual arousal or my lack of interest in physical sexual activity is because of depression). Scores ranged from 0 - 31; 9 items on post-surgical sexual activity with scores ranging from 0 - 9 assessed specific sexual behaviors. One representative item is: My sexual activity consisted of vaginal intercourse, oral sex less than twice a month. 12 items assessed patient/partner concerns with scores ranging from 0 - 12. For example: Partner's concern about causing additional pain after patient's surgery. The Index of Sexual Satisfaction also measured these variables. A

representative sample of the ISS is "Sex is fun for me and my partner."

Onset or age of menopause versus sexual activity

9 items on specific physical sexual pre and post-surgical behaviors comprised these variables. For example, My sexual behaviors consisted of kissing, fondling... . Scores ranged from 0 - 9 assessing different kinds of physical sex and 2 questions on menopause also comprised these variables (e.g., Have you experienced menopause? If so, at what age? and Did you experience any difficulty while undergoing menopausal changes?

Partner and age versus post-surgical activity

These variables were measured by the following:

Specific post-surgical sexual behaviors consisting of items with a score of 0 - 9 assessing frequency and types of physical sex (e.g., My sexual activity consists of fondling, oral sex less than twice a week).

Patient/partner concerns containing 12 items assessing concerns that may affect sexual activity. Scores range from 0 - 7 and a representative sample would be: Partner's decreasing interest in sexual activity.

Reasons for engaging in sex contains 4 items (e.g., My interest in sex is because of sexual arousal). Scores ranged from 0 - 4.

Reasons for avoiding sex contains 12 items with scores ranging from 0 - 12 (e.g., My lack of interest because of feeling pressured/coerced).

Global concerns affecting sexual responses contains 7 items (scores ranging from 0 - 7). For example: Worried that my partner would not be emotionally supportive.

Partner availability (one item) inquiring: If you are presently living with someone in a sexual relationship, how do you believe that your partner would describe you?

Anxiety, body image versus pre-surgical sexual functioning

To assess these variables the following scales were used: The Profile of Mood States, Adaptation to Cancer, the Beck Depression Inventory, Clinical Anxiety Questionnaire, The Cognitive-Somatic Anxiety Questionnaire, The CES-Depressed Mood Scale and 9 items on pre-surgical sexual functioning. One representative item is: My sexual activity consists of oral sex, vaginal intercourse, hugging and kissing.... . This scale ranged from 0 - 9 assessing a variety of pre-surgical behaviors.

Mood States versus relationship and compatibility with partner

The following factors comprised these variables: Profile of Mood States with pre- and post-surgical perceived partner support (e.g., I would describe my overall

relationship with my partner as lonely) with pre-surgical and post-surgical body image, and the Clinical Anxiety Scale assessed these variables. A representative sample of the Clinical Anxiety Scale is: I feel suddenly scared for no reason.

Interval between time and surgery

Length of time between the interviews and the number of post-surgical reasons for engaging in sexual activity and the number of reasons for avoiding sexual activity were used to assess these variables. The post-surgical number of reasons for engaging in and avoiding sex contained 31 items with a score of 0 - 31.

Partner (social) support versus body image (social desirability)

The following were used to measure these variables: Seven items of overall relationship after surgery (e.g., I would describe my overall relationship with my partner as emotionally supportive) with the scores ranging from 0 - 7; Five items on compatibility with a score range of 0 - 5. For example: I would describe the most compatible areas of my relationship to be a physical sexual relationship; and one item regarding body image after surgery (e.g., When I think about my body after surgery I feel negative).

Treatment differences versus sexual functioning and adjustment

Reported sites of gynecological cancer, treatment modalities (e.g., surgery, surgery combined with chemotherapy and surgery combined with radiation); Twelve items on perceived partner concerns (e.g., Partner's fear about causing additional pain from treatment) with scores ranging from 0 - 12; Thirty-one items on pre- and post-surgical reasons for engaging in sexual activity and reasons for avoiding sexual activity. Subject scores ranged from 0 - 31. Two examples of these items are: My interest in sex is because of loving my partner and My lack of interest in sex is because of feeling bad about myself; Eight items of pre- and post overall satisfaction on a rating from 0 - 8 of very satisfying to very unsatisfying were used to assess these variables.

Procedure

Participants for the current study were referred through their primary physician at the Kaiser Hospital, Fontana, California. Subjects' confidentiality was protected by being initially contacted via letter through their primary physician. Only those subjects who expressed interest in participating and who agreed to be contacted were subsequently invited to participate in the study. Of the 66 cancer patients contacted by their primary physician, 29 patients did not respond at all. Thirty-six patients

responded, 16 of whom declined to participate while the remaining 20 patients agreed to be interviewed.

The questionnaires were administered individually to the participants at the patient's home or at the Kaiser Hospital by a clinical interviewer. The clinical interviewer filled out the specifically designed questionnaire during the first portion of the interview. The participants themselves then completed the scales in the presence of the interviewer who was available for any questions or assistance. The time of interview per subject ranged from two and one-half hours to three and one-half hours each. In addition to information regarding research findings, the additional time per interview was allowed to permit patients to express their feelings regarding their disease and the nature of the information elicited during the interview. Moreover, the participants were invited to contact the interviewer for a follow-up time if the participant felt the need for additional closure, particularly regarding the more sensitive areas of inquiry contained in the questionnaire. To date, no one has requested additional clinical time.

RESULTS

OVERALL ANALYSIS

Several means of overall sexual adjustment were computed by combining the questionnaire designed for this study with 9 standardized scales measuring pre and/or post surgically the following dependent variables:

(1) emotional sexual concerns (2) patient concerns that may affect the post-surgical sexual relationship (3) number of reasons for engaging in sex (4) number of reasons for avoiding sex (5) perceived partner concerns that may affect the post-surgical sexual relationship (6) global attitude toward sex and (7) specific physical sexual behaviors. These variables were each converted to Z scores in order to standardize them with body image pre and post-surgically.

OVERALL RESULTS

Fifty-five percent of the women who reported being sexually active prior to diagnosis reported definite declines in sexual activity after surgery, while 40% reported no change in their sexual activities. Twenty-five percent of the patients reported some diminution of sexual intercourse while 30% of these patients reported total cessation of sexual intercourse. Only one patient (a widow) reported total abstinence of sexual activity both 1 year prior to diagnosis and after surgery. Sexual activity for this descriptive analysis is defined by three categories:

(1) Hugging and kissing (2) Intercourse (3) Fondling (petting). Four endometrial patients and one vulvar patient reported total cessation of sexual intercourse post-surgically. While patients with all four sites reported declines in intercourse after surgery, only the ovarian patients reported declines in the other two aforementioned categories of sexual activity.

An overall assessment of age with sexual functioning before surgery ($r(18) = -0.61, p = .01$) suggests that younger women were better adjusted sexually than older women.

When measuring partner availability with post-surgical functioning, an analysis of variance ($F(2,14) = 3.54, p = .10$) showed a marginal effect indicating that a lack of partner may be associated with post-surgical functioning. However, interaction between partner availability and age was significant ($F(2,14) = 5.98, p = .05$.) suggesting that as age increased there were fewer sexual partners available. Using the least squared means to compute for partners who were unmarried or married and those without partners indicated that married partners showed the best post-sexual functioning ($M = .87$) among all the groups. The unmarried subjects with partners showed the next lower score on sexual functioning ($M = -.96$) while women with total partner unavailability scored the lowest ($M = -3.44$). Both the

younger and older women in the married group showed similar and better sexual functioning ($M_s = 1.46$ and 0.27 respectively) than women who had partners but were unmarried ($M = -.32$). The group that exhibited the lowest level of sexual functioning were the younger women totally without partners ($M = -.8.10$).

A strong association was found between partner support with body image pre and post-surgically ($r(18) = 0.53, p = .05$). As women subjects perceived their partner support to be positive, the better their body images were both before surgery ($r(18) = 0.55, p = .05$) and after surgery ($r = 18) = 0.55, p = .05$). Moreover, the overall relationship of adjustment with partner support showed that the patient's partner support significantly correlates with the emotional adjustment (anxiety-body image variable) of the patient ($r(18) = 0.68, p = .01$) indicating that the more partner support that the patients have the better their overall emotional adjustment (anxiety-body image variable).

SPECIFIC RESULTS

The first hypothesis that women with satisfactory premorbid sexual satisfaction will be more likely to report good post surgical outcome adjustment was supported. The Pearson's Product Moment correlation coefficient between the overall relationship and post-sexual concerns was significant ($r(18) = 0.48, p = .05$). The overall pre-

surgical sexual relationship with the overall post-surgical sexual relationship showed ($r(18) = 0.53, p = .05$). Table Three shows the correlations for pre- and post-surgical sexual adjustment measures. As seen in Table Three, significance was found for the following correlations between:

(1) Relationship prior to diagnosis with sexual concerns after surgery ($r(18) = -.48, p = .05$) suggested patients who perceived their relationships as positive had fewer sexual concerns after surgery.

(2) Relationship prior to diagnosis with relationship since surgery ($r(18) = .53, p = .05$) indicated that patients whose relationship prior to surgery was positive also remained positive after surgery.

(3) Compatibility before diagnosis with compatibility since surgery ($r(18) = .69, p = .001$) showed that as patients reported being very compatible before surgery remained compatible post-surgically.

(4) Patient's who exhibited more physical sexual activity prior to surgery also reported more reasons for engaging in sex after surgery ($r(18) = .50, p = .05$).

(5) Patients who reported more sexual behaviors prior to surgery also reported having more reasons to avoid sex afterward suggests that these patients may have more need to explain changes in sexual activities after surgery as a

means for reducing dissonance and adjusting psychosexually ($r(18) = .65, p = .01$).

(6) Patients who also were more physically sexually active prior to surgery also reported being more physically sexually active post-surgically ($r(18) = .49, p = .05$).

With 6 significant statistical outcomes out of a total of 27 with the alpha level of .05 means that 1 out of 20 times significance would occur by chance on the average. In other words, the statistical outcome of 1.35 occurring by chance supports the significance of these 6 correlations. Therefore, any 1.35 by chance is a meaningful difference, particularly with some of the statistical significances at much lower probabilities concurring with the first hypothesis.

The second hypothesis (2a.) that post-surgical concerns regarding (body image) desirability will be greater than pre-surgical concerns with desirability (body image) was supported ($t(19) = 2.78, p = .05$).

The results of the Chi square supported the hypothesis (2b.) that women would report more concern regarding mutilation or survival than frequency of sexual concerns, ($\chi^2(2) = 10.00, p = .01$).

The third hypothesis that post-surgical sexual activity is related to libido defined as variable combining interest and satisfaction was supported ($r(18) = -0.47, p = .05$).

indicating that the more sexually satisfied patients reported being they engaged in more physical sexual activity after surgery. Even though the patients reported more sexual satisfaction post-surgically, they also reported more apprehension and concern for both them ($r(18) = .49, p = .05$) and their partners ($r(18) = .55, p = .05$) regarding potential problems that may occur from engaging in physical sex after surgery. These same concerns were also given as reasons for avoiding sex ($r(18) = 0.62, p = .05$) even though they continued to engage in some form of physical sex while voicing these concerns. Significance was also found between the number of reasons for engaging in sex with the frequency of sexual activity. This outcome suggests that while patients may express their apprehension about engaging in sex after surgery, some forms of physical sex continue even when patients express both interest and concerns for doing so. The results of the Pearson's Product Moment correlations are shown in Table 4.

Hypothesis four was supported ($t(18) = 2.19, p = .05$). This finding is consistent with the expectation that post-surgical sexual activity would be related to menopausal status showing that non-menopausal women have more sexual activity post-surgically than women in menopause.

Hypothesis five which predicted that post-surgical activity would be associated with partner availability was

supported ($F(2, 14) = 12.78, p = .001$). The Hotelling-Lawley Trace shows significance for overall partner effect. However, there were no overall effects for age or interaction with partner interest and age. Specific effects for the partner included the following: When looking at the means, married women ($M = 34.4$) were more positive and scored higher than either of the single women with ($M = 30.9$) or without ($M = 30.5$) partners. An analysis of variance ($F(2, 14) = 12.78, p = .001$) on partners and sexual behaviors shows the main effect that single women with partners ($M = 14.38$) are more sexually active (including masturbation) followed by married women ($M = 6.12$) and the least sexually active to be the single women without partners ($M = 0.80$).

The sixth hypothesis that if the levels of pre-surgical sexual relationships and functioning are low, higher anxieties and concerns for body image will occur after surgery was supported ($r(18) = -.58$, and ($r(18) = -.54, p = .01$). These findings indicated that the greater the patients' anxiety and despair the less compatible they perceived their relationships to be. Strong associations of despair with body image ($r(18) = -0.52, p = .01$) and with overall sexual relationships ($r(18) = -0.52, p = .01$) suggest the greater the despair that the women expressed the worse their perceptions of their bodies and their overall

sexual relationships. The more concerned the women were about general cancer issues, the fewer the overall sexual activities ($r(18) = -0.45, p = .05$). Six out of 36 correlations are significant suggesting that the women who reported lower levels of sexual adjustment and functioning were significantly more stressed about their body images and how their body images affected their relationships. Significance was not found when correlating the above factors with (a) reasons for sex (b) reasons to avoid sex (c) and global sex. Similarly when using the POMS subscales with the above variables only the fatigue scale showed significance with compatibility ($r(18) = -0.52, p = .01$) indicating that the more fatigued the patients were, the less the patients perceived their partners to be generally compatible.

The seventh hypothesis that general mood states will be associated with interpersonal support for cancer patients was supported ($r(18) = -0.53, p = .05$) indicating that the more highly anxious the women were the less partner compatibility was exhibited. Body image after surgery was also significant ($r(18) = 0.57, p = .01$) suggesting that the better the body image the better the partner support. Although not specifically stated in this hypothesis, using the Profile of Mood State subscale of vigor with overall partner support was significant ($r(18) = -0.48, p = .05$)

indicating that the less the partner support the more vigor the cancer patients displayed.

The eighth hypothesis which predicted that the longer the interval of time between surgeries and interviews, patients will report more reasons for engaging in sex was supported ($r(18) = 0.52, p = .05$) and ($r(18) = 0.45, p = .05$). The intervals correlating both with the post-surgical number of reasons for engaging in sexual activity and with the post-surgical number of reasons for avoiding sexual activity suggest that as time went on sexual issues became more important. The time between the subjects' interviews and time of surgery ranged from one to eight years.

Significance was not found regarding age difference with partner and social desirability (body image) for the first part of the ninth hypothesis. However, for the second part (9b.) a significant relationship was found between partner support and body image both prior to and after surgery, ($r(18) = 0.53, p = .05$) and for partner support and body image after surgery ($r(18) = 0.55, p = .05$) which showed that partner support is relevant to the way women with gynecological cancer view their bodies.

Hypothesis 10 states that treatment differences would significantly affect sexual functioning and that women treated surgically (excluding pelvic exenteration and radical vulvectomy which also excludes the vulvar group)

would report better sexual functioning and adjustment than women with combined treatments of chemotherapy with surgery or radiation with surgery. As predicted, treatments significantly affected sexual functioning ($F(2, 16) = 4.12$, $p = .05$). When looking at the means, women who had surgery with chemotherapy had the most difficulty in adjusting sexually. However, before surgery these cancer patients did not differ significantly from the other two groups who were radiated with surgery or had surgery without additional treatment. The means also showed that the group with radiation combined with surgery functioned somewhat slightly better than the group with surgery only ($M = 0.23$ and $M = 0.31$ respectively).

When looking at the perceived partner concerns for sexual adjustment and functioning with treatment effects, significance was also found ($F(2, 16) = 4.38$, $p = .05$). The means show that patients treated surgically with chemotherapy reported lower levels of sexual adjustment and functioning ($M = -0.73$) than either the surgery with radiation ($M = 0.41$) or those patients who had surgery only ($M = 0.37$). The means also showed that those who had received surgical treatment with chemotherapy reported the lowest level in sexual adjustment ($M = -0.60$) compared with the group treated with radiation ($M = 0.62$) and those with surgery only ($M = 0.07$).

For overall sexual satisfaction, significance was also found ($F(2, 16) = 11.93, p = .001$). The Tukey test showed that the radiation with surgery patients differed significantly from both the surgery only group and those with chemotherapy and surgery. Although the radiation-surgery patients showed better overall adjustment than either the chemo-surgery patients or the surgery-only patients, the means suggest that the radiation-surgery patients were less sexually satisfied overall ($M = -1.00$) than either the surgery-only group ($M = 0.41$) or the surgery with chemotherapy group ($M = 0.59$).

Significance was not found when assessing pre- and post-surgical variables for reasons for sex or reasons to avoid sex, sexual behaviors and responses. The overall mood total was marginally significant indicating that there may be some differences among the groups regarding affect. A larger sample of subjects might yield significance.

DISCUSSION

The outcome of this exploratory and retrospective study provides support for the differences found in pre- and post-surgical sexual functioning and adjustment. Before discussing the results, it is important to note that these data are from a small number of subjects. A larger number of subjects may yield different findings or perhaps greater data to further support the hypotheses under study.

Although there is a lack of research in women with ovarian cancer, these findings are similar to previous studies conducted on other gynecologic cancer sites of mainly cervical and endometrial patients (Andersen and Anderson, 1987; Andersen, 1986; Adelus, 1980). This present study differs from previous research in that it includes ovarian cancer patients and focuses specifically on sexual functioning with several combined cancer treatments with surgery rather than separate treatment modalities.

As hypothesized, a significant association was found between premorbid sexual functioning and good post-surgical sexual adjustment. The more positive and compatible that patients reported their relationships to be before surgery, the more compatible and positive they reported their relationships to be after surgery. Patients with more positive premorbid compatibility also reported fewer sexual concerns post-surgically. Together, these findings suggest

that patients with good premorbid sexual functioning and adjustment may possess a stronger and more stable base for coping with the post-surgical stressors, especially the psychosexual issues of this catastrophic disease. The data suggest that partner availability is integral to positive post-surgical activity, especially among married women.

Moreover, the data show that the more frequently patients engaged in physical sex prior to surgery, the more likely they were to be sexually active after surgery. The correlational data also indicate, however, that while pre-surgically sexually active patients continued to engage in some forms of physical sexual activity post-surgically, they were also expressing more reasons for avoiding sexual activity than less active subjects. This seeming paradox is not surprising considering the traumatic nature of this disease and treatment regimens. The post-surgical reasons that patients express for lack of interest in sex are "feeling ill," "tired," "depressed," "shame over my body," and "partner unavailability." Even though patients reported their experiencing all of these reasons, the very nature of their expressing all of these reasons for wishing to avoid engaging in sexual activity suggests that they are continuing to focus on sexual issues. It may be that patients' expressing less enthusiasm for sex but continuing to participate in sexual activity anyway, is a means for

reducing dissonance, in that patients may continue to feel "okay" about themselves sexually even though they are less enthusiastic about having post-surgical physical sex or patients who are less enthusiastic about but engaging in sex anyway may be doing so only to please their partners. Patients who were inactive sexually before surgery would find lack of sex after surgery less dissonance producing and therefore would be less likely to generate reasons for avoiding sexual activity.

Although not specifically stated in this hypothesis, it was anticipated that patients would be likely to shift their views and/or behaviors to cope with post-surgical sexual matters. Another possible explanation for patients continuing to participate in sexual activity while voicing more reasons for diminished interest after surgery may be because of reprioritization of life issues. Andersen (1987, p. 2127) writes that "for many women and couples, the experience of cancer and its treatment is so impactful that a reprioritization of current concerns occurs." The findings in this study, however, suggest that immediate concerns or crisis concerns subside as patients resume a more routine existence and the ever present sexual concerns emerge as important to the gynecologic cancer patient.

A significant finding in this study to support this assumption was that post-surgical concerns regarding

desirability (body image) were found significantly greater than pre-surgical concerns for desirability (body image) and indicates that (1) after surgery psychosexual issues emerge as important and (2) pre-surgical crisis concerns with survival and/or treatment issues may temporarily obfuscate the psychosexual impact. These latter concerns are contiguous to the significance found in the second part of this hypothesis that pre-surgically women continue to be more immediately concerned about mutilation/survival issues than frequency of sexual concerns. From these findings, the major pre-surgical concerns continue to be on survival or body disfigurement rather than anticipating psychosexual difficulties. After surgery, however, sexual issues become important. The importance of sexual issues post-surgically also found support in another hypothesis suggesting that after surgery as time passed women become significantly more interested in sex. This outcome suggests that with time as patients began to readjust to more routine living, sexual matters became more important. This finding and the previous one may have implications for the timing of clinical interviewing regarding psychosexual issues. These findings also emphasize the need for providing not only better information but adequate therapy to prepare women for the trauma of gynecologic treatment protocols.

Correlational data also indicate strong support for the hypothesis that low levels of pre-surgical functioning and adjustment would be associated with anxiety over body image post-surgically. Support for this hypothesis suggests that in order for women to compensate for less sexual activity, it is important for them to focus their sexuality on body image, that is, to look attractive and sensuous to their partners even if not actually engaging in much physical sex. Linkage between lower levels of sexual functioning and adjustment with increased stress over the cancer patient's body image and how their body images affected their partner relationships were especially significant. Such outcomes indicate that if sexual activity is lacking or low then looking attractive may be important, perhaps even essential in maintaining partner relationships for women who have undergone surgical treatments for gynecologic cancer. The gynecologic cancer patient may not wish to lose her partner because of cancer. Losses abound for the cancer patient. Physical loss of body parts, jobs, and significant relationships are shared phenomena among cancer patients (Stahly, 1988; Andersen, 1985; Mantell, 1983). While not specifically looked at in the area of sexual and relationship issues in this study, fear and loss in this context may be an important factor for future investigation.

Strong associations between libido and post-surgical sexual activity were found. Even though patients reported positive sexual satisfaction post-surgically they also reported greater sexual concerns for themselves and their partners that may affect or alter their physical sexual activity. Most of these concerns centered on the patient's or her partner's apprehension regarding pain that may occur from engaging in sexual activity such as intercourse. Only one patient reported that her partner feared her being contagious. As the number of reasons to either engage in sex or to avoid sex increased so did the patient's concerns for her body relative to the physical sexual problems that may occur post-surgically. Fear of pain was the most cited reason by both patients and partners regardless of whether they expressed a preference for engaging in or avoiding sexual activity. Interestingly, while patients had increased reasons either for engaging in or expressing reasons for avoiding sexual activity, they continued to report increased sexual satisfaction along with increased sexual activity regardless of their reasons for wishing to participate or not. Together these findings suggest that although patients may have real reasons for wishing to avoid sexual activity they continue to perceive themselves as being sexually satisfied and active sexual participants even after the trauma of surgery and/or combined treatments.

While patients may have to alter their emotional and physical sexual routines, their desire for sex continues to be intact. These findings are similar to those found by Andersen (1987) that women with gynecological cancer did not experience significant loss of desire compared to the other groups. In sum, these correlates indicate that the patient's desires haven't waned but are definitely influenced by her perceptions of her partner's attitude towards her post-surgically, the patient's own sexual constructs about herself and, though not explicitly stated in this hypothesis, the impact of surgical treatment.

As expected, post-surgical activity was significantly related to menopausal status and pre-menopausal women have more sexual activity post-surgically than post-menopausal women. The findings here may also suggest that as gynecological cancer occurs later in life, sexual activity may be negatively affected by hormonal levels, or by the unavailability of male partners. These possible explanations should be explicitly tested in some future study. Partner availability was tested, however, with post-surgical sexual activity. The data were significant and logically supported that the least sexually active women were those who were single and without partners. One such response from one of the single women when asked how surgery affected her dating relationships was: "I just don't

entertain that thought--can blame that on surgery." Single women with partners were the most sexually active followed by married women. It may be with the changing social structure that women may be less bound by traditional psychosexual mores and therefore are freer to engage in serial relationships as indicated by the general responses of two lesbian patients interviewed in this study. Interestingly, the lesbian patients reported similar issues regarding their relationships to those reported by heterosexual patients, namely that of their partner's leaving them or having negative altered sexual perceptions of them post-surgically. Perhaps single women with partners as well as the married women may enjoy a sense of "ego-safety" within a pre-existing relationship prior to surgery that single women without a regular partner have not experienced. Single women without regular partners may find that it is too great a risk to pursue an intimate relationship sexually following the trauma of surgical treatment for gynecological cancer.

General mood states were significantly related to the nature of interpersonal support for cancer patients. Although specific mood states were not predicted in this hypothesis, certain mood states that are likely to be congruous with the cancer patients' general condition and functioning were significantly correlated with interpersonal

(partner) support. The somewhat surprising association of vigor with partner support suggests that as partner support diminished, women exhibited more vigor. One explanation may be that women are expending more energy in order to maintain partner support or as suggested in another hypothesis for future exploration--to avoid partner loss. As noted in the literature, self-blame and spousal distancing is a common occurrence among cancer patients (Stahly, 1988). Other topics for future heuristic endeavors associated with patients assuming responsibility for having cancer or expending more energy (vigor) in keeping the relationship going may be related to abandonment fears and/or sex differences (particularly the way men handle the cancer problems of their partners).

As mentioned previously, diminished spousal support (Stahly, 1988) or even spouse abandonment is common among women who have had mastectomies (Andersen and Jochimsen, 1985) and therefore may have significant implications for future psychosexual intervention. To support these notions a significant association was also found between anxiety and declining compatibility suggesting that the more anxiety that the women displayed the more negative the effect on their relationship (compatibility). To further support this outcome between anxiety and compatibility was the significance found between better body image with better

partner support which also indicates that the better women feel about their bodies, the greater the partner support. It may be that as women are comfortable (non-anxious) about their bodies, their partners may respond to such positive non-verbal cues or body language. It also may be possible that women who are less mutilated may be more likely to be supported by their partners.

Although predicted, no significance was found between women's age differences and partner (social desirability) support. Perhaps this surprising lack of significance of age with partner support may be a cohort effect as the baby boomers who once dominated the youth culture are now in their middle years. For these former youth boomers, who now comprise the greater part of the United States population--and more specifically among this population of women with cancer most of whom are middle aged--it now may be that other issues are more important than age-related ones.

For the second part of this hypothesis, however, a significant association found between partner support (social desirability) and body image pre- and post-surgically suggests that women's partners may significantly influence women's self-image.

As expected, treatment differences significantly affected sexual functioning and adjustment. Because of the small number of vulvar subjects and the radical surgical

treatment, these patients were excluded from this hypothesis. Cancer patients who were treated surgically with chemotherapy (ovarian patients) had the most difficulty in adjusting sexually. The means show, however, that the group with surgery combined with radiation actually functioned somewhat better sexually than the group who had surgery only. This is contrary to both the hypothesis and most of the data showing that the outcome of cervical patients who were radiated usually fared more poorly than the groups treated surgically or with chemotherapy (Adelusi, 1980; Siebel et al., 1980). Site of cancer and/or extent and kind of treatment modalities may explain the differences in the outcome. For future study, a larger number of subjects in each site may yield more specific data and clarify these contradictory findings. Significance was also found when looking at partner concerns and sexual adjustment. The means show that ovarian patients treated surgically with chemotherapy reported the lowest levels of support in overall sexual functioning and adjustment followed by the surgically radiated patients. The surgery-only group, as expected, reported the highest levels of partner support. Marginal significance was found between patients' own perceptions of their sexuality and sexual adjustment. It may be that partner influence and the form

of treatment may impact on their intrapersonal views of themselves and how they adjust sexually.

As mentioned throughout the discussion, areas for future investigations affecting the sexual functioning and adjustment in women with gynecological cancer include site (Andersen, 1987), sex differences in handling cancer problems, fears over losses and/or abandonment issues and, certain demographic information especially those related to cultural issues. Information is lacking, for example, as to whether psychosexual difficulties may vary among women with different ethnic backgrounds. While data exist on Black women there is a need for future study of Hispanic and Asian women.

In conclusion, the outcome of this study suggests that pre-morbid sexual functioning and adjustment with partners predicted the best post-morbid psychosexual adjustment and that partner relationships are significant to the way the gynecologic cancer patient adjusts psychosexually. It follows that psychosexual therapeutic interventions are indicated to enhance and aid recovery. Current information and support groups are not designed to intervene and therapeutically address the personal and more complex psychosexual needs of the gynecologic cancer patient. Therefore, empirically evaluated therapeutic strategies and interventions are needed to ease the negative psychosexual

impact that medical treatment modes may impose on the gynecologic cancer patient.

APPENDIX A

Variables

APPENDIX A: VARIABLES

Variables

The following variables were used in the statistical analysis to test the main hypotheses:

1. Sexual satisfaction saliency before surgery vs. sexual adjustment since surgery.
Questions 70, 72, 73, 80-83, 85-86, 88.
2. Perceived desirability (body image) after surgery vs. before surgery.
Questions 63, 64.
3. Post-surgical sexual functioning vs. libido response post-surgically.
Questions 72, 73, 81-83, 86.
4. Onset or age of menopause vs. sexual activity
Questions 61, 62, 70, 72, 73, 78, 85.
5. Partner availability and age of patient vs. post-surgical sexual activity.
Questions 65, 70, 72, 73, 78, 86.
6. Anxiety, body image vs. pre-surgical sexual functioning.
Profile of Mood States, Adaptation to Cancer Scale, Beck Depression Inventory, Clinical Anxiety Scale, The Ces-Depressed Mood Scale and Question 80.
7. Mood States vs. relationship and compatibility with partners.
Profile of Mood States, Clinical Anxiety Scale and Questions 63, 64, 72-78.
8. Interval between time and surgery.
Questions 41, 41b, 78, 81, 82.

9. Partner (social support) vs. body image (social desirability).

Questions 63, 64, 75, 76.

10. Treatment differences vs. sexual functioning and adjustment.

Reported sites of cancer and surgical treatment from medical records, Questions 39, 41, 72, 73, 78-83, 87, 88.

APPENDIX B

Questionnaires and Scales

Psychosocial Questionnaire
for
Women with Gynecological Cancer

1. Subject I.D.# _____
2. Referring Medical Center _____
3. Place of Interview _____
4. Sex _____ Age _____
5. Ethnic background (race or nationality) _____
6. Marital Status _____
7. List members of household living with you at the present time
by first name , age, and relationship to subject.

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

8. Do you own a pet? _____ (Describe) _____

9. Which below best describes your current employment situation?

- Working full-time
- Working part-time
- Laid off or on strike
- Unemployed (looking for work)
- Unemployed (not looking for work)
- Retired
- Disabled, permanent (on permanent disability)
- Disabled, temporary (on temporary disability)
- On public assistance
- Full time homemaker
- Full time student
- Other, if volunteered (specify) _____

9a. If unemployed, is this related to cancer? If yes, describe.

10. Has your unemployment situation changed in the last 6 months?

No

Yes (If yes, explain.) _____

11. What is your current occupation or your most recent occupation?

- Nurse, Teacher, Accountant, Clergy, Editor, Technical (i.e. lab tech, computer programmer, etc.)
- Clerical: Secretary, Bookkeeper, Typist, Cashier, Postal worker
- Physician, Attorney, Professor, Natural or Social Scientist
- Sales (including real estate and insurance)
- Foreperson and Craftsperson: Electrician, Machinist, Carpetner, etc.
- Service Work: Cook, Bartender, Maid, etc.
- Laborer: Farming, Gardener, Domestic and Private household, etc.
- Other not among above categories (Specify) _____

12. If you are currently married or living with a partner which below describes your partner or spouse's current employment situation?

- Working full-time
- Working part-time
- Laid off or on strike
- Unemployed (looking for work)
- Unemployed (not looking for work)
- Retired
- Disabled, permanent (on permanent disability)
- Disabled, temporary (on temporary disability)
- On public assistance
- Full-time homemaker
- Full-time student
- Other, if volunteered, specify _____

13. What is your approximate family income for one year?

- | | |
|--|--|
| <input type="checkbox"/> under 10,000 | <input type="checkbox"/> 20,000 - 30,000 |
| <input type="checkbox"/> 10,000 - 15,000 | <input type="checkbox"/> 30,000 - 45,000 |
| <input type="checkbox"/> 15,000 - 20,000 | <input type="checkbox"/> 45,000 - 75,000 |
| | <input type="checkbox"/> above 75,000 |

14. How are your medical bills paid? _____

15. How do you see your financial situation at this time?

- Cannot make ends meet
- Can get by with some help
- Have just enough to get by
- Comfortable
- More than enough to get by
- Well-to-do
- Wealthy

16. Religious preference _____

- 16a. Do you attend church: weekly
 monthly
 less often
 never

17. How often do you participate in religious activities?

more than weekly occasionally
 weekly rarely
 monthly never

18. How important are the spiritual aspects of your life to you now?

extremely important
 very important
 somewhat important
 not very important
 not important at all

19. Have you sought any professional help (e.g., psychologist, social worker, counselor, religious leader) in the 6 months preceding your diagnosis? (Describe) _____

20. Have you received any professional help since your illness?

21. From whom did you receive help? (Check below as applicable)

<u>6 months prior</u>	<u>Since diagnosis</u>	
<input type="checkbox"/>	<input type="checkbox"/>	Religious/spiritual leader
<input type="checkbox"/>	<input type="checkbox"/>	Social worker (hospital)
<input type="checkbox"/>	<input type="checkbox"/>	Psychologist
<input type="checkbox"/>	<input type="checkbox"/>	Psychiatrist
<input type="checkbox"/>	<input type="checkbox"/>	Other counselor (specify)

22. Have you received a referral to any patient support group? (Describe) _____

22.a How often did/do you attend? _____

22.b How beneficial has the group been?

extremely helpful
 very helpful
 somewhat helpful
 not very helpful
 not helpful at all

23. Think of the most serious problem you faced, not necessarily related to your health, prior to your illness. What was the problem? _____

24. What action did you take to deal with this problem? _____

24 a. How helpful was that action in taking care of the problem?

- _____ Extremely helpful
- _____ Very helpful
- _____ Somewhat helpful
- _____ Not very helpful
- _____ Not helpful at all

25. Did you ask anyone for help or advice in dealing with this problem?

- _____ No
- _____ If yes, who? _____

25a. How adequate was the advice or help that you received?

- _____ Extremely adequate
- _____ Very adequate
- _____ Somewhat adequate
- _____ Not very adequate
- _____ Not adequate at all

26. Thinking about your family during the year preceding your illness, please list the three most important conflicts or disagreements that you recall between you and your spouse.

1. _____

2. _____

3. _____

27. Prior to your illness, did you smoke? _____
 27a. If yes, on the average, how many packs per day in the year preceding your diagnosis? _____
28. Since your illness, do you smoke? _____
 28a. If yes, on the average, how many packs per day since your diagnosis? _____
29. Prior to your illness, did you drink alcoholic beverages? _____
 29a. If yes, what did you drink? _____
 29b. Considering an average month the year before your diagnosis, how many days in the month would you drink alcohol?
 _____ none of them
 _____ some of them
 _____ about half of them
 _____ most of them
 _____ all of them
 29c. On the day(s) that you drank, about how many drinks would you usually have? (Consider 1 drink to be 1 oz. liquor, 1 can of beer, or 4 Oz. of wine.) _____
30. Since your illness, do you drink? _____
 30a. If yes, what do you drink? _____
 30b. Considering an average month the year before your diagnosis, how many days in the month would you drink alcohol? _____
 _____ None of them
 _____ Some of them
 _____ About half of them
 _____ Most of them
 _____ All of them
 30c. On the day that you drank, about how many drinks would you usually have? (Consider 1 drink to be 1 oz. liquor, 1 can of beer, 4 oz. of wine.) _____
31. Prior to your illness, how would you describe your awareness of nutrition?
 _____ Very aware of nutrition
 _____ Somewhat aware of nutrition
 _____ Didn't pay much attention

32. How would you describe the nutrition of your diet?

- Excellent
- Good
- Average
- Poor
- Not sure

32a. Since your illness, how would you describe the nutrition of your diet?

- Excellent
- Good
- Average
- Poor
- Not sure

33. Prior to your illness, how often did you engage in vigorous exercise?

- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Daily | <input type="checkbox"/> Occasionally |
| <input type="checkbox"/> At least 3X per week | <input type="checkbox"/> Rarely |
| <input type="checkbox"/> Weekly | <input type="checkbox"/> Never |

34. Can you tell me about your illness? _____

35. Are you experiencing any symptoms now?
If yes, describe. _____

36. Are you taking medication? (Describe) _____

37. Who noticed the first symptom of your illness? _____

What was it? _____

Date symptom was noticed _____

What did you do about it _____

38. When did you see a physician? (Date) _____

What treatment did you receive? _____

39. When did you receive a diagnosis? (Date) _____

What was it? _____

40. What did the physician tell you about your illness? _____

41. What treatment have you received? _____

Dates of treatment _____

Were you hospitalized? (Dates) _____

42. Did you ever choose not to have recommended treatment?
(Describe) _____

43. Did you ever choose to discontinue treatment before it was completed? (Describe) _____

43A. Did anyone encourage you to discontinue treatment?

Who? _____

44. Have you sought alternative treatment? (Describe) ----

44A. Were those treatments in addition to or instead of recommended treatment? (describe) _____

45. What member of your family has had the most difficulty with your illness? (describe) _____

46. Do you think differently about yourself since your illness? _____

47. Have you noticed a change in other people's attitude toward you since your illness? _____

48. What are the most difficult aspects of your illness? _____

49. Are there any positive aspects or experiences as a result of your illness? _____

50. How well can you communicate with your physician? _____

51. Are there any questions you would like to ask your physician but feel reluctant to ask? _____

If yes, what are they? _____

52. What kind of information did you have or receive about your illness prior to your surgery? (Describe) _____

53. What kind of information did you receive about your illness after your surgery? _____

54. If there is any other information about your illness or treatment that you would like to have that you haven't already received? _____

55. Do you have any idea about why you might have developed this illness? If yes, please explain. _____

56. Is there anything you can do to help your recovery? (Describe) _____

57. How have the following areas of your life been influenced by your illness?

a) Social activities _____

b) Family _____

c) Friends _____

d) Work _____

e) Time by yourself _____

f) Spiritual aspects of your life _____

i) Other areas _____

j) Sexuality _____

58. Prior to surgery what kind of information did you receive about any possible effects that gynecological surgery might have regarding your: _____ emotions
_____ social life
_____ sexual activities
_____ physically

(Describe) _____

59. What kind of information did you receive about how any possible effects that chemotherapy might have regarding your _____ emotions
_____ socially
_____ sexual activities
_____ physically

(Describe) _____

60. What kind of information did you receive about the possible effects that radiation might have regarding your : _____ emotions
_____ social life
_____ sexual activities
_____ physically

(Describe) _____

61. Have you experienced menopause? If so, at what age? _____

(Describe) _____

62. Did you experience any difficulty while undergoing menopausal changes? (Describe) _____

63. When I thought about my body before surgery I felt:

- a) positive
- b) somewhat positive
- c) neutral
- d) somewhat negative
- e) negative

64. When I think about my body since surgery I feel:

- a) positive
- b) somewhat positive
- c) neutral
- d) somewhat negative
- e) negative

65. If you are presently living with someone in a sexual relationship, how do you believe your partner would describe you?

a) Before surgery? _____

b) After surgery? _____

66. If you are single, has your surgery affected your dating relationships? (Describe) _____

67. If you are single and currently in a physical sexual relationship have you experienced any change in either yours or your partners sexual commitment since your surgery? (Describe) _____

68. When I realised that I needed surgery I felt:

- Very positive about the outcome of my surgery
- Somewhat positive about the outcome of surgery
- Did not want to think about the outcome of surgery
- Very apprehensive about the outcome of surgery
- Totally pessimistic about the outcome of surgery

69. What aspects of the surgery concerned you the most? _____

(Describe) _____

70. When I considered the possible changes that might alter or change the physical sexual aspects of my sexual activities with my partner I felt: (Check all that apply and record the numerical equivalent.)

NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS
(1)	(2)	(3)	(4)	(5)

- Fearful for my overall health
- Angry that this had to happen to me
- Did not believe that it would change my sexual desires for my partner in any way
- Believed that it would not change my partner's sexual desires for me in any way
- Sad
- Worried that my partner would end the relationship
- Worried that my partner would not be emotionally supportive

71. Prior to your surgery did you and your partner talk about any changes that might occur in your physical sexual relationship as a result of your surgery?
If yes, what kinds of changes did you talk about? (Describe)

71 A. Were you able to discuss these changes in the following manner? (Check all that apply)

Calmly Awkwardly Openly
 Stressfully Other _____

B. If no, did you want to talk about it? _____

C. If no, did your partner want to talk about it? _____

72. Have any of the following concerns altered or changed your sexual activities because of patient's illness due to : (Check all that apply)

- (a) Partner's concern about causing additional pain after patient's surgery
- (b) Partner's concern about causing additional pain from other treatment
- (c) Partner's fear of contagion
- (d) Partner's increasing interest in physical sexual activity
- (e) Partner's decreasing interest in physical sexual activity
- (f) Other concerns of partner _____

73. Have any of the following concerns altered or changed your sexual activities because of patient's illness due to: (Check all that apply)

- (a) Patient's additional pain incurred from surgery
- (b) Patient's additional pain incurred from other treatment
- (c) Patient's fear of contagion
- (d) Patient's increasing interest in physical sexual activity
- (e) Patient's decreasing interest in physical sexual activity
- (f) Other concerns of patient _____

Please choose the number that best represents you and write the appropriate number next to each item in following question.

NEVER RARELY SOMETIMES FREQUENTLY ALWAYS
(1) (2) (3) (4) (5)

74. One year prior to my diagnosis, I would describe my overall relationship with my partner as:

<input type="checkbox"/> Emotionally supportive	<input type="checkbox"/> Stressful
<input type="checkbox"/> Lonely	<input type="checkbox"/> Close, Intimate
<input type="checkbox"/> Generally fulfilling	<input type="checkbox"/> Distant
<input type="checkbox"/> Neutral	

75. Since my surgery, I would describe my overall relationship with my partner as:

<input type="checkbox"/> Emotionally supportive	<input type="checkbox"/> Stressful
<input type="checkbox"/> Lonely	<input type="checkbox"/> Close, Intimate
<input type="checkbox"/> Generally fulfilling	<input type="checkbox"/> Distant
<input type="checkbox"/> Neutral	

76. One year prior to my diagnosis, I would describe the most compatible areas of my partners's and my relationship to be:

<input type="checkbox"/> Financial/Economically
<input type="checkbox"/> Spiritually
<input type="checkbox"/> Careerwise (Not necessarily the SAME career)
<input type="checkbox"/> Physically sexually compatible
<input type="checkbox"/> Emotionally sexually compatible

77. Since my surgery, I would describe the most compatible areas for my partner and me to be:

<input type="checkbox"/> Financial/Economically
<input type="checkbox"/> Spiritually
<input type="checkbox"/> Careerwise (Not necessarily the SAME career)
<input type="checkbox"/> Physically sexually compatible
<input type="checkbox"/> Emotionally sexually compatible

78. One year prior to my diagnosis, my interest in physical sexual activity was because of:

- loving my partner
- sexual arousal
- needed affection
- stressed; need to relax
- guilt
- wanted to get it over with
- wanted a favor in return
- wanted to be pregnant
- fear of losing partner
- reassurance

79. One year prior to my diagnosis, my lack of interest in physical sexual activity was because of:

- tiredness
- feeling ill---generally ___ surgery ___ other treatment
- depressed ___ generally ___ surgery ___ other treatment
- angry
- hurt
- feeling coerced
- resentful
- not sexually aroused
- partner unavailable
- ashamed of my body
- feeling bad about myself
- punishing partner

Please choose what is true for you and record the following:

NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS
(1)	(2)	(3)	(4)	(5)

80. One year prior to my diagnosis :

- I was not concerned if my partner did not approach me for sex.
- I initiated a physical sexual relationship with my partner.
- I felt obligated to have sex with my partner.
- I lack vaginal lubrication during sex.
- I experience genital pain during sexual intercourse.
- I have no interest in sex and could go without it.
- I have used alcohol or drugs as an aid to sex.
- I often fantasize as a part of my sexual routine.
- I experience orgasm during sex.

Please choose the number that best represents you and write the appropriate number next to each item in the following question.

NEVER RARELY SOMETIMES FREQUENTLY ALWAYS
(1) (2) (3) (4) (5)

81. Since my surgery, my interest in physical sexual activity is because of:

- loving my partner
- sexual arousal
- needed affection
- stressed; need to relax
- guilt
- want to get it over with
- want to be pregnant
- fear of losing partner
- reassurance

82. Since my surgery, my lack of interest in physical sexual activity is because of:

- tiredness
- feeling ill generally surgery other treatment
- depressed generally surgery other treatment
- angry
- hurt
- feeling coerced
- resentful
- not sexually aroused
- partner unavailable
- ashamed of my body
- feeling bad about myself
- punishing partner

Please choose what is true for you and record the following:

NEVER RARELY SOMETIMES FREQUENTLY ALWAYS
(1) (2) (3) (4) (5)

83. Since my surgery:

- I am not concerned that my partner does not approach me for sex.
- I initiate my partner for sex.
- My partner approaches me for sex.
- I feel obligated to have sex with my partner.
- I lack vaginal lubrication during sex.
- I experience genital pain during sex.
- I have no interest in sex and could go without it.
- I use alcohol or drugs as an aid to sex.
- I often fantasize during my sexual routine.
- I experience orgasm during sex.

84. Have your physical sexual activities changed? _____
 If yes, (Describe) _____

84a. Have you found sexual alternatives to intercourse
 become either more or less important since surgery?

85. Before my surgery, my sexual activities 1 year prior
 to my diagnosis consisted of: (Check all that apply)

	1X	2-3X	4+X	1X	less 1X
	week	week	week	month	month
(1) Affectionate hugging and kissing	___	___	___	___	___
(2) Affectionate fondling	___	___	___	___	___
(3) Vaginal intercourse	___	___	___	___	___
(4) Masturbation - self	___	___	___	___	___
(5) Masturbation - partner	___	___	___	___	___
(6) Anal intercourse	___	___	___	___	___
(7) Oral sex - Fellatio	___	___	___	___	___
(8) Oral sex - Cunnilingus	___	___	___	___	___
(9) Other _____	___	___	___	___	___

86. Since my surgery my sexual activities consist of:
 (Check all that apply)

	1X	2-3X	4+X	1X	Less 1X
	week	week	week	month	month
(1) Affectionate hugging & kissing	___	___	___	___	___
(2) Affectionate fondling	___	___	___	___	___
(3) Vaginal intercourse	___	___	___	___	___
(4) Masturbation - self	___	___	___	___	___
(5) Masturbation - partner	___	___	___	___	___
(6) Anal intercourse	___	___	___	___	___
(7) Oral sex - Fellatio	___	___	___	___	___
(8) Oral sex - Cunnilingus	___	___	___	___	___
(9) Other _____	___	___	___	___	___

87. How would you best describe your physical sexual activities
 before surgery?

(4) Very satisfying _____
 (3) Somewhat satisfying _____
 (2) Not very satisfying _____
 (1) Very unsatisfying _____

88. How would you best describe your physical sexual activities
 after your surgery?

(4) Very satisfying _____ (2) not very satisfying
 (3) Somewhat satisfying _____ (1) very satisfying

True False

1. If I get sick, it is my own behavior which determines how soon I get well again.
2. No matter what I do, if I am going to get sick, I will get sick.
3. Having regular contact with my physician is the best way for me to avoid illness.
4. Most things that affect my health happen to me by accident.
5. Whenever I don't feel well, I should consult a medically trained professional.
6. I am in control of my health.
7. My family has a lot to do with my becoming sick or staying healthy.
8. When I get sick I am to blame.
9. Luck plays a big part in determining how soon I will recover from an illness.
10. Health professionals control my health.
11. My good health is largely a matter of good fortune.
12. The main thing which affects my health is what I myself do.
13. If I take care of myself, I can avoid illness.
14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.
15. No matter what I do, I'm likely to get sick.
16. If it's meant to be, I will stay healthy.
17. If I take the right actions, I can stay healthy.
18. Regarding my health, I can only do what my doctor tells me to do.

READ THE STATEMENTS BELOW. IF THE STATEMENT DESCRIBES YOU, MARK LIKE ME. IF THE STATEMENT IS NOT DESCRIPTIVE OF YOU, MARK UNLIKE ME.

	LIKE ME	UNLIKE ME
1. I often wish I were someone else.	1. _____	_____
2. I find it very hard to talk in front of a group.	2. _____	_____
3. There are lots of things about myself I'd change if I could.	3. _____	_____
4. I can make up my mind without too much trouble.	4. _____	_____
5. I'm a lot of fun to be with.	5. _____	_____
6. I get upset easily at home.	6. _____	_____
7. It takes me a long time to get used to anything new.	7. _____	_____
8. I'm popular with people my own age.	8. _____	_____
9. My family expects too much of me.	9. _____	_____
10. My family usually considers my feelings.	10. _____	_____
11. I give in very easily.	11. _____	_____
12. It's pretty tough to be me.	12. _____	_____
13. Things are all mixed up in my life.	13. _____	_____
14. Other people usually follow my ideas.	14. _____	_____
15. I have a low opinion of myself.	15. _____	_____
16. There are many times when I'd like to leave home.	16. _____	_____
17. I often feel upset about the work that I do.	17. _____	_____
18. I'm not as nice looking as most people.	18. _____	_____
19. If I have something to say, I usually say it.	19. _____	_____
20. My family understands me.	20. _____	_____
21. Most people are better liked than I am.	21. _____	_____
22. I usually feel as if my family is pushing me.	22. _____	_____
23. I often get discouraged at what I am doing.	23. _____	_____
24. Things usually don't bother me.	24. _____	_____
25. I can't be depended on.	25. _____	_____

In order for the staff to be more sensitive to the social and psychological needs of cancer patients, we need to know how people are affected by the disease. For each of the Items 1.-24. below, please:

- (1) Compare yourself now with the way you were before your spouse had cancer and circle one of the choices: (2) Decide if the way you are now is

- (a) MUCH WORSE than before cancer
 (b) WORSE than before cancer
 (c) ABOUT THE SAME as before cancer
 (d) BETTER than before cancer
 (e) MUCH BETTER than before cancer
 (f) does not apply to me
- (x) because of cancer
 (y) because of treatment
 (z) has nothing to do with cancer

		<u>worse-better</u>									
1.	OUTLOOK ON LIFE	a	b	c	d	e	f		x	y	z
2.	SELF RESPECT	a	b	c	d	e	f		x	y	z
3.	RELATIONSHIP WITH MY SPOUSE	a	b	c	d	e	f		x	y	z
4.	RELATIONSHIP WITH MY CHILDREN	a	b	c	d	e	f		x	y	z
5.	RELATIONSHIPS WITH MY FRIENDS	a	b	c	d	e	f		x	y	z
6.	ABILITY TO EXPRESS MYSELF	a	b	c	d	e	f		x	y	z
7.	ABILITY TO ENJOY MYSELF	a	b	c	d	e	f		x	y	z
8.	ABILITY TO RELAX	a	b	c	d	e	f		x	y	z
9.	ABILITY TO BE INDEPENDENT	a	b	c	d	e	f		x	y	z
10.	GENERAL ABILITY TO HANDLE EVERYDAY EVENTS	a	b	c	d	e	f		x	y	z
11.	LOVE FOR MY SPOUSE	a	b	c	d	e	f		x	y	z
12.	ABILITY TO BE ACTIVE	a	b	c	d	e	f		x	y	z
13.	ABILITY TO GET ALONG WITH OTHERS	a	b	c	d	e	f		x	y	z
14.	ABILITY TO PLAN DAILY ACTIVITIES	a	b	c	d	e	f		x	y	z
15.	ABILITY TO PLAN FOR THE FUTURE	a	b	c	d	e	f		x	y	z
16.	SATISFACTION WITH WORK	a	b	c	d	e	f		x	y	z
17.	SENSE OF ANXIETY	a	b	c	d	e	f		x	y	z
18.	SENSE OF PEACE	a	b	c	d	e	f		x	y	z
19.	SATISFACTION WITH MATERIAL THINGS	a	b	c	d	e	f		x	y	z
20.	SATISFACTION WITH BEING ALONE	a	b	c	d	e	f		x	y	z
21.	SATISFACTION WITH SEX	a	b	c	d	e	f		x	y	z
22.	FEAR OF DEATH	a	b	c	d	e	f		x	y	z
23.	SATISFACTION WITH RELIGION	a	b	c	d	e	f		x	y	z
24.	ABILITY TO THINK THINGS THROUGH CLEARLY	a	b	c	d	e	f		x	y	z

This questionnaire is designed to measure how much anxiety you are currently feeling. It is not a test so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by placing a number beside each one as follows:

- 1 = Rarely or none of the time
- 2 = A little of the time
- 3 = Some of the time
- 4 = A good part of the time
- 5 = Most or all of the time

- ___ 1. I feel calm.
- ___ 2. I feel tense.
- ___ 3. I feel suddenly scared for no reason.
- ___ 4. I feel nervous.
- ___ 5. I use tranquilizers or antidepressants to cope with my anxiety.
- ___ 6. I feel confident about the future.
- ___ 7. I am free from senseless or unpleasant thoughts.
- ___ 8. I feel afraid to go out of my house alone.
- ___ 9. I feel relaxed and in control of myself.
- ___ 10. I have spells of terror or panic.
- ___ 11. I feel afraid in open spaces or in the streets.
- ___ 12. I feel afraid I will faint in public.
- ___ 13. I am comfortable traveling on buses, subways, or trains.
- ___ 14. I feel nervousness or shakiness inside.
- ___ 15. I feel comfortable in crowds, such as shopping or at a movie.
- ___ 16. I feel comfortable when I am left alone.
- ___ 17. I rarely feel afraid without good reason.
- ___ 18. Due to my fears, I unreasonably avoid certain animals, objects, or situations.
- ___ 19. I get upset easily or feel panicky unexpectedly.
- ___ 20. My hands, arms, or legs shake or tremble.
- ___ 21. Due to my fears, I avoid social situations, whenever possible.
- ___ 22. I experience sudden attacks of panic which catch me by surprise.
- ___ 23. I feel generally anxious.
- ___ 24. I am bothered by dizzy spells.
- ___ 25. Due to my fears, I avoid being alone, whenever possible.

Please read the following and rate the degree to which you generally or typically experience each symptom when you are feeling anxious. Rate each item by filling in *one* number from 1 through 5 in the left-hand column, with 1 representing "not at all" and 5 representing "very much so." Be sure to answer every item and try to be as honest and accurate as possible in your responses.

1	2	3	4	5
Not at all				Very much so

- 1. Some unimportant thought runs through my mind and bothers me.
- 2. I perspire.
- 3. I imagine terrifying scenes.
- 4. I become immobilized.
- 5. My heart beats faster.
- 6. I can't keep anxiety-provoking pictures out of my mind.
- 7. I nervously pace.
- 8. I find it difficult to concentrate because of uncontrollable thoughts.
- 9. I can't keep anxiety-provoking thoughts out of my mind.
- 10. I feel like I am losing out on things because I can't make up my mind soon enough.
- 11. I feel tense in my stomach.
- 12. I get diarrhea.
- 13. I worry too much over something that doesn't really matter.
- 14. I feel jittery in my body.

This questionnaire is designed to measure the degree of satisfaction you have in the sexual relationship with your partner. It is not a test, so there are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a number beside each one as follows:

- 1 = Rarely or none of the time
- 2 = A little of the time
- 3 = Some of the time
- 4 = Good part of the time
- 5 = Most or all of the time

- ___ 1. I feel that my partner enjoys our sex life.
- ___ 2. My sex life is very exciting.
- ___ 3. Sex is fun for my partner and me.
- ___ 4. I feel that my partner sees little in me except for the sex I can give.
- ___ 5. I feel that sex is dirty and disgusting.
- ___ 6. My sex life is monotonous.
- ___ 7. When we have sex it is too rushed and hurriedly completed.
- ___ 8. I feel that my sex life is lacking in quality.
- ___ 9. My partner is sexually very exciting.
- ___ 10. I enjoy the sex techniques that my partner likes or uses.
- ___ 11. I feel that my partner wants too much sex from me.
- ___ 12. I think that sex is wonderful.
- ___ 13. My partner dwells on sex too much.
- ___ 14. I feel that sex is something that has to be endured in our relationship.
- ___ 15. My partner is too rough or brutal when we have sex.
- ___ 16. My partner observes good personal hygiene.
- ___ 17. I feel that sex is a normal function of our relationship.
- ___ 18. My partner does not want sex when I do.
- ___ 19. I feel that our sex life really adds a lot to our relationship.
- ___ 20. I would like to have sexual contact with someone other than my partner.
- ___ 21. It is easy for me to get sexually excited by my partner.
- ___ 22. I feel that my partner is sexually pleased with me.
- ___ 23. My partner is very sensitive to my sexual needs and desires.
- ___ 24. I feel that I should have sex more often.
- ___ 25. I feel that my sex life is boring.

Using the scale below, indicate the number which best describes how often you felt or behaved this way--DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
- 2 = Some or a little of the time (1-2 days)
- 3 = Occasionally or a moderate amount of time (3-4 days)
- 4 = Most or all of the time (5-7 days)

DURING THE PAST WEEK:

- ___ 1. I was bothered by things that usually don't bother me.
- ___ 2. I did not feel like eating; my appetite was poor.
- ___ 3. I felt that I could not shake off the blues even with help from my family or friends.
- ___ 4. I felt that I was just as good as other people.
- ___ 5. I had trouble keeping my mind on what I was doing.
- ___ 6. I felt depressed.
- ___ 7. I felt that everything I did was an effort.
- ___ 8. I felt hopeful about the future.
- ___ 9. I thought my life had been a failure.
- ___ 10. I felt fearful.
- ___ 11. My sleep was restless.
- ___ 12. I was happy.
- ___ 13. I talked less than usual.
- ___ 14. I felt lonely.
- ___ 15. People were unfriendly.
- ___ 16. I enjoyed life.
- ___ 17. I had crying spells.
- ___ 18. I felt sad.
- ___ 19. I felt that people disliked me.
- ___ 20. I could not get "going."

- Yes No 1. Do you worry a lot about your health?
- Yes No 2. Do you think there is something seriously wrong with your body?
- Yes No 3. Does your illness interfere with your life a great deal?
- Yes No 4. Are you easy to get on with when you are ill?
- Yes No 5. Does your family have a history of illness?
- Yes No 6. Do you think you are more liable to illness than other people.
- Yes No 7. If the doctor told you that he could find nothing wrong with you would you believe him?
- Yes No 8. Is it easy for you to forget about yourself and think about all sorts of other things?
- Yes No 9. If you feel ill and someone tells you that you are looking better, do you become annoyed?
- Yes No 10. Do you find that you are often aware of various things happening in your body?
- Yes No 11. Do you ever think of your illness as a punishment for something you have done wrong in the past?
- Yes No 12. Do you have trouble with your nerves?
- Yes No 13. If you feel ill or worried, can you be easily cheered up by the doctor?
- Yes No 14. Do you think that other people realize what it's like to be sick?
- Yes No 15. Does it upset you to talk to the doctor about your illness?
- Yes No 16. Are you bothered by many pains and aches?
- Yes No 17. Does your illness affect the way you get on with your family or friends a great deal?
- Yes No 18. Do you find that you get anxious easily?
- Yes No 19. Do you know anybody who has had the same illness as you?
- Yes No 20. Are you more sensitive to pain than other people?
- Yes No 21. Are you afraid of illness?
- Yes No 22. Can you express your personal feelings easily to other people?
- Yes No 23. Do people feel sorry for you when you are ill?
- Yes No 24. Do you think that you worry about your health more than most people?
- Yes No 25. Do you find that your illness affects your sexual relations?
- Yes No 26. Do you experience a lot of pain with your illness?
- Yes No 27. Except for your illness, do you have any problems in your life?
- Yes No 28. Do you care whether or not people realize you are sick?
- Yes No 29. Do you find that you get jealous of other people's good health?
- Yes No 30. Do you ever have silly thoughts about your health which you can't get out of your mind, no matter how hard you try?
- Yes No 31. Do you have any financial problems?
- Yes No 32. Are you upset by the way people take your illness?
- Yes No 33. Is it hard for you to believe the doctor when he tells you there is nothing for you to worry about?
- Yes No 34. Do you often worry about the possibility that you have got a serious illness?
- Yes No 35. Are you sleeping well?
- Yes No 36. When you are angry, do you tend to bottle up your feelings?
- Yes No 37. Do you often think that you might suddenly fall ill?
- Yes No 38. If a disease is brought to your attention (through the radio, television, newspapers, or someone you know) do you worry about getting it yourself?
- Yes No 39. Do you get the feeling that people are not taking your illness seriously enough?
- Yes No 40. Are you upset by the appearance of your face or body?
- Yes No 41. Do you find that you are bothered by many different symptoms?
- Yes No 42. Do you frequently try to explain to others how you are feeling?
- Yes No 43. Do you have any family problems?
- Yes No 44. Do you think there is something the matter with your mind?
- Yes No 45. Are you eating well?
- Yes No 46. Is your bad health the biggest difficulty of your life?
- Yes No 47. Do you find that you get sad easily?
- Yes No 48. Do you worry or fuss over small details that seem unimportant to others?
- Yes No 49. Are you always a cooperative patient?
- Yes No 50. Do you often have the symptoms of a very serious disease?
- Yes No 51. Do you find that you get angry easily?
- Yes No 52. Do you have any work problems?
- Yes No 53. Do you prefer to keep your feelings to yourself?
- Yes No 54. Do you often find that you get depressed?
- Yes No 55. Would all your worries be over if you were physically healthy?
- Yes No 56. Are you more irritable towards other people?
- Yes No 57. Do you think that your symptoms may be caused by worry?
- Yes No 58. Is it easy for you to let people know when you are cross with them?
- Yes No 59. Is it hard for you to relax?
- Yes No 60. Do you have personal worries which are not caused by physical illness?
- Yes No 61. Do you often find that you lose patience with other people?
- Yes No 62. Is it hard for you to show people your personal feelings?

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the PAST WEEK, INCLUDING TODAY. Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

- 1 0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad or unhappy that I can't stand it.
- 2 0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless and that things cannot improve.
- 3 0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.
- 4 0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.
- 5 0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.
- 6 0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.
- 7 0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.
- 8 0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.

- 9 0 I don't have any thoughts of killing myself.
 1 I have thoughts of killing myself, but I would not carry them out.
 2 I would like to kill myself.
 3 I would kill myself if I had the chance.
- 10 0 I don't cry anymore than usual.
 1 I cry more now than I used to.
 2 I cry all the time now.
 3 I used to be able to cry, but now I can't cry even though I want to.
- 11 0 I am no more irritated now than I ever am.
 1 I get annoyed or irritated more easily than I used to.
 2 I feel irritated all the time now.
 3 I don't get irritated at all by the things that used to irritate me.
- 12 0 I have not lost interest in other people.
 1 I am less interested in other people than I used to be.
 2 I have lost most of my interest in other people.
 3 I have lost all of my interest in other people.
- 13 0 I make decisions about as well as I ever could.
 1 I put off making decisions more than I used to.
 2 I have greater difficulty in making decisions than before.
 3 I can't make decisions at all anymore.
- 14 0 I don't feel I look any worse than I used to.
 1 I am worried that I am looking old or unattractive.
 2 I feel that there are permanent changes in my appearance that make me look unattractive.
 3 I believe that I look ugly.
- 15 0 I can work about as well as before.
 1 It takes an extra effort to get started at doing something.
 2 I have to push myself very hard to do anything.
 3 I can't do any work at all.
- 16 0 I can sleep as well as usual.
 1 I don't sleep as well as I used to.
 2 I wake up 1-2 hours earlier than usual and find it hard to go back to sleep.
 3 I wake up several hours earlier than I used to and cannot get back to sleep.
- 17 0 I don't get more tired than usual.
 1 I get tired more easily than I used to.
 2 I get tired from doing almost anything.
 3 I am too tired to do anything.
- 18 0 My appetite is no worse than usual.
 1 My appetite is not as good as it used to be.
 2 My appetite is much worse now.
 3 I have no appetite at all anymore.

- 19 0 I haven't lost much weight, if any lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less.
Yes _____ No _____

- 20 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains;
upset stomach; or constipation.
2 I am very worried about physical problems and it's hard to
think of much else.
3 I am so worried about my physical problems, that I cannot think
about anything else.
- 21 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

Table 1.

Frequency Table of Site of Cancer by Marital Status
Marital Status

Site of Cancer	Married	Single/Separated	Widowed	Totals
Ovarian	3 15	5 25	1 5	9 45
Cervical	2 10	1 5	0 0	3 15
Endometrial	3 15	2 10	1 5	6 30
Vulvar	1 5	1 5	0 0	2 10
Totals	9 45	9 45	2 10	20 100

-Note-: The first row for each cancer site is actual frequency.
The second row is the percentage of the total sample represented by that frequency.

Table 2.

Frequency Table Showing Site of Cancer by Income

Site of Cancer	Income				
	Under \$20,000	\$20,000-\$30,000	\$30,000-\$45,000	\$45,000-\$75,000	
Ovary	3 15	1 5	2 10	3 15	9 45
Cervix	0 0	0 0	2 10	1 5	3 15
Uterus	2 10	3 15	1 5	0 0	6 30
Vulva	0 0	1 5	0 0	1 5	2 1
Totals	5 25	5 25	5 25	5 25	20 100

-Note-: The first row for each cancer site is actual frequency.

The second row is the percentage of the total sample represented by that frequency.

TABLE 3
CORRELATIONS OF PRE- AND POST-SURGICAL SEXUAL FUNCTIONING MEASURES

POST-SURGERY	PRE-SURGERY		
	Compatibility	Relationship	Sexual Activity Frequency
Emotional Sexual Concerns	-.286 .221	R -.477* P .033	.288 .218
Partner Physical/ Sexual Concerns for Patient/Self	.014 .954	R -.075 P .752	-.057 .810
Patient Physical/ Sexual Concerns	.412 .071	R .067 P .780	.261 .266
Relationship	.164 .489	R .528* P .017	.045 .850
Compatibility	.686*** .001	R .288 P .219	-.061 .798
No. Reasons for Engaging in Sex	.103 .665	R -.142 P .550	.500* .025
No. Reasons for Avoiding Sex	.069 .774	R -.267 P .255	.652** .002
Global Attitude toward Sex	.156 .512	R .169 P .478	-.118 .619
Sexual Activity Frequency	.392 .088	R .096 P .688	.493* .027

*-p<.05. **-p<.01. ***-p<.001.

Note: First rows contain correlations. Second rows contain probabilities indicating prob> |R| under HO:RHO = 0.

TABLE 4
CORRELATIONS OF MEASURES OF POST-SURGICAL SEXUAL FUNCTIONING WITH LIBIDO

	No. of Reasons for Engaging in Sex		No. of Reasons for Avoiding Sex		Sexual Satisfaction
Emotional Concerns Altering Physical Sex	R	.201		.386	.306
	P	.395		.092	.190
Perceived Partner Physical/Sexual Concerns for Patient and Self.	R	.106		.128	.542*
	P	.658		.590	.014
Patient Physical/ Sexual Concerns for Self	R	.545 *		.579**	.486*
	P	.013		.008	.030
Global Attitude toward Sex	R	-.043		-.320	.009
	P	.858		.170	.970
Sexual Activity Frequency	R	.517 *		.622**	.473*
	P	.020		.003	.035

*-p<.05.

**-p<.01.

Note: First rows contain correlations. Second rows contain probabilities indicating prob > |R| under H₀:RHO = 0.

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