Treatment for Gynecologic Cancer: A Review of the Effects on Female Sexuality

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Abstract

Approximately 75,000 new cases of gynecologic cancer are diagnosed in the United States each year. Since few women can be treated by chemotherapy alone, most undergo extensive treatments that directly alter their sexuality either by causing specific anatomic changes or by generating concerns about continued responsiveness or activity. The major treatments for gynecologic malignancies including radiation therapy or radical hysterectomy for cervical carcinoma, radical vulvectomy for vulvar carcinoma, and pelvic exenteration for recurrent disease, are outlined. Research relating to their effects on female sexuality is critically reviewed. Also discussed are the relevant domains of treatment and patient characteristics that need assessment and investigation in this new and important research area.

INTRODUCTION

Each year approximately 75,000 women are diagnosed as having some form of invasive gynecologic cancer (Cancer Statistics, 1982). Malignancies of the female genital organs are second in frequency only to breast cancer among women. With earlier diagnosis and aggressive modes of treatment, it has been estimated that two-thirds of these women will survive five years.

Although these prognostic factors have improved, concerns for the quality of life for gynecologic oncology patients remain (Newton, 1979). In addition to the distress that comes with a cancer diagnosis, a gynecologic site poses additional problems. Authors have speculated that pelvic operations produce greater psychological distress for women than do other surgeries (Daley, 1976; Hollender, 1960). Many women are depressed and anxious anticipating treatments or adjusting to their effects. Still others refuse surgical procedures such as pelvic exenteration knowing that death is the alternative because of concerns about body image and lifestyle following the surgery. Other lines of data also point to the importance of this research. The first comes from an investigation by Vincent, Vincent, Greiss, and Linton (1975) which provides the only survey of gynecologic oncology patients need for sexual information. Thirty-five of 50 women (70%) receiving either surgery or radiation therapy reported that they had received no information regarding sexual adjustment before, during, or after treatment. However, while the majority (80%) of the sample desired information, the women also stated that they would not bring up the subject themselves but preferred discussion initiated by the medical team. Marital and sexual difficulties after surgery have also been found among other female oncology patients (Wellisch, Jamison, &

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Pasnau, 1978). In one study 33% of the mastectomy patients interviewed up to one year post-operatively reported such difficulties in comparison to 11% of a comparison group of benign breast tumor biopsy patients (Lee & Maguire, 1975). Finally, in a survey of cancer patients and their spouses, female patients emerged as the most depressed subgroup (Leiber, Plumb, Gertenzang, & Holland, 1976). Additionally, 60% of the female sample reported a decline in desire for intercourse in comparison to only 27% of the male cancer patients. It is important to note, however, that a large portion of the female sample was made up of mastectomy patients; raising the hypothesis that concern over change to a sexual part of the body may have a direct and negative effect on sexuality. Thus, examination of the psychosexual impact of treatment for female genital cancer has been advocated (Donahue & Knapp, 1977; Johnson, 1976; Twombly, 1968; Weinberg, 1974) and seems essential.

This article overviews the major treatments for gynecologic malignancies and what is presently known of their effects on female sexuality.[1] This includes radical hysterectomy and radiation therapy, alternatives for early stage carcinoma of the cervix; radical vulvectomy in the treatment of vulvar. cancer; and, pelvic exenteration for recurrent disease. A final portion of the paper discusses relevant domains of treatment and patient characteristics that need assessment and investigation in this new and important research area.

RADICAL HYSTERECTOMY AND RADIATION IN THE TREATMENT OF CERVICAL CANCER

Cancer of the cervix is the second most common malignancy of the female genital tract. An estimated 30,000 new cases are detected annually in the United States and of these approximately 40% will be Stage I lesions.[2] Etiological investigations of cervical carcinoma are of interest in that there has been considerable research into the possibility of sexually transmitted carcinogenic factors (Gagnon, 1950). Search for a transmissable agent has rested on three lines of data: (1) demographics of cultural variables associated with increased risk; (2) an epidemiological focus on sexual factors maximizing risk; and (3) a hypothesis that cervical cancer begins and develops according to a multistage continuum of intra-epithelial neoplasia. An early review by Rotkin (1973) noted the onset of active sexual behavior before age 17 as a discriminating variable and a history of multiple sexual partners as an important factor, though the latter may be less contributory (Sebastian, Leeb, & See, 1978). These correlational data are of particular note in that their dissemination in the popular press linking sexuality with cancer could easily worsen a woman's already vulnerable sexual

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[1]No relevant data are available for patients with ovarian or endometrial cancer, though the standard treatment for both includes a total abdominal hysterectomy and ovary removal. Numerous investigations have been conducted on the psychosocial response following this surgery for benign conditions (Kolodny, Masters, & Johnson, 1979). However, because of the guarded prognosis associated with malignant disease and the likely need for postoperative chemotherapy and/or radiotherapy, the psychosocial response of these patients is likely to be different from the population with benign disease and perhaps more similar to cervical cancer patients undergoing radical hysterectomy or radiation therapy

[2]Gynecologic cancers are staged depending on the extent of the local disease and the presence or absence of distant metastases. The stage correlates well with prognosis. For cervical cancer the stages are presented along with current estimates of survival of at least five years duration following treatment. These survival figures are from the Annual Report edited by Kottmeier (1972):

Stage 0 Disease not extending below the basement membrane and sometimes referred to as a premalignant condition. It is commonly called in situ or intraepithelial carcinoma (cancer). Five-year survival 100%.

Stage I Carcinoma confined to the cervix. Five-year survival 80.0%.

Stage II Carcinoma extending beyond the cervix but not to the pelvic sidewall. Disease extending into the vagina, but not as far as the lower one-third. Five-year survival 58.9%.

Stage III Carcinoma extending to the pelvic sidewall or to the lower one-third of the vagina. Five-year survival 31.2%.

Stage IV Carcinoma extending beyond the true pelvis or clinically involving the mucous membrane of the bladder or rectum. Five-year survival 8.3%.

response. Regarding her cancer as a form of venereal disease or as a product of her sexual needs would do little to enhance a woman's adjustment following treatment.

Controversy exists regarding the optimal mode of therapy for patients with Stage I carcinoma of the cervis, both radical hysterectomy[3] and radiation therapy[4] having their proponents. Since numerous studies have demonstrated that the cure rate is approximately equal (McGowan, 1978), physicians have been urged to consider the quality of life when choosing therapy for an individual patient. Surgical treatment allows preservation of ovarian functioning, an advantage for premenopausal women in that the continuation of sex steroid production keeps the vaginal walls healthy. Presumably sexual functioning should remain unchanged, though some women report coital discomfort from vaginal shortening (Abitbol & Davenport, 1974;Seibel, Freeman, & Graves, 1980). It has also been suggested that responsiveness may be indirectly affected due to emotional concomitants of loss of the uterus (Polivy, 1974). Radiation treatment destroys ovarian functioning, and estrogen replacement can only minimally compensate for the vaginal atrophy and stenosis which may occur following treatment (Abitbol & Davenport, 1974;Kaufman, Topek, & Wall, 1961;Vasicka, Popovich, & Brausch, 1958). Not surprisingly, dyspareunia may be a problem for such patients. While unhampered sexual functioning is a frequently voiced argument in favor of surgical management, particularly for younger women, there have been few assessments of sexual functioning following either treatment.

The first descriptive study of the posttreatment sexual adjustment of radiation patients was done by Vasicka, Popovich, and Brausch (1958). Sixteen patients with either Stage I or Stage II disease were interviewed. The average length of time since each patient had received treatment was four years and eight months. In addition to providing descriptions of vaginal change and posttreatment symptomatology, particular effort was made to elicit information regarding loss of sexual desire, difficulties during sex with a partner, intercourse pain, and continuing gynecologic problems (e.g., vaginal discharge, post-coital bleeding). The gynecologic findings indicated that in approximately ⅔ of the patients the vaginal barrel was markedly shortened and only minimally functional for ⅓ of the patients. For one woman the vagina was completely closed. In light of these data, the findings of disrupted sexual adjustment were not surprising. Approximately ½ of the patients reported noteworthy decreases in sexual activity and ¼ reported dyspareunia.

These investigators provided the first descriptive report of the physical consequences of radiation treatment on the lower genital tract, yet sample selection difficulties limit the generalizability of the findings. In addition to the small sample size, particular characteristics of the patients are noteworthy. First, 14 of the 16 women surveyed were black. While only limited data concerning the sexual practices of various ethnic populations are available (Wyatt, Strayer, & Lobitz, 1978), this factor could alter the findings. Second, the sample included patients with both Stage I and II disease, and it is possible that disruption in sexual functioning covaries with the severity of the disease or the dosage of radiation used. Nevertheless, this pioneer report provided clinical information on the vaginal changes following radiation therapy and discussion of the emotional and cognitive variables that may affect sexual adjustment.

Decker and Schwartzman (1962) presented the first treatment comparison data with the addition of a type of control. The primary group of patients included women with Stage I, II, or III cervical cancer. There were 29 radiation therapy patients and 32 radical hysterectomy

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[3]Radical hysterectomy includes removal of the uterus, cervix, tissues lateral to the uterus, and upper one-third of the vagina.
[4]Radiation therapy for cervical cancer usually includes a combination of external irradiation to the pelvis and the placement of radium implants into the uterus and vagina.

patients interviewed by the investigator, however the two subgroups were not equated for stage of disease. Unfortunately, an unreported number of the hysterectomy patients were also treated with radiation, a factor which confounds the treatment comparison. Another group consisted of 17 patients with carcinoma in situ treated with total abdominal hysterectomy and ovary removal. This group controls for hysterectomy, per se, however other differences (e.g., prognosis) which could potentially affect sexuality remain as well. While age at treatment and interview was reported, this was not a matching variable and significant differences between groups probably existed, particularly for the radiation group which was older than the carcinoma in situ group.

All patients were interviewed at least 6 months posttreatment, though ½ of the sample were interviewed 3 to 10 years after they had been treated. The patients were asked to recall their sexual adjustment prior to treatment and provide a global evaluation of the changes in frequency of sexual contact, interest, and gratification that had subsequently occurred. Reports that sexuality remained unchanged or improved were obtained for 38% (11 of 39) of the radiation, 63% (20 of 32) of the radical hysterectomy, and 76% (13 of 17) of the in situ patients. Estimates that sexuality was diminished or absent following treatment were obtained for 55% (16 of 29) of the radiation, 19% (6 of 32) of the radical hysterectomy, and 12% (2 of 17) of the in situ patients. It would appear from these data that the sexual adjustment following radiation therapy is less favorable than that following hysterectomy. However, due to the design limitations and the lack of statistical analyses, it is unknown whether or not these group differences reflect original pretreatment differences in sexual functioning, differences in stages of disease, or actual treatment differences.

Abitbol and Davenport (1974) provided additional treatment comparison data and added another group which received combined treatment. Seventy-five women with either Stage I or II disease were interviewed. Thirty-two had surgical treatment, 28 radiation therapy and 15 combined surgery and radiation. The groups were not equated on any variable and the number of premenopausal women in whom the ovaries were preserved at the time of surgery is not reported. Subjects provided global retrospective evaluations of sexual functioning prior to treatment and current reports of adjustment. Estimates of no change or improvement in sexual functioning were reported by 11% (3 of 28) of the patients following radiation, 81% (26 of 32) following surgery, and 47% (7 of 15) following combined treatment. Estimates of only minimal changes in activity were reported by 10% to 20% of all patients. Sexual activity was markedly reduced or completely halted for 79% (22 of 28) of the patients following radiation, 6% (2 of 32) following surgery, and 33% (5 of 15) following combined treatment.

This investigation also reported on the anatomical changes (i.e., narrowing and/or obliteration of the vagina). Major vaginal changes were noted in 78% of the irradiated, 10% of the surgical, and 60% of the combined treatment cases. Overlap between the women having vaginal change and also reporting significant sexual disruption occurred in 91% (20 of 22) of the irradiated group, 50% (1 of 2) of the surgical group, and 60% (3 of 5) of the combined group. Thus, when treatment produces major change to the vaginal canal, it appears likely, particularly in the case of radiation treatment, that disrupted sexual functioning occurs as well. It is unknown whether or not disrupted sexual functioning contributes to alterations in the vaginal canal, or if sexual adjustment could improve despite such permanent change.

Vincent, Vincent, Greiss, and Linton (1975) also reported on the marital-sexual concomitants of carcinoma of the cervix in the only well controlled prospective investigation. Fifty women, diagnosed as having Stage I or II disease and considered equally treatable by either surgery or radiation, were randomly assigned to treatment and

interviewed on three occasions: immediately after diagnosis and before treatment, during treatment, and 6 months posttreatment. The groups were matched for such important factors as age, education, socioeconomic status, marital status, parity, race, and cancer stage at diagnosis. Unlike the results of previous investigations, the changes in sexual desire and activity from pretreatment to 6 months posttreatment appeared comparable for the two interventions. Estimates of no change or improvement in desire for coitus were reported by 48% of irradiated and 52% of the operated patients; similar reports were obtained for the frequency of coitus (i.e., 43% and 39% of the irradiated and operated patients, respectively, reporting no change or improvement). Reports of diminished desire for coitus were obtained from 24% of the radiation therapy patients and 20% of the surgical patients. Decreased frequency of intercourse was reported by 29% of the radiation and 33% of the surgical patients.

This investigation is noteworthy due to its methodological rigor in comparison to prior and recent reports. However, difficulties in the manner in which the data were collected require mention. While subjects provided estimates of their current frequency of intercourse at the time of admission, such data were not obtained at followup. Instead, patients were asked whether desire for or frequency of intercourse was greater, less, or equal to their recollections of pretreatment level. Since exact frequency data were not again obtained and compared with the pretreatment estimates, the followup determinations are essentially *retrospective* reports rather than pre- and posttreatment comparisons. It is also important to note that a 6-month followup period may not be sufficient to assess the full impact of radiation therapy, since vaginal atrophy and stenosis from this treatment continue for two years.

The most recent investigation was conducted by Seibel, Freeman and Graves (1980). One group of 22 patients was treated for Stage I, II, or III disease by radiation, and the other group consisted of 20 patients who had undergone hysterectomy with or without partial vaginectomy for carcinoma in situ. Thus, this is a report of two different populations differing not only in treatment but also in such variables as age and presence or absence of life threatening invasive cancer. Estimates that sexual enjoyment was the same or greater following treatment were reported by 28% (6 of 22) of the patients with invasive disease treated with radiation and 70% (14 of 20) of the in situ patients treated surgically. Estimates that sexual enjoyment was diminished after treatment were reported by 45% (10 of 22) of the radiation and 25% (5 of 20) of the surgical patients. Reports of the change in frequency of intercourse also indicated a significant reduction for the radiation group.

Summary

While the reports of the psychosexual impact of hysterectomy and radiation treatment can be summarized, it is difficult to draw conclusions. First, the research strategy selected by several of the investigators is methodologically weak. For decades psychologists have questioned both the reliability and validity of the interview, either structured or unstructured, as a primary data source. In addition, in all studies the same individuals provided the treatment and conducted the interviews. Thus, bias either on the part of the interviewer or interviewee could exist. Second, with the exception of one investigation (Vincent, Vincent, Greiss, & Linton, 1975), the data are uncontrolled and confounded by relevant domains of variables such as age, stage of disease, and so forth, which potentially covary with outcome. Third, the sexuality data is either broadly or narrowly defined. Typically women were asked to provide global estimates of previous, current, or changed sexual functioning, without defining the constructs of "sexual adjustment" or "change." In other studies sexuality was equated with frequency of intercourse or orgasm. Either strategy has numerous problems.

Finally, the results from the previous investigations are conflicting. In the poorly controlled retrospective investigations, estimates of diminished or completely disrupted sexuality ranged from 44% to 79% for the radiation therapy patients and from 6% to 19% for the hysterectomy patients. However, when the stage of disease and other variables were controlled prospectively, comparable percentages of patients from both treatments (i.e., 29% and 33% of radiation and hysterectomy patients, respectively) reported difficulties. Thus, a well-controlled, prospective, and comprehensively assessed psychosexual investigation of the effects of radiation and surgical treatment for cervical carcinoma is necessary.

RADICAL VULVECTOMY IN THE TREATMENT OF VULVAR CARCINOMA

Cancer of the vulva is the fourth most common female genital malignancy, accounting for approximately 5% of all gynecologic cancers. Pruritus is often a longstanding and common presenting complaint, though most women present with a lump (Morley, 1976). In either case, it is not surprising for a woman to think that she may have a vaginal infection or venereal disease from the symptomatology. It is even alarmingly common for physicians to ignore or misinterpret such complaints so that patients undergo months of unsuccessful local treatment before a biopsy is taken and the cancer diagnosed.

While vulvar carcinoma can remain localized for considerable time, it eventually spreads in predictable fashion to the regional lymph nodes (Way, 1948). In either case, the typical treatment includes radical vulvectomy.[5] Radiation therapy is seldom used because of severe vulvitis that results from such treatment. There appears to be an increasing incidence of in situ disease, particularly in younger patients (Buscema, Woodruff, Parmley, & Genadry, 1980) and a subgroup of patients with superficial invasion is also being defined (Parker, Duncan, Rampone, & Creasman, 1975; Wharton, Gallager, & Rutledge, 1974). For these entities less radical but presumably equally effective treatments have been advocated because of the serious impact radical vulvectomy has on body image and sexual functioning. Alternatives for carcinoma in situ include local excision of the lesion, application of topical 5-fluorouracil cream, and cryosurgery (Forney, Morrow, Townsend, & DiSaia, 1977). For microinvasive carcinoma, wide local excision rather than total vulvectomy has been suggested (DiSaia, Creasman, & Rich, 1979).

Despite the severely disfiguring nature of the surgery and the difficult postoperative period these patients experience, there had been only two reports of the psychosocial or psychosexual course of these patients. One case report described a counseling effort for the post-operative recovery and continued sexual activity and orgasmic response[6] of a 27 year old patient (Cheek, 1976). The other was a short questionnaire survey of 18 patients treated with wide local excision rather than vulvectomy for microinvasive disease (DiSaia, Creasman, & Rich, 1979). All women in the sample described themselves as continuing to be orgasmic during sexual activity without any reports of dyspareunia. This information was in contrast to two radical vulvectomy patients who reported loss of orgasmic ability and dyspareunia.

We recently completed the first investigation of vulvar cancer patients which included a posttreatment assessment of current psychological, social, and sexual adjustment (Andersen & Hacker, in press). Fifteen patients treated surgically were individually interviewed and

[5]Treatment of invasive vulvar cancer involves radical vulvectomy (which includes removal of the clitoris and all labial tissue), and bilateral groin lymph node removal, with or without pelvic lymph node removal.

[6]As noted previously, the clitoris is typically removed with this surgery, though for some patients it may be preserved depending on the nature and extent of disease. It has been suggested that the clitoris plays two important roles in the sexual response, that of an organ for focused sexual stimulation and an endpoint for neurogenic pathways (Masters & Johnson, 1966). However, this case report and our own research suggest that the orgasmic response, per se, need not disappear despite clitoral excision.

they then completed a battery of self-report measures. The mean age of the sample was 55 years, with a range from 30 to 85 years. Time since surgery for the patients ranged from 5 to 216 months, with a mean interval of 5 years. Descriptive statistics indicated that as a group the patients appeared mildly distressed as indicated on the Symptom Checklist-90 (Derogatis, 1977), although on the Katz Adjustment Scales (Katz & Lyerly, 1963) they reported moderate levels of and satisfaction with their current social and leisure activities. Significant disruption in sexuality appeared to be a notable outcome, however, for this sample of patients. The Sexual Functioning Inventory (Derogatis & Melisaratos, 1979) used to estimate their current range and frequency of sexual activity provided values that were 50% lower than those for the normative samples of sexually active healthy women. There were discrepancies between the current and the ideal frequency of particular sexual behaviors, such as intercourse (i.e., once per month vs. once per week). Emotionally and cognitively the sample indicated a limited capacity for sexual arousal, with the sample mean score on the Sexual Arousability Index (Hoon, Hoon, & Wincze, 1976) reaching only the eighth percentile. This latter aspect of their sexual functioning may be partially due to the blunting of genital and pelvic sensitivity which occurs following vulvar surgery. Many women mentioned persistent numbness, so much so that on some intercourse occasions they were unsure when penile penetration occurred. Finally, the loss of the orgasmic response postsurgery was reported by women who had and who had not undergone clitoral excision at the time of vulvectomy. Further research is necessary to clarify the covariation of the magnitude of genital surgery and the range of sexual responsiveness. While these data represent an important preliminary effort, readers are reminded that they are limited by the absence of pretreatment observations, repeated assessment, and comparison groups.

Vulva cancer typically occurs during the post menopausal years, most commonly between 65 and 70 years of age. The paucity of psychosocial data may be due to an attitude that sexuality is unimportant or expendable at this age. The stability of sexual needs through the life cycle, however, has been demonstrated. While a decline in the frequency and range of sexual activity occurs with advancing age, the presence of a healthy and interested partner appears to be the variable of importance to maintenance of female sexual activity rather than age, per se (Newman & Nichols, 1960; Pfeiffer & Davis, 1972). The available data indicate that vulva cancer patients attempt to maintain a sexual life despite major physical losses and emotional disruption. In addition, the increasing incidence of in situ disease, particularly in younger patients, warrants investigation of this gynecologic cancer population.

PELVIC EXENTERATION IN THE TREATMENT OF RECURRENT GYNECOLOGIC CANCER

Since its original description by Brunschwig in 1948, pelvic exenteration has become an accepted operation for advanced and recurrent gynecologic malignancy. Because of the unique propensity of tumors of the lower genital tract to remain localized to the pelvis even when recurrent, 5-year survival rates for pelvic exenteration patients in excess of 60% have been reported (Morley & Lindenauer, 1976).

The operation is both radical and morbid, and usually involves removal of the uterus, tubes, ovaries, urinary bladder, rectum and vagina, as well as part of the vulva. There are few surgical procedures which so dramatically alter a woman's sexual body. Patients must learn to manage one, if not two, abdominal stomas following removal of the urinary bladder and rectum. The few studies available on the sexual adjustment of female ostomates with either a colostomy or ileostomy have reported reduction in sexual arousal (Dlin, Perlman, & Ringold, 1969), dyspareunia (Burnham, Jones, & Brooke, 1976), and significant disruption in body image (Dlin, Perlman, & Ringold, 1969) not only immediately after surgery but also after lengthy followup.

The permanent closure of body openings, the vagina and/or rectum, can also be distressing. In recent years increasing attention has been directed towards reconstructive surgery (Lagasse, Berman, Watring, & Ballon, 1978). Various techniques for vaginal reconstruction have been described, including the use of split thickness skin grafts (West, Ketcham, & Smith, 1964; Morley & Lindenauer, 1976), the Williams vulvovaginoplasty procedure (Williams, 1964; Day & Stanhope, 1977), and the gracilis myocutaneous graft (McCraw & Massey, 1976; Becker, Massey, & McGraw, 1979). However, even women with reconstructed vaginas often do not resume intercourse due to persistent vaginal discharge or fears of pain, bleeding, cancer recurrence, or sexual anesthesia; partners of these women have such concerns as well (Andersen, Jakubowski, & Karlsson, 1982). Together these factors can combine to make a woman's sexual adjustment uncertain at best.

While much has been written about the technical aspects of exenterative surgery, vaginal reconstruction, and the postoperative morbidity, there is little description of the psychological difficulties of these patients and less of the functional aspects of the neovaginas. Knorr (1967) was the first to comment on the difficult posttreatment adjustment of the pelvic exenteration patient and described it as " a depressive syndrome." Fourteen patients were followed through a convalescent period from 8 weeks to 8 months. All were married and ranged in age from 39 to 63 years. Knorr saw all patients exhibiting symptoms of depression either immediately or within two weeks of surgery. Difficulties included vegetative signs, periods of crying, feelings ranging from apathy to mild depersonalization, and anxiety. Four of the patients were said to have considerable difficulty on returning home due to marital difficulties apparently exacerbated by the surgery. Major disruption of body concept was evidenced by all patients in that they were extremely careful to keep their abdomen covered and consistently exhibited increased anxiety and depression after stoma appliance care. Additionally, Knorr reported that all the women felt unattractive and confused as to what their sexual roles would be. Similar confusion was also reported by the patients' partners. Thus, this first report suggested major emotional concomitants to pelvic exenteration, which appeared early and continued during the lengthy recovery time.

Another descriptive report of the adjustment of 15 patients was provided by Brown, Haddox, Posada, and Rubio (1972). At the time of surgery the patients ranged in age from 35 to 59, and they were interviewed from 2 to 13 years after treatment. In terms of general adjustment, 80% of the women reported major disruptions in their social lives. In terms of sexuality, there was a significant alteration. While 87% of the sample reported that sexual activity had given them pleasure in the past, after treatment 73% of the sample reported no sexual interest. Only four women acknowledged any form of autoerotic activity such as erotic dreams or masturbation to orgasm. In addition, major disruptions in body concept were hypothesized by the authors from analysis of projective assessments. Thus, this report again suggested poor sexual adjustment for the majority of the patients.

The adjustment pattern of 16 patients was described by Dempsey, Buchsbaum and Morrison (1975). All patients were interviewed pre- and postoperatively and the mean age for the sample was 50 years. In terms of their emotional response, 10 of the 16 women reported feeling quite depressed preoperatively and two of them considered suicide. For approximately ⅓ if the women, depressive symptomatology continued after surgery. The investigators reported that sexuality was dramatically affected by the surgery. Of the ten women who had been previously sexually active only three remained so, partly due to the fact that these were the only women with neovaginas. The frequency of intercourse and orgasm also declined for these three women, and they became either anorgasmic or only rarely so.

A report by Vera (1981) again portrays a rather dismal outlook with respect to maintenance of sexual functioning. Nineteen patients ranging in age from 38 to 62 years were interviewed postoperatively. One woman had never engaged in sexual activity and three others refused participation in this portion of the investigation. Of the remaining 15 patients who had once been sexually active, only three remained so and even they reported a decrease in intercourse frequency and sexual desire. The sexually inactive women reported that the major reasons for the loss of activity was vaginal removal without reconstruction and anxiety about abdominal stomas. Three other women with neovaginas found intercourse painful and discontinued it. At the time of these interviews, 9 of the 19 patients were divorced or separated and one was single.

Our own research (Andersen & Hacker, 1983) has sought to provide convergent evidence with these previous reports and detailed preliminary data on the outcome following vaginal reconstruction. In an initial effort, 15 patients were interviewed postoperatively and completed a battery of self-report measures. At the time of assessment, the mean age of the sample was 54 years (range 28–73 years), and the mean time since exenteration was 5½ years (range from 7 to 135 months). As with the vulva cancer sample we studied, these patients also appeared to maintain a moderate but satisfying level of social and free-time activities. Also, to the extent that patients could do this, they reported less depressive symptomatology and general psychological distress. The majority of the sample had undergone vaginal reconstruction and it appeared that there were two important subgroups within this sample. One group reported that vaginal reconstruction had gone well and they were able to maintain as satisfactory sexual life. The other group reported disruption in the frequency of sexual activity, dissatisfaction with the variety of the activities or their arousal, or problems with the neovagina (e.g., the length was too short, the cavity too large, there was a chronic discharge, dyspareunia). Some women could maintain their orgasmic ability, but for others orgasm was lost or achieved only with extra effort. Finally, those women who were without sexual partners at the time of assessment were uniformly reluctant to initiate or respond to friendly contact with men due to sexuality concerns. Not knowing how to describe their bodily changes or fear of being seen as repulsive kept some women from any form of male companionship.

These descriptive data uniformly indicate considerable disruption in women's sexual adjustment following exenteration surgery. That this need not be the case is suggested by the report of Lamont, DePetrillo and Sargeant (1978) who described a comprehensive program designed for the psychosexual rehabilitation. The most unique aspect was the inclusion of a sexual counselor who provided assessment, specific information, and suggestions regarding sexuality pre- and postoperatively. They reported that 8 of 12 exenteration patients who participated in this program had a good postoperative sexual adjustment. In fact, for six of the patients orgasmic ability returned within 6 months of surgery. The authors attributed their positive outcome to a team approach in establishing comprehensive care.

Summary

At present some descriptive data exist concerning the psychosocial adjustment of these patients. It is important to note, however, that all of the research methodology problems present in the hysterectomy/radiation therapy literature exist for this small sample of descriptive studies as well. Yet, when looking across the reports some commonalities emerge. While some women can return their lives to preexenteration "normality," at this point it appears that the majority may experience significant disruption in major life areas. While an obvious cause of the emotional upset may be the treatment, there is no information on the base rate of depression and anxiety in such a population. However, if as many as 80% of the patients become sexually incapacitated, effects on other major life areas might be inevitable if specific counseling or rehabilitative efforts are not undertaken.

CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Study of the psychosocial/sexual adjustment of gynecologic oncology patients is a behavioral medicine research and clinical area at the earliest stages. However, careful experimental design and research methodology can provide immediately useful data for such areas as: (1) the magnitude of psychosocial and sexual difficulties that gynecologic treatments present; (2) the relative psychological merits of treatments offering comparable cure rates; (3) the variables which may be useful as predictors of posttreatment adjustment; and, (4) the type and range of sexual responsiveness possible with major pelvic and genital alterations. Analysis of these data should facilitate the designing of preventive or rehabilitative programs targeted for specific problems areas or patient subgroups, and should also form the basis for modifying current treatments for female sexual dysfunction to suit the needs of oncology patients.

Investigators need to select research strategies which advance previous efforts and begin study of neglected populations. Additional retrospective studies of hysterectomy/radiation patients seem unnecessary, while such a rapid data collection strategy may be reasonable for vulva or pelvic exenteration patients since so little is known about these populations. In beginning longitudinal study, careful decisions must be made regarding the time intervals for assessment of patient functioning. It is difficult if not impossible to assess women prior to diagnosis without a large-scale project. It is more probable that study will begin immediately after diagnosis or during the admission prior to the first treatment. While this is a difficult time for patients, it will be such for all. However, a factor which could contribute systematic error to this early assessment would be the existence of early cancer symptoms which may have already affected a woman's sexual responsiveness or the frequency of her activity. For instance, some women experience post-coital bleeding while others do not. Thus, any such symptomatology needs description. Posttreatment assessment must be conducted after adequate recovery and the treatment effects have stabilized. As mentioned, progressive fibrosis following radiation therapy is likely to continue for two years, so that prior assessment would not be definitive.

Beginning investigators need to be particularly cognizant that this research will be conducted in a context unfamiliar to psychologists in general or sex researchers in particular. Certainly for prospective study, gynecology cancer patients and their partners are initially sensitized to life-threatening conditions rather than sexual disruption. Thus, assessment interviews and testing need to provide a rationale to the patient which communicates concern about an important area of health functioning. Such research could easily prompt sexual worries or suspicion since sexual functioning is rarely mentioned or assessed by physicians. Also, the gynecologic cancer population in large part does not resemble the "typical" participant in sex therapy outcome studies (e.g., Andersen, 1981; Andersen, 1983; Heiman & LoPiccolo, 1981; Masters & Johnson, 1970). The average age of gynecologic cancer patients is in the late 50's or early 60's and two types of cancer, cervix and vaginal, have a higher incidence among blacks. These factors combined with lower SES and education levels as found in the majority of the research reviewed here, yield a population with which the majority of sex researchers have limited familiarity. Such factors necessitate an interviewer knowledgeable of the interaction between these demographic variables and sexuality, and an investigator selecting an understandable and nonoffensive assessment battery with individual tests having reliability and validity data appropriate for the "average" gynecology cancer patient.

In relation to relevant patient characteristics that require assessment, this would include description of the patients general health, stage of disease, treatment, and global psychological adjustment. Chronic medical conditions, such as diabetes mellitus or obesity,

can affect treatment selection or influence sexuality. Stage of disease influences the extent of treatment as well as the prognosis, which may in turn influence subsequent sexual adjustment. When comparing different modes of therapy, groups need to be equated for such variables as pretreatment sexual activity, age, marital status, education, and socioeconomic status. As mentioned, comparisons must be made between relatively pure groupings of treatment methods. For instance, whether or not ovarian functioning is preserved or replacement estrogen therapy is given will probably influence sexuality among premenopausal women. Or, the extent of dissection and hence pelvic nerve damage following radical surgeries must be noted. And finally, recognition must be made that these patients are suffering from a life-threatening disease, and evaluation of sexual functioning should occur in the context of a more general psychological evaluation. Anxiety and depression, which may significantly influence sexuality, are common and persistent conditions for cancer patients generally (Craig & Abeloff, 1974) and for gynecologic oncology patients in particular (Hughes, 1966). Therefore, global measures of adjustment or specific measures of affective states should be considered.

An assessment of sexual activity and responsiveness for gynecology oncology patients need not differ in substance from that completed for other patient groups,[7] therefore mention is made of those areas which might be uniquely appropriate for gynecology cancer patients. One basic component is the level of knowledge of normal sexual functioning since some data indicate ignorance, per se, may contribute to sexual dysfunction in healthy populations (Masters & Johnson, 1970). Autoerotic activity (e.g., fantasy, masturbation) and partner activities such as oral-genital contact or anal intercourse may need particular inclusion because they may necessarily become a larger component of sexual activity following some treatments. Since these women undergo substantial changes in body areas that define sexuality, assessment of sexual identity or sexual self concept is important. Easily obtainable information such as age, menopausal status, and partner availability can be used to describe the stage of a woman's sexual life. Another area hypothesized to have a significant impact on sexual identity is gender or sex role flexibility. Preliminary research indicates that individuals with polarized rather than androgynous sex role definitions may be more prone to sexual difficulties (Derogatis, Meyer, & Dupkin, 1976). Cancer patients often undergo substantial shifts in their role behaviors simply due to their illness. In addition, women with gynecologic cancer lose considerable flexibility in their sexual responsiveness and activity. Thus, women with "feminine" sex role orientations rather than androgynous ones may experience greater psychological or sexual disruption. Finally, inclusion of measures of "real" versus "ideal" responsiveness and body image should also be useful indicators of adjustment in that both areas are uniformly targeted by medical staff as having major significance for these patients. These additional topics may provide a more complete clinical picture of the areas of particular importance for women with gynecologic cancer.

To some, sexual problems may appear minor when compared to the other anxieties of patients with life-threatening diseases. As well, the sexual goals of gynecologic oncology patients may be different from those of healthy women or even women with cancer at a different site. Also, many people get over sexual problems with time. Regardless of their validity, these positions often reflect an attitude which ignores or minimizes the suffering of people when it is tolerable, not potentially fatal, inconvenient with which to deal, or out of the realm of expertise of direct care personnel. Perhaps the greatest rationale for research rests with the need for improved quality of life for the survivors of gynecologic cancer. With advances in treatment, intervention for many women will be curative and more will be living

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[7]Several recent reviews of psychological and sexual assessment that may be of particular help to the beginning investigator have been written. These include Schiavi, Derogatis, Kuriansky, O'Connor, and Sharpe (1979); Spanier (1979); and, Waskow and Parloff (1975).

with permanent body changes. The focus for these women needs to shift from staying alive to living.

Acknowledgments

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