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Psychosexual Adjustment After Vulvar Surgery

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Abstract

Fifteen patients treated surgically for vulvar cancer from two institutions participated in semistructured interviews and objective assessment to examine postoperative psychologic, social, marital, and sexual adjustment. Descriptive statistics indicate that after vulvar surgery patients report mild distress, but they report reasonable levels of and satisfaction with their free-time and social activities. Mild levels of marital distress may exist. Sexual functioning and body image appear to undergo major disruption despite the fact that intercourse remains possible. Women reported levels of sexual arousal at the eighth percentile and body image at the fourth percentile. Although replication of these findings is clearly necessary, this investigation provides the first substantive look at the posttreatment life circumstances for these patients and offers a data base for future investigation.

Cancer of the vulva is the fourth most common female genital malignancy, accounting for approximately 5% of all gynecologic cancers. Except for superficially invasive lesions, the minimum treatment is radical vulvectomy and bilateral inguinal-femoral lymph-adenectomy. Despite the severely disfiguring nature of the surgery arid the difficult postoperative period, there have been only brief descriptions of the psycho-sexual outcome for these patients.[1,2] A short questionnaire survey of 18 patients treated with wide local excision rather than vulvectomy for microinvasive disease was reported by DiSaia and colleagues.[3] All women maintained their sexual responsiveness, in contrast to two radical vulvectomy patients who reported loss of orgasmic ability and dyspareunia.

The present authors give the first substantive description of the psychosocial sequelae of vulvar cancer treatment. The plan of the investigation was to obtain a posttreatment description of psychologic, social, marital, and sexual functioning. Self-report measures that have previously demonstrated reasonable reliability and validity and provided data for normal and clinical samples were used. This strategy enabled the authors to compare these data with those from their previous study of pelvic exenteration patients[4] and with those of other investigators who have used the measures with other clinical groups.

Materials and Methods

Subjects participated in an extensive descriptive assessment lasting approximately two hours. Patients were contacted by an author and the investigation was conducted during a follow-up clinic visit to the department of gynecologic oncology at the University of California at Los Angeles or the University of Iowa at Iowa City. During the first hour an individual semi-structured interview was conducted by the first author, who was unfamiliar to the patient and naive to all aspects of the subject's gynecologic treatment and psychosocial functioning. A

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questionnaire battery was completed by the subject during the second hour. Because of time limitations, a few subjects completed a portion of the questionnaires at home. A listing of the measures is provided below and descriptions of them can be found in the authors' previous reports.[4,5]

The 15 participants are described in Table 1. At the time of the interview, the mean age of the sample was 55 and the average interval since vulvar surgery was five years. The highest level of education completed for the majority of the sample was high school. The sample was predominantly Protestant, with the typical patient describing herself as religious. Average total family income was in the range of $18,000 to $30,000, with the patient's assets contributing approximately 25% annually. Four patients lived alone or with their children, and 11 patients lived with their spouse; three of those women also lived with their children.

Results

Descriptive Statistics

Data from the measures of psychologic distress and social adjustment for the entire sample are presented in Table 2.[6–8]

In terms of psychologic distress, subtest scores for the Symptom Checklist-90 were 1 to 1.5 standard deviations above the mean expected for normal, healthy individuals.[7] The summary score, the Global Severity Index, suggests that this vulvectomy sample as a group is more than 1 standard deviation above the mean, at the 88th percentile. A specific measure of depression, the Beck Depression Inventory,[9] was also administered. A score of 10 on this inventory has been recommended as a cut-off score for medical patients.[10] The 12.3 mean score obtained for this sample corroborates the findings from the Symptom Checklist-90 and indicates a mild to moderate level of depression and/or distress among these patients.

The measures assessing psychosocial adjustment reflect satisfactory adjustment. The Katz subscores assessing the level of social and free-time activity fall midway between the norms for well-adjusted and poorly adjusted normative samples.[6] These activity scores are significantly and negatively correlated with the measures of psychologic distress, ρ ranging from −.50 to −.85. This may indicate that if women are able to maintain their activities, they may be less prone to psychologic distress, or vice versa. The mean score of 93 on the marital adjustment measure also falls midway between the mean scores provided for nondistressed couples and those who have been divorced. This may indicate some mild distress among these couples; however, further research is necessary to validate this finding.

The summary of the measures assessing sexual functioning in Table 3[11–13] indicates that the vulvectomy sample reported considerable sexual disruption. In their previous sexual repertoire, they report having experienced comparable numbers of sexual activities to healthy women, although their level of current activity was approximately half that provided in the normative data for healthy women.[11] Emotionally and cognitively these women also report a very limited capacity for sexual arousal and considerable sexual anxiety.[12,13] The sexual satisfaction score is below the normative values for healthy normal women.[11] The measures assessing sexual identity/self-concept also reflect general disruption. In global terms, these women rated their sexual relationships as somewhat inadequate. There is a discrepancy between their current and ideal frequency of intercourse. Finally, the body image score is lower than that for healthy women.[11]

Analysis of Variance

One-way analysis of variance comparisons and Mann-Whitney tests on the ranked data were made for three main effects: time since surgery (36 months or less versus more than 36 months),

disease severity (invasive versus noninvasive), and current sexual activity (active versus not active). These factors were not crossed for the analyses because of the small number of subjects for comparison. Both parametric and non-parametric statistics were used because of the interpretive difficulties with data coming from small sample sizes. Differences between groups at the level of $P < .05$ for a two-tailed test were regarded as significant for both statistics.

Analysis of variance and Mann-Whitney tests on the ranked data first compared patients whose surgery had been performed up to 36 months earlier (mean interval for these patients, 14 months) with those operated upon more than three years earlier (mean interval seven years, seven months, for this group). Specific measures within all areas generally characterized the patients with the longer follow-up interval as adjusted and the patients recently treated as distressed. First, there were significant differences between groups on the Beck Depression Inventory[9] and the Symptom Checklist-90.[7] On the latter measure the Global Severity Index score for the short-term follow-up group was in the range of the 98th percentile, and the score for the long-term follow-up group was in the range of the 70th percentile. Second, on the Katz Social Adjustment Scales there was a significant analysis of variance ($P < .03$) and Mann-Whitney test ($P < .06$) for the level of social activities measure. Scores for the short-term follow-up group were within the range of the "poorly adjusted" normative samples and those for the long-term follow-up group were within the range of "adjusted"normative samples.[6] Finally, there was a significant analysis of variance ($P < .04$) and a Mann-Whitney test approaching significance ($P < .06$) for the sexual satisfaction measure. The score for the short-term follow-up group was within the range of that provided for the normative sample of healthy sexually dysfunctional women for this measure, and the score for the long-term follow-up group was slightly below that provided for the normative sample of healthy women.

Comparisons were next made between patients with invasive and those with noninvasive disease. As survival estimates would vary considerably between such groups, it is conceivable that differential psychosocial adjustment would be evidenced. A demographic characteristic, age, approached significance ($P < .08$), indicating that the sample with invasive disease was on the average older than the sample with noninvasive disease. There were, however, no significant differences between the groups on any psychologic distress, social adjustment, or sexual functioning variable. Only for the frequency of current sexual activities did the differences between the groups approach significance ($P < .06$) on the Mann-Whitney test. This finding was not, however, observed with the analysis of variance. Thus, any conclusion finding patients treated for noninvasive disease to be more sexually active than those treated for invasive disease must be regarded as tentative. It is more probable that this sexual activity difference is due to a third factor, age, which is significantly and negatively correlated ($p = -.45$) with current sexual activity.

Comparisons were also made between currently sexually active and nonactive subjects. Women who had engaged in sexual intercourse or an equivalent activity at least once per month for the preceding six months were defined as sexually active. The only demographic difference between the sexually active and not active samples was in the level of annual family income. However, a higher income level for sexually active women is partially due to the greater numbers of these women also having partners who contributed to their annual income. The area of major difference between the groups, as indicated on both the parametric and nonparametric analyses, was in the realm of sexual activity, as might be expected. Sexually active women reported a mean of ten different sexual activities occurring during the previous two months, whereas not active women reported no activities for the same period. This difference included significantly greater frequencies of intercourse and kissing. For the sexually active women, intercourse occurred on the average of once a week and kissing with their partner on four to six occasions per week. For the women defined as not sexually active, these activities reportedly never occurred. In contrast to these findings, there were no

differences between the sexually active and not active subjects on the remaining measures of sexual functioning or those assessing psychologic distress or social adjustment.

Discussion

These are the first data to describe the psychosocial and sexual outcomes after surgery for vulvar cancer. Although they represent an important preliminary effort, readers are reminded that they are limited by the absence of pretreatment observations, repeated assessment, and comparison groups. These data can, however, provide a foundation for more rigorous research designs.

In terms of psychologic distress and/or depression, these women reported substantial and significant levels of distress in comparison to healthy women as indicated on the Symptom Checklist-90[7] and the Beck Depression Inventory.[9] The scores on these measures are comparable to those of pelvic exenteration patients[4] and other female cancer patients.[14] Without a pretreatment assessment it is not possible to determine whether or not these findings represent a continuation of precancer distress. A more plausible hypothesis is that these convergent data indicate a chronic life circumstance for cancer patients, even when they have been treated for preinvasive conditions.

The data on social functioning indicate that this sample of patients was able to maintain reasonable social and free-time activity, although not optimal levels in terms of the available comparison data[6] Reports obtained from the interviews may be useful in interpreting these findings. Many activities, such as shopping, dancing, and housekeeping, become difficult or impossible for some patients because of chronic fatigue or leg edema. For the latter, supportive hose offer only partial relief and hours must be spent daily with the leg(s) elevated. Other women complained of restriction in such activities as watching television, going to the movies, and taking trips in the car. In these situations the loss of fatty tissue around the perineum makes extended periods of sitting uncomfortable. Finally, urination difficulties for several patients were sufficiently upsetting and bothersome to cause hesitation in venturing far from home. Urination for some women was described as a “spray” or a stream with an unpredictable direction. Such difficulty often resulted in dampened clothing or leakage onto bathroom floors or carpets. Difficulties such as these may account for the disruption of social and free-time activities that some women reported.

Significant disruption in sexual activity appeared as a notable outcome for this sample of patients. These women reported having previously varied sexual lives, but when assessed postoperatively, there was a marked reduction in sexual activity. This sample did, however, report a significantly higher frequency of intercourse than patients having pelvic exenteration.[4] Levels of sexual arousal were in the eighth percentile, an estimate lower than that reported by sexually dysfunctional healthy women.[12,15] This may be partially caused by the blunting of genital or pelvic sensitivity after surgery. Many women described persistent and unexpected numbness, so much so that on some occasions during intercourse they were unsure when penile penetration occurred. The loss or maintenance of orgasm was reported by those with and those without clitoral excision. Conclusions regarding the extent of surgery and the maintenance of the orgasmic response are not possible from these data; further research is necessary to clarify the covariation of these variables.

A final area of importance for these women is sexual identity or self-concept. Previous investigators have noted the importance of this area for gynecologic cancer patients,[16] and Sewell and Edwards[17] noted greater disruption of body image after pelvic exenteration than after vulvectomy. The authors’ findings[4] suggest comparable disturbance, body image being at the fourth percentile for vulvectomy patients and at the fifth percentile for pelvic exenteration

patients. However, there is a significant difference between the samples on the measure of sexual satisfaction. Scores for the pelvic exenteration sample were at the 14th percentile and scores for the vulva sample were at the 30th percentile. In any respect, the magnitude of body image disruption reported by women after vulvectomy was extreme, and for some this was an important deterrent to sexual activity.

Vulvar cancer typically occurs during the postmenopausal years; the average age at onset is around 65.[18] The majority of the participants in the present study ranged in age from 50 to 70 years. The previous absence of psychosocial data for vulvar cancer may be caused by prevalent attitudes about sexuality in later life such as those indicating the activity is inappropriate, unimportant, or readily expendable. The constancy of sexual needs through life, however, has been demonstrated. While some natural decline in sexuality occurs with age, the presence of a healthy and interested partner appears to be the variable of critical importance to the maintenance of female sexual activity rather than age per se.[19,20] The present data indicate that these patients attempt to maintain a sexual life despite major physical losses and substantial emotional disruption. Thus, attention to the psychosocial and sexual needs of the patient and her partner seem of critical importance.

Some closing remarks may be useful to professionals assisting future patients. The majority of the patients felt they had been adequately informed as to the surgical details of their operations; however, no patient reported that she would ever be comfortable explaining the procedure to anyone but the most intimate friend. This fact alone can often make the vulvectomy patient feel embarrassed, burdened, and isolated. Most women felt that information regarding sexuality was either absent or falsely reassuring. For example, some would have preferred realistic appraisals of likely genital numbness so they could have altered their sexual expectations or activities. Since many patients underwent long recuperative periods necessitated by the extensive surgery and complications, many partners were involved in assisting the patients with such activities as wound dressing. Some couples saw no difficulty and certain advantages to such assistance, while other women thought this period was instrumental in their partner's ending future sexual activity. In the absence of additional data, it appears that decisions to encourage such assistance from the partner during recovery should be made on an individual basis.

In summary, an initial profile of psychosocial and sexual adjustment for women undergoing surgery for vulvar cancer is presented. Psychologically these women remain a mildly distressed group, although they engage in reasonable levels of social and free-time activities. Disruption of sexuality, however, is a major outcome. This includes reduction in the frequency of activity, very low sexual arousal, sexual anxiety, limited sexual satisfaction, and disruption in body image. It appears that the continuation of sexual activity remains important to this group of patients in that efforts are made to maintain functioning despite substantial genital change, reduced pelvic and genital sensitivity, sexual arousal deficits, and disturbance in the woman's feelings toward her body.

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Table 1

Patients Undergoing Vulvar Surgery

Subject	Location	Age (yr)	Months since operation	Marital status pre-post treatment	Employment or position	Initial diagnosis	Primary treatment
1	CA	46	48	D-D	Factory worker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection
2	CA	48	5	M-M	Homemaker	Invasive carcinoma	Partial vulvectomy, clitoris retained, with bilateral groin dissection
3	CA	54	6	M-W	Unemployed; attending school	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection
4	CA	35	21	M-M	Homemaker and mother	Carcinoma in situ	Total vulvectomy; subsequent local excisions and laser therapy; clitoris retained
5	IA	30	4	M-M	Homemaker and mother; not yet resumed factory employment	Carcinoma in situ	Total vulvectomy
6	IA	38	6	M-M	Substitute teacher; mother	Paget's disease	Total vulvectomy
7	IA	63	216	M-M	Retired; homemaker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection; bilateral gracilis myocutaneous grafts for vulvar reconstruction
8	IA	51	84	M-M	Homemaker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection
9	IA	85	108	W-W	Retired; homemaker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection
10	IA	67	108	M-M	Retired; homemaker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection
11	IA	63	64	M-M	Homemaker; parttime crafts teacher	Vulvar melanoma	Partial vulvectomy
12	IA	62	32	M-M	Homemaker	Carcinoma in situ	5-fluorouracil cream; partial vulvectomy
13	IA	70	54	M-M	Homemaker	Invasive carcinoma	Radical vulvectomy with bilateral groin dissection

Subject	Location	Age (yr)	Months since operation	Marital status pre-post treatment	Employment or position	Initial diagnosis	Primary treatment
14	IA	51	96	M-M	Stable manager; homemaker	Carcinoma in situ	Total vulvectomy
15	IA	56	41	M-M	Homemaker	Carcinoma in situ	Total vulvectomy

CA = California; IA = Iowa; M = married; D = divorced; W = widowed.

Table 2

Descriptive Statistics for Psychosocial Adjustment

Measure	Mean raw score	Percentile	Description
Psychologic distress			
Symptom Checklist-90[7]			
Global Severity Index	0.79	88th	Mild/moderate psychologic distress
Social adjustment			
Katz Social Adjustment Scales[6]			
Level of social activities	37.56		Moderate frequency of social activities
Level of free-time activities	45.19		Moderate frequency of leisure activities
Marital adjustment			
Dyadic Adjustment Scale[8]	92.78		Satisfactory marital adjustment

Table 3

Descriptive Statistics for Sexual Functioning

Measure	Mean raw score	Description
Sexual repertoire and frequency of activities		
Past sexual activity[11]	19.50	Level is comparable to that for healthy women
Current frequency of intercourse	2.13	1–2/month
Current frequency of masturbation	0.69	Less than 1/month
Current frequency of kissing	3./69	2–3/week
Current frequency of sexual fantasy	0.91	Less than 1/month
Current sexual activity	7.25	Level is 50% lower than that for healthy women and is in the 3rd percentile range
Emotional, attitudinal, and cognitive component		
Sexual arousability[12]	48.44	Level is indicative of only slight arousal for a variety of sexual activities and is in the 8th percentile range
Sexual anxiety[13]	33.00	Score is indicative of a variety of sexual activities being regarded as slightly anxiety provoking
Sexual satisfaction[11]	6.75	Level is indicative of only moderate sexual satisfaction and is in the 30th percentile range
Sexual identity/self-concept		
Body imag[11]	21.44	Level is indicative of significant body image disruption and is in the 4th percentile range
Ideal frequency of intercourse	2.63	4–5/month
Global evaluation of sexual life[11]	3.33	Score indicates the present sexual life was regarded as “somewhat inadequate,” which is in the 20th percentile range