Occasional Survey

Mastectomy and its consequences

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We have previously commented on the human costs of surgery for anorectal cancer¹ and in particular have been impressed by the problems of rehabilitation posed by these patients. Others have described the considerable emotional consequences of mastectomy for breast cancer.^{2,3} We have reviewed our experience of women after mastectomy and identified some deficiencies in the service at present provided.

Patients and methods

Altogether 128 women who had undergone unilateral simple mastectomy for cancer more than nine months previously were interviewed. They were aged from 29 to 79 and at the time of review were clinically free of disease.

The patients were called to the hospital and interviewed using a structured form derived from our previous studies.⁴ Information was sought about the preoperative investigation and management, about the hospital experience, and, most importantly, about the rehabilitation process.

Some results

Five women (3.9%) complained of a lag of more than one year from initial presentation with a breast lump to their family doctor to referral to a consultant outpatient clinic; a further 14 women suffered a delay of from one to 12 months before referral.

Nearly a quarter of the sample, 29 women, complained that they were given insufficient information about their disease and its treatment before operation. Indeed 13 claimed that they were unaware of the likelihood of mastectomy until they woke up without their breast. All these patients had signed valid consent forms for mastectomy.

Paradoxically, when asked directly whether the medical and nursing staff could have been more helpful only six replied "yes." Although posters about mastectomy are widely displayed in local health service premises, of 102 patients who replied that they had never heard of the Mastectomy Association, 26 had actually been given the booklet *Living with the Loss of a Breast* while in hospital.⁵ Nearly all (124) thought that there would be a role for a special nurse/counsellor to guide them through the treatment period.

Many anxieties were expressed about their disfigurement and the prosthesis given to conceal it. Preoperatively 90 married women regularly dressed in their husband's presence, after mastectomy 35 (38%) no longer did so. Twenty-one of the 101 married women said that their husbands had never seen their scar, indeed 15 patients said that only medical and nursing personnel had seen it.

All patients were given a prosthesis after surgery, although 42 did not receive one for more than a month postoperatively. Twenty-six learnt about the prosthesis from nursing staff, 22 from the surgeon, and 60 from the appliance fitter. Sixty-nine complained that they

were not given adequate time or privacy to choose their prosthesis, and 121 were not allowed to try more than one type or size of prosthesis. Eleven never wore their prosthesis and eight wore it only occasionally, four of whom wore it only when visiting the outpatient department. Forty-one women often wore an alternative such as cotton wool. When asked about their degree of satisfaction with the prosthesis 77 women scored the prosthesis three or under on a scale of one to five. Thirty-six had had difficulty in obtaining a second prosthesis within two years of their first, many patients needing a special letter from a consultant before one would be issued.

Conclusion

The findings of this small study of 128 women who had had a mastectomy cause us much anxiety. The observation that many women did not understand the nature of their surgery before operation is particularly worrying. As the humanitarian sequelae of surgery for cancer have been well documented already,¹⁻³ a failure to act on these earlier observations is highlighted. Particularly unfortunate are the administrative shortcomings in the prosthesis service.

What can be done to improve things? We would plead for a specialist mastectomy counsellor, preferably with a nursing background, to counsel patients preoperatively, to provide support in hospital, and to oversee rehabilitation.

As many of the problems of women who have undergone a mastectomy are very personal and private, advice about their social lives and clothing can only easily be given by a woman, hence we feel the counsellor should be female. Lastly, the prosthesis problem needs thought. Perhaps the best solution would be to give the counsellor "prescriptive rights," allow her to keep a range of prostheses, and supply them directly to patients. More male medical involvement in this process is probably unhelpful.

We thank our colleagues who have allowed us to interview their patients. We also thank Miss J A Plant who advised us on the design of the questionnaire and the methodology of interviewing the women.

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(Accepted 5 March 1982)

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