McGILL UNIVERSITY

MASTECTOMY: THE ROLE OF THE SOCIAL WORKER

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ABSTRACT

The purpose of this study was to determine the attitudes and needs of mastectomy patients, and to determine in what way social workers could most effectively help these women.

The research sample was made up of thirty-one mastectomy patients and a comparison group of twenty-nine other female surgical patients. A questionnaire was administered to each subject to obtain certain personal and demographic data; and information about the nature and timing of her operation, amount of help and support received, length of time before return to normal activity, and feelings, concerns and needs at various stated times before and after her operation. Data were analyzed using standard computer programs.

The findings indicated two significant differences between the two sample groups: mastectomy patients in the

sample were both older and less well educated than the comparison group of other surgical patients.

Mean levels of anxiety and/or depression were reported as being highest immediately before surgery, and during the first six weeks after surgery. For most of the time periods considered, mastectomy patients reported less anxiety and/or depression than did other surgical patients; several years after surgery the level of anxiety and/or depression of the other surgical patients had dropped below that of the mastectomy patients.

Mastectomy patients reported themselves as being concerned most about their appearance and next about being ill. They expressed more concern about their appearance than did other surgical patients; also, younger mastectomy patients indicated more concern about appearance than did older mastectomy patients. Younger, married mastectomy patients with higher incomes and a higher level of emotional support were more concerned about being ill than were patients who were older, not currently married, and with lower incomes and a lower level of support.

The more anxiety and/or depression a woman reported feeling, the longer she took to return to her normal preoperative activities.

About half the subjects showed interest in some form of social work services and the same proportion showed interest in a possible group experience. Mastectomy patients showed less interest in social work services which involved talking about their feelings than did other surgical patients.

There were, however, indications that the anxiety and concern of mastectomy patients were greater than the findings showed--first, because the more successfully rehabilitated mastectomy patients may have been over-represented in the sample; and second, because these patients may have been denying their real level of concern.

A number of recommendations were made for more effective delivery of social work services to mastectomy patients.

ACKNOWLEDGMENTS

This study is dedicated to Sydney Duder, a dear friend and wise mentor whose zeal and enthusiasm have carried and sustained me throughout this project.

Special thank you to Ellen Cohen for her ready assistance during the initial phase of this study. Also thank you to the members of Reach to Recovery/Toujours Femmes and all the other patients who freely contributed their time and effort to this study.

I wish to express my gratitude to Sheila McKay and the staff of the Jewish General Hospital's Social Work Department for their interest and co-operation in making this study possible.

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S.C.B.

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CHAPTER I

INTRODUCTION

The Problem of Breast Cancer

In 1975 breast cancer was found to be the number one killer of women aged thirty-five to fifty in Canada.[1] According to the March 1975 publication of M.D. Canada on "Mammary Malignancy", every three minutes a Canadian woman is diagnosed as having breast cancer.[2] The implications of these alarming statistics are magnified by the fact that the disease is highly complex and poorly understood by the medical profession.[3]

Approaches to breast cancer treatment are the topic of major medical debates. At present there is no statistical proof as to which form of treatment is best.[4] Here in Montreal,

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[1] Zoe Bieler, "Breast Cancer Menace Rising Despite Earlier Detection," The Montreal Star, November 3, 1975, p. 4.

[2] Ray Lawson, M.D., "Mammary Malignancy," M.D. of Canada 16 (March 1975).

[3] "Editorials," C.M.S. Journal (April 8, 1972).

[4] Richard Margolize, M.D., Statement made at Annual Meeting of Reach to Recovery Inc., June, 1976.

however, the most widely used treatment for breast cancer to date is mastectomy, the surgical removal of the breast.

Until 1974 there was almost no public discussion of breast cancer. Then in the autumn of that year, the wives of the President and the Vice-President of the United States of America were diagnosed as having breast cancer. Both Mrs. Betty Ford and Mrs. Happy Rockefeller were treated by mastectomies. Mrs. Rockefeller, having multiple tumours, had both breasts removed.[1] Following these widely-publicized mastectomies, a new candour seemed to develop about the subject of breast cancer.

This appeared to have a considerable effect on the attitudes of North American women to breast cancer. Thomas L. Dao, M.D., the chief of both breast cancer surgery and breast cancer research at Roswell Park Memorial Institute, Buffalo, New York, the oldest cancer hospital in the world, supports this belief. He has stated that ". . . an enlightened consumerism seems to be taking over, as a result of the flood of information and publicity given the subjects of breast

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[1] "Problems of Adjustment," Newsweek, October, 1974, p. 23.

cancer and mastectomy since these two prominent women's surgery."[1] This attitude is best summarized in the words of one woman who has had a mastectomy--"To save a woman by surgical intervention and then deny her emotional support necessary to form a different lifestyle and accept an altered body image is a contradiction in terms."[2] Accordingly, the medical profession has had to respond to a new challenge.

Setting for this Study

The setting for this study is Montreal's Jewish General Hospital. It is a seven hundred bed, acute care institution. The Jewish General Hospital is non-sectarian; but, as it serves a predominantly Jewish area, the patient population is largely Jewish.

It appears that the Jewish General Hospital is striving to meet the challenges of the new discoveries in the field of

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[1] Rose Kushner, Breast Cancer: A Personal History and an Investigative Report (New York: Harcourt Brace Jovanovich, 1975), xii.

[2] Helen C. Harrell, "To Lose a Breast," American Journal of Nursing (1972): 677.

breast cancer. Notable accomplishments have been achieved in the diagnosis, treatment and rehabilitation aspects of breast cancer. One such example is their participation in the National Surgical Adjuvant Breast Project. At present, this research project has several on-going protocols, e.g. comparison of segmented mastectomy patients with radical mastectomy patients and comparison of post-operative chemotherapy patients with non-chemotherapy mastectomy patients.[1]

Also, following current medical trends, the Jewish General Hospital has organized its treatment and rehabilitation of breast cancer patients under the care of a multidisciplinary medical team. The team is composed of doctors, nurses, a physiotherapist, a long term mastectomy patient and a medical social worker.

According to Dr. Guy F. Robbins, Chairman of the 1971 American Cancer Society's symposium on the Rehabilitation of The Breast Cancer Patient, "The values of multidisciplinary programs have been subjected to professional evaluation. These

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[1] Interview with Dr. Richard Margolize, Principal Investigator of the National Surgical Adjuvant Breast Project, Montreal, June, 1976.

studies have confirmed the belief that a structured multidisciplinary team for patients with cancer of the breast will improve the quality of care for these women."[1]

Implication for Social Work

Interviews with the members of the medical team serving women with breast cancer at the Jewish General Hospital--both surgeons and other professionals--revealed a universal endeavour to improve the quality of care. It seemed that all recognized the potential trauma which this type of surgery may cause and so were examining in particular the rehabilitation problems of a mastectomy.

Members of the social work profession at the Jewish General Hospital indicated a strong desire to improve their role in this multidisciplinary approach to rehabilitation of the breast cancer patient. The Medical/Surgical Unit of the Social Work Department has addressed itself to the subject of mastectomy. There has been considerable uncertainty as to

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[1] Guy F. Robbins, M.D., "Rehabilitation of the Breast Cancer Patient," Cancer 28 (1971): 1659.

what type of social work intervention would be most efficient and effective in reaching these women.

An obvious prerequisite is that social work interventions should be responsive to the needs of the client. Therefore, before any program planning can be developed, it is first necessary to determine the needs of the specific patient population. Therefore, this study will attempt to define what a mastectomized woman experiences post-operatively and what her consequent needs might be. From this knowledge it is hoped that appropriate social work programs can be developed.

Recent medical literature indicates recognition of the importance of psycho-social factors in all types of physical illness. Jaco, for example, stressed the importance of treating the entire person rather than collected and selected parts.[1]

Studies have been undertaken of the psycho-social consequences of surgery. The psychological and social consequences of surgical interventions specifically for cancer have been considered. Sutherland and Orbach contend that, "The impact of the surgical experience and the organ loss upon any

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[1] E. Jaco, ed., <u>Patients, Physicians and Illness</u> (New York: Free Press, 1958), p. 6.

patient are highly individual and can be assayed only in terms of the meaning of these events in each patient's total life adaptation."[1] Roberts and associates concluded that, ". . . psychological and physical morbidity occur with all types of operations." Accordingly, they identified anxiety and depression as the iatrogenic effects of any major surgery. Their study of mastectomy morbidity showed that fifty percent of population in their study admitted anxiety and/or depression.[2]

From a non-medical viewpoint, North American society's attitudes place a great deal of meaning on a woman's breasts. In the last few years, these attitudes and values relating to woman's body and sexuality have begun to change, but for the most part it appears that the breast continues to be seen as a symbol of sexuality.

Regardless of the meaning which a particular individual or society places on the breast, it is a sexual body part, the

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[1] Arthur M. Sutherland and Charles E. Orbach, "Psychological Impact of Cancer and Cancer Surgery," Cancer 6 (September 1953): 959.

[2] M. Maureen Roberts, Isobel G. Furnival, and A.P.M. Forrest, "The Morbidity of Mastectomy," British Journal of Surgery 59 (April 1972): 302.

significance of which is influenced, according to Dietz, by ". . . each individual's national social and family attitudes and customs and by one's occupation and personal experiences."[1]

Sexuality is a basic human trait. The degree of sexuality may vary with the individual, but according to Ervin, ". . . sexual attention and response are measured by each individual and constitute an important yardstick of self-esteem."[2] Changes in and/or misconceptions of an individual's body image can, according to Dietz, generate great fear and depression.[3]

As a result of a mastectomy, a woman loses a sexual body part and has permanent disfigurement. Consequently, psychological ramifications of such surgery must be extremely serious. According to the report of Ervin, ". . . no woman escapes serious emotional trauma" and further he expresses the

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[1] J. Herbert Dietz, Jr., M.D., Commentary on "Psychologic Adjustment to Mastectomy," Medical Aspects of Human Sexuality 7 (February 1973): 65.

[2] Clinton V. Ervin, M.D., "Psychologic Adjustment to Mastectomy," Medical Aspects of Human Sexuality 7 (February 1973): 61.

[3] Dietz, Commentary, p. 65.

belief that, ". . . the emotional suffering outweighs the physical pain in mastectomy cases."[1]

In addition to the above, the fact of the occurrence of disease which is generally regarded as ". . . ravaging and destructive and almost always fatal"[2] must be considered. According to Goldsmith and Alday's study, mastectomized women have ". . . an omnipresent fear of death."[3] Trachtenberg, in her report of work with a group of mastectomy patients, identified one set of common problems as, "the patient's fear of, and worry over, possible recurrence, possible removal of the remaining breast, and possible death from cancer."[4]

Asken's work suggests that appropriate therapeutic interventions, if they are going to deal with the overall trauma of mastectomy, must involve both physical and psycho-

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[1] Ervin, "Psychologic Adjustment to Mastectomy," p. 51.

[2] Sutherland and Orbach, "Impact of Cancer," p. 958.

[3] Harry S. Goldsmith and Edgardo S. Alday, "Role of the Surgeon in the Rehabilitation of the Breast Cancer Patient," Cancer 28 (1971): 1675.

[4] Judith M. Trachtenberg, "Team Involvement and the Problems Incurred," paper presented at the 15th Annual Clinical Conference on Progress in the Rehabilitation of the Cancer Patient, Huston, Texas, 1970.

logical considerations.[1] The literature identifies three main aspects upon which rehabilitative measures should focus: these are physical rehabilitation, cosmetic restoration and psychological adjustment.

According to Beeby and Broeg, the goal of physical rehabilitation is to restore and maintain the range and function of the operative arm and shoulder.[2] The goal of cosmetic rehabilitation is to restore the external appearance. Prosthetic devices are suggested. Psychological adjustment, according to Asken, means ". . . acceptance of breast loss, reintegration of the self-image as being worthy of love and the rewards of life, and adjustment to the possibility of cancer recurrence in the following year."[3]

Klein, a medical social worker, perceives breast cancer as a crisis. She states that, . . .

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[1] Michael J. Asken, "Psychoemotional Aspects of Mastectomy: A Review of Recent Literature," American Journal of Psychiatry 132 (January 1975): 57.

[2] J. Beeby and P.E. Broeg, "Treatment of Patients with Radical Mastectomies," Physical Therapist 50 (1970): 41.

[3] Asken, "Psychoemotional Aspects of Mastectomy," p. 57.

> Crisis has been defined as an insoluble problem precipitated by stressful or hazardous events and causing a loss of equilibrium for the individual. No former problem-solving mechanisms seem adequate for this extraordinary task. It is obvious that in this helpless state, without stasis, the individual may tip in either direction--towards mental health or away from it. All depends on whether the individual is able to utilize healthy coping patterns rather than unhealthy ones. Although previous experience with stress as well as the gravity of the current crisis have some pertinence, the final outcome is more dependent on the interplay between external influences and the inner forces of the individual.[1]

Parad argues that a crisis characteristically is time-limited, usually lasting between four and six weeks.[2]

Klein offers specific suggestions as to how those involved in the rehabilitation process could help. Included in these are helping the woman to express her feelings and to master those feelings which are unacceptable to her; helping her to sort out the real from the unreal concerning diagnosis, prognosis and treatment, so to give sincere reassurance; helping her to understand how long her physical rehabilitation should take and what part she must play in it; helping the

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[1] Roberta Klein, "A Crisis to Grow On," Cancer 28 (1971): 1661.

[2] Howard J. Parad, ed., Crisis Intervention, Selected Readings (New York: Family Service Association of America, 1965), p. 24.

family to understand the patient's feelings and to express their own feelings concerning the situation; and helping the patient to consider how and what to tell those significant persons in her life, especially children.[1]

Klein's suggested form of social work intervention is on a one-to-one basis which, inevitably, is both a time-consuming and expensive method of reaching only a small proportion of this patient population. Trachtenberg, on the other hand, uses a group approach. The purposes of the group are to instruct the women in beneficial exercises, to discuss common concerns about the practical aspects of their surgery and to give them an opportunity to help each other with the overwhelming feelings generated by their common diagnosis and surgery.[2]

Another approach is adopted by Reach to Recovery Inc., a charitable organization designed to help women who have had breast surgery. This organization is composed of women who have undergone mastectomies, at least two years ago, and have

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[1] Klein, "Crisis," pp. 1662-1663.

[2] Trachtenberg, "Team Involvement," p. 3.

made a successful adjustment to their situation. These women exemplify in their attitudes, their dress and their way of living the recovery that is possible. Their role is to talk with the patient undergoing treatment about what is happening. Each volunteer also describes her own experience. These Reach to Recovery volunteers give each woman a kit containing equipment for exercises, the patient's first breast prosthesis, and a booklet with helpful information. In this booklet, the various needs of the mastectomy patient are classified as to physical, cosmetic and psychological needs.[1]

Research Questions

The overall purpose of this present study was to determine the attitudes and needs of mastectomy patients, and gain some insight into possible ways in which the social work profession might help these patients.

Specifically this study attempted to answer four basic questions:

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[1] Terese Lasser, A Manual for Women Who Have Had Breast Surgery (New York: Reach to Recovery Inc., 1969), p. 7.

1. What is a mastectomized woman's pattern of emotional reaction over time?

As previously stated, Roberts and associates identified anxiety and depression as the two primary emotions evoked during the period surrounding any major surgery. The possibility that an operation such as a mastectomy would create extensive anxiety and depression had to be borne in mind. Therefore, the study attempted to define the extent and duration of these two feeling states in mastectomy patients as compared with other female surgical patients, thereby giving some indication as to exactly when social work intervention would be most needed.

2. What kinds of concerns does a mastectomized woman have?

An attempt was made to look at some of the factors that might worry mastectomy patients in an effort to confirm some of the findings of other researchers. These factors were examined in three broad ways. First, the intensity of the different kinds of concerns felt by mastectomy patients were compared. Second, these kinds of concerns were compared between mastectomy patients and other female surgical patients.

Finally, an attempt was made to relate these concerns to certain personal characteristics of the patients, such as age, marital status, income level, and level of emotional support.

3. Is rate of recovery related to feeling state?

An effort was made to determine the relationship between the patients' statements about their level of anxiety and depression and the length of time it took them to return to their normal activities.

4. How can a social worker best help a mastectomized woman?

The literature suggests various types of social work interventions used with mastectomy patients. An attempt was made to determine which of these are seen as most important by mastectomy patients, and relate them to the various personal and demographic characteristics of the patients.

CHAPTER II

METHODOLOGY

General Design

This piece of social research was a quantitative-descriptive study. According to the definition of such a study given by Fellin, Tripodi and Meyer, the primary function here was ". . . to obtain an accurate description of quantitative characteristics of selected populations."[1]

The general approach of this study was to make a comparison between two sample groups, mastectomy patients and other female surgical patients.

Sample and Administration

The administration process determined to a large degree the nature of the sample in this study. The sample came from three sources: the Jewish General Hospital (Tumour Clinic and Surgical Clinic); Reach to Recovery Inc.; and a group of

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[1] Philip Fellin, Tony Tripodi, and Henry J. Meyer, Exemplars of Social Research (Itasca, Illinois: F.E. Peacock Inc., 1971), p. 141.

women, known personally to the researcher, who had had operations.

The largest group was that which originated from the Jewish General Hospital's clinics. Arrangements were made with the Surgeon-in-Chief to interview female patients coming to these two clinics. All women who came to the Tumour Clinic had had surgery for cancer. It was not known at the time the questionnaires were administered if a woman had breast cancer or another form of cancer. Respondents from the Surgical Clinic were all non-cancerous post-operative patients.

During a six-week period in April and May, 1976, every woman who visited these two clinics was approached personally and asked to volunteer for the study. This represented a population of approximately one hundred women. The responses were varied. Generally, women seemed eager to cooperate. Some women who were more reluctant in the first instance were urged to take the questionnaire and study it; subsequently, many of these women showed an interest in the study. If a woman did not wish to complete the questionnaire in the clinic, she was asked to take it home and complete it, and was given an addressed and stamped envelope in which to return the questionnaire. To ensure anonymity, subjects' names were not recorded, so follow-up of these cases was impossible. Frequently, older women had trouble reading the questionnaire, so they were given help. This process proved extremely effective--it guaranteed completion of the questionnaire, and it also gave the women an opportunity to express thoughts and feelings which they might be reluctant to write on paper. A total of thirty-eight subjects was obtained from these two clinics.

The second sample group was composed entirely of women who had had mastectomics and who belonged to Reach to Recovery. Responses from this group were obtained by selected telephone interviews, and by questionnaires given out at the annual meeting of this organization. The six women interviewed by telephone were selected by the President of Reach to Recovery as being women whom she thought would be particularly helpful. All those contacted were extremely interested in the study. Even on the telephone all were able to discuss with ease their thoughts and feelings associated with their mastectomy. Those women contacted at the annual meeting of Reach to Recovery did not respond as well as those interviewed by telephone. Twelve questionnaires with stamped return envelopes were given out at the meeting of which only three were returned.

The third group of respondents was composed of thirteen women, known personally to the researcher, who had had surgical operations other than for cancer. All of this group completed and returned their questionnaires immediately.

Instrument

The final instrument was a seven page questionnaire (see Appendix). Considerable difficulty, however, was encountered before deciding on the most effective format. The questionnaire was accompanied by a covering letter which told the subject about the purpose and sponsorship of the study, and what was required of her. The first section of the questionnaire, to be completed by checking the appropriate boxes, asked the subject for certain basic personal information, such as facts about age, marital status, religion and level of education. This section also asked for certain basic medical information, such as the type and time of her operation and how often she saw her physician. These preliminaries were relatively simple to develop.

The second section, attempting to measure attitudes and needs, proved to be troublesome to construct. Use of the

Rosenberg Self-Esteem Scale was considered.[1] However, the physicians and other members of the Social Work Department at the Jewish General Hospital believed that it would be undesirable to use this scale because it might provoke fears or feelings within the respondents that might be best left untapped. Therefore this scale was not used.

It was then decided that a semantic differential approach might be useful. Osgood and associates have defined a semantic differential as ". . . a device used to measure the connotative meaning of concepts as points in a semantic space."[2] The concepts used were: "myself before surgery", "myself during hospitalization", "myself now", "myself as I would like to be", and a neutral concept, the name of a well known public figure. These concepts were selected on the basis of their ability to produce large variance among persons, and their coverage of the semantic space. Scales consisting of bi-polar

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[1] Morris Rosenberg, Society and the Adolescent Self-Image (Princeton, New Jersey: Princeton University Press, 1965).

[2] Charles E. Osgood, George J. Suci, and Percy H. Tannenbaum, The Measurement of Meaning (Urbana, Illinois: University of Illinois Press, 1957), p. 20.

adjective pairs were then used to rate these concepts. Twelve adjective pairs were chosen for their factor representatives and relevance to the concepts. They were designed to cluster around three central factors: attractiveness, self-esteem and health; which were considered to correspond to Osgood and associates' factors of evaluation, potency and activity.[1]

The semantic differential was pretested with six women from the Tumour Clinic at the Jewish General Hospital. These women found the covering letter to be clear and the section requesting information about personal characteristics to be easy to complete. However, the semantic differential proved to be very difficult for them to understand and complete. They were all sceptical, and feared that there was some hidden meaning to the instrument. Despite drastic simplification, the semantic differential continued to be unacceptable in later pretests. Therefore, an alternative method had to be found of tapping subjects' attitudes.

Accordingly, it was decided that the section on attitudes should follow essentially the same style as the section on

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[1] Osgood et al., The Measurement of Meaning, p. 21.

personal characterics, that is, direct questions were asked, and the subject responded either by checking the appropriate box (e.g. yes or no) or by marking what was relevant to themselves within a range of possible responses (e.g. very nervous, nervous at times, not nervous). These direct questions attempted to measure changes in the feeling states of anxiety and depression over time, amount of support needed by the subjects, and the level of activity before and after surgery.

In an effort to elicit frank responses, several of these questions were prefaced by statements which attempted to normalize the situation; for example:

> Not everyone has the same reaction to an operation, but we know that for everyone an operation is a trying experience. Therefore, it is only natural that a person will feel nervous and/or sad at times both before and after an operation.

Since, in their final form, the questions in this section were generally simple and straightforward, the whole questionnaire was considered to have face validity. Selltiz explains that face validity occurs when, ". . . the relevance of the measuring instrument to what one is trying to measure is apparent on the face of it."[1]

Analysis

Data Cleaning

Responses to three of the questions--numbers twenty, twenty-one and twenty-two--were often incomplete or missing. Question number twenty, which asked the subject to indicate the degree of anxiety and/or depression which was felt at various specified times, was dealt with in the following manner. If a subject left this question totally blank, then it was assumed that nothing at all was known about her feelings, and she was excluded from analysis. If however, some parts of the question were completed, then it was assumed that failure to mark other parts constituted in fact a negative answer, and the blanks were interpreted as meaning that the subject was "not nervous" and/or "not sad" at that particular time. This same procedure was also followed for questions twenty-one and twenty-two.

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[1] Claire Selltiz et al., Research Methods in Social Relations. Revised, 1 volume edition. (New York: Henry Holt & Co., Inc., 1959), p. 165.

Recoding and Scoring

The question dealing with marital status was recoded from six categories to two--married and non-married. The latter group was composed of all those subjects who indicated that they were either separated, widowed, divorced or single. This consolidation was deemed necessary, in view of the fact that the individual categories of non-marrieds had too few cases to show any meaningful differences.

The question dealing with educational level was treated in a similar manner. In recoding, two categories were used: one composed of women who reported completion of elementary and high school, and the other composed of those who had gone on beyond high school. The rationale for grouping these responses was the same as that for grouping the responses to the marital status question--the numbers were too small to show meaningful differences.

The responses to the question dealing with type of operation were also treated this way. Two categories were formed--mastectomy patients and other female surgical patients. There were thirty-one mastectomy patients. The numerical breakdown by type of operation for the second group was as follows:

nine hysterectomy due to cancer, six other cancer patients treated surgically, four orthopedic operations, four appendectomies, two tonsillectomies, two abortions, and two non-cancerous hysterectomies.

Question number twenty asked subjects to indicate the degree to which they felt anxious and/or depressed at five stated times. Responses were given a numerical value so that scores could be calculated for each specific time. The procedure adopted was that the response "not nervous" was given the value one, "nervous at times", the value two, and "very nervous", the value three. The feeling state of sadness was dealt with in the same manner. A feeling score for each stated time, with a possible range from two to six, was obtained by adding the nervousness and sadness scores--the higher value indicating greater nervousness and sadness. A total feeling score was also calculated for each subject by adding the feeling scores at all of the five stated times.

Question twenty-one asked subjects to indicate their reasons for post-operative concern from a list of six possible reasons. If a certain reason was checked at any of the time periods indicated, then the subject was scored as having that concern, and a value of one was assigned. However, if the subject did not check a listed reason at any time, then they were assigned a zero for that reason. A total concern score for each subject was also calculated, by adding the number of reasons checked--a higher score indicating a greater level of concern.

Question twenty-two asked whether or not, when the subjects felt nervous and/or sad, they had someone who:

(1) noticed their discomfort;
(2) helped them face it realistically; and
(3) helped them plan a course of action.

Each positive response was given a numerical value of two, and each negative response, a value of one. The responses to these three items were then added to give a value indicating the degree of support received--a higher number indicating more support.

Question number twenty-eight asked subjects about their activities pre- and post-operatively. They were also asked to indicate how long it took them to return to certain specified activities. These time periods were grouped as shown below, with each group given the indicated value for calculation of correlation coefficients.

TABLE 1

LENGTH OF TIME TAKEN TO RETURN TO AN ACTIVITY

Times	Numerical Value
One to two weeks	1
Three to four weeks	2
Five to six weeks	3
Seven to eight weeks	4
Two to five months	5
Six months to one year	6
More than one year to two years	7
Over two years	8

Statistical Procedures

Data were analyzed by computer, using standard programs:[1]

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[1] Norman H. Nie et al., SPSS: Statistical Package for the Social Sciences (New York: McGraw-Hill Book Company, 1975). Subprograms FREQUENCIES, CONDESCRIPTIVE, CROSSTABS, T-TEST, PEARSON CORR.

1) Frequency distributions were made of responses to all questions (except age, years married, and cost of prosthesis).

2) Mean, minimum and maximum values were determined for age, years married, and cost of prosthesis.

3) Responses to a number of questions were crosstabulated by type of operation, menopausal status, and marital status; and values of chi square were calculated to test the significance of the observed relationships.

4) T-Tests were performed to determine whether pairs of sample means differed significantly (e.g. mean feeling scores for mastectomy patients and for other surgical patients).

5) Pairs of continuously-scaled variables (e.g. feeling score and length of time for return to normal activity) were correlated to determine whether any significant relationship existed.

CHAPTER III

FINDINGS

Profile of the Sample

The differential response rate according to the source of subjects is shown in table 2.

TABLE 2

RESPONSE RATE BY SOURCE OF SAMPLE

Source	Number Distributed	Number Returned	Percent Returned
Tumour Clinic	90	34	37.7
Surgical Clinic	10	4	40.0
Reach to Recovery Annual Meeting	12	3	25.0
Telephone Interviews Reach to Recovery	6	6	100.0
Women known personally to researcher	13	13	100.0
TOTAL	131	60	45.1

There were sixty women in the total sample. Of these thirty-one were mastectomy patients, and twenty-nine had had other kinds of surgery. Of the thirty-one mastectomy patients, twenty-seven (87.1%) had their surgery in one stage--that is biopsy and amputation at the same time. Except as indicated below, there were no statistically significant differences on other variables between mastectomy patients and other surgical patients.

Twenty-eight of the women (46.7%) indicated that they were married and thirty-two women (53.3%) indicated that they were not married. The average length of time married was twenty years.

The ages of the women involved in this study ranged from twenty-one to seventy-eight years, with a mean age of fifty. When women were categorized according to whether or not they had experienced menopause, there was a statistically significant relationship between type of operation and menopausal status. As in shown in table 3, about half the total sample was post-menopausal, but there were relatively more post-menopausal women in the group of mastectomy patients.

TABLE 3

CROSSTABULATION OF MENOPAUSAL STATUS BY TYPE OF OPERATION

Menopausal Status	Mastectomy Patients		Other Patients		Total	
	N	%	N	%	N	%
Pre-menopausal	9	29.0	19	65.5	28	46.7
Post-menopausal	22	71.0	10	34.5	32	53.3
TOTAL	31	100.0	29	100.0	60	100.0

$X^2 = 6.61$, df = 1, $p = 0.010$

The sample was primarily English speaking. Forty-nine women (81.7%) stated that English was the language mainly spoken in their homes, while eight women (13.3%) spoke French, one woman Spanish, one Rumanian and one Czechoslovakian.

Thirty-two women (53.3%), a little over half of the total sample, were Jewish; while sixteen (26.7%) were Catholic, eight (13.3%) Protestant, one Muslim, one WICCA[1] and two stated that they had no religion.

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[1] White witchcraft group.

When asked how important their religion was to them, thirty-two women (53.3%), more than half of the sample, chose the middle response "somewhat important". Twenty women (33.3%) rated their religion as "very important", while eight (13.3%) rated it as "not important".

There was a significant difference between the level of education of mastectomy and other surgical patients, as shown in table 4. Relatively few (22.6%) of the mastectomy patients had gone beyond high school, while 61.1% of the other surgical patients had done so.

TABLE 4

CROSSTABULATION OF LEVEL OF EDUCATION BY TYPE OF OPERATION

Level of Education	Mastectomy Patients		Other Patients		Total	
	N	%	N	%	N	%
Elementary and/or High School	24	77.4	11	37.9	35	58.3
Beyond High School	7	22.6	18	61.1	25	41.7
TOTAL	31	100.0	29	100.0	60	100.0

$X^2 = 8.01$, df = 1, p = 0.01

Out of the total sample of sixty women, nineteen (33.3%) stated that paid employment was their main source of income; eighteen (31.6%) were supported by family or friends; fifteen (26.3%) received an Old Age Pension; while two received Unemployment Insurance, two public assistance, and one woman received a widow's pension.

The modal category for household annual income in this study was $5,000 - $10,000--twenty women (33.9%) were in this category. Thirteen women (22.0%) had annual incomes of less than $5,000, while ten women (16.9%) had incomes of over $20,000.

Thirty-eight women (63.3%) had children, and twenty-two (36.6%) did not. The number of children per subject ranged from one to eight, with a median value of two. The age level of the children ranged from pre-school to over twenty-five. The modal age group for children of subjects in this study was over twenty-five.

The sample had a wide representation of women at various time periods post-operatively. The times ranged from one week since surgery to over ten years. The exact breakdown is indicated in table 5.

TABLE 5

FREQUENCY DISTRIBUTION OF
TIMES SINCE SURGERY

Times since surgery	N	%
0 to 8 weeks	2	3.3
2 to 6 months	7	11.7
more than 6 months to 1 year	7	11.7
more than 1 year to 2 years	12	20.0
3 to 4 years	9	15.0
5 to 10 years	9	15.0
over 10 years	14	23.3
TOTAL	60	100.0

Nineteen (54.3%) of the patients who reported attending the Jewish General Hospital clinics saw the same doctor on all visits. Some individual patients reported seeing as many as eight doctors. Intervals at which all subjects saw their doctors ranged from every week to once a year, with a median time interval of two to three months.

With regard to attention and information wanted while in hospital, forty women (67.8%) indicated that they were satisfied "most of the time", fourteen women (23.7%) "some of the time", and five women (8.5%) were satisfied "not at all".

Twenty-one (67.8%) of the mastectomy patients reported that they had bought a prosthesis; while ten women (32.2%) had not, giving the following as their reasons:

TABLE 6

REASONS FOR NOT BUYING A PROSTHESIS

Rank	Reason	N	%
1	"the one from Reach to Recovery was adequate"	4	40.0
2	"you did not need it"	3	30.0
3	"the cost was too high"	2	20.0
4	"you did not know where to buy one" and "you felt uncomfortable about buying it"	1	10.0
TOTAL		10	100.0

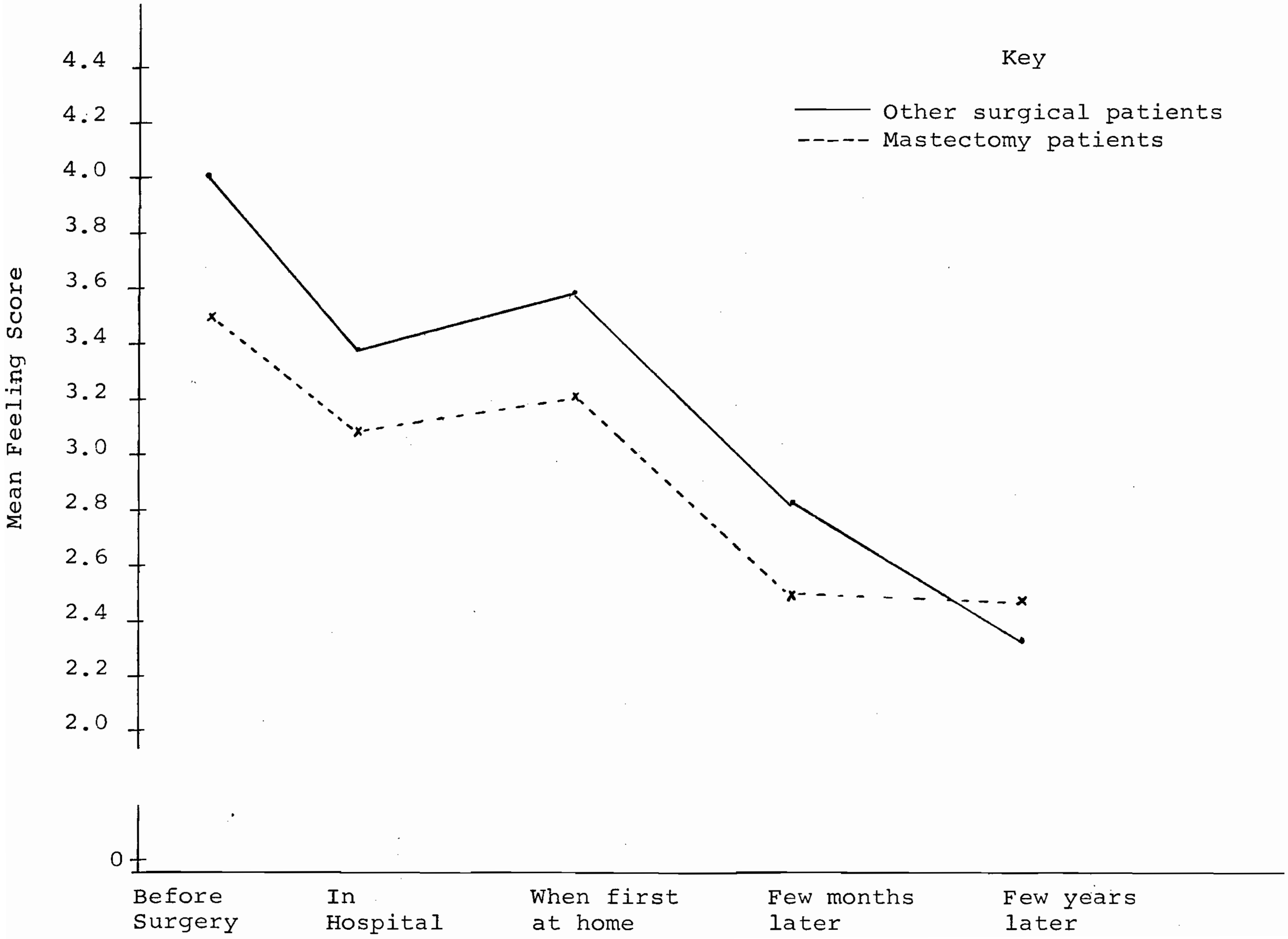
Only three (30.0%) of the mastectomy patients who did not have a prosthesis might perhaps have liked to have one (categories 3 and 4 in table 6).

Pattern of Emotional Reaction Over Time

The mean feeling scores for each time period, calculated as shown on page 25 from the responses to the "nervous" and "sad" parts of question twenty, are shown in figure 1. Feeling scores for mastectomy patients and other surgical patients are shown separately for comparison. A high feeling score indicates a greater degree of nervousness and/or sadness. (See figure 1 on following page.)

As can be seen in figure 1, the two scores run almost parallel, with scores for mastectomy patients lower than scores for other surgical patients, for every time period except the last. For both groups of patients, feeling scores are highest immediately before surgery, and on first returning home from the hospital. The overall mean feeling score, for all the time periods together, was slightly lower for mastectomy patients ($\overline{X} = 2.93$) than for other surgical patients ($\overline{X} = 3.11$). However, neither this difference, nor the differences between the two groups at any one time period, reached statistical significance.

Figure 1.- MEAN FEELING SCORE BY TIME PERIOD



Comparison of Kinds of Concern

Mastectomy Patients

There are many reasons why a person might feel nervous and/or sad following major surgery. Question twenty-one asked the women to indicate, from the list given, what their reasons for concern were. The results showed that twenty-two out of the thirty-one mastectomy patients, or about 70%, felt at least one concern at some time after their operation. Some women reported that they were concerned for more than one of the listed reasons. Table 7 shows a ranking of the six reasons given, from the most frequently to the least frequently mentioned.

TABLE 7

RANKING OF CONCERNS FOR MASTECTOMY PATIENTS

Rank	Reasons for Concern	N	%
1	"the way you look"	16	72.7
2	"being ill"	11	50.0
3	"your sleeping patterns"	9	40.9
4	"reaction of family or friends"	6	27.3
5	"sexual relationships"	5	22.7
6	"ability to be self-sufficient"	5	22.7

As table 7 shows, concern for "the way you look" was mentioned most often. Mean score for this concern (see page 26 for method of calculation) was significantly higher than mean scores for the last three reasons--"reaction of family or friends",[1] "sexual relationships",[2] and "ability to be self-sufficient".[3] Differences in mean scores between "the way you look" and "being ill" or "sleeping patterns" did not quite reach statistical significance.

Comparison of Mastectomy and Other Surgical Patients

The comparison of levels of concern for mastectomy patients and the other female surgical patients was managed in two different ways. First, the six individual reasons for concern were crosstabulated by type of operation. The only significant difference found between the two groups was in concern for "the way you look" (see table 8). A higher percentage of mastectomy patients than of other surgical patients was concerned for this reason.

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[1] $t = 3.58$, $df = 21$, $p = 0.002$

[2] $t = 3.92$, $df = 21$, $p = 0.001$

[3] $t = 3.99$, $df = 21$, $p = 0.002$

TABLE 8

CROSSTABULATION OF CONCERN FOR "THE WAY YOU LOOK" BY TYPE OF OPERATION

	Mastectomy Patients		Other Patients		Total	
	N	%	N	%	N	%
A concern	16	72.7	7	28.0	23	48.9
Not a concern	6	27.3	18	72.0	24	51.1
TOTAL	22	100.0	25	100.0	47	100.0

$X^2 = 7.66$, df = 1, $p = 0.006$

Second, the mean scores for total concern (see page 26) were compared between mastectomy patients ($\overline{X} = 2.36$) and other surgical patients ($\overline{X} = 2.24$). These mean total concern scores were not significantly different.

Relationship Between Concerns and Personal Characteristics

The six individual reasons for concern were cross-tabulated by menopausal status and marital status; and correlated with level of income and amount of help with post-operative discomfort. This was done separately for both mastectomy patients and other surgical patients.

Menopausal Status

For mastectomy patients, concern about "the way you look" showed a statistically significant relationship with menopausal status. As table 9 shows, pre-menopausal mastectomy patients in the sample were relatively more concerned about their looks then post-menopausal mastectomy patients.

TABLE 9

CROSSTABULATION OF CONCERN FOR "THE WAY YOU LOOK" BY MENOPAUSAL STATUS (MASTECTOMY PATIENTS)

	Pre-menopausal		Post-menopausal		Total	
	N	%	N	%	N	%
A concern	8	100.0	8	57.1	16	72.7
Not a concern	0	0.0	6	42.9	6	27.3
TOTAL	8	100.0	14	100.0	22	100.0

Fisher's Exact Test 0.040

For the other surgical patients, there was no significant relationship between menopausal status and expressed concern for "the way you look". In this group, seven women (28.0%) stated that they were concerned about their looks, and eighteen (72.0%) indicated no concern.

It was also found that, for mastectomy patients, there was a significant relationship between menopausal status and a concern about "being ill" (see table 10). Pre-menopausal subjects who responded were relatively more concerned about their illness than post-menopausal subjects.

TABLE 10

CROSSTABULATION OF CONCERN FOR "BEING ILL"
BY MENOPAUSAL STATUS (MASTECTOMY PATIENTS)

	Pre-menopausal		Post-menopausal		Total	
	N	%	N	%	N	%
A concern	7	87.5	4	28.6	11	50.0
Not a concern	1	12.5	10	71.4	11	50.0
TOTAL	8	100.0	14	100.0	22	100.0

Fisher's Exact Test 0.012

A similar relationship existed between menopausal status and concern about illness for patients who had had other surgical operations, but for this sample the relationship did not reach statistical significance.

No significant difference was found between pre- and post-menopausal women in either sample group, for any of the other reasons for concern.

Marital Status

For the sample of mastectomy patients there was a significant relationship between marital status and concern about "being ill". As can be seen in table 11, married mastectomy patients were relatively more concerned about their illness than non-married mastectomy patients. (See table 11, on following page.)

For the other surgical patients, there was no significant relationship between these variables; and no significant difference was found between married and non-married women, in either sample group, for any of the other reasons for concern.

TABLE 11

CROSSTABULATION OF CONCERN FOR "BEING ILL" BY MARITAL STATUS (MASTECTOMY PATIENTS)

	Non-married		Married		Total	
	N	%	N	%	N	%
A concern	2	28.6	9	75.0	11	50.0
Not a concern	8	71.4	3	25.0	11	50.0
TOTAL	10	100.0	12	100.0	22	100.0

$X^2 = 4.58$, $df = 1$, $p < 0.05$

Level of Income

For the sample of mastectomy patients, a significant correlation was found between level of income and amount of concern about "being ill".[1] Those women with a higher level of income indicated that they had more concern about their illness than those with a lower level of income. For the

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[1] $r = 0.67$, $df = 19$, $p = 0.001$

other surgical patients, no significant correlation was found between these two variables.

Emotional Support

For the sample of mastectomy patients, a significant correlation was found between amount of help received (see page 26 for calculation of score) and concern about "being ill".[1] Those mastectomy patients who had had more help with their discomfort indicated that they were more concerned about their illness. For the other surgical patients, there was a similar correlation, but it did not reach statistical significance.

It is interesting to note that eight of the mastectomy patients (34.8%) and seven of the other surgical patients (26.9%) stated that they had managed their discomfort alone.

Relationship Between Rate of Recovery and Feeling State

A number of significant correlations were found between mean feeling scores for various time periods and the length of

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[1] $r = 0.43$, $df = 18$, $p = 0.029$

time subjects took to return to normal activity. Most of these significant correlations occurred in the sample of other surgical patients (see table 12 on following page). Most of the correlations were positive--that is a longer time to return to normal activity is associated with greater feelings of nervousness and/or sadness--but one, the correlation for other surgical patients between feeling score "when first at home" and length of time to return to "work outside of the home", was negative.

Desired Social Work Services

Ranking of Social Work Services

The questionnaire offered five ways in which a patient might want to become involved with a medical social worker (see Appendix, question twenty-two). Thirty-four subjects (56.7%) expressed interest in at least one of these; some in more than one.

The service which received the most positive responses was "talking together abour your feelings and concerns around the surgery". Here there was a statistically significant

TABLE 12

CORRELATION BETWEEN FEELING SCORES AT VARIOUS TIMES AND LENGTH OF TIME TAKEN TO RETURN TO NORMAL ACTIVITY

Activity after Surgery	Sample Group	Mean Feeling Scores at Various Times			
		In hospital	When first at home	Few months later	Few years later
Work within the home	mastectomy	NS	NS	NS	.58* (12)
	others	.65** (13)	.61** (13)	.52* (12)	.60* (10)
Work outside the home	mastectomy	NS	NS	NS	NS
	others	NS	-.63* (10)	NS	NS
Groups outside the home	mastectomy	NS	NS	NS	NS
	others	.90* (3)	NS	NS	NS
Individual activities	mastectomy	NS	NS	NS	NS
	others	.71* (8)	NS	NS	NS

* $p < 0.05$
** $p < 0.01$
NS = not significant

Figures in brackets represent number of cases. These are often small, as few women reported any one type of activity.

difference between mastectomy patients and other surgical patients, as shown in table 13. Mastectomy patients were relatively less interested in this service.

TABLE 13

CROSSTABULATION OF INTEREST IN TALKING ABOUT FEELINGS BY TYPE OF OPERATION

	Mastectomy Patients		Other Patients		Total	
	N	%	N	%	N	%
Wanted	7	22.6	15	51.7	22	36.7
Not wanted	24	77.4	14	48.3	38	63.3
TOTAL	31	100.0	29	100.0	60	100.0

$X^2 = 4.30$, df = 1, $p = 0.038$

Fourteen women (23.3%) indicated a desire for the social work service "sorting out the real from the unreal about your medical condition so you can receive sincere reassurance". Here there was no significant difference between the two sample groups. The same number of women--fourteen (23.3%)--indicated that they would like the social work service "helping arrange practical needs".

The next most wanted social work service was "helping family and/or friends to express their feelings". Here again there was a statistically significant difference between mastectomy and other patients, with the former again expressing relatively less interest, as can be seen in table 14.

TABLE 14

CROSSTABULATION OF HELPING FAMILY AND/OR FRIENDS BY TYPE OF OPERATION

	Mastectomy Patients		Other Patients		Total	
	N	%	N	%	N	%
Wanted	3	9.7	10	34.5	13	21.7
Not wanted	28	90.3	19	65.5	47	78.3
TOTAL	31	100.0	29	100.0	60	100.0

$X^2 = 4.07$, df = 1, p = 0.044

The least wanted service was "to help you better understand the future". Only ten women (16.7%) expressed an interest in this type of counselling.

Relationship Between Interest in Social Work Services and Personal Characteristics

Menopausal Status

No significant relationship was found between menopausal status and interest in social work services for either the sample of mastectomy patients or the sample of other surgical patients.

Marital Status

The sample of non-married mastectomy patients showed more interest than the married mastectomy patients in becoming involved with a social worker "to talk together about your feelings and concerns around surgery,"[1] and "to help arrange practical needs".[2]

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[1] $r = 0.41, \quad df = 29, \quad p = .024$

[2] $r = 0.57, \quad df = 29, \quad p = .002$

Income Level

There was no significant correlation between income level and the expressed desire for any one-to-one social work service.

Desire for Group Work

Question number twenty-seven on the questionnaire (see Appendix) asked the women if they would like to participate in an organized group with other women who had the same type of surgery. The overall level of interest expressed in this social work service was almost the same as the interest expressed in one-to-one social work services. Thirty-one women (51.7%) indicated interest in a group, while thirty-four (56.7%) indicated interest in becoming involved with a social worker on a one-to-one basis. There was no significant difference between mastectomy and other surgical patients in their interest in a group experience.

Four possible purposes for this type of group were offered on the questionnaire. Table 15 shows a ranking of the various purposes, from the most frequently to the least frequently mentioned. None of these showed significant difference between the sample of mastectomy patients and the sample of other surgical patients.

TABLE 15

RANKING OF DIFFERENT GROUP PURPOSES IN ORDER OF INTEREST EXPRESSED

Rank	Group Purpose	N	%
1	"sharing concerns about the practical aspects of your surgery"	17	32.7
2	"sharing feelings and/or concerns about the changes in your body"	15	28.8
3	"talking about how to deal with family and friends"	11	21.2
4	"doing physical exercises to help speed recovery"	9	17.3
TOTAL		52	100.0

CHAPTER IV

DISCUSSION OF FINDINGS

Pattern of Emotional Reaction Over Time

As shown in figure 1 on page 47, mastectomy patients reported themselves as most nervous and/or sad immediately before surgery. While they were in hospital, the level of these feelings dropped. Upon discharge, it rose again, but did not reach the pre-operative level. A few months later these feelings of nervousness and sadness diminished considerably, and they remained at the same level for the remainder of the period under consideration.

It is not surprising that a mastectomy patient would have the highest level of anxiety and/or depression pre-operatively, as at that time most of the women in this survey were in a state of uncertainty as to whether or not they had breast cancer. (As seen on page 30, 87% of the mastectomy patients had their surgery in one stage--that is, the diagnosis and treatment were concurrent.)

It also seems reasonable that nervous/sad feelings would drop considerably when the patient is in hospital, due to the extensive support system which exists in most hospitals. This notion is confirmed by the fact that forty women (67.8%) stated that "most of the time" they had received the attention and information that they felt they needed while in hospital. These findings then tend to support Harrell's statement that ". . . post-surgical hospitalization aids in the prevention of adverse psychological reactions."[1]

The findings in this study show that a few months after surgery the level of depression and/or anxiety drops to its lowest point. This confirms Klein's idea that a mastectomy is a time-limited crisis in the life of a woman. It seems safe to conclude that the periods of greatest difficulty, and therefore the time the patient is in the greatest need of help, are immediately before surgery and within the first four to six weeks after they have been discharged from hospital. Klein is of the opinion that this is the optimal time for intervention, ". . . it is more efficient and economical to

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[1] Harrell, "To Lose a Breast," p. 676.

help people take advantage of such a short-term disequilibrium than to attempt to pick up the pieces months or years later when an incapacitating problem shows itself."[1]

In comparing the emotional reactions of mastectomy patients to those of other surgical patients, there were two interesting findings. First, throughout most of the time period under consideration, the mean scores for the mastectomy patients were consistently lower than those for other surgical patients. Second, the mean score for other surgical patients dropped below the mean score for mastectomy patients in the last time period, indicating that, at this point, they felt better than the mastectomy patients. Though none of these differences reached statistical significance, they are interesting enough to warrant some discussion. The first finding is puzzling, as, considering the nature of their illness, mastectomy patients might be expected to feel more concern. This finding can perhaps be explained in part by the fact that the sample of mastectomy patients might have been biased. Though an exact breakdown is not possible (see page 17), it is the writer's impression that the response rate was generally

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[1] Klein, "Crisis," p. 1971.

lower for mastectomy patients than for other surgical patients. It seems reasonable to suppose that those women who had done relatively well post-operatively would be relatively more likely to respond. Kushner, in her study, found such a sample bias--that is, she received disproportionately more answers from those subjects who had been more successfully rehabilitated.[1]

Another possible explanation for the lower feeling scores expressed by mastectomy patients is that there were significant differences in the two sample groups. A higher percentage of the mastectomy patients was post-menopausal; and thus, presumably, this group of women was substantially older than the sample of other surgical patients (see table 3, page 31). Also, the educational level of the mastectomy patients was significantly lower than the educational level of the other surgical patients (see table 4, page 32). It is interesting to speculate that perhaps older and less well educated women may have lower expectations for their own state of health, and may therefore have less anxiety and/or depression.

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[1] Kushner, Breast Cancer, p. 210.

It is also conceivable that the mastectomy patients were denying their feelings, thus causing the profile of their reported emotional reaction over time to appear more positive than that for the other surgical patients. This theory is supported by the fact that significantly fewer mastectomy patients than other surgical patients wanted to talk with a social worker about their feelings and/or concerns about their surgery, or about the feelings of their family about their condition, (see tables 13 and 14, pages 48 and 49). Trachtenberg found, in her experience with mastectomy patients, that ". . . there is a desire to move toward a healthy denial of the total experience, but these women doubt that they will be able to do so if other people--friends, neighbours and sometimes even family members--are told about the surgery".[1] Also Maguire, in his study of mastectomy patients, found that women failed to mention post-operative difficulties to those involved in their after-care. Maguire's explanation for this was that ". . . those women seemed to accept their problems as the inevitable cost of physical survival and believed that

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[1] Trachtenberg, "Team Involvement," p. 4.

little could be done to help them."[1]

The second interesting point--the fact that a few years after surgery the sample of other surgical patients reported that they felt better than did the mastectomy patients--is relatively easy to understand, as there is an appreciable risk of recurrence with breast cancer. Goldsmith and Alday report that ". . . thirty percent of women with local breast cancer and negative axillary nodes die from recurrent breast cancer within five years after a mastectomy."[2] It seems reasonable, therefore, that the mastectomy patients would continue to be anxious and/or depressed longer than the other surgical patients. Also, Freeman states that ". . . anxiety is an inherent feature of the disease, and the emotional impact after mastectomy in women is always profound and usually permanent."[3]

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[1] Peter Maguire, "The Psychological and Social Consequences of Breast Cancer," Nursing Mirror (April 3, 1975): 4.

[2] Goldsmith and Alday, "Role of the Surgeon," p. 1673.

[3] B. Freeman, Commentary on "Psychologic Adjustment to Mastectomy," Medical Aspects of Human Sexuality 7 (February 1973): 65.

Comparison of Kinds of Concern

One of the key research questions in this study was to determine which is the more traumatic element for the mastectomized women--the fact that she has a life threatening disease, or the fear that, as a result of her mutilating surgery, she will be unacceptable in interpersonal and sexual relationships.

Though the difference did not quite reach statistical significance, the mastectomy patients in this study ranked concern for "the way you look" higher than concern for "being ill" (see table 7, page 38). The concern for appearance may reasonably be interpreted as the mutilation aspect, and concern for illness may reasonably be interpreted as a possible fear of death. This agrees with Bard's findings concerning the sequence of emotional reaction in radical mastectomy patients. He suggests that the mutilation factor is a greater source of depression than the fear of recurrence.[1]

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[1] Morton Bard, "The Sequence of Emotional Reaction in Radical Mastectomy Patients," Public Health Report LVII (November, 1957): 1145.

Further supporting evidence is provided, in this current study, by responses to the question about use of groups (see table 15, page 52). The mastectomy patients--like other patients--most wanted a group experience to talk about the practical aspects of their surgery and about the changes in their bodies.

Cultural values provide a final possible explanation as to why these mastectomy patients rated their appearance as their greatest concern. In today's breast conscious North American society, it seems reasonable to suppose that the loss of a breast would be highly undesirable. Of all the possible reasons for concern, only concern about appearance showed a significant difference between mastectomy patients and other surgical patients (see table 8, page 40). Mastectomy patients indicated a much greater concern for their appearance than did other surgical patients. Considering the nature of the surgery, this is hardly surprising.

When the various concerns were examined according to personal characteristics of subjects, it was found that, as before, only differences in concern about appearance and in concern about illness reached statistical significance.

Younger mastectomy patients were significantly more concerned about their appearance than older mastectomy patients (see table 9, page 41); while marital status, level of income and degree of support appeared to cause no significant difference in level of concern about appearance. Such findings seem reasonable, as, in general, younger women might well be more concerned about how they look than older women. Freeman, in talking about illnesses generally, reported that ". . . seemingly the psychological stress is less with the increase of age of the patient."[1]

Concern about illness, which the mastectomy patients rated as their second major concern, was significantly related to several personal characteristics (see pages 42-45; especially tables 10 and 11). The younger, married mastectomy patients, with higher income and a higher level of emotional support, indicated a greater concern about being ill.

It is perhaps not surprising that younger patients would be more concerned about their illness. This tends to confirm the findings of other researchers. Goldsmith and Alday

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[1] Freeman, Commentary on "Psychologic Adjustment to Mastectomy," p. 65.

found that young mastectomized women have increased fears, as they are prematurely forced to confront their own mortality.[1] Klein found, in her work with mastectomy patients, that ". . . younger patients are extremely shocked to find that the future they had counted on might be curtailed."[2]

The fact that the married mastectomized women in this sample showed a greater concern for their illness than the non-marrieds also seems reasonable. It seems logical to assume that a married woman might have more dependents, and might therefore express greater anxiety over the fact that she is ill, and thus unable to care for these dependents as well as she would like.

It is interesting to find that women with higher incomes report more concern about their illness than women with lower incomes. This supports the previously mentioned speculation that women from a lower socio-economic group might have lower expectations for their own health.

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[1] Goldsmith and Alday, "The Role of the Surgeon," p. 1673.

[2] Klein, "Crisis," p. 1662.

The final personal characteristic found to be related to concern about illness was the degree of emotional support that a patient received. Here, it was found that those mastectomy patients who received more help with their felt discomfort indicated a greater concern for their illness. This seems logical, in the light of Parad's finding that a certain amount of anxiety is essential to motivate the individual to seek the help of others.[1]

Relationship Between Rate of Recovery and Feeling State

The relationship between the amount of nervousness and sadness felt by subjects, and the time taken to return to an activity, are largely as expected--that is, the worse a woman says she felt, the longer she says she took to return to various activities (see table 12, page 47). An exception is the negative correlation for other surgical patients between feeling score "when first at home" and length of time to return to "work outside the home". It is worth noting here that samples for any one activity are very small. It is

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[1] Parad, Crisis Intervention, p. 30.

interesting to note that there are fewer significant correlations for the mastectomy patients than for the other surgical patients. This may be due to the nature of the sample--that is, the fact that the mastectomy group tended to be made up of older and less well educated women, who might well have different kinds of responsibilities at work and at home. Considering the observed relationship between feeling score and rate of return to normal activity, the question arises as to which is the cause and which the effect. Since some of the significant correlations involve feelings "in hospital" and "when first at home", it may be that feelings are the causal variable. However, it also seems reasonable that, if those who returned to activities faster felt better, then post-operative patients should be encouraged to become active as soon as it is medically sound to do so. Harrell, a medical professional who has herself had a mastectomy, has found that she ". . . hasn't whipped fear but can recognize the face of fear and most times can banish it with productive action."[1]

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[1] Harrell, "To Lose a Breast," p. 677.

Desired Social Work Services

"Talking together about your feelings and concerns around surgery", was the social work service which received the greatest response (table 13, page 48). The particular focus would presumably depend upon the needs of the individual woman at a particular time. This study showed that a woman's anxiety and/or depression was highest before surgery, so that it would seem that she could use this service at that time. The intensity of these feelings drop immediately after surgery, but the woman still has many concerns. Involvement with a social worker on a one-to-one basis for the purpose of talking about feelings would allow the woman to express her sadness at having breast cancer, and the anger that such a thing should have happened to her. A patient might possibly feel guilty about expressing grief at the loss of a precious body part to a doctor, and so welcome the opportunity to discuss such matters with a more neutral figure like a social worker.

Younger women in particular indicated a lot of concern in this study. Also, non-married women, more than married women, wanted this service. Perhaps the loss of a sexually significant body part generated fears of not being physically attractive to men, and/or feelings of demeaned self-worth. For these women, a group experience would seem to be particularly helpful. "Sharing feelings and/or concerns about the changes in your body", was the second most wanted group purpose in this study (table 15, page 52). Such a group experience could offer mastectomy patients mutual support.

The second most wanted social work service was "sorting out the real from the unreal about your medical condition so you can receive sincere reassurance". The fact that this was given such a high priority by the women would seem to indicate that these patients have a need to know about their medical condition and the course of treatment. Trachtenberg has said that . . .

> Articles by professionals and patients alike remind us that patients want and need information in order to cope with their conditions. Without such information, patients are left to fantasize about what will happen to them. More often than not, their imaginations, free to run wild, will be worse and lonelier than the truth, no matter how painful the latter is.[1]

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[1] Judith M. Trachtenberg, "How Much Does the Cancer Patient Really Want to Know When Being Prepared for Treatment?" paper presented at National Conference on Human Values and Cancer, Atlanta, Georgia, June, 1972, p. 3.

At all times, all members of the team should try to help the patient sort out the real from the unreal, as the patient is trying to find stability. One-to-one involvement with a social worker may help the patient by identifying any misconceptions. It may be necessary for the social worker to mediate between the patient and the doctor in order to clarify a situation. Also, the Reach to Recovery volunteer can be helpful in translating into practical language the things that the doctor, nurses and social worker are saying about possible recovery.

"Helping arrange practical needs, e.g. job, unemployment insurance, a homemaker or prosthesis", was the third most wanted social work service. Arrangement of such practical matters could do a lot to quell the anxiety of the married woman before surgery. Also, a social worker can help to lower the level of anxiety shown when the patient first goes home by preparing for hospital discharge in a practical manner. The young woman who is concerned about her appearance can be helped by having assistance in arranging for a prosthesis. For the married woman, the social worker can motivate and support the family in their attempts to arrange for practical needs; for a single woman, the social worker can herself provide some of the necessary help. "Sharing concerns about the practical aspects of your surgery", was the highest ranking group purpose. A group composed of women at various times post-operatively could be very helpful in passing on suggestions to more recent mastectomy patients about practical solutions to problems.

The fourth social work priority in this study was "to help family and/or friends to express their feelings and to help you better deal with family and/or friends". The best time for this type of social work involvement might be while the patient is still in hospital, when the patient and the family can be seen together, so that common problems, questions, and wrong beliefs can be attended to. The level of anxiety and/or depression when the patient first returns home may then be lower. The related group purpose was "talking about how to deal with family and friends" and Trachtenberg's work suggests that groups might also be initiated while the patient is in hospital.[1]

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[1] Trachtenberg, "Team Involvement," p. 2.

"To help you better understand the future" was the least wanted social work service. The fact that many of the women were concerned about their illness would indicate a need to discuss their prognosis. This might best be done on a one-to-one basis in the hospital. Special attention might well be given to the younger mastectomy patient and to the married woman, as these expressed the greatest concern about their illness. Involvement with a Reach to Recovery volunteer, and a group experience, would seem particularly helpful in illustrating how long the rehabilitation process should take, and the role that the patient has to play in it.

CHAPTER V

CONCLUSION

Social Work Recommendations

As our health facilities strive for better delivery of services and more comprehensive patient care, greater stress is placed on the importance of utilizing professional skills to the maximum. As a result of this study, certain recommendations have been made as to how the social work role can be improved, to achieve the best possible care for the mastectomy patient.

1. It is recommended that, despite their apparently better situation, social workers pay special attention to younger, married mastectomy patients with higher income and an apparent higher level of emotional support. These women may have high levels of concern and may need help from a social worker to express these concerns and to feel that they have a greater involvement in their own care.

2. It is recommended that there be a closer liaison between the social worker and the Reach to Recovery volunteer. It is suggested that the volunteer might be the most acceptable helping person to make the first approach to the mastectomy patient. Together the volunteer and the social worker can attempt to meet the emotional and practical needs of the patient.

3. It is recommended that the time in which the social worker become involved with the patient be during hospitalization. Ideally, the time for intervention should be before surgery. However, this is seldom possible, as the diagnosis of the disease and the treatment are concurrent. Social work follow-up should be encouraged, and can be achieved through the use of a patient group. A group begun during hospitalization can ensure continuity of care upon discharge.

The two next recommendations do not arise directly out of the findings; first is the universal referral of all mastectomy patients to a social worker, second, the establishment of a dance therapy program.

4. The present random referral of mastectomy patients to a social worker has a hit-or-miss quality as to the help offered. It is recommended that every mastectomy patient--not just the ones who are exhibiting clear problematic symptoms--be approached by a social worker, who could explore with the patient the kinds of help she might need.

5. The second innovative approach that might be worth considering is dance therapy. This study gives some indirect hints that such therapy might be worthwhile. For those women who have indicated that their number one concern is for their appearance, performing ballet might help restore the lost feeling of grace. Ballet builds up the very arm and chest muscles that are weakened by a mastectomy. The movements are slow and flowing, preventing any jerking or jarring that could damage the muscles further. One such program has been in operation at the University of Santa Clara and has been endorsed by the American Cancer Society.[1]

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[1] Rick Du Brow, "Ballet is Therapy for Women's Emotional Turmoil," <u>The Gazette</u>, December 18, 1975, p. 23.

CHAPTER VI

SUMMARY

The purpose of this study was to determine the attitudes and needs of mastectomy patients, and to determine in what way social workers could most effectively help these women.

The research sample was made up of thirty-one mastectomy patients and a comparison group of twenty-nine other female surgical patients. A questionnaire was administered to each subject to obtain certain personal and demographic data; and information about the nature and timing of her operation, amount of help and support received, length of time before return to normal activity, and feelings, concerns and needs at various stated times before and after her operation. Data were analyzed using standard computer programs.

The findings indicated two significant differences between the two sample groups: mastectomy patients in the sample were both older and less well educated than the comparison group of other surgical patients.

Mean levels of anxiety and/or depression were reported as being highest immediately before surgery, and during the first six weeks after surgery. For most of the time periods considered, mastectomy patients reported less anxiety and/or depression than did other surgical patients; several years after surgery the level of anxiety and/or depression of the other surgical patients had dropped below that of the mastectomy patients.

Mastectomy patients reported themselves as being concerned most about their appearance and next about being ill. They expressed more concern about their appearance than did other surgical patients; also, younger mastectomy patients indicated more concern about appearance than did older mastectomy patients. Younger, married mastectomy patients with higher incomes and a higher level of emotional support were more concerned about being ill than were patients who were older, not currently married, and with lower incomes and a lower level of support.

The more anxiety and/or depression a woman reported feeling, the longer she took to return to her normal pre-operative activities.

About half the subjects showed interest in some form of social work services and the same proportion showed interest in a possible group experience. Mastectomy patients showed less interest in social work services which involved talking about their feelings than did other surgical patients.

There were, however, indications that the anxiety and concern of mastectomy patients were greater than the findings showed--first, because the more successfully rehabilitated mastectomy patients may have been over-represented in the sample; and second, because these patients may have been denying their real level of concern.

A number of recommendations were made for more effective delivery of social work services to mastectomy patients.

APPENDIX

COVERING LETTER AND QUESTIONNAIRE

McGill University,
School of Social Work,
3506 University Street,
Montreal, Quebec. H3A 2A7

Dear Madam,

McGill University in collaboration with the Social Work Department of the Jewish General Hospital is undertaking a small survey of female surgical patients' experiences at various times following their surgery. We are trying to learn more about what actually occurs after an operation so that new programmes can be developed which are more in tune with women's physical and emotional needs.

As you are the only person who really knows how you felt after surgery, your participation is vital for this survey and ultimately for all women. I hope that you will take fifteen minutes or so now and volunteer a few important facts and feelings about yourself.

Please be so kind as to fill in your questionnaire as soon as possible. There is no need to put your name on the questionnaire. Everything is totally confidential. If you are in the clinic why not take a few minutes now to complete it and give it back. Or if you prefer to fill it in at home, a self-addressed stamped envelope is attached for your convenience.

If you have any questions please do not hesitate to approach me here in the clinic or to call me at 342-3230 any Tuesday or Wednesday.

Once again, the purpose of this survey is not just to gather a lot of facts and figures but to use the information which you give to create new programmes for female surgical patients.
If you wish to know the results of the survey you can leave your name at the above mentioned number.

Thank you very much for all your time and effort.

Sincerely,

Susan C. Bennett

INSTRUCTIONS: Check off the appropriate box ie. ☑
Please feel free to add comments where ever you wish.

1. Your status is...

☐ single
☐ married for ____ years
☐ separated for ____ years
☐ divorced for ____ years
☐ widowed for ____ years
☐ other ______________
specify

2. Do you live...

☐ alone
☐ with husband and/or children
☐ with other family members
☐ in a group
☐ with another woman
☐ with a man

3. Your age is ________.

4. Have you experienced menopause or the change of life? ☐ Yes ☐ No

5. The language mainly spoken in your home is...

☐ English ☐ French ☐ other ______________
specify

6. Your religion is...

☐ Catholic ☐ Protestant ☐ Jewish
☐ None ☐ other ______________
specify

7. How important is your religion to you now...

☐ very important ☐ somewhat important ☐ not important

8. Which level of schooling did you complete?

☐ elementary ☐ some college ☐ some post graduate
☐ high school ☐ college degree ☐ post graduate degree

9. What is/are your main source(s) of income at present?

☐ paid employment
☐ unemployment insurance
☐ family or friends support
☐ social assistance

10. What is your present household level of annual income?

☐ less than $5,000
☐ $5,000 to $9,999
☐ $10,000 to $14,999
☐ $15,000 to $19,000
☐ over $20,000

11. How many children do you have?________

12. How old are your children?______________________________________.

13. What type of surgery did you have?______________________________.
Note: If you had more than one operation indicate the most recent

14. How long ago did you have this surgery?______ months ______ years

15. At present how often do you see your doctor?
Note: Check the box and fill in the blank ie. ☑ every 2 week(s)

☐ every _____ week(s)
☐ every _____ month(s)

16. Which clinic do you come to?____________________________________.

17. Do you see the same doctor when you come to clinic? ☐ Yes ☐ No

18. How many different doctors have you seen at this clinic since your operation? ________ doctors

19. Answer this question only if you had breast surgery.

A. Did you have...

☐ one breast removed
☐ both breasts removed
☐ your armpit operated on as well
☐ swelling of your arm for _____ weeks or _____ months.

B. Was your operation done in...

☐ one stage (biopsy and mastectomy at same time)
☐ two stage (time between biopsy and mastectomy)

comments____

____

C. If you bought a prosthesis what was the cost?______________

D. If you did not buy a prosthesis, why not?

☐ the cost was too high
☐ you did not need it
☐ the one from Reach to Recovery was adequate
☐ you did not know where to buy one
☐ you felt uncomfortable about buying it

E. Were you visited by a Reach to Recovery volunteer? ☐ Yes ☐ No

F. Would you have liked her to call on you at home? ☐ Yes ☐ No

G. Was the Reach to Recovery manual helpful? ☐ Yes ☐ No

H. Would a breast surgery manual addressed to men be helpful to both you and your partner? ☐ Yes ☐ No

I. Comments:____
____
____
____

20. Not everyone has the same reaction to an operation, but we know that for everyone an operation is a trying experience. Therefore, it is only natural that a person will fee nervous and/or sad at various times both before and after an operation.

You are asked here to check off how nervous and/or sad you felt at these various times. Simply place a check (✓) in the box which matches how you felt at the indicated times.

Not Nervous	Nervous At Times	Very Nervous	TIME PERIODS	Not Sad	Sad At Times	Very Sad
			just before your surgery			
			during the hospital			
			when you first went home			
			a couple of months later			
			a couple of years later			
			other times specify			

21. There are many reasons why a person might feel nervous and/or sad following major surgery. Some of the reasons for concern that other women have mentioned are listed below.

You are asked here to check the reasons why you felt nervous and/or sad at the various times indicated. Again, just check the box which matches your thoughts.

POSSIBLE REASONS FOR CONCERN	TIME PERIODS					
	Before Surgery	During Hospital	When first at home	Few months later	Year or so later	Others:
the way you look						
being ill						
reaction of family or friends						
your sleeping patterns						
your sexual relationships						
your ability to be self-sufficient						
others: ____________ ____________						

22. When you felt nervous and/or sad did you have someone who...

A. Noticed your discomfort? ☐ Yes ☐ No

B. Helped you face it realistically? ☐ Yes ☐ No

C. Help you plan a course of action? ☐ Yes ☐ No

23. Who was this helper? ________________________________

24. We all know that hospitals are extremely busy places, and individuals may sometimes feel that they are not always getting the attention and information which they feel they need.

Did you get the attention and information you felt you wanted...

☐ most of the time ☐ some of the time ☐ not at all

25. There are many different people who can give us attention and/or information when we are ill.

Please indicate here...

A. who actually gave you some attention and/or information both before and after surgery.

B. who would you have liked more attention and/or information from both before and after surgery.

A. Who gave you some attention?		PEOPLE	B. Who would you have liked more from?	
Before	After		Before	After
☐	☐	your doctor	☐	☐
☐	☐	a woman who had the same type of surgery	☐	☐
☐	☐	a nurse	☐	☐
☐	☐	a medical social worker	☐	☐
☐	☐	a psychiatrist	☐	☐
☐	☐	your partner	☐	☐
☐	☐	your children	☐	☐
☐	☐	other family members	☐	☐
☐	☐	friends	☐	☐
☐	☐	others ________________ specify	☐	☐

26. A medical social worker is someone many people do not know too much about. The medical social worker can work for and with a patient in many different ways. Below is a list of some of the ways in which medical social workers have become involved with people who have had surgery.

You are asked here to check off (✓), on the list given, how you might like to become involved with a medical social worker.

- ☐ talking together about your feelings and concerns around surgery.
- ☐ sorting out the real from the unreal about your medical condition so you can receive sincere reassurance.
- ☐ helping arrange practical needs ie. a job, unemployment insurance, a homemaker, prosthesis, etc.
- ☐ to help you better understand the future.
- ☐ to help family and/or friends to express their feelings.
- ☐ to help you better deal with family and/or friends.
- ☐ others: ____

____

27. After your discharge from hospital would you have liked an opportunity to share some of your experiences and feelings in an organized group with other women who had the same type of surgery?

☐ Yes ☐ No

What purpose would you see this group having?

☐ sharing concerns about the practical aspects of your surgery.

☐ doing physical exercises to help speed recovery.

☐ talking about how to deal with family and friends.

☐ sharing feelings and/or concerns about the changes in your body

☐ others: ______________________________

____

28. It is only natural that any surgery will bring a change in your activities. You are asked in this question to indicate what your activities were before surgery and after surgery. Also please show how long it took you to return to an activity or to begin a new one.

Before Surgery	ACTIVITIES	After Surgery	How long after did you begin this...
☐	full time student	☐	
☐	work within the home	☐	
☐	paid work outside the home	☐	
☐	volunteer work outside the home	☐	
☐	group activities outside the home ie. clubs, "Y", courses	☐	
☐	individual activities ie. crafts, reading, sports	☐	
☐	others: ______________ ______________	☐	

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