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COUNSELING NEEDS OF MASTECTOMY PATIENTS:
REACH TO RECOVERY PROGRAM

by

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of the requirements for the degree of

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INTRODUCTION AND ACKNOWLEDGMENTS

The following is a descriptive and exploratory study of the counseling needs of mastectomy patients and how they are met, and of the Reach to Recovery program through the American Cancer Society as a way of meeting these needs.

The writer has surveyed the professional literature and, briefly, some popular literature on the subject. In addition, a questionnaire was addressed to a group of Portland Reach to Recovery volunteers who served as a target population, one of whom was interviewed more fully.

I would like to acknowledge with thanks the most helpful cooperation of Mrs. Nancy Brice, Service Director, American Cancer Society, Oregon Division and Mrs. Nora Janik, State Co-ordinator, Reach to Recovery, American Cancer Society, Oregon Division, without whom the study could not have been done. My thanks, too, to Mrs. Ada Wilson of the School of Social Work, Portland State for her continuing guidance and assistance and to Dr. Frank Miles for his assistance in designing the questionnaire and to my husband and family who not only helped but bore with me.

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CHAPTER I

REVIEW OF LITERATURE

I BREAST CANCER IN THE UNITED STATES

Breast cancer is the leading cause of cancer death in women in the United States.[1] In 1973, the estimated deaths from breast cancer in this country were 32,650 and, according to the American Cancer Society, nearly 7% of the American female population will develop breast cancer.[2]

Research has shown that those women most likely to develop breast cancer are obese, 40-44; over 60 who have never had children; women who bore their first child over 30. Further characteristics are:

1. history of benign breast disease
2. daughters of parents with a familial history of cancer and whose female, blood relatives have had a history of breast cancer.[3]

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[1] Justin J. Stein, M.D., "Hi-Risk Groups", <u>Cancer News</u>, Spring/Summer, 1974, Vol. 28, #1, p. 4.

[2] American Cancer Society, "'73 Cancer Facts & Figures", New York, 1973.

[3] Justin J. Stein, M.D., "Hi-Risk Groups", <u>Cancer News</u>, Spring/Summer, 1974, Vol. 28, #1, p. 4.

Risk of cancer in the above group is 70 - 500% higher than the average, depending on the combination of characteristics. The two age peaks are 40 - 44 and over 60, and much of the educating activities regarding early detection are directed to women in the 40 - 44 age range.[4]

The process which a woman must go through when a lump is discovered in her breast is to be hospitalized to have a breast biopsy to determine whether the lump is malignant or benign. In the majority of cases (60 to 80%) the breast biopsy is benign.[5] For those women in whom the lump has been discovered to be malignant, the method of treatment is almost always a mastectomy or surgical removal of the breast. The operation is performed, if necessary, immediately upon discovering that the lump is malignant and within a short period of time after the biopsy itself. This means that when a woman goes into surgery for a biopsy, she may have a breast removed as well. The procedure is explained to her ahead of time, but she doesn't know until the operation is over whether in addition to the biopsy, she has had a mastectomy as well.

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[4] Ibid.

[5] Margaret Owen, "Special Care for Patient Who Has Breast Biopsy", Nursing Clinics of North America, June, 1972, Vol. 7, p. 373-82.

The above method of treatment is used extensively, and in the United States today, over 500,000 women are living who have had a mastectomy.[6] The 5-year survival rate of women who have had this operation is 80 - 85%.[7] However, when the cancer has spread to the lymph nodes outside the breast, the 5-year survival is cut to 40 - 45%.[8]

The operation itself often results, in addition to the removal of the breast, in difficulty in arm movement and use of the arm.

Ninety five percent of patients discover the condition themselves, but of this group 60% have cancer which has already spread to the lymph nodes outside the breast.[9] The American Cancer Society directs its educational efforts towards early detection and encourages breast self-examination and regular physical examination. There is literature printed indicating what to look for in self-examination and films on the subject as well which some gynecologists show to their patients for educational purposes.

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[6] John L. Sawyers, M.D., "Reach to Recovery - A Post Mastectomy Rehabilitative Program", Journal Tennessee Medical Association, January, 1973, Vol. 66, p. 28-9.

[7] American Cancer Society, "'73 Cancer Facts & Figures", New York, 1973.

[8] Ibid.

[9] Ibid.

Unfortunately, despite better treatment and means of detection, the mortality rate from breast cancer has not significantly decreased over the past 35 years.[10] Because of this, in 1972, the American Cancer Society launched a nationwide attack on breast cancer. Since the chances of survival are so much greater when the malignancy has not spread to areas outside the breast, their thrust was to develop methods to diagnose the cancer when it is in an early or pre-clinical stage -- so early as to be 100% curable. More than $2,000,000 was spent to help support 12 major detection centers as part of this effort.[11] One of these centers is at Good Samaritan Hospital in Portland where there is a new emphasis on the use of mammography (x-ray examination) and thermography (heat sensitive photograph) to detect the cancer in its earliest and most curable stages.

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[10] Ibid.

[11] Ibid.

II COUNSELING NEEDS OF THE MASTECTOMY PATIENT

Historically, the interest of the medical profession has been in survival times of breast cancer patients and in assessing medical success. More recently, there has been a growing concern among medical people about the quality of life of a mastectomy patient after the operation. As Dr. William Markel pointed out at the Second National Conference on Cancer of the Breast, "If the patient cannot come to terms with her surgery, return to her family and get back to a fairly normal life, there is a question of the validity of the survival time."[12]

Much time at this conference was given to directing itself to the issue that the medical community had failed to provide the necessary emotional support needed to help women confront and deal with the issues of fear of dying and/or recurrence of disease, the mutilation of her body and how she will be regarded by others close to her. Although her general physical health following the operation may be good, the emotional and physical impact may be temporarily devastating. The woman who has had a mastectomy must not only concern herself with her physical rehabilitation in obtaining and becoming accustomed to an artificial breast and perhaps in regaining the use of her arm,

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[12] William M. Markel, M.D., "Program for the Rehabilitation of the Breast Cancer Patient", <u>Cancer</u>, December, 1971, Vol. 28, p. 1676-78.

but, in addition somehow resolve her own feelings about a life threatening disease and the consequences of the mastectomy itself. She is facing a totally new situation where old coping methods will not necessarily work.

Helen Harrell, now a Director of Education at Hermann Hospital School of Vocational Nursing in Houston, Texas, expressed her own thoughts in an article in the April, 1972 Journal of Nursing.[13] She had had a mastectomy and one of her many fears following the operation was that she was having a nervous breakdown. She had never been warned that crying jags would occur, but would also pass, that others had bad dreams, that the inner part of her arm would be numb. She said she became depressed and death oriented. Her own emotional reaction motivated her to reach out to help others and reinforced her idea that it is the quality and not the quantity of life that counts.

Recently, in the popular literature, there has been much attention given to some of the problems faced by women who have breast cancer and mastectomies. What once was a taboo subject and referred to as "mom's shame" has now become

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[13] Helen C. Harrell, "To Lose a Breast", American Journal of Nursing, April, 1972, Vol. 72, p. 676-77.

common and well publicized knowledge.[14]

Many women who are public figures have expressed their feelings about their own surgeries and breast cancer in the press. In two recent articles in women's magazines, Marvella Bayh and Betty Ford related some of their own experiences and feelings regarding their breast surgery.[15] Mrs. Ford stated that one of her reasons for granting an interview was that she hoped it would help other women to discuss their operation freely. Both women looked upon the surgery as life saving and emphasized the importance of the support of those closest to them. They both offered an optimistic view in spite of the potentially fatal nature of breast cancer and said that life was more meaningful for them now.

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[14] Marvella Bayh, "Betty, Happy and Me", Ladies Home Journal, January, 1975, Vol. 92, p. 63.

[15] Ibid.
Betty Ford, "I Feel Like I've Been Reborn", McCall's February, 1975, Vol. 102:5, p. 98.

III SOME COUNSELING APPROACHES

In reviewing the medical literature, it seemed apparent that there was an acknowledgment, at least in the past five or six years, that there is a need to offer emotional support and guidance to women who have mastectomies to offset some of the potentially damaging psychological consequences of the disease and the operation.

Roberta Klein, M.S.W., in presenting her paper at the ACS 1971 Breast Cancer Conference,[16] stated that general mental health concepts on how to handle crisis as outlined by Caplan and Lindeman, are applicable to breast cancer patients. In her paper, she defined a crisis as "an insolvable problem precipitated by stressful or hazardous events which cause a loss of equilibrium for the individual". At this time, she stated, previous coping methods don't work and the patient may tip toward or away from mental health. When considering a breast cancer patient, several characteristics are important:

1. The crisis is time limited. It is better to take advantage in treatment of a short term disequilibrium rather than to try picking up the pieces months or years later when an incapacitating problem presents itself.

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[16] Roberta Klein, "A Crisis to Grow On", <u>Cancer</u>, December, 1971, Vol. 28, p. 1659-65.

2. The crisis may call forth old feelings and unresolved conflicts, a remembrance of another loss, and this may vary with the individual.
3. The individual must actively work on the problem rather than centering their activities on avoiding it in order to bring about a healthy resolution of the crisis.
4. The family members may help or hinder in how they do or do not allow the patient to express her feelings, in how much they are willing to give her extra love, in how sensitive they are in picking up cues to the patient's needs, or if they are in a crisis themselves they may find the problem too painful to face.
5. A certain amount of tension and anxiety is essential to motivate the individual toward resolving their crisis.

Ms. Klein sees the tasks to be performed by the patient as:

1. accepting the loss of the breast by being allowed to fully mourn as well as to feel and express the grief around the fear of the possible further loss of perhaps her husband or even her life;
2. re-integrating her self-image worthy of love and the rewards of life;
3. beginning to make peace with the idea of a potential recurrence in five to ten years.

The patient who successfully accomplishes these tasks is using strengths she has probably never had to use before and in so doing becomes a different and stronger person.

In general, Ms. Klein further outlines ways the patient can be helped to perform the above tasks.

1. Help her to express her feelings. These could be fear that no man could ever love her, that she is being punished for a sin, anger that this should happen to her or grief at the loss of part of her body. Permit her to express her grief, and help her master feelings that are unacceptable to her.
2. Help her sort out real from unreal. What she imagines is much worse than actual facts. Knowledge of the facts will dissipate the imagined consequences.
3. Don't give false reassurances.
4. Help her to anticipate the future and think through what it will be like after the operation and what she will have to do. Help her to understand that depression is normal under the circumstances. A woman's age may have much to do with her attitude as well as how much emphasis she places on physical appearance.
5. Help the family to understand the patient's feelings and to express theirs. In particular, it is important to help the husband express his feelings which if hidden may become a matter of concern to his wife. Both should be helped to express their anxieties together.

6. Help the patient to consider how and what to tell significant people about the mastectomy and breast cancer.

Ms. Klein states that who helps may be any one of several people -- the doctor, the family, the nurse or Reach to Recovery volunteer.

As evidenced in the literature, there are some hospitals that already have an organized effort to help breast cancer patients with the above concerns. Ms. Klein mentioned the Memorial Hospital in New York, where a team of M.D., physical therapist, nurse, social worker and Reach to Recovery volunteer meet daily with every patient still hospitalized. They teach the patient the necessary exercises for physical functioning, as well as about prostheses and their proper care and offer an opportunity to air questions about cancer and their fears. The group of mastectomy patients in itself is a great help and helps the patient cope with overwhelming feelings of the operation and disease.

Dr. Harry S. Goldsmith and Dr. Edgardo S. Alday in their description of the role of the surgeon in rehabilitating the breast cancer patient[17] stated that dealing with psychological problems should begin prior to the operation. They pointed out that this is a good time to indicate any favorable clinical

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[17] Harry S. Goldsmith, M.D., et al, "Role of the Surgeon in Rehabilitation of Breast Cancer Patient", Cancer, December, 1971, Vol. 28, p. 1672-75.

aspects to the patient and to help her air her fears of the operation itself. It is also helpful to have another family member present when discussing the various aspects of breast surgery since it may be helpful later on in dealing with the patient's concerns. The authors stated that after the operation is usually a time when the patient experiences depression and that the sight of another woman such as a Reach to Recovery volunteer is particularly reassuring in addition to giving the patient an opportunity to help herself by starting exercises to prevent limitation of arm movement.

Helen Harrell, a member of Reach to Recovery and a nurse who is the Director of Education at Hermann Hospital School of Vocational Nursing in Houston, Texas,[18] feels that the best time to counsel and offer emotional support are the ten days while the patient is hospitalized and that intensive emotional and physical rehabilitation can be done with continuity at this time. It is a time when most family members are available and their questions can be answered. Through careful teaching many of the patient's fears can be diminished. By receiving proper information she will be spared the results of half-truths and misinformation from well meaning friends that could otherwise be fear provoking. Hopefully, by the time the patient leaves the

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[18] Helen C. Harrell, "To Lose a Breast", <u>American Journal of Nursing</u>, April, 1972, Vol. 72, p. 676-77.

hospital, and as a result of the counseling, she will be able to cope with herself and other's reactions to her.

Margaret Owen, a clinical specialist in surgical nursing at Good Samaritan Hospital in Phoenix, Arizona writes of a program at this hospital to plan for the special care of the patient who has a breast biopsy.[19] She points out that even before the patient is hospitalized she has begun to cope with the idea of breast surgery and breast cancer and so the coping mechanism which she has already developed must be recognized. The patient is admitted to Good Samaritan Hospital on the afternoon prior to the operation and is approaching a crisis point. She needs all her strengths to deal with it. The nurse who will be with her throughout the operation and afterwards is introduced to her and carries back to the medical team her information and impressions regarding the patient to assist in planning for her. In the pre-operative period the patient is given information regarding the surgery and what to expect afterwards. The nurse either answers questions or respects the patient's wishes not to talk about it. If the husband or other family member is there they may be included in the conversation. A permit must be signed by the patient prior to the mastectomy should it be necessary. If the biopsy is malignant, the husband should be

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[19] Margaret Owen, "Special Care for Patient Who has Breast Biopsy", Nursing Clinics of North America, June, 1972, Vol. 7, p. 373-82.

told right away. The nurse sees the patient immediately when she wakes up and hopes to provide an atmosphere that is comfortable and relaxing which will allow the patient to ventilate her feelings. The exercises begin the following day and the Reach to Recovery volunteer may visit then if the physician so desires. The patient is in the hospital about seven days and during this time has an opportunity to make a psychological adjustment, get information and receive any professional help needed. The nurse plans a home visit two to four months after discharge.

Recently, the University of Texas Southwest Medical School received a $1,000,000, three year contract from the National Cancer Institute to fund a new program which will assemble teams of experts to provide rehabilitative services for cancer patients.[20] The purpose is to provide a model for similar projects elsewhere and to counter "unwarranted pessimism among medical personnel regarding such patients' rehabilitation".

Services will include physical restoration programs, specialized nursing, prosthetic consultation, dietary counseling and counseling for the patients' families.

All of the above programs seem to take advantage of the

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20 "After Cancer Effort Funded", Oregon Journal, February 3, 1975, Portland Oregon, The Oregonian Publishing Company.

theories of crisis intervention as outlined by Ms. Klein in attempting to deal with the patient's psychological problems immediately and to prevent further and more serious emotional problems from developing and to resolve the crisis and provide the tools for a healthy adjustment to a life threatening and mutilating illness. The issues of fear of recurrence of disease, death, bodily mutilation and relationships with family and others can be dealt with in a supportive atmosphere where professional help is available.

IV REACH TO RECOVERY PROGRAM

A. Background

Reach to Recovery is the name given to a volunteer program under the auspices of the American Cancer Society which is designed to assist post-mastectomy patients. The volunteers themselves are all women who have had mastectomies.

Although there have been other women active in counseling post-mastectomy patients, it is Terese Lasser who is most commonly associated with starting the Reach to Recovery program as it is known now. Mrs. Lasser is a woman who had a mastectomy in 1952 in New York. She felt a need herself at that time for some kind of emotional support and physical rehabilitation which was lacking. According to her book "Reach to Recovery",[21] it was through her own personal experience by trial and error that she developed a basic philosophy which turned out to be a useful approach to the problems of a mastectomy patient. Her own experiences of wondering how active she could be, how the loss of a breast would affect her relationship with her husband, and her feelings of depression and despair made it possible for her to understand the feelings of other women in the same situation.

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[21] Terese Lasser and William Randall Clarke, Reach to Recovery, New York: Simon and Schuster, 1972.

Because she had no one to guide her in specific exercises, she developed her own to regain the use of her arm. Another difficulty Mrs. Lasser encountered was finding a place to buy an artificial breast.

Perhaps because of her own personality and background as a woman who had been very active as a mother and wife and involved in activities outside the home, it was a natural move for her to want to do something to develop some kind of a program to assist other post-mastectomy patients.

Mrs. Lasser tells of being asked by a friend to visit a mutual friend in the hospital after a mastectomy with the idea that her own efforts at recovery might be helpful to their friend who was extremely depressed. During the visit, all efforts to reach her seemed to fail until Mrs. Lasser told her that she herself had had a mastectomy. Her friend took such hope at this that Mrs. Lasser states, "At that precise moment, I think, the idea for Reach to Recovery was born."[22]

She discussed with her own surgeon her idea for Reach to Recovery and he approved, but cautioned her about the resistance she would probably find from the medical community. Fortunately, she had the time, the money and the will to finance and carry through her ideas. Her husband, J. K. Lasser, was an author and

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[22] Ibid., 27

publisher and published a manual written by his wife, which was a "how-to" for other mastectomy patients.[23] As Mrs. Lasser states, "the program's core was my own experience in achieving maximum mental and emotional recovery as well as physical health after having a breast removed. This is what enabled me to speak to other women in the same situation with understanding, hope and confidence".[24] Mrs. Lasser's surgeon was indeed correct in cautioning her about the resistance she would meet. Her activities were greeted with some suspicion by physicians who were skeptical of her because she was not a trained professional. However, after much personal effort, traveling across the country talking to individual women and to groups and training others to do the same, her program began to catch on and be accepted.

The Reach to Recovery Program merged with the American Cancer Society in 1969. The Society could offer its own organization of 58 divisions, 3,000 units and more than 2,000,000 volunteers. Mrs. Lasser became a national consultant to Reach to Recovery, and her program benefited from the medical supervision at a local level, which included physician, nurse, physiotherapist and

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[23] Terese Lasser, Reach to Recovery, A Manual for Women Who Have Had Breast Surgery, Revised Edition, 1969, New York.

[24] Terese Lasser & William Kendall Clarke, Reach to Recovery New York: Simon and Schuster, 1972.

trained Reach to Recovery volunteer.[25]

Some interesting statistics are reported by William Markel, M.D., Vice President for Service and Rehabilitation, American Cancer Society.[26] In 1969-70, the first year the program was part of American Cancer Society, 1,825 volunteers visited andassisted 7,671 women in 952 hospitals, with 2,907 physicians requesting this service for their patients. In 1970-71, there was a dramatic increase; 3,355 volunteers visited and assisted 17,481 patients in 1,571 hospitals. The number of physicians requesting their service was 5,694.

B. Oregon Chapter

In Oregon, according to Mrs. Nora Janik, State Coordinator for Reach to Recovery, the program under American Cancer Society has been functioning for five years.[27] She herself has been active as a volunteer for 15 years when she was requested by her own surgeon to visit other women who had had mastectomies or were about to have the operation. She described to me how the program operates in Oregon.

Volunteers must be women who have had mastectomies themselves. Originally, there was a requirement that they have had their

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[25] Ibid., 12

[26] Ibid., 158

[27] Personal interview with Mrs. Nora Janik, State Coordinator Reach to Recovery, American Cancer Society, Oregon, February, 1975

operation five years prior. However, because more volunteers are needed, this restriction was recently dropped to three years. The idea behind this requirement is to assure that the potential volunteer will have had the opportunity to resolve her own feelings regarding her operation. She also needs a letter from two physicians attesting to the fact that she is emotionally and physically recovered.

She must then take a training program to help her in visiting mastectomy patients. This serves as a screening process as well for the few who would not be well suited for the program's activities. As Mrs. Janik states, the emphasis is on what not to say. Some of the "don'ts" are:

Never compare surgeries.

Never talk about your own surgery.

Never use doctors' names.

Never use patients' names.

Never answer questions that require a medical answer.

After the training, the "visitor" or volunteer contacts women in hospitals only at the patient's doctor's request. One of the purposes of the visit is to present to the patient a woman who has gone through the surgery, is alive and well, active and attractive, on the theory that one picture is worth a thousand words. The volunteer, in addition to presenting this morale-boosting image demonstrates the exercises that are necessary to regain the use of the arm. A pamphlet showing the exercises is left with the patient. The visitor may also put the patient through these exercises, if the doctor so desires and give her a temporary prosthesis.

The visitor may offer emotional support as well. She tries to help the patient anticipate what to expect such as:

1. unexpected crying periods
2. strange physical feelings
3. discomfort and pain from the exercises
4. the "well meaning friend" who may have false information
5. worries about relation with husband
6. how and what to tell the children

After the initial visit, which the visitor tries to make in the hospital, she may make a follow-up visit and invite the woman to attend Reach to Recovery meetings. Mrs. Janik stressed the fact that the meetings provide rehabilitative services and are not merely a club. The visitor may also help the woman with advice on where to obtain a permanent prosthesis.

Emphasized throughout the program is the idea that no one is visited without being referred by the surgeon who performed the patient's mastectomy. Any medical questions are referred to him and no one is visited who doesn't desire to be. The visitor works in cooperation with and only with the approval of the attending surgeon.

Presently, there are about 65 visitors in Oregon and there are 50 physicians in the state who refer their mastectomy patients to Reach to Recovery, Mrs. Janik states. According to her, one of the problems now is getting enough volunteers. Some drop out after a time, some may have a recurrence of the disease or develop other ailments. As more physicians become aware of and interested in the service, there is a greater need for more volunteers. A fairly active recruitment effort is made in checking the tumor registries of the state for the names of potential volunteers.

When asked why some physicians or surgeons performing mastectomies do not use the volunteers, Mrs. Janik said she thought it was because they don't know about it, don't see a necessity for it or prefer not to have a lay person talk to their patients.

In reviewing the literature, the only negative comment I could find was that of Dr. John Healey who felt that the medical profession was relegating an important aspect of medical rehabilitative care to a non-professional and that there could be some unfortunate consequences from an over-zealous volunteer who may not understand the physician's limitations of the patient.[28] The American Cancer Society has provided some safeguards for this in having a medical advisor for each

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[28] John E. Healey, Jr., M.D., "Role of Rehabilitative Medecine in Care of Patient with Breast Cancer", Cancer, December, 1971, Vol. 28, p. 1666-71.

unit. Mrs. Janik reported that in the five years the program has operated in Oregon, they have never received a complaint about the volunteers' activities.

Other activities that are undertaken by Mrs. Janik as state coordinator for the program are addressing nurses groups as to the needs of post-mastectomy patients and talking at ministerial conferences as well. In addition, she has worked to develop new resources for breast prostheses, and these can now be purchased in most department stores.

The Reach to Recovery program appears to be a very sophisticated one in which the stumbling blocks have been anticipated and the volunteer offers the kind of support she feels she is best suited for. She leaves all medical and/or deep-rooted psychological problems to the experts and operates as an adjunct to the medical doctor, working under his aegis.

CHAPTER II

DESIGN OF THE STUDY

I METHOD OF INQUIRY

A four-page questionnaire of 59 questions was designed. (See Appendix B) Included in the questionnaire were two open-ended questions allowing the volunteers to comment further on their feelings at the time of their operation and what might have been helpful to them then.

The questionnaire was given to the volunteers at one of their meetings in February, 1975 with Mrs. Janik's permission and after she had reviewed it and made a few suggestions. Seventeen of the 32 Portland volunteers were present at this meeting. The questionnaires were filled out by all 17 and returned at this time. Being present when the questionnaire was filled out was an advantage since any questions that came up regarding the form could be answered then.

At Mrs. Janik's suggestion, questionnaires were mailed from the American Cancer Society at their expense to the 15 volunteers who were not at the meeting. None of these questionnaires was returned.

In addition, Mrs. Janik was interviewed for a more in-depth response to her own feelings regarding her mastectomy. Mrs. Janik also supplied a great deal of information regarding the Reach to Recovery program and her own experience as a volunteer.

Mrs. Nancy Brice, American Cancer Society, was interviewed regarding the Reach to Recovery program and its association with the American Cancer Society. It was she who suggested seeing Mrs. Nora Janik for more information.

II TARGET POPULATION

The writer decided to use the 32 Reach to Recovery volunteers actively participating as "visitors" in the Portland area as a target population to whom a questionnaire could be addressed. The reason for using this group was that they are women who have had mastectomies themselves as well as presently engaged in counseling other mastectomy patients. Approval for contacting the volunteers was given by Mrs. Nancy Brice, Service Director, American Cancer Society, Oregon Division, and Mrs. Nora Janik, State Coordinator Reach to Recovery, American Cancer Society, Oregon Division.

III QUESTIONNAIRE DESCRIPTION

Questions 1-21 related to the characteristics of the social, economic, educational and religious background of the volunteers.

Questions 22-49 were questions relating to the volunteers' experiences and feelings at the time of their mastectomy.

Questions 36, 46, 47, and 48 related to the effect of the illness on their present life.

Questions 51-59 related to their experiences as a Reach to Recovery volunteer.

Question 56 concerned the issues covered in counseling post-mastectomy patients.

IV LIMITATIONS OF STUDY

A. Review of Literature

Although there was not a lot of material written on the subject in professional journals, what was written related directly to the psychological aspects of breast cancer and mastectomies.

It would have been helpful in updating the material to have had available the proceedings from the Third National Conference on Breast Cancer sponsored by the American Cancer Society held in Dallas in 1974. These had not been published at the time the study was undertaken.

B. Target Population

It would have been interesting to administer the same questionnaire to a group of post-mastectomy patients who were not Reach to Recovery volunteers to compare the responses of the two groups and their characteristics. However, because the American Cancer Society protects the people who avail themselves of their services by maintaining a strict confidentiality regarding their names, there was no access to this population of post-mastectomy patients whom the volunteers see.

C. Most Recent Mastectomy Three Years Ago

In order to be accepted as a volunteer in the Reach to

Recovery program, a period of three years must have passed since the potential volunteer's breast surgery.

For this reason, information regarding more recent experiences with counseling prior and post-surgery was not available. It would have been interesting to know if there has been greater emphasis on counseling mastectomy patients at the time of their operation in the last three years.

CHAPTER III

RESULTS OF THE QUESTIONNAIRE

I QUESTIONNAIRE

Questions 1 - 21 dealt with the general characteristics of the women who are volunteers in the Portland program and their social, educational and religious background. The results showed a remarkable homogeneity. The "profile" of the Portland Reach to Recovery volunteer is that of a woman, over 45, married, with children in their late teens or older, who has attended college and probably has a degree either from a college or professional training school. She has lived in Portland over ten years and is most likely employed in a full or part-time job. Her family income is over $15,000 a year, and she belongs to from one to three other community organizations in which she is moderately to actively involved. She considers herself a religious person and belongs to a church which she attends regularly.

Table I, following, shows in more detailed form some of the characteristics of the volunteers.

TABLE I

DATA FOR THE ANALYSIS OF CHARACTERISTICS OF VOLUNTEERS

Under 34 years of age	0	%	
35-44	12		
45-54	35		
55 and over	53		100%
Single	0	%	
Married	88		
Divorced	0		
Widowed	12		100%
High School Graduates	41	%	
Attended College	59		100%
Under two years residence in Portland	0	%	
2-10 years	18		
Over 10 years	82		100%
Presently employed	65	%	
Not presently employed	35		100%
Under $5,000 yearly income	0	%	
$5,000-$9,999	18		
$10,000-$14,999	6		
$15,000-$19,999	30		
$20,000 and over	34		
No Answer	12		100%
0-1 other organizations involved in	24	%	
2-3	52		
Over 3	24		100%
Considers herself religious	100	%	100%
Church member	88	%	
Not church member	12		100%
Very often attends church	47	%	
Often or sometimes	48		
Never	5		100%

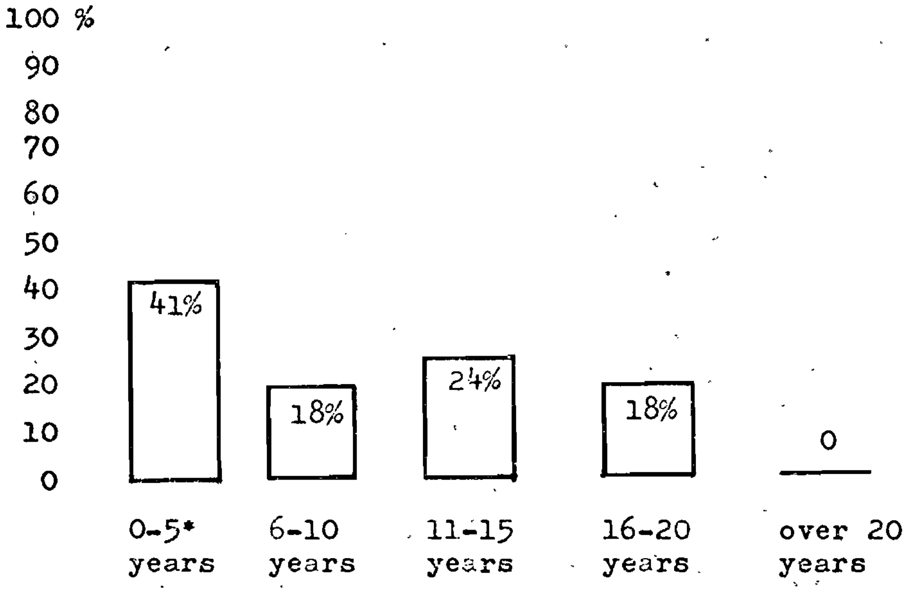
Questions 22 - 49 dealt with the volunteers' own experiences regarding their mastectomies. The respondents indicated as shown on Table II below the length of time it had been since their surgery.

It is important to note that the Reach to Recovery program will not accept women as volunteers who have had their mastectomy more recently than 3 years prior to entering the program.

Two of the women had had mastectomies at two different times.

TABLE II

PERCENTAGE OF VOLUNTEERS HAVING SURGERY FROM ZERO TO 20 YEARS



* None less than three years.

Table III below shows how different people are seen as being helpful to the respondents both before and after their mastectomies. It is interesting to note that both before and after, the doctor and husband appear to be the most emotionally helpful people -- both male figures.

TABLE III

PERCENTAGE OF TIMES SIGNIFICANT PERSONS INDICATED AS BEING MOST HELPFUL EMOTIONALLY BEFORE AND IMMEDIATELY AFTER MASTECTOMY

	Before	After
Doctor	29%	29%
Nurse	0	8
Social Worker	0	0
Husband	43	43
Family Member	0	8
Friend	21	0
R/R Volunteer	7	10
Other	0	0

Only 18% of the respondents indicated that they had received prior counseling, whereas 53% indicated they had received post-operative counseling.

The following Table IV shows who the people were who did the counseling. Since most of the counseling was received after the operation, it is interesting to note that the nurse was most often the counselor.

Since the most recently that the operation could have been done was three years ago, it is important to remember that social workers were not employed in most local hospitals then and the Reach to Recovery program in Oregon was only two years old.

TABLE IV

PERCENTAGE OF TIMES SIGNIFICANT PERSONS INDICATED AS DOING COUNSELING BEFORE AND IMMEDIATELY AFTER MASTECTOMY

	Before	After
Doctor	40%	13%
Nurse	0	47
Social Worker	0	0
R/R Volunteer	20	20
Other	40	20

Questions 35 and 36 asked the respondents to indicate what issues were of greatest concern to them at the time of their operations and presently.

Table V shows how the respondents rated the significance of the following concerns. It appears that fear of recurrence of disease was and is of greatest concern.

TABLE V

DATA RELATING TO SOME ISSUES SURROUNDING BREAST CANCER AND MASTECTOMIES AND THEIR RELATIVE SIGNIFICANCE TO RESPONDENTS.

	* At Time of Mastectomy	* Presently
Fear of recurrence of disease	9	9
Fear of change in body image	0	0
Equally fearful of both	4	1
Not fearful of either	3	6

* Number of times indicated as significant by volunteers.

In answering whether they felt a need to talk about these fears to someone, 65% of the respondents said they did. Of those who answered "yes", 91% of them felt there was someone to whom they could turn.

65% of the respondents indicated they had adjusted to their mastectomies "easily" -- 35% "reasonably well" and 0% "with great difficulty".

In answering questions about how others had reacted to them after their operations, 94% said there had been no withdrawal from them on the part of their family members; 82% stated they felt no withdrawal on the part of those outside the family.

In discussing their family members' difficulties in accepting the diagnosis, 70% reported their husbands as having no difficulty; 53% reported their children as having no difficulty.

88% of those questioned reported their marriage relationship was either the same or better now than prior to their mastectomy.

65% indicated that life had changed for the better since then; 29% reported it to be different but neither worse nor better and 0% reported it to be worse. (6% did not answer.)

Questions 51 - 59 dealt with the respondents' experiences as a Reach to Recovery volunteer.

In answering the question regarding her motivation for joining Reach to Recovery, some of the following were indicated more than once by each volunteer, as shown on Table VI.

The reason, "because I was not counseled and felt a need for it" was chosen almost twice as often as any other category, and second to this was "another R/R volunteer".

TABLE VI

REASONS GIVEN FOR JOINING REACH TO RECOVERY

	# Of Times Indicated By R/R Volunteers
Another R/R volunteer	5
Because I was helped myself by R/R	4
Because I was counseled myself and it was helpful	4
Because I was not counseled and felt a need for it	8
My doctor encouraged me to volunteer	3
Other	2

The volunteers were asked to indicate whether the women they visited described their husband (or male friends) as being very sympathetic, or, in varying degrees to the opposite end of showing hostile feelings toward them after their operation.

There was an extremely high percentage of choices in the sympathetic, concerned and helpful range, and one only reported hearing of negative feelings. Three of the volunteers said they didn't know.

Table VII below related to the kind of subject matter discussed with the consultees by the R/R volunteers. Each volunteer made more than one selection, showing which topics she discussed. "Physical rehabilitation" and "Personal appearance" appear to take up much more time than the deeper issues of "Fear of recurrence of disease" and "Fears regarding change in body image".

TABLE VII

TOPICS RELATING TO CONSULTEES' MASTECTOMIES MOST FREQUENTLY DISCUSSED WITH THEM BY REACH TO RECOVERY VOLUNTEERS

	# Of Times Indicated By R/R Volunteers
Physical rehabilitation	13
Personal appearance	12
Fears regarding recurrence of disease	5
Fears regarding change in body image	6
Others	1

52% of the volunteers indicated they made one visit to the patient; 25% made two and 23% made one to three visits.

86% of the respondents said that their husbands supported their Reach to Recovery activities "very enthusiastically".

According to the table below, the highest percentage of volunteers has been involved with the program from four to six years.

TABLE VIII

LENGTH OF TIME VOLUNTEERS HAVE SERVED IN PROGRAM

Under one year	12 %	
One to three	35	
Four to six	41	
Seven and over	*12	100%

* Had done volunteer work before Reach to Recovery program started in Oregon.

Two open-ended questions were included in the questionnaire. One of the questions was in regard to the respondent's own feelings at the time of her operation and now.

Some of the responses were:

"the fear is ever present"

"I try to encourage myself that they got it all"

"I have a bright outlook on my condition"

"I think I keep my concern minimized by being involved with R/R"

The second question asked the respondents to mention what was done or might have been done to make the time around their operation an easier one.

Some answers were:

"accept the situation and be yourself"

"I was lucky to have been given an optimistic attitude by God, a wonderful family, a loving circle of friends and a very deep faith in God's choice for me"

"would have liked a concentration on me and my needs"

"would have been easier if I had had a R/R visitor"

II INTERVIEW WITH MRS. NORA JANIK

Mrs. Janik, as state co-ordinator for Reach to Recovery has been involved with the program since its inception five years ago, and, as mentioned previously in the study, did volunteer counseling of mastectomy patients before then at her doctor's request.

Because of her long involvement in the program, it seemed important to gain a more "in-depth" approach to some of the issues raised by breast cancer and a mastectomy by interviewing Mrs. Janik.

In speaking of her own primary concerns, she said that fear of the recurrence of the disease was surely a major concern, but that the saving aspects of the surgery were what she felt to be most important. She expressed the thought that she would like to see the positive aspects of cancer therapy emphasized more often. Because of surgery and therapy people are able to live longer lives.

Her own philosophy, as she described it, is that she wants something good to come out of her own experience with breast cancer and that helping others is a way to bring a positive aspect to her ordeal.

Mrs. Janik feels that the emphasis on sexual concerns following a mastectomy is highly over-drawn. Her own experience was that she was glad to be alive and concerned about how well she could function -- when she could drive a car or use her arm, for example -- and return to a normal life.

Her emphasis in how to deal with others in her family after her operation is to do the same things and behave in the same way as before. She particularly stressed the importance of taking her husband into her confidence and honestly telling him of her feelings.

Mrs. Janik is a very attractive, well groomed and well dressed, middle aged woman who brings a great deal of energy to her endeavors, and this is true of the other volunteers I met as well. She must present a very reassuring and hopeful image to the mastectomy patients she visits.

CHAPTER IV

CONCLUSIONS AND RECOMMENDATIONS

I BACKGROUND AND CHARACTERISTICS OF THE VOLUNTEER

As mentioned earlier, the similarities among the volunteers are striking. It would be expected that the age group would cluster in the above 45 category since the peak age group in breast cancer is 40 - 44 years of age.

The above $15,000 income level, high educational achievement, strong religious involvement, as well as the fact that none are single or divorced, and have long-standing community ties, sets these women well apart from the general population. One might speculate that their medical care would have been better than average and perhaps their counseling experiences at the time of their operation the best that could have been had.

II COUNSELING EXPERIENCES AND PERSONAL FEELINGS

It is interesting that very few received counseling before their mastectomy but more than half received some post-operative counseling. In the literature, it was pointed out that it is well to start the counseling prior to the operation since the woman is in a crisis state from the moment she knows she will have to have a breast biopsy.

Where counseling was done post-operatively, the nurse is the person most often mentioned as the counselor. In the literature, a plan in operation at Good Samaritan Hospital in Phoenix is described where a nurse is assigned to a woman when she is admitted for a breast biopsy and remains with her until she is discharged.[29] The nurse not only counsels and supports the patient but takes back to the medical team information that will be helpful in planning for her hospital care and discharge.

It was interesting that in responding to the questions of who seemed most supportive to them before and after the operation, the respondents mentioned husbands first and their doctor second. Although it is the nurse who is most often

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[29] Margaret Owen, "Special Care for Patient Who has Breast Biopsy", <u>Nursing Clinics of North America</u>, June, 1972, Vol. 7, p. 373-82.

charged with the counseling, she was mentioned only by one respondent as being a significantly supportive and emotionally helpful person.

This may indicate a need for greater consultation services in mental health concepts and specifically the emotional needs of post-mastectomy patients be made available to nurses. Such a service might be provided by the hospital's social service staff and/or a Reach to Recovery representative.

It was interesting that the most sympathetic persons, as seen by the respondents, (husband and doctor) are both male figures. The first choice of "husband" may well reflect the marital status of the respondents and it may be that post-mastectomy patients need and seek out the reassurance of a male figure who can make them feel "okay" about themselves as women.

Social workers were not mentioned by any respondents as doing the counseling or as being significantly helpful or supportive. This is not surprising since so few Oregon hospitals used the services of social workers three years ago or earlier. It would be interesting to know if any hospitals now use their social service workers for direct service to post-mastectomy patients or consultation to medical personnel. Again, Reach to Recovery volunteers were not mentioned as often as doctors or husbands, but the program was only two years old or not in existence at all at the time the respondents' surgeries were performed.

In speaking of their own feelings and concerns regarding the disease and operation at the time of their surgeries, the respondents most often stated that fear of recurrence of the disease was predominant and any concerns regarding body image were secondary. They also indicated they felt they had someone to turn to who would be a sympathetic listener and this was most often their husbands. It would be interesting to know if divorced or single women would choose a male figure as being a sympathetic listener or if they would feel they had someone to turn to at all.

In answering the question regarding their present fears, again, fear of disease recurrence was mentioned as often as previously, but the number expressing some fears of change in body image dropped and the numbers professing to be not fearful rose. This suggests that perhaps one must learn to live with the idea of recurrence of the disease, but that fears and concerns involving body image can be resolved.

III COUNSELING SERVICES

From the results of the questionnaire, it seemed that the post-mastectomy patients visited by Reach to Recovery volunteers overwhelmingly viewed their husband and/or male friends as being sympathetic and concerned. This again supports the conclusion of the male figure being seen as very supportive and making patient feel good about herself.

It was particularly interesting to note that by far the greatest amount of time in the volunteer's counseling service is spent on physical rehabilitation and personal appearance and very little time is spent relating to fear of recurrence of disease or change in body image. In light of the previous information that the volunteers themselves consider recurrence of the disease a primary concern, it is interesting that this matter doesn't come up more often in their counseling.

This particular finding raises more questions than it answers. One might speculate that because the number of visits made is from one to three, there is not enough time to develop a relationship that would encourage the discussion of such matters. Or, it could be that the volunteer does not feel comfortable in discussing an issue that is of such great concern to herself, and she needs to defend herself against these feelings. It might also be that since the possibility of recurrence of the disease is an ever-present reality, each person must come to terms with it in their own way and learn to live with that fear.

In addressing itself to the needs of physical rehabilitation and personal appearance, the Reach to Recovery program aims at reassuring and helping the patient regain her self-confidence and improve the quality of her life. Perhaps one can deal better with the deeper issue of a life-threatening disease if the time left is an enjoyable one.

To summarize, it seems clear from both the literature and the results of the questionnaire that there is a need for counseling mastectomy patients and that within the past five years the need has become recognized by both professional and lay people. It appears also, that although progress has been made in this area, more needs to be done. The Reach to Recovery volunteer program is a recognized and effective method of providing rehabilitative and emotional support to mastectomy patients. It would appear that the counseling provided by medical personnel, in most cases the nurse, needs improving in the way of better training, that more hospitals need counseling programs and that the counseling be made available to more patients. The most often given reason for joining Reach to Recovery was that the volunteer had not been counseled herself and felt the need for such counseling.

IV INDICATION FOR FURTHER STUDY

The areas where further study is indicated are as follows:

1. Update the current status of breast cancer patients by referring to the proceedings of the 1974 Breast Cancer Symposium, sponsored by the American Cancer Society in Dallas.
2. Extend the target population to a general group of post-mastectomy patients and those who have had the operation more recently than three years ago.
3. Survey counseling methods used in Portland and/or Oregon hospitals and what staff is available for counseling.
4. Investigate possible job and insurance discrimination, which may be directed toward mastectomy victims.

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APPENDIX A

DEFINITION OF TERMS*

Benign Tumor - An abnormal swelling or growth that is not malignant or cancerous.

Biopsy - The removal of a minute section of body tissue for microscopic examination for the diagnosis or prognosis of disease (usually cancer).

Cancer - A general term indicating a variety of malignant tumors which originate in a single abnormal body cell and multiply and spread wildly. In its natural course, if unchecked, cancer causes death by invading vital body organs.

Clinical - Pertaining to the study and treatment of disease in human beings, as distinguished from laboratory research.

Diagnosis - Recognition of the nature of a disease by its signs, symptoms, course and laboratory findings.

Lymph Node - A small mass of lymphatic tissue, often bean-shaped.

Lymphatic Tissue - Body tissues which are filled with lymph, a clear fluid which carries white blood cells, nourishing substances and some of the body's various disease-fighting materials.

Malignant Tumor - One that grows and spreads and threatens life; cancer.

Mastectomy - Surgical removal of a breast.

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* Cancer Word Book, American Cancer Society, New York.

Prognosis - Prediction of the course of a disease and the future prospects.

Therapy - The treatment of disease.

Tumor - A swelling or enlargement; an abnormal mass, either benign or malignant, with no useful body function.

APPENDIX B

Mrs. Elaine Lowe
2740 SW Talbot Rd.
Portland 97201
227-3894

QUESTIONNAIRE FOR REACH TO RECOVERY VOLUNTEERS

1. Sex Male ___ Female ___
2. Age Under 25 ___ 25-34 ___ 35-44 ___ 45-54 ___
55 and over ___
3. Marital Status Now Single ___ Married ___ Divorced ___
Widowed ___ Other ___
4. Please list the ages of your children (if applicable)
5. Please circle highest year of schooling completed
Under 8 8 9 10 11 12 College 1 2 3 4
6. What subject or subjects in school were you most interested in?
____
7. Did you attend a secretarial school or some other kind of training school? ___________
8. If you graduated from college or training school what was it that you received your degree or training in? ___________
9. Have you ever resided outside the state of Oregon? ___________
10. Have you lived in Oregon Under 2 years ___ 2 to 10 years ___
Over 10 years ___
11. Have you lived in Portland area Under 2 years ___ 2 to 10 years ___
Over 10 years ___
12. Are you presently or have recently been employed in a salaried occupation? ___________
13. If yes to 12, part time ___ full time ___
14. If yes to 12, what is your job title? ___________
15. What is your husband's occupation? ___________

16. Please check below the category which comes closest to your total family income before taxes:
Under $5,000 ____ $10,000-$14,999 ____
$5,000- $9,999 ____ $15,000-$19,999 ____
$20,000 and over ____

17. How many other community organizations are you involved in?
____

18, If so, if this involvement very active ___
moderately active ___
not very active ___

19. Do you consider yourself a religious person? yes ___ no ___

20. Do you belong to a church? yes ___ no ___

21. Do you attend church very often ___ often ___ sometimes ___
seldom ___ never ___

The following questions relate to your own experiences and feelings as a woman who has had a masectomy.

22. How long has it been since your operation? ___________

23. What was your marital status at the time of your operation?
single ___ married ___ divorced ___ widowed ___ other ___

24. Was there any advice or counseling given to you to prepare you psychologically for the possibility of a masectomy immediately prior to your operation? yes ___ no ___

25. If yes to 24, by whom was this given? (If more than one of the following, please number 1, 2, 3 etc. in order to importance to you) doctor __ nurse __ social worker __ family __ friend __ church person __ any other ____

26. If there was counseling done in the hospital, as far as you know was this part of a regular hospital program ___
individual effort by medical personnel ___ don't know ___

27. If you could choose one person who was most helpful to you emotionally immediately prior to your operation when you knew there was a possibility of a masectomy, was it the
doctor ___ nurse ___ social worker ___ other medical personnel ___ husband ___ other family member ___
friend ___ church person ___

29. Immediately after your masectomy, did you receive any advice or counseling while in the hospital? yes ___ no ___

30. If yes to 29, by whom was this done? doctor ___ nurse ___ social worker ___ Reach to Recovery volunteer ___ other ___

31. Do you feel that the information regarding a masectomy given you was adequate ___ more than I wanted to know ___ would liked to have had more information ___

32. Was this information given prior to the operation ___, after the operation ___ both ___ not at all ___.

33. Were you visited by a Reach to Recovery volunteer after your operation? yes ___ no ___.

34. If so was this visit very helpful ___ moderately helpful ___ helpful, but could have done without it ___ not helpful ___

35. If you can recall your feelings immediately after your masectomy would you say a fear of recurrence of the disease was predominant ___ fear of change in body image was dominant ___ equally fearful of both ___ not fearful of either ___

36. At this time would you say your feelings involve a fear of recurrence of disease ___, fear of change in body image ___ equally fearful of both ___ not feaful of either ___.

37. Are there any remarks you would like to add to questions 35 or 36? ______________________________

____

____

38. At that time, did you feel a need to talk about these fears to someone? yes ___ no ___

39. If yes to 36, was there someone you could turn to as a sympathetic listener yes ___ no ___

40. If yes to 37, although more than one person may have been helpful to a degree, who was most helpful in this pparticular way ? doctor ___ nurse ___ social worker ___ husband ___ family member ___ Reach to Recovery volunteer ___ any other ___

41. In looking back, would you say you adjusted to your masectomy easily ___ reasonably well ___ with great difficulty ___

42. After your operation, did you feel that some of your family members drew away from you?
Very much so ___ Somewhat ___ Slightly ___
Not at all ___

43. Did you feel that some outside your family drew away from you? Very much so ___ Somewhat ___ Slightly ___
Not at all ___

44 . Was it difficult for your husband to accept your diagnosis and operation? very ___ somewhat ___ not very ___
not at all ___

45. Was it difficult for your children to accept your diagnosis and operation? very ___ somewhat ___ not very ___ not at all ___

46. Like any stressful event, a masectomy may put a strain on a marital relationship or with members of the opposite sex, if unmarried. Since your operation, would you say that your relationship with your husband (or male friends, if unmarried) has become stronger ___ about the same ___
not as strong ___.

47. If you are now divorced, or have been divorced, would you say that your operation played a role that was very significant ___
moderately significant ___ slightly significant ___
not significant at all ___

48. Since your operation, do you feel that your life has changed for the better ___ different but neither worse nor better ___
for the worse ___

49. Are there any comments you would like to make about what could have or was done that made this an easier time for you and your family ______________________________
____
____
____

51. Approximately how long have you been a Reach to Recovery volunteer? ______________________

52. Could you rank the following in order of their importance in your decision to volunteer your services in the Reach to Recovery program.
Another R/R volunteer ___ because I was helped myself by R/R ___ because I was counseled at the time of my operation and it was helpful to me ___ because I was not counseled at the time of my operation and I felt a need for it ___
my doctor encouraged me to volunteer ___ other ___

53. What proportion of those women whom you visit indicate that your visit was important to their recovery?
a great many ___ almost all ___ about half ___
some ___ very few ___

54. Approximately how many women have you visited who are welfare recipients? ______________________

55. Among the women you see how would you describe the attitudes of the husband or male friend toward the woman? very sympathetic ___ concerned ___ helpful ___
feeling uninformed ___ feeling left out ___
indifferent ___ negative feelings ___ don't know ___
(if more than one of above applies, mark more than one)

56. Could you indicate what proportion of your time with your consultees you spend, in general, on the following:
physical rehabilitation ___ matters regarding personal appearance ___ fears regarding recurrence of disease ___
fears regarding change in body image ___ others ___

57. How often do women you see express satisfaction with the kind of emotional support they were given by medical personnel at the time of their operation?
Very often ___ sometimes ___ occasionally ___ seldom ___
never ___

58. On the average, how many visits do you personally make to each women? __________

59. My husband has encouraged my Reach to Recovery activities
very enthusiastically ___ moderately ___ not particularly ___
not at all ___