Postmastectomy Rehabilitation in a Community Hospital

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The need for, operation, and outcomes of an in-hospital postmastectomy rehabilitation program are described as operating at a general community hospital, the Mt. Sinai Hospital of Cleveland. Patient outcomes in terms of range of motion (94 and 98 percent normal 90 days after discharge, right and left arm respectively); resumption of normal activities and return to work (94 percent had resumed normal activities within 90 days and 85 percent had returned to work); and emotional stress (fewer than one in ten reported moderate to severe emotional stress) are demonstrated to be indicative of good rehabilitation. These results are comparable to those reported achieved in a specialized oncology setting. This type of program can be successfully conducted in a community hospital with the limited use of regular hospital personnel, although problems related to physician resistance and assuring the regular availability of appropriate staff members for even a short time each day must be overcome.

The importance of rehabilitating the mastectomy patient is often discussed in the professional literature, but rarely described in a manner relevant to the great majority of physicians and surgeons. Most mastectomy patients are cared for in a community hospital; most mastectomy rehabilitation programs, however, are operated or described within specialized oncological treatment settings. This article describes the rationale, process, and outcomes of a mastectomy rehabilitation program in a community hospital setting.

Background

There is little question that a complex set of physical, emotional, and attitudinal problems accompany the process of medical diagnosis and treatment of breast cancer, problems that must be dealt with in a rehabilitative fashion. For example, a number of physical problems are likely to follow mastectomy, particularly a radical one, including lymphedematous arm, shoulder stiffness, or numbness of the chest wall and arm. Most radical mastectomy patients (50 to 70 percent) are affected to some degree by transient lymphedema and the problem is considered "severe" in about ten percent of these cases.[1] Shoulder stiffness as well as back pain and neck stiffness may result from mastectomy, and a numbness in the shoulder, arm, or chest area is often present as a result of the severing of nerves during mastectomy. Likewise, a tingling or painful feeling may occur in the areas of amputated tissue. While most of these sensations gradually disappear[2] (often following great discomfort and reduced activity levels), some of these problems, particularly the numbness, may be permanent. While sensory nerve severance will not severely affect the use of the arm and shoulder, experience has shown that the

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combination of physical sensations or "problems," informational gaps on the part of the patient, and emotional and psychological barriers do often result in reduced activity for long periods following mastectomy, even when the clinically measurable physical problems would indicate otherwise.[3-5]

Many of the psychological, emotional, and attitudinal problems associated with mastectomy are fairly typical of most cancers: cancer is almost always viewed as a crisis, often as a stigmatizing event.[6] Anxiety, fear, guilt, and hopelessness are often reported to be endemic among cancer patients who may feel responsible for their fate.[7,8] Moreover, the patient often becomes the victim of isolation; almost everyone fears cancer and no one knows when or whom it will strike next. Myths abound and few know how to talk to cancer patients who are thus, too often, left alone with their dread.[9]

Mastectomy patients face these emotional problems especially along two dimensions: the fears, anxieties, and angers that accompany most cancers, and the specific adjustment to loss of the breast.[10] Obviously, different women cope very differently with the loss of a breast, but almost all women must confront some serious feelings of sexual inadequacy, poor body image, and loss of a sense of femininity. Many women link their feelings of self-esteem, desirability, and sexuality very closely to their breasts. While any body amputation is traumatic, the woman whose self-esteem and femininity are strongly represented in her breasts is often more severely depressed following mastectomy than a woman whose self-esteem is based upon other attributes such as achievement, intelligence, personality, or athletic ability. The extent of depression following mastectomy is related to age, marital status, previous mental health, and to a large extent upon the kinds of information given by her physician during diagnosis and treatment. Healey, for example, has noted "the greatest stumbling block in the rehabilitation of the cancer patient is educational in nature."[11] Even studies which conclude that depression may not be such a severe postmastectomy problem still find that at least one out of every five breast cancer patients reported the syndrome of depression, lowered self-esteem, increased health concerns, and loss of energy for fairly long periods following mastectomy.[12]

Postmastectomy Rehabilitation

The physical and emotional problems described above set the stage for the rehabilitation phase of the mastectomy treatment program. Rehabilitation must focus upon information sharing, teaching, and demonstration for self-care. Moreover, more rapid adjustment, both physical and emotional, to normal life and activities following mastectomy is enhanced by sharing and "discovering" together with other individuals undergoing similar experiences.

Surgeons and other primary health care providers are often quite skeptical (and justifiably so) about so-called rehabilitation programs, particularly in terms of the kinds of information and advice proffered. However, many physicians seem to translate their skepticism and strong sense of professional responsibility for the patient's overall welfare into an attitude of "I can rehabilitate my own patients." This attitude can tie up the physician needlessly for long periods on non-medical issues and ignores the contribution to be made by allied health professionals such as nurses, social workers, and physical therapists. Unfortunately, this attitude often results in little meaningful rehabilitation for the patient.

Many kinds of activities and programs are described as "mastectomy rehabilitation," in fact, many more than actually should be. These range from the visit of a Reach-To-Recovery volunteer in the hospital (either prior to or after surgery) all the way to long-term group counseling for men whose wives have had mastectomies. Such activities may take place before the operation (or even before the biopsy), in the hospital following surgery, or after discharge. In addition, adjuvant treatment programs and reconstruction programs may also be considered rehabilitative in nature. However, some of these activities are obviously more complete and "more rehabilitative" than others, particularly considering the range and type of activities involved, the informational content of the program, and, perhaps most importantly, the degree and extent of physician involvement and encouragement.

In-hospital programs after surgery offer a rehabilitation approach to which the physician can perhaps best relate. They offer the opportunity for assurance as to content, monitoring of patient reaction and learning, time economy, familiarity of the hospital setting, and personal acquaintance

with (and confidence in) the other professionals involved in the rehabilitation program.

The most widely cited example of a comprehensive in-hospital postsurgical program is the Postmastectomy Rehabilitation Group (PMRG) at Memorial Sloan-Kettering Cancer Center in New York City. This program has been thoroughly documented and studies evaluating the Postmastectomy Rehabilitation Group report that the teaching and interpersonal support each person received hastened rehabilitation time and the woman's return to normal activities.[13]

Few hospitals can match the resources or patient flow of Memorial Sloan-Kettering Cancer Center; therefore, one can legitimately ask whether the Postmastectomy Rehabilitation Group is for the average hospital; can it be put together and can it work in the typical community hospital setting?

The Postmastectomy Rehabilitation Program

The original PMRG was begun at New York's Memorial Sloan-Kettering Cancer Center to work with breast cancer patients while they were in the hospital. The program has been active since the early 1970s and has been supplemented over time by a couples group and, in some cases, by postdischarge group meetings. The basic program of the group consists of "all" in-patients (as approved by their physicians) and meets for 90 minutes a day, five days a week. The group is led by a team consisting of a physical therapist, a nurse, a social worker, and for three days each week a Reach-To-Recovery volunteer.

In the Memorial Sloan-Kettering program, the nurse usually visits the patient the first day after surgery and tells her about the group. The patient begins to attend group meetings on the second postoperative day. Each meeting begins with arm and shoulder exercises led by the physical therapist, followed by a discussion of the patient's feelings about breast surgery, possible physical discomforts, and hand and arm care. This type of group combines the opportunity for the patient to learn self-care with the opportunity to verbalize her feelings about the psychological and social consequences of her breast cancer.

This program, also called Postmastectomy Rehabilitation Group, has been largely adopted and adapted by the Mt. Sinai Hospital of Cleveland, an accredited, not-for-profit general medical and surgical hospital in Cleveland, Ohio. The program's rehabilitation goals at Mt. Sinai Hospital are:

1. to regain completely the functional use of the arm and shoulder on the side of the mastectomy;
2. to enable patients to care for their wound, arm, and hand;
3. to return patients to their usual activities in as short a time as possible; and
4. to reduce the emotional stress, anxieties, and fears which typically accompany mastectomy.

Since diagnosis of breast cancer is usually established by preliminary biopsy at Mt. Sinai Hospital, the mastectomy rehabilitation nurse visits the patient at bedside before the operation to describe the group program. The patient's family is involved and informed to the fullest extent possible. The rehabilitation nurse usually accompanies the patient to the operating room to lend emotional support until anesthesia is induced. Concurrently, another team member, usually the social worker, is counseling family members waiting during surgery. The objective of the program is to establish a continuous relationship between the team, the patient, and the family during and after the hospital stay.

On the first postoperative day, the mastectomy rehabilitation nurse visits the patient at bedside to initiate program activities.

The second postoperative day is usually the group session for most patients, barring delays due to medical contraindications. On this day the patient is introduced to the other participants. The goals and structure of the program are reoutlined briefly by the social worker and reinforced by members of the group who have been there on previous days. At the end of her first session, the new group member receives literature that serves to reinforce the group activities. Patients attend the group session each day until their discharge from the hospital.

Each patient's chart is reviewed daily prior to the group by one of the participating professionals, usually the nurse. In this way the staff is aware of changes in the patient's general physical and emotional condition as commented upon by the physicians and staff nurses. Exercises are demonstrated by the physical therapist and performed daily by the patients. The exercise regimen includes activi-

ties which will increase range of active shoulder motion and deep breathing for relaxation and prevention of postoperative complications.

Exercise takes about half of most sessions. These exercises are usually begun on the patient's second or third postoperative day, unless the surgeon has indicated otherwise.

Most patients are involved in at least two sessions led by the participating nurse, who provides a description of the various types of mastectomy surgery and reviews the importance of specific points about hand and arm care. The use and availability of prostheses and bras are demonstrated and discussed. Patient inquiries about the various types of mastectomies (ie, extended, radical, modified, and simple) are answered as to "what" they consist of, while questions concerning "why" are referred to the individual patient's surgeon. Increasingly, it should be noted, patient questions concern reconstruction options and possibilities. Requests for individual medical data are always referred to the patient's surgeon, but general information regarding drainage systems, dressings, aspiration procedures, stitches, and wound healing is discussed. Patients are provided with information about what, if any, discomfort they will be experiencing and what various discomforts mean. Self-care is particularly stressed and taught.

The social worker participating in the group leads a discussion with the patients on alternating days. This discussion offers women in the group an opportunity to deal with their grief and fear in a setting with others experiencing similar emotions. When a woman's fears appear more pervasive than those of patients around her, the social worker will counsel the patient individually. Unusually intense patient reactions are promptly reported to the patient's physician for possible referral to appropriate specialists. Most important is the fact that the woman may hear the answer to a question that she is afraid or embarrassed to ask; while it is true that many individuals cannot ask questions freely, particularly in a group, most people can listen. An advantage of the group is that it can often answer questions that may not have occurred to the patient.

A key aspect of the Postmastectomy Rehabilitation Group is the manner in which the team of physician, nurse, social worker, and physical therapist operate. The physician is a part of the overall team; he/she knows what the other team members are doing and need to do; moreover, the rest of the team understands how best to involve the physician in making the program work. Flexibility on the part of team members is required and effective; to a large extent the nurse, social worker, and physical therapist can "cover" for each other in appropriate ways. This flexibility is absolutely essential in a community hospital setting where each of these professionals has other major responsibilities. The nurse often fills in for the physical therapist in demonstrating exercises, or the social worker covers for the nurse in explaining the program to the patient and family. The patient benefits from this approach because it reduces the formality and distance of the team; also, such flexibility makes the program easier and less expensive to operate on a day-to-day basis since no special arrangements are needed when members are ill, on vacation, or tied up with other duties.

Moreover, the PMRG provides the patient with appropriate professionals whom the patient can contact after discharge to answer questions or deal with concerns. Many of these questions or concerns would ordinarily, and usually unnecessarily, go to the surgeon or other primary care physician. This is one of the key benefits of conducting a patient group with a team of health professionals—it utilizes professional time in appropriate ways while providing the continuity to assure that the various problems end up with the appropriate professionals, especially the physician. The Mt. Sinai program was instituted in January 1977 and currently serves about 90 patients per year. Operations are not clustered, but experience has shown that there are usually enough inpatients to comprise a group of three to eight patients. The groups go on continuously, with patients entering or leaving on an ongoing basis. When there are not enough inpatients to comprise a group, the same content is discussed on an individual basis. The program is being operated out of a community hospital with limited utilization of regular hospital resources and facilities. Some adaptations from the Memorial Sloan-Kettering Cancer Center Program have obviously been made in terms of resources and facilities, since the settings are so different. However, as is illustrated here, a program such as this can be operated quite successfully in the community hospital setting.

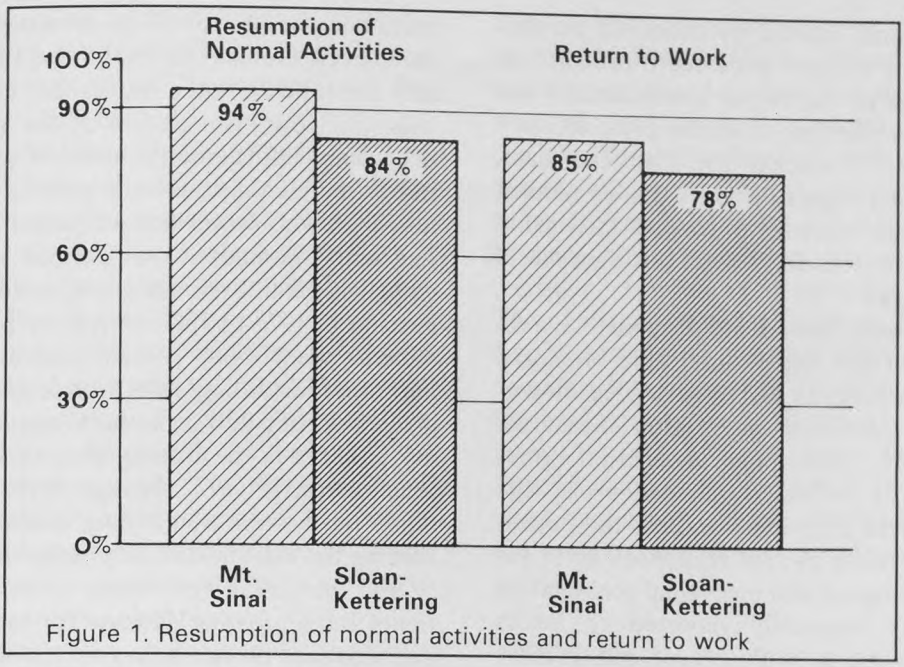

Figure 1. Resumption of normal activities and return to work

Comparative Rehabilitation Outcomes

The data for Memorial Sloan-Kettering Cancer Center are based upon 172 patients whose breast cancers were treated by modified radical mastectomies and who responded sufficiently to the questionnaire. The data for Mt. Sinai Hospital of Cleveland are based upon 107 patients who were treated with generally comparable mastectomies. Each of these groups was actually part of a larger group; however, they are used here for comparative purposes. One out of every five Memorial Sloan-Kettering patients was treated with a modified mastectomy (applicable period 1971 to 1974) while almost all of the Mt. Sinai PMRG patients had a comparable type of surgery (time period 1976 to 1979). Data for Memorial Sloan-Kettering Cancer Center patients are based upon published reports.[13]

Physical recovery and rehabilitation: Range of motion. Normal range of motion was considered to include self-report of full or near full arm extension. Memorial Sloan-Kettering reported that 94 percent of patients with a right side mastectomy had recovered to normal range of motion in the right arm at about 90 days after discharge; they go on to report that a like percentage of patients (94 percent) who had a mastectomy on the left side had achieved normal range of arm motion in their left arm during the same period. Based upon the analysis of the Mt. Sinai experience, the data indicate that all patients with a right side mastectomy had recovered to normal range of motion in their right arm and virtually all (98 percent) patients with a left side mastectomy had recovered to normal range of motion in the left arm. These findings should not be interpreted as meaning that the Mt. Sinai program is better, because variations in age and previous health history may account for these small differences. The important point is that results at least as good as those achieved at Sloan-Kettering for this particular group of patients can be and have been achieved in a community hospital setting.

Resumption of normal activities and return to work. Eighty-four percent of the Memorial Sloan-Kettering patients have resumed normal activities at the time of the 90-day follow-up questionnaire; the average number of weeks prior to resuming such activities was stated as 7.7 weeks. The Mt. Sinai patients also had a very high rate of return to normal activities, 94 percent (Figure 1), with a somewhat lower interval, 6.1 weeks. The higher percentage and the lower average number of weeks may reflect differences in social attitudes and changes that have taken place in physician and employer attitudes regarding activity resumption for mastectomy patients; the Sloan-Kettering data are based upon a period of from four to six years earlier than the Mt. Sinai data. The same type of result occurs in relationship to the number of patients who returned to work. The data for Memorial Sloan-Kettering Cancer Center indicate that 78

percent of patients treated by modified mastectomies who had worked previously returned to work at the time of the 90-day questionnaire and that the average number of weeks prior to work resumption was 7.1 weeks. The Mt. Sinai data, once again slightly higher, indicate that 85 percent of the patients had returned to work at the time of the questionnaire with an average duration out of work of 5.9 weeks.

Emotional stress. Winick and Robbins have reported that eight percent of applicable Memorial Sloan-Kettering patients had experienced moderate to severe emotional stress after discharge. They note that the "psychological benefit . . . does not seem to be reflected adequately in the data." The patient questionnaire does not appear to successfully focus patient responses upon the kinds of psychological and emotional problems so observable and frequently reported to health professionals working with recent mastectomy patients.[13] The Mt. Sinai experience echoes these conclusions. The same proportion of patients reported moderate to severe emotional stress and this self-report seems "low" to the professionals involved. This area is being explored further, and future reports from the program may be able to evaluate the emotional and psychological impact of the PMRG with greater refinement.

Implementation Issues and Concerns

The Postmastectomy Rehabilitation Group is a program that can be implemented in a general hospital setting. There are, however, a few points regarding the implementation of such a program which must be understood and accepted by the surgeon or other involved physicians, as well as by other hospital personnel.

Working with the breast cancer patient involves three key components: diagnosis, treatment, and rehabilitation. Each of these components must receive attention and emphasis by the physician. Physicians who have treated breast cancer patients know that the sense of crisis is very prevalent, particularly at the outset; however, the authors' experience and data indicate that beyond crisis patients are increasingly aware that there are "options" of treatment and rehabilitation. Patients need and are demanding more in-depth information. For example, an analysis of data based upon a seven-day postdischarge questionnaire shows that patients increasingly want more information about such areas as prostheses and wound care, even though content in the PMRG program has continually been upgraded and expanded. Likewise, during a period of the program when discussion and demonstration of prostheses was more limited than normal, patient feedback was negative. The proportion of patients totally satisfied with the amount and kind of information received regarding wound care declined from 59.4 percent in 1977 to 33.3 percent in 1979; generally, patients want more content and discussion. Perhaps the most telling indicator of the ever growing awareness and self-articulated needs of mastectomy patients is the finding that each year of program operation (1977 through 1979) has found patients to be more demanding and less passive regarding the Postmastectomy Rehabilitation Group.

The increasing knowledge of breast cancer patients and a growing demand for both information and feedback place a heavy informational and time burden upon the surgeon or other physician. The Postmastectomy Rehabilitation Group can reduce this burden while insuring that the patient receives the full amount of information that she and the physician desire. Patients want and respond well to rehabilitation efforts. Three out of every four patients indicated that "participation in the group helped them talk with family and friends"; negative responses were usually because patients felt that they personally did not need the group experience. But, most patients feel that they need and benefit from such rehabilitation programs.

The physician's role in rehabilitation cannot be over-emphasized. Patients are more demanding, certainly not satisfied to hear, "Don't worry, we'll stuff your bra," or "Let me do the worrying." Patients and staff are better informed, and want to discuss sex, cancer, and dying.

Physicians who cannot or do not find a way to deal constructively with such concerns may well find that their patients become angry and dissatisfied, a result that only compounds problems already existing for the mastectomy patient. The authors' experience indicates that patients who are not offered a meaningful rehabilitation program will often seek one out.

The Mt. Sinai experience has shown that the program can be easily implemented in a community hospital setting. There are problems and pitfalls. The Mt. Sinai program has encountered

three major types of problems which must be guarded against in future efforts to establish new programs in settings where "programs" are the exception rather than the rule. These three areas have been the resistance of other physicians, the ambivalence of hospital administration, and the difficulty of assuring continuity in the daily availability of team members and time commitment—even though the actual time commitment is not that large on a day-to-day basis.

Some physicians have tended to be resistant at Mt. Sinai because they see the program as the property of the initiating physician, because they feel they can "do a better job themselves," because they sometimes worry that the patient will come back asking too many questions, or, unfortunately, because of professional jealousies. While most breast cancer patients at Mt. Sinai *now* go to the Postmastectomy Rehabilitation Group, this reality took three years to accomplish. Even today, some physicians will send a patient to the program with no explanation or with no preparation, or will not mention the group at all to the patient. Recent experience indicates that such patients usually confront the physician with the fact that they want this rehabilitation program.

Hospital administrative support is critical to any well-functioning program. The Mt. Sinai experience has indicated that gaining such support for a small program can be difficult, but possible. The program requires a physical facility and continuous, though minimal, staff continuity. Lack of administrative priority can impede the program. For example, initial announcement of the program's inception brought great anticipation on the part of the paramedical employees of the hospital; however, this enthusiasm was never followed-up by any real opportunity for training and orientation for other hospital personnel. In fact, at this point, many nurses on the floor do not know enough about the program to be able to reinforce the effect of the group. This lack of continuity is, in large part, a function of hospital administration reluctance to commit itself fully to the Postmastectomy Rehabilitation Group effort, both financially and in physical space allocation. Happily, the Mt. Sinai experience also indicates that administrative attitudes do change with time and that support from this critical quarter makes program operation much more effective.

The program requires a team of a social worker, a nurse, and a physical therapist. The direct time involved in group activities averages less than five hours per week per professional team member, but even this has been hard to ensure on a day-to-day basis because of competing demands. Of course, the actual time involved is considerably more because of personal contact and follow-up; but most hospitals have such professionals in place already; it is mainly a matter of focusing hospital resources. The continuity of team members cannot be overemphasized; program experience indicates, for example, that during the one year of the program when several physical therapists, as opposed to primarily one or two, were involved in the Postmastectomy Rehabilitation Group in a somewhat haphazard fashion, patient feedback about the program was not as positive as during other periods.

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