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I am submitting herewith a dissertation written by Muriel Ann Levin entitled "Patient Participation in the Development of Breast Cancer Patient Education Materials: A Pilot Study." I recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Education, with a major in Health Education.

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PATIENT PARTICIPATION IN THE DEVELOPMENT OF BREAST CANCER PATIENT EDUCATION MATERIALS: A PILOT STUDY

A Dissertation

Presented for the

Doctor of Education

Degree

The University of Tennessee, Knoxville

Muriel Ann Levin

August 1979

1398062

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Dedicated to

my two daughters

Deborah and Jennifer

with much appreciation for their continued

love, understanding and moral support

and to

my late husband

Dr. Alfred P. Levin

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A great number of people helped to make this study possible. My doctoral committee has been exceptional in their support of both mind and spirit. Without my committee chairman, Dr. Bill Wallace's unflagging patience and astute advice, I would have faltered many times. Dr. Warren Huffman helped me to clarify and focus my ideas. Dr. Robert Kirk had the special knack for pinpointing special problem areas. Dr. Andrew Brown generously shared his own valuable patient education experience. Ms. Margaret Strong spent many hours helping me to identify and present the psychosocial issues engendered by cancer and its treatment.

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study, I am deeply grateful. They have unselfishly shared their most personal feelings in the hope that future patients would be better served.

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ABSTRACT

The purpose of this study was to demonstrate the use of patient participation during the development of a breast cancer patient education module. The population involved in this study were 22 post-surgical breast cancer patients who were receiving drug therapy from The University of Tennessee's Hematology-Oncology Consultation Service. The Oncology Service's population base encompassed the educational and scientific communities of Knoxville and Oak Ridge, Tennessee, as well as the southern confines of Appalachia. Therefore, the patients in this study represented a broad range of socioeconomic and educational backgrounds.

The patient education developmental process was adapted from a model used by the Mayo Clinic. The process was based on the premise that patients know their own educational needs and interests better than anyone else and it recognized the patients as the educational "experts." Following the Mayo Clinic methodology, this study not only relied upon the patients to determine the content of the patient education booklets, but it also used the patients to critique the booklets once they were written.

A 75-item needs assessment questionnaire was constructed and orally administered to study participants. Based on the results of this survey plus input from the oncology staff and a review of the literature, two booklets

(Hand and Arm Care, Chemotherapy and Hormone Therapy were written which focused on the patients' most immediate educational needs and interests. The booklets were checked for accuracy by members of the oncology staff before being distributed to the study's patients for their review and comment. Patients were given specific directions on how to identify those portions of the text which were unclear, not useful, or undesirable. They were also asked to indicate those portions which contained new information, to show where additional information was needed, and to comment upon the art work. Other comments from the patients were encouraged. Additionally, all patients completed a brief questionnaire about each booklet.

The booklets were revised according to the patients' comments, rechecked for accuracy by the oncology staff, printed, and distributed.

Results from this study indicated that patients from widely varying backgrounds would participate effectively throughout the formulation of patient education materials. This was evidenced by the consistency in quality and quantity of the responses of all patients to the needs assessment interview. It was also evidenced by the fact that patients from a broad range of backgrounds completed the critique of the materials.

The data generated by this study indicated that the patients had numerous informational needs and interests.

Specific topics evoking interest included hand and arm care, prostheses and wigs, nutrition, treatment modalities, exercise, pain control, important signs and symptoms, emotional stress, and sexuality. The breast cancer patients were interested in learning about all phases of cancer detection, diagnosis, treatment, rehabilitation, and self-care. They were eager to receive this information through a variety of formats including one-to-one teaching by the physician, all types of written materials and visual aids, and group discussions where they could receive peer support and exchange ideas.

The study also pointed to the pressing need for adequate understanding of and attention to the psychosocial ramifications of breast cancer. Although it has been well documented that cancer causes profound emotional and economic stress, all patients, except those employed in the health-care professions, were totally unfamiliar with local mental health and social service resources. Moreover, almost all patients were loathe to reach out and seek help deeming that a sign of weakness.

Recommendations have been offered concerning the role of patient education in the health-care system, the role of the patient in the patient education system, and replication of this study.

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CHAPTER I

INTRODUCTION

Over the past 10 to 15 years, there has been a growing recognition of the importance of providing patient education as an integral part of health care. Many organizations, the American Medical Association (1) and the American Hospital Association (2) among them, have issued statements strongly supportive of the concept of planned educational experiences which will develop knowledgeable health consumers.

Moreover, the concept of patient education itself has been expanding in several directions. First, it has changed from its original narrow focus on the giving of disease-specific information to the current broad-based goals of creating sophisticated consumers who are knowledgeable about many aspects of health including the health-care system. Second, the patient is being asked to assume a much more active role in determining what the educational experiences should be and how and when these experiences should take place. Third, there is a growing interest in reaching a much wider segment of the "patient" population, i.e., involving not only patients confined in the hospital as well as patients being treated on an outpatient clinic-physician office basis, but also the community at large. Concomitantly, there is the belief that there should be

continuity of patient education to match continuity of patient care. Fourth, there is the belief that patient education should be an organized activity with specifically delegated responsibilities for program planning, implementation and evaluation.

Unfortunately, however, practice lagged far behind theory. With few exceptions, patient education in 1979 was still confined to a few disease/topic-specific programs which were available mainly for the institutionalized patient. The bulk of the teaching was being directed toward the heart patient, the diabetic, or new mother. Most patients still were not being consulted as to their needs and interests, and patient education was often being doled out on a "catch-as-catch-can" basis whenever a harried nurse, nutritionist, or physician with the inclination could find a free moment. Although educational needs for the cancer patient are particularly critical, at the time of this study few cancer education programs had been reported in the literature. Moreover, little documentation was evident in the literature of formative evaluation procedures such as sustained patient involvement in the patient education developmental process. A Survey of the 18 National Cancer Institute designated comprehensive cancer centers by this investigator in early 1978 indicated most cancer centers had just begun developmental work on patient education activities.

I. NEED FOR THE STUDY

Cancer is a complex and traumatic illness. Cancer care can often entail numerous diagnostic procedures, complicated multimodal therapeutic regimens, frequent laboratory analyses, and extensive rehabilitation efforts. The patient often must be trained to pay strict attention to a variety of crucial medical and physical details such as nutritional status, personal hygiene, exercise routines, and medication schedules. Confounding the educational problems, the profound psychosocial ramifications of the illness tend to magnify educational needs while at the same time making communication between the patient, family, and the health-care team more difficult. Recent statistics showed that 1 out of every 14 women in the United States will develop breast cancer making it the leading cause of cancer incidence and mortality among women (3).

The Hematology-Oncology Consultation Service of The University of Tennessee Center for the Health Sciences/ Knoxville, served a population base of about one million people in and around east Tennessee. During 1977, the Oncology Service had 140 breast cancer patients under their care and, according to the health-care team members, the vast majority of these women lacked essential information. The challenge, therefore, was to develop an educational unit which, in filling some of the educational gaps, would be sensitive to the unique cultural characteristics of

east Tennessee residents. Since few educational resources were available for the oncology patient, this study was undertaken in an attempt to develop an educational program which would meet the needs of local breast cancer patients. Because patients know better than anyone else their educational needs and interests, a formative evaluation process which utilized extensive patient participation was employed throughout the developmental process.

II. PURPOSE OF THE STUDY

The purpose of this study was to demonstrate the use of patient participation during the development of a patient education module for breast cancer patients being served by the Hematology-Oncology Consultation Service, The University of Tennessee Center for the Health Sciences/ Knoxville.

III. STATEMENT OF THE PROBLEM

This study was designed to answer the following questions concerning the development of a breast cancer patient education module using patient participation:

1. What are the educational needs and interests of breast cancer patients receiving drug therapy from the Hematology-Oncology Consultation Service?
2. Will patients of varying educational and socio-economic backgrounds participate meaningfully in

the process of developing the patient education materials?

IV. DELIMITATIONS

The major delimitations of this study were:

1. The population was restricted to the 22 female breast cancer patients who had or were currently receiving drug therapy, who were being seen at least once a month by the Oncology Service during the period of November 1978 to April 1979, who could read, and who were willing to participate in the study. Additionally, all but one patient (who had an inoperable tumor) had previously undergone a single or double mastectomy.
2. The needs assessment instrument and the patient education materials were based on the socio-economic factors common to east Tennessee. These factors included: a strongly fundamentalist religious background, a large proportion of poorly educated patients, a significant number of patients from the lower socioeconomic bracket, a large number of patients from isolated rural areas, and regional dietary habits and tastes.
3. Because many patients did not possess audiovisual equipment, the patient education materials were restricted to a series of self-contained small

booklets.

4. Individual teaching activities by health-care workers were excluded from this study.
5. Family members were not included in this study since they might inhibit the patient from expressing her true feelings and needs.

V. LIMITATIONS

The patient education materials and the needs assessment instrument were specifically tailored for a particular breast cancer patient population and, therefore, may not be suitable for other breast cancer patient populations.

Since the medical status of the cancer patients was very unpredictable, an atrophying of the study population due to deteriorating health or death was a possibility.

VI. BASIC ASSUMPTIONS

The basic assumptions of this study were that all patients want information. An educated patient is better able to cope medically and emotionally with her illness, will participate more effectively in her own health care, is better able to make necessary health decisions, and can make more efficient use of the health-care system. Yet harried health-care workers often do not have the time for adequate patient education activities. Moreover, patients often do not hear and/or have difficulty remembering

information received orally from health care workers. Thus, patient education must be presented in a variety of formats to reinforce information previously given, to fill in the educational gaps, and to appeal to a wide spectrum of consumers. Written materials are a preferred source of information and play a major role in the patient education process. Booklets containing basic information can be developed which will appeal to patients with a broad range of literacy levels.

VII. GLOSSARY

Adjuvant chemotherapy--the use of chemotherapy post surgically in symptom-free women in hopes of preventing a recurrence of disease.

Affective aspects of a program--dealing with the emotional impact of a program; the effect upon a person's belief system.

Behavioral aspects of a program--dealing with the actions one takes as a result of a program.

Breast self examination (BSE)--a simple procedure to examine breasts thoroughly for suspicious lumps or thickening of tissues. It is recommended that the procedure is done monthly by all women, especially those women who have had a cancerous mass in one breast.

Chemotherapy--the treatment of disease (often cancer) by chemical compounds.

Cognitive aspects of a program--dealing with the gain in information; the knowledge aspect of a program.

Combined modality treatment--the use of two or more modes of treatment--surgery, chemotherapy, radiotherapy, immunotherapy, hormone therapy--in combination, alternating or together, to achieve maximum results against cancer.

Formative evaluation--also called process evaluation. Feedback conducted during the development or alteration of a program or product. Formative evaluation is information and judgments gathered to assist in revision and improvements of an instructional program.

Hematology-Oncology Consultation Service--a group of health professionals located at The University of Tennessee Center for the Health Sciences/Knoxville, who treat patients with cancer and blood diseases. The team members are expert in the selection and use of anticancer drugs. Since the Oncology Service is part of one of several national study groups, they are involved in clinical trials of new chemotherapeutic drugs. Types of patients eligible to be included in the studies, the administration of drugs, the monitoring of side effects and patient status and record-keeping procedures are all very rigidly defined. The treatment regimen is called a protocol.

Hormone therapy--the use of hormones to treat cancer.

Immunotherapy--the treatment of disease by stimulating the body's own defense mechanisms against the disease.

Mastectomy--surgical removal of a cancerous breast to prevent the spread of disease. A woman with a double mastectomy has had both breasts removed, usually at different times.

Metastasis--the process by which cancer cells break away and spread to other places in the body by way of the lymph and blood systems and start new malignant tumors.

Needs assessment--the process of ascertaining and documenting the discrepancy between "what is" and "what should be."

Oncologist--a physician who specializes in the treatment of cancer.

Oncology--the study of the group of diseases commonly referred to as cancer.

Palliative treatment--the providing of relief from the symptoms of a disease but not directly curing the illness; alleviating pain.

Protocol--a written treatment design employing a particular combination of chemotherapeutic drugs or other therapy administered to specific cancer patients on a defined time schedule.

Protocol nurse--the oncology nurse who supervises the administration of chemotherapy to cancer patients on protocol, monitors side effects of treatment and illness, and is responsible for all records of patients on protocols.

Remission--complete or partial disappearance of the

signs and symptoms of a disease, or the period during which a disease is under control.

Stage--the extent of spread of cancer in a patient. Breast cancer patients are separated into stages I, II, III, or IV. Stage I disease indicates a very small localized tumor with no nodal involvement. Stages II and III indicate progressively greater involvement of the body system by the cancer. Stage IV disease indicates a large tumor with extensive invasion of surrounding tissues, nodal involvement and metastases to other body site(s).

Staging--an internationally used system for determining the extent of growth of a cancer so that a specific treatment can be planned, results of treatment can be compared, and prognosis offered.

Summative evaluation--evaluation conducted at the completion of the development of a program or product. The assessment of the "end result."

CHAPTER II

REVIEW OF RELATED LITERATURE

This review of the literature covers the following topics: the evolving definitions of patient education, an overview of the changing status of patient education, benefits of patient education, developmental methodology, evaluation guidelines, financing considerations, psychosocial impact of cancer, and summary.

I. CHANGING DEFINITIONS

In a 1974 report, the American Hospital Association stated:

> The maintenance of health and the prevention of disease can be achieved by a cooperative effort between knowledgeable and motivated consumers and health care personnel. Health education is a planned process that entails the joint identification of needs, the exchange of knowledge and concerns and the clarification of personal responsibilities for health-all designed to encourage positive health practices and to improve delivery of care (2).

The key concepts were: 1) health education is planned, 2) health education is a joint effort between client(s) and health care workers, and 3) health education enhances health care delivery. Ulrich and Kelley progressed one step further in recognizing the inseparability of patient education from patient care when they stated:

> Patient education should consist of organized health educational experiences, planned by physicians, professional health care workers and the patient

> himself to meet the patient's specific learning needs, interests and capabilities, and offered as an integral part of the patient's total health care (4).

But perhaps the most comprehensive description is found in the 1968 Health Education Monograph devoted to patient education. Young, who has perceptively understood the universality of patient education has written:

> Patient education is an integral component of total patient care. In its various facets patient education spans all the important dimensions of patient care, for example: the sociocultural factors related to illness and its management; the dynamics of patient-care systems; inter and intraprofessional communication and the language of patient care; the diagnostic process; quality of care; the effect of various patterns and characteristics of patient care organizations; and the design of care facilities (5).

In keeping with the growing though sometimes still grudging recognition of the patient's right to be an active participant in his/her health care, the concept of patient education of necessity has been broadened to equip the patient and family to make an array of intelligent choices. Thus, patient education has moved from impersonal disease-specific teaching to highly individualized educational planning which encompasses a myriad of topics such as nutrition, disease prevention, early detection techniques, psychosocial issues, and how to make effective use of the health care delivery system. In the future some sort of system will have to be devised to follow the educational needs and interests of the patient as she/he moves back and forth through the various components of the health care

system and as she/he progresses through different stages of illness and wellness.

II. STATUS OF PATIENT EDUCATION

In 1965 a report from the American Hospital Association (A.H.A.) emphasized the hospital's increasing responsibility for teaching about health and illness to patients, their families, and the community at large. Yet an A.H.A. survey of member hospitals conducted 10 years later in the summer of 1975 found that 43 percent of the institutions did not have at least one adult education program with written goals and objectives and only 28 percent of the hospitals had created a specific department to coordinate inpatient activities (6). A perusal of the National Library of Medicine's literature search on Patient Education covering the period of January 1973 through June 1975 revealed numerous articles devoted to illness-specific patient education projects but almost no papers devoted to exploring the concept of comprehensive, coordinated, institution-wide patient education. The same literature search made it obvious that the nursing profession was doing the bulk of the teaching and was at the time of this study, the profession probably most concerned with the quality and quantity of these educational experiences. The three articles by Harper, Miller, and Reiser in the book Patient Education exemplify the nursing

profession's attempt to "create a climate of care" and to grapple with patient education in an organized manner (7, 8, 9).

At present, we do not seem to have progressed much beyond Couch's findings as reported in Shaw in 1973 (10). Patient education is still carried out primarily in disparate, isolated instances; the greatest barrier being the lack of understanding of the value of patient education by the administration and medical staffs of health-care institutions. In the few instances where physicians have initiated patient education programs and have gotten other physicians involved, the programs have fared better. At the time of this study, not one Knoxville hospital had a comprehensive coordinated patient education program.

III. BENEFITS OF PATIENT EDUCATION

Perhaps the foremost reasons for patient education is simply the patient's right to information. There is the right to be informed and understand about one's health status, the right to understand proposed treatment plans (and the right to reject treatment), the right to know how to take care of oneself for optimum functioning, the right to know how to make appropriate, effective efficient use of the health care delivery system. In looking at more clinically pratical reasons for health education, informed patients are more compliant patients (Hulka et al., 11; Komaroff,

12; Blackwell, 12; Gabriel, 14; Francis et al., 15; Hertz, 16). There are less broken appointments and better adherence to medication regimens leading to better control of the patient's illness, better awareness of crucial signs and symptoms, and less rehospitalizations. Green has pointed out that educated patients and community members make better and more efficient use of health services (17).

Education also increases patient satisfaction (Benson et al., 18; Korsch et al., 19). Korsch's group found in their study of a pediatric clinic that if parents were not told the cause and nature of their child's illness, then over two-thirds of the parents were dissatisfied by the visit. More critically, if the physician persistently ignored the mother's concerns (which might not even be verbalized), then the mother no longer listened to the physician nor observed his actions. Thus, vital information was unheard and the mother was incapable of carrying out the prescribed medical regimens.

That patients want information is poignantly illustrated by Schwartz's experience with mastectomy patients. He offered a three session combination didactic and small group discussion program for any woman who had undergone a mastectomy and found women who had had breast surgery up to 28 years previously still eagerly searching for information (20). Even more compelling evidence for the desire for information is presented in books and articles written

by cancer patients (for example, Rollins, 21; Lasser, 22; and Keeling, 23).

Cancer patients, because of the complexity of their disease, have a particularly "desperate need" for education (Klagsbrun, 24). Yet despite their need to gain information to satisfy their concerns and to participate appropriately in the healing process, patients are often quite reluctant to ask questions (Kirscht, 25; Francis et al., 15; Korsch et al., 19). They do not wish to seem ignorant and/or they do not wish to take the time of a busy important person. Moreover, even when physicians do try to communicate with their patients, the new patients quite often find it difficult to emotionally tolerate and/or comprehend a detailed discussion of the disease (Schmale, 26).

Easton et al. looks upon the dereliction of patient education responsibilities "as a cause of morbidity equal in magnitude to medical malpractice" (27). He cited a 1915 Supreme Court decision:

> It is encumbent upon a physician to give such instructions as are proper and necessary to enable the patient or his nurses and attendants to act intelligently in the further treatment of the case, and a failure to do so is negligence which will render him liable for injury resulting therefrom.

The American Law Review has also commented on the subject in much the same language. "It is the duty of a physician to give instructions for the patient's care and treatment, if necessary, and a failure to do so will render him

liable for any injury resulting therefrom" (28).

The Easton paper delineated several common educational malpractices and related them to the health setting. Some examples are:

1. Giving patients educational materials too complex and too technical for their comprehension.
2. Requiring illiterate patients to learn from written materials.
3. Dismissing a patient before ascertaining whether she/he has learned the necessary information.
4. Assuming all patients learn at the same rate and in the same way.
5. Assuming some patients can not learn.

Easton emphasized his belief that all patients can learn and should be given information. He felt it was improper to withhold information from some patients in the belief that the patients would misapply the knowledge.

IV. DEVELOPMENTAL METHODOLOGY

If we start with the basic premise that comprehensive coordinated patient education is an integral part of health care, how then shall this difficult task be approached? Obviously there are many factors to be considered. The foremost consideration is the securing of support from the institution's administration and medical staff. Shaw pointed out that failing this commitment those programs

which have managed to be initiated soon wither and die (10).

Patient education takes time, money, and expertise. For these three factors to be available, the administration and medical staff must be involved and willing to allocate the necessary resources. Although Green has pointed out that patient education is cost effective (17), nevertheless, a continuing investment must be made at the front end of the process.

Since a "patient education program must be planned, supported, and implemented in a manner in which all complexities inherent in total patient care are considered" (Simmons, 29), four levels of planning ought to be undertaken.

1. The systems level--the patient education program in toto, and how it integrates into the local health-care system.
2. The individual institutional level.
3. The individual program level.
4. The individual patient level.

Harper and Kucha used Mager's conceptual framework in their approach to developing a system for patient education (7, 30); a framework roughly followed by the American Public Health Association in developing their preliminary patient education guide (31). Mager advocated the development of broad based GOALS, specific measureable OBJECTIVES, the breaking down of objectives into METHODS, and

EVALUATION (32). Morrisey offered a similar guide although he broke the planning process down into more numerous steps: RULES and MISSIONS, FORECASTING, OBJECTIVES, PROGRAMMING, SCHEDULING, BUDGETING, REVIEWING, CONTROLLING, and MEASURING performance (33).

Deeds delineated four basic principles of education which should be used as a guide in planning patient education programs:

1. Behavior is complex. In order to change behavior more than one intervention is usually required. The interventions should be consistent, reinforce previous ones, and be planned over time.
2. Not all messages and media appeal to everyone. Therefore variations on the messages in a variety of formats enhance the potential for impact.
3. Group methods provide reinforcement and support in many cases, as well as being cost-effective in terms of staff time.
4. Because behavior is complex, a careful educational diagnosis of the factors which predispose the person toward desirable behavior, enable the behavior to take place, and reinforce the behavior once it is tried, enhances the potential for success (34).

Kucha proposed that alternatives in planning be examined in the light of five factors: 1) desirability, 2) relevance, 3) feasibility, 4) economy, and 5) effectiveness. She also reminded the reader to be cognizant of the impact of new patient education programs; there will be altered relationships, roles, rates of change, and altered perceptions with not all groups receptive to change. Simmons, Brown, and Kucha discussed preplanning information needs (29, 35, 36). Simmons looked at personnel and resource availability, Brown was also concerned with

current patient education practices, potential barriers, extent of financial commitment, hospital and community resources, and, along with Kucha and Harper, a host of patient needs and interest factors. Kucha suggested general methods for analyzing needs.

Fylling in noting that "nationwide, total outpatients now exceed inpatients sevenfold," was particularly concerned with including outpatients in patient education systems. She identified factors which must be considered when conducting programs in an outpatient setting.

1. Characteristics of staff (number, type, qualifications and responsibilities).
2. Characteristics of the outpatient population (number of patients, types of patients, type of care given in the setting, patient's readiness for learning).
3. Contact time of the staff with the patient.
4. Space available for patient education.
5. Audiovisual equipment available.

> To provide quality education in the outpatient department, there should be continuity and compatibility between the patient education program in the inpatient setting and the patient education program in the outpatient setting. The two types of programs should complement each other. . . . and be designed to meet the needs of its populace in all stages of the health/sickness continuum (37).

V. EVALUATING PATIENT EDUCATION

Two points must be made about patient education evaluation at the onset. First, the state of the art is still very much in its infancy. Many techniques are being adapted from other disciplines, especially education and psychology. However, many questions remain to be resolved

before the methodology can be considered to be refined. For example, the ultimate goal of all health care is improved patient health. Yet, especially with the cancer patient, tying improved health status to any one particular intervention strategy is particularly difficult to achieve. There are numerous intervening variables, not the least of which is the totally unpredictable course of the disease. Indeed, one may not be able to make the cancer patient "better" no matter what the intervention. So, secondary indicators of success such as fewer broken appointments, better adherence to medical regimens, and improved patient satisfaction are being used until more sensitive measurements can be developed.

Secondly, evaluation is usually seen as a separate process; one that measures the attainment of objectives. In reality, evaluation must be integrated into all activities and should be ongoing and continuous throughout all the phases of planning and implementation (i.e., formative as well as summative) (Suchman, 38; Scriven, 39; Baker, 41). Constant feedback is imperative to assess the efficacy of each step. Goals must be reevaluated, objectives reassessed, materials and methods continually reexamined for relevance and effectiveness. Without this constant review, one is never sure that the end product is really the most effective one possible. Moreover, even if the initial programs developed are of excellent caliber, without regular

reevaluation procedures, there is the danger of slipping into routine execution of stock programs unsuitable for differing treatment modalities, changing patient needs and interests, and new or modified health-care professional roles. However, most of the health evaluation literature to date has focused on end product evaluation (summative) and guidelines for formative evaluation are scarce.

The term "formative evaluation" was first used by Michael Scriven in 1967 (42). In his Evaluation Thesaurus, the term is defined as an assessment process which "is conducted during the development or improvement of a program or product" (39). Baker defined formative evaluation as information and judgments used to assist in the revision and improvement of instructional programs. Formative evaluation demands a feedback mechanism by which data collected and judgments made are used to improve instruction as it is undergoing development (41).

Baker listed five criteria to be utilized in formative evaluation procedures.

1. Content accuracy--are materials accurate? This assessment is usually carried out by asking experts to review the educational materials.
2. Content scope--does content reflect a range of ideas, concepts, and opinions?
3. Content relevance--are the materials well designed instructionally? Does the content meet the goals

and objectives specified for the educational unit?

4. Content comprehensiveness--does the content account for all planned outcomes?
5. Content quality--are all materials, pages, figures, tables, etc., in order? Do ideas, units fit together properly?

As the last step in formative evaluation, new materials should be tried out on a small sample of students with the evaluator looking at the consumers' reactions, behavior changes, and increase in knowledge and satisfaction (41). A small pilot testing of materials allows extensive interplay between the developer and the student and ideally results in better feedback. Given the fiscal restraints that usually prevail with any program, the responses of a few students can be economically analyzed in great detail.

The National Cancer Institute in 1978 underscored its concern for process evaluation by developing an extensive pretesting service for commercial cancer communications and by publishing a guidebook for cancer educators (43).

Communication plays an essential role in cancer control. It is necessary for heightened public awareness to the importance of prevention and early detection. Communication is also important for enabling cancer patients and their families to cope with the disease.

> At each state of communication planning and development, pretesting can inexpensively assess comprehension, attitudes, and other perceptions among respondents representing the intended audience. The diagnostic information learned from pretesting can lead to improvements in concepts, messages, and materials while revisions are still possible and affordable (43).

In one of the few articles relating formative evaluation to the development of patient education materials, the Mayo Clinic has described an assessment procedure they have used to guide the development of educational materials directed towards patients undergoing a relatively new surgical procedure (44, 45). Phase I consisted of a needs assessment instrument designed to focus on the patients' learning needs and adjustment experiences. Data were collected about both medical problems and psychosocial adjustments.

Phase II consisted of the development of the educational materials in rough form. Based on the information collected from the needs assessment and input from health professionals, educational objectives for the unit were formulated and then a book written. The book's manuscript was checked for accuracy by appropriate medical and allied health personnel. Phases III and IV consisted of appraisals of the book by preoperative and postoperative patients. The preoperative patients kept the book draft with them throughout their hospitalization and thus focused in on the immediate problems of undergoing a traumatic surgical procedure. The postoperative patients reviewed the contents

in light of their psychosocial adjustment experiences as well as their medical experiences. Both sets of patients were asked to make comments directly in the manuscript and to complete a questionnaire about the book. Phase V consisted of a revision of the book in accordance with the responses of the patients.

Bryant has identified several problem areas for evaluation in general. These are:

1. Having objectives clearly stated but not measureable (especially costs and extent of behavior modification).
2. Not planning evaluation from the beginning of program development and so not having appropriate data available.
3. Deciding who collects data and who pays for it.
4. Not having evaluation expertise or manpower available (46).

Green, who has written extensively on evaluation, in one of his recent articles explored "seven dilemmas of evaluation and measurement." One dilemma treats with the timing of a particular program's evaluation and pointed to the impact of several time-related variables: 1) the sleeper effect, 2) decay of impact, 3) borrowing from the future, 4) adjusting to secular trends, and 5) backlash from a cessation of a program (47). Another Green paper dealt with the question of internal versus external validity and proposed a "hierarchy of options" for experimental design. Looking at the five elements of the true experimental design (posttest, pretest, control group, random assignment, representative sample) the one essential

for any evaluation is the posttest. Depending upon need, optional use and combination of the other four elements can be utilized for a quasi-experimental design (48).

Brown was concerned with some of the quandaries posed by the control group. Since most health professionals find it difficult to withhold treatment from any group, he suggested several techniques for circumventing this problem. One technique was simply to replicate another study. The second suggestion was to assign the patient population to several groups with each group getting a different educational intervention. Results from the pretests and the posttests would then be compared. The third option was a variation of the second. If one educational program had several components, each group of patients would be exposed to only one program component with the exception of one group of patients who would be exposed to the whole program. Again, pre- and posttest results would be analyzed (35).

As Deeds has observed, "evaluation should occur whenever it is possible to change things" (34). In measuring program effectiveness, evaluation can assist in the allocation of scarce resources as well as lead to improved formulation of policies and programs, aid in accountability, and in the end, better serve the patient.

VI. FINANCING CONSIDERATIONS

Pritchett has pointed out that in the past whatever patient education was haphazardly dispensed in the doctor's office, clinic or hospital "came with the price of admission" (49). In a sense, we still have not progressed much beyond that manner of remuneration although we are advocating consistent, organized, accountable patient education which takes time, manpower, and resources. Although third party payers now agree that patient education is a legitimate activity which should be reimbursed, in fact, few companies are as yet doing so if the educational activity is billed as a separate charge. Pritchett felt this may be due more to the reticence of hospital administrators and associations than the insurance companies to negotiate the matter. This leaves the hospitals and clinics, etc., the usual option of incorporating the increased cost due to patient education into the general per diem rate. Occasionally when specific patient education materials have been dispensed to the patient, the cost of the materials has been covered by the insurance companies providing the item(s) were billed nonspecifically as a general central supply charge. Pritchett also found that in a few instances where separate charges were made for patient education consultation, the hospital had hired a single health educator to do all the patient teaching. This turned out to be counterproductive since a single person can see just a few

patients each day and in every case the other health-care workers now ceased all teaching activities.

If patient education is an integral part of health care, then the cost of that activity ought to compete in the budgeting process just as any other health care activity (Pritchett, 49; Green, 17). Part of the problem has been that to date the cost of teaching time has not been calculated when fees are established for patient services. For example, it may take a minute or two to give a medication or do a laboratory procedure, but it also takes two to four minutes to explain what is being done and why and to give the patient a chance to ask questions. The fine art of analyzing the cost of education in a health care setting must be learned and the expense evaluated and included in the general budget just as any other activity.

VII. PSYCHOLOGICAL IMPACT OF CANCER

Cancer causes profound psychological stress on most patients. The usual initial reactions to the diagnosis include shock, terror, numbness, panic, anger, denial, and disbelief (Klein, 50; Bard and Sutherland, 51). These reactions are then modified by experiences during the course of diagnosis and treatment and also vary according to each patient's own previous life experiences. Subsequent feelings to the illness may include depression, vulnerability, loneliness, fear, guilt, resentment, and self hatred.

The cancer patient must face the threat to life, increased expense, loss of employment, changes in body function and appearance, shift in family roles, prolonged discomfort, and a bewildering array of tests and treatments (50, 52, 53). Breast cancer patients must deal with the additional trauma of the involvement of a sexually significant body part (51).

The term cancer itself has a particularly negative connotation when compared to other chronic diseases, even those with similar prognosis. Cancer patients, families, and friends often perceive cancer as "rotting" and being "dirty" with the social implications akin to the image of a leper in historic days (Creech, 54; Bahnson, 55). Because of these perceptions, the cancer patient often is shunned by family, friends, and employers. This stigma has contributed to the myth that cancer is a dread disease. In turn the myth has amplified realistic fears of pain, disfigurement, loss of sexual attractiveness, loss of social esteem, and loss of self worth. The health-care team must attend to these psychosocial implications as well as to the medical problems so that the patient and family may learn to cope effectively with the illness. Patient education plays a crucial role in this adjustment process.

Lefebvre's 1977 pilot study of cancer patients with various diagnoses being treated by the Hematology-Oncology Consultation Service revealed that sexual activity, appetite,

and sleep were adversely affected in the majority of patients. Additionally, self concept as a productive person was also disturbed (56). These results correlate with findings of other oncology workers (Schmale, 26; Creech, 54; Bahnson, 55; Bard and Sutherland, 51; Mantell and Green, 57, 58). One of the most devastating adjustments the cancer patient must face is the loss of autonomy and an increased dependence upon other people and upon assorted medical regimens. At the very least, the patient is periodically at the mercy of the medical team being prodded, poked, tested, retested, treated, and retested again. There are the constraints of the medical regimens, side effects of treatment and disease, and important selfcare rituals which must be followed (good dietary practices, attention to personal hygiene due to increased susceptibility to infection, avoidance of certain drugs, etc.). The patient with advanced cancer, who must deal with the ravages of the illness (diminished energy, altered body functions, pain, etc.) must learn to accept a fair degree of dependence upon other people. Involvement in the usual work and home activities can be severely restricted for these patients, leaving them feeling useless and unproductive.

The side effects of drug and radiotherapy can be considerable with the type and intensity of reaction varying with the type of treatment and the patient. Fortunately, many patients experience only a few side effects and the

reactions are usually temporary. However, some patients do experience severe, very unpleasant reactions to therapy with debilitated patients being most at risk. Side effects of therapy include:

1. Gastrointestinal disturbances--nausea, vomiting, diarrhea, constipation, stomach ulcers, loss of appetite.
2. Oral effects--mouth ulcers, loss of saliva, alterations in taste and smell.
3. Muscle and nerve effects--weakness, numbness, lethargy.
4. Hair loss--partial or complete loss of all body hair including scalp, eyebrows and eyelashes, leg hair, and pubic hair.
5. Reproductive system alterations--sterility, irregularity, or cessation of menstruation.
6. Skin rashes and itching.
7. Bone marrow involvement--decrease in white cells makes the patient very susceptible to infections; decrease in red cells can cause shortness of breath, fatigue, and heart failure; decrease in platelets decreases the blood's ability to clot (59).

A review of the preceding reactions makes it clear that many cancer patients must contend with a variety of very disagreeable physical and emotional assaults on their

integrities. Small wonder that even the patient with the strongest ego defenses may have difficulty coping with the disease.

Breast cancer and its treatment introduces very special problems since different body parts acquire special meaning in the emotional life of each individual. The development of breasts plays an extremely important role in the psychic as well as physiological maturation of women. The female breast has been so idealized in our culture that it has become the primary source of a woman's identification with the feminine role (Mantell and Green, 57). Therefore the stigmatizing effect of a mastectomy places a tremendous psychological burden on a woman. Many women have great difficulty relating to other people without an intact and acceptable body. Loss of a breast threatens their self concept as a worthy sexual partner and mother. Nor does age seem to be an important factor in a woman's acceptance of her altered body. Rather, personality characteristics seem to determine her ability to adapt. However, even for women who seem to have accepted their physical loss and who seem to have made a good adjustment, a psychological wound remains. Most women feel that they "will never be the same again" (Bard and Sutherland, 51).

For the mastectomy patient to regain equilibrium she must master three tasks. She must accept the loss of her breast by fully mourning for that loss. She must

reintegrate a self image worthy of love and the rewards of life. She must come to terms with the albatross of potential recurrence with which she will have to live for the rest of her life (Klein, 50).

VIII. SUMMARY

In 1979 patient education was getting not only increased attention, but also the concept of what constituted patient education was being expanded. However, there still remained a considerable disparity between what was being advocated and what was being practiced. Patient education still faced the common obstacles of lack of support from key administrators, lack of resources, inadequate funds, and untrained personnel. Most patient education theorists followed the systems approach to developmental activities borrowing heavily from Mager's Management by Objectives conceptual framework.

Evaluation was a crucial element in program development but the methodology was not yet always equal to the challenge. Formative evaluation techniques particularly were lacking. The Mayo Clinic's formative evaluation procedures of patient education developmental activities provided one of the few guides available in the literature.

Common psychological reactions of cancer patients include shame, insecurity, fear, guilt, depression, anger, anxiety, despair, hopelessness, and loneliness. Although

these reactions can be temporal in nature, nevertheless they constitute a real crises for the cancer patient. Appropriate and timely intervention strategies are crucial for working towards the patient's optimal rehabilitation.

Patient education plays a vital role in health care and contributes to the patient's well being in many ways.

* allays fears--one of the worst fears is fear of the unknown
* permits active participation in the decision process which in turn helps psychological recovery
* aids in understanding of medical regimens leading to better compliance
* tells patients which are significant signs and symptoms; when to call the doctor and what to tell him/her
* tells patient what to expect after surgery and treatment; how she can be rehabilitated; gives hope
* helps the patient to mobilize needed resources; tells patients what is available, where, and at what cost
* allays feelings of isolation; helps patient to realize the universality of her feelings
* provides important information for activities of daily living; defines restriction, exercise routines, sexual counselling, information about prosthesis selection, etc.

Bard and Sutherland advocate the establishment of a

warm and supportive relationship between the patient and the health-care team before any effort is made to give information. If such a relationship is not established, factual discussion or impersonal distribution of information may well result in emotional disorganization (51).

CHAPTER III

METHODOLOGY

I. INTRODUCTION

Although there has been a recent wave of enthusiasm for patient education programs, many educational materials have been developed without adequate planning and evaluation, and more importantly, without adequate patient participation. This study sought to describe a specific method for actively involving the patients in the program development process. The formative evaluation approach to the program development was adapted from a model utilized by the Mayo Clinic (44, 45). The rationale for this approach was based on the premise that patient education programs:

> . . . fall far short of the ideal unless they are designed to meet the cognitive and/or affective needs of the patients as these are described by the patient, not solely as they are perceived by the program developers. The patient must participate actively in the evaluation process, from the time the project is conceived until it is complete (44:334).

Another reason for choosing a patient participation format was the concept enunciated by Watson in the social science literature on change (60) and recognized by the Mayo Clinic staff and other health professionals, that patients would be more open and involved in the criticism of patient education materials if they thought they really

could influence the selection and presentation of information. Health professionals have reported that patients shy away from expressing disapproval of completed programs fearing that their negative reactions would be construed as ungratefulness and thus somehow jeopardize their care (44, 46). However, if the project is still in the developmental stage and the patients feel that they really can have an impact, then they may be more willing to risk expressing their true feelings.

II. EXPERIMENTAL DESIGN

A very brief overview of the study's design is now presented with each facet being described in greater detail later in this chapter. A pool of 30 breast cancer patients receiving drug therapy was identified. Five very ill patients were eliminated and the remaining 25 patients were given an explanatory letter about the study by a nurse or physician of the Oncology Service. The study's purpose and methodology were then explained to the 25 patients in greater detail by the investigator. Three patients not wishing to participate were dropped from the study and the remaining 22 patients signed letters of consent. Meanwhile, a needs assessment questionnaire was developed which was submitted to a local jury for their review and comment. The questionnaire was revised in accordance with the jury's recommendations and then pilot tested on five breast cancer

patients who had recently completed a course in chemotherapy. The questionnaire was revised again in light of this pilot test experience and then the first 15 patients recruited to the study were interviewed using this final version of the needs assessment questionnaire. The results from the needs assessment were analyzed. Based on this information, input from the Oncology Service staff and the literature, educational goals and objectives for two booklets attending to the patients' most immediate educational needs were formulated. Two booklets on Hand and Arm Care and Chemotherapy and Hormone Therapy were written and checked for accuracy by members of the Oncology Service. The 22 patients were then given packets containing the following materials to look over at home: drafts of the two booklets, questionnaires about the booklets, pens, a letter with directions, and a self addressed stamped envelope. The patients reviewed the booklet drafts at their leisure at home and then mailed them back along with the accompanying questionnaires with their comments and suggestions. The booklets were revised according to the patients' comments and rechecked for accuracy by the Oncology Service staff. Finally, the booklets were printed and distributed. Figure 1 depicting this process appears on the following page.

Thus, following the Mayo Clinic model, three evaluation instruments were employed to help establish the learning objectives, determine initial content, and then make

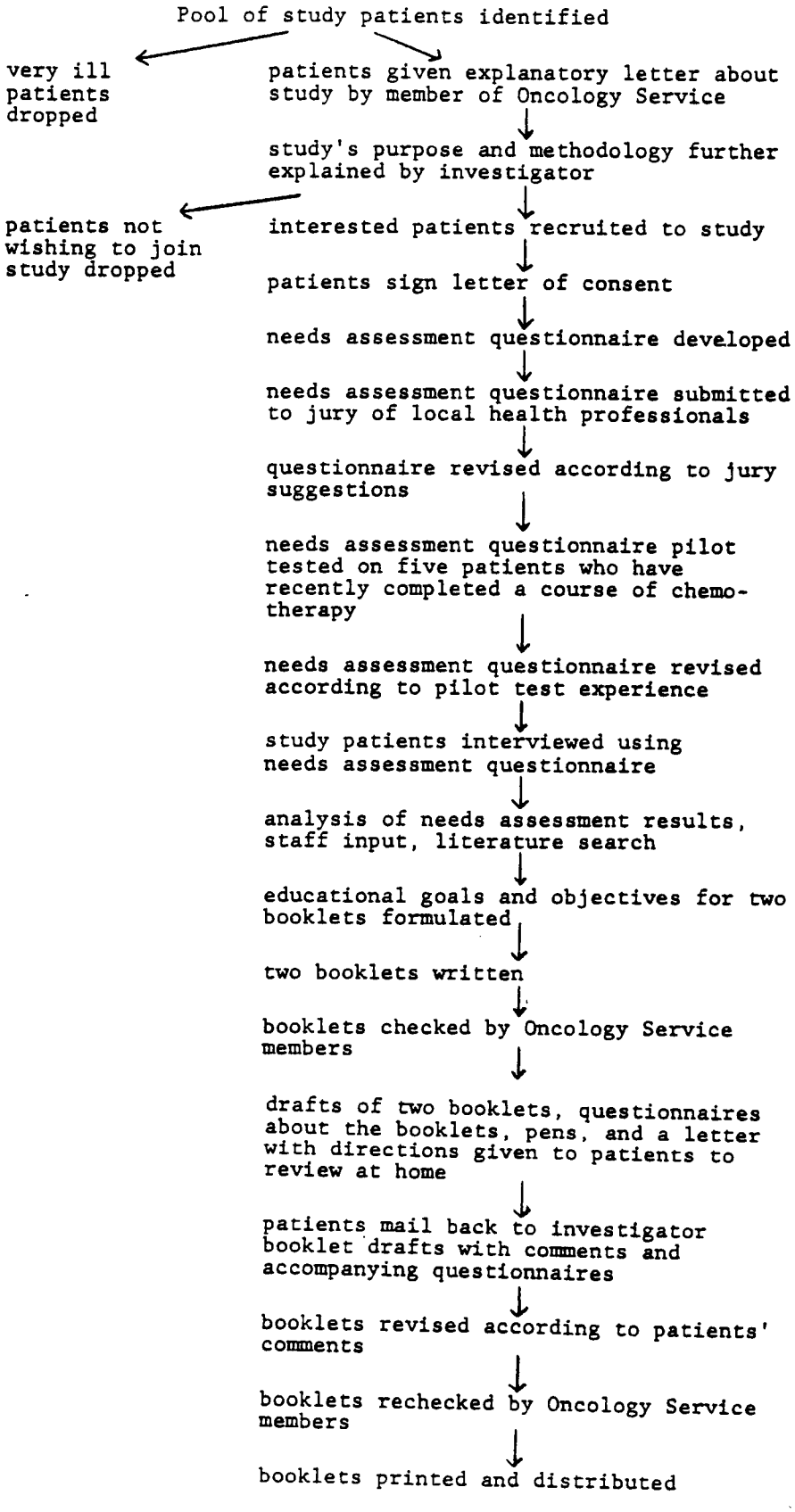

Figure 1. Outline of study methodology.

appropriate modifications in the group of booklets which comprised the breast cancer patient education unit. The first instrument was the needs-assessment survey. The second was a formative evaluation questionnaire which accompanied the rough draft of each booklet. The third instrument was the rough draft of each booklet. These will be described later in this chapter. Family members were not encouraged to participate along with the patient in this study although it is known that families, and in particular spouses, are crucial in the rehabilitation of breast cancer patients. The exclusion of the family was deemed necessary in order to separate patient needs from family needs. It was also feared that in some instances patients would refrain from expressing their true opinions because of negative feedback from their family.

III. PATIENT POPULATION

The patients included in this study were all patients in whom breast cancer was the primary neoplasm, who were being seen by the Hematology-Oncology Consultation Service at least once a month during the period of November 1978 through April 1979, who were receiving or had recently received drug therapy, who could read, and who were willing to participate in the study. The Hematology-Oncology Consultation Service (a group of health professionals skilled in drug therapy) was located in the Family Practice

Building in The University of Tennessee Center for the Health Sciences/Knoxville. Of a potential pool of 30 study patients, five were deemed too ill to participate, and three declined to join the study making a total of 22 persons who entered the study.

Of the 22 patients in the study, 14 patients had received radiotherapy and all but one patient had previously undergone breast surgery, either a single or double mastectomy. This one exception was a patient with an inoperable tumor who was being treated solely by radiotherapy and drug therapy. Time since surgery varied from two patients being less than six months postoperative to two patients having undergone surgery more than five years previously (see Table 1). Seventeen patients were receiving chemotherapy for metastatic disease at the time of this study, one

TABLE I

TIME SINCE BREAST SURGERY

No. of Months Since Surgery	No. of Patients
0-5 months	2
6-12 months	6
13-14 months	3
25-60 months	8
Over 61 months	2

patient was receiving hormone therapy for metastatic disease, three patients with stage II disease were receiving adjuvant therapy, and one patient had recently finished a course of adjuvant therapy. Table II shows the distribution of the patients on the various drug treatment regimens.

TABLE II

DISTRIBUTION OF PATIENTS ON VARIOUS DRUG REGIMENS

Type of Treatment	No. of Patients
Chemotherapy	17
Adjuvant therapy (current)	3
Adjuvant therapy (finished)	1
Hormone therapy	1

Time since the patient first began drug therapy varied from five patients having started drug therapy less than three months previously to three patients having first started chemotherapy more than two years previously (see Table III). As a rough indicator of prognosis, data about the patients' disease stage were collected. Four patients were classified as having stage II disease, seven patients were classified as being stage IV (see Table IV).

Since the number of noncaucasians residing in east Tennessee was extremely low (less than 5 percent), all patients in this study were white. Twelve patients resided

TABLE III

TIME SINCE START OF FIRST DRUG THERAPY

No. of Months Since Start of Drug Therapy	No. of Patients
0-3	5
4-6	2
7-12	7
13-24	5
25-36	3

TABLE IV

STAGE OF PATIENTS' DISEASE

Disease Stage	No. of Patients
II	4
III	11
IV	7

in Knoxville or two small cities nearby, and 10 patients came from outlying small towns in rural areas. The ages of the patients ranged from 35 years to 71 years with a median of 56 years. See Table V for age distribution data. Two patients had never been married, one patient was divorced, six patients were widowed and 13 patients were married.

TABLE V

DISTRIBUTION OF PATIENT AGES

Age	No. of Patients
Under 40	2
40-49	2
50-59	10
Over 60	8

Eighteen patients had a high school education or less and only four patients had received more than a high school education. Patient data are summarized in Appendix A. Because of the small size of the study group, little attempt was made to analyze responses of a particular subgroup. However, other investigators may find the descriptive data useful for guiding further research efforts.

IV. PATIENT RECRUITMENT

The initial study contact to the patient was made by an Oncology staff member familiar to the patient. The protocol nurse or an oncologist very briefly introduced the study's purpose and handed each patient an information letter explaining the purpose and method of the study (a copy of the letter is found in Appendix B). The investigator then followed up with a personal interview at which time she discussed the project in greater depth and answered

any questions. Each patient agreeing to participate in the study signed a consent form (see Appendix C). It was stressed that participation in the study was entirely voluntary and that in no way would a refusal jeopardize their care. In the dissemination of the study's results all data would be presented as group data so as to protect the confidentiality of each patient. It would be impossible for anyone other than the investigator to identify any one patient's opinions and/or informational needs. All patients would be free to withdraw from the study at any time.

V. NEEDS ASSESSMENT

As an initial step in the program development process, six members of the Oncology Service (chief oncologist, two protocol nurses, head oncology floor nurse, chief laboratory technologist, social worker) were interviewed to determine what content areas and learning formats should be included in the patient education module. Based on their comments, a review of the literature (20-26, 50-59, 61-70) and personal communication with a wide range of health professionals who have specialized in the care of cancer patients, a semi-structured patient needs questionnaire was developed to assess learning needs and interests as well as to collect data about psychosocial adjustment from the patients. The needs questionnaire was first submitted to a jury of nine persons drawn from the health professions and the social

sciences (members of the jury are listed in Appendix D). The jury members were asked to do three things:

1. Alter the wording of any question.
2. Indicate which questions they felt should be deleted.
3. Suggest additional questions.

All jury suggestions which were relevant to the scope of the needs assessment questionnaire and to the overall objectives of the study were adopted. The revised version was then pilot tested on five breast cancer patients who had recently just completed a course of chemotherapy. The questionnaire was revised again and the first 15 patients recruited to the study were interviewed using this final version of the needs assessment instrument (Appendix E). The questionnaire addressed the following issues: the patient's understanding of arm care, use of the Reach to Recovery program, experience with prostheses and wigs, information sources, cancer myths, breast self examination, nutritional practices, emotional reactions, family reactions, knowledge of mental health resources, side effects of treatment, sexual adjustments, patient information needs and interests.

To facilitate rapport with the patient and thus encourage openness and honesty with answers, the investigator administered the needs assessment instrument in an informal atmosphere sitting beside the patient on a couch.

The questionnaire was placed openly between the patient and the interviewer to foster the feelings of trust and equality. However, it was noticed that the patients actually read very little of the questionnaire.

Many questions on the needs assessment were open ended or had multiple choice answers. The patients were always allowed to respond at will first before the investigator read the list of choices as a reminder of other options.

VI. EDUCATIONAL UNIT DEVELOPMENT

Based on the information obtained from the needs assessment survey of the patients and from members of the health-care team, specific goals and objectives were developed for each section of the patient education module. The first two booklets in a projected series of six booklets were developed using print and graphics. Each booklet focused on a separate interest area. The overall purpose of the final patient education unit was to help breast cancer patients being served by The University of Tennessee Hematology-Oncology Consultation Service gain the basic information needed for the patients' optimal physical and emotional functioning.

A major factor in determining the educational format was the desire to have an educational unit which the patients could use at home. This would enable the patients and their families to refer to the materials at their

leisure and as often as needed. Since it was assumed that a significant number of patients would not possess audio-visual equipment (slide projectors, tape recorders, etc.), the educational package was restricted to print and graphics. However, the information gathered from the needs assessment concerning other desired learning opportunities will guide the Oncology Service in the development of additional patient education activities.

To provide the flexibility necessary to facilitate easy future revision, each topic was developed as a self contained booklet. This arrangement also permitted patients to select those booklets for which they had a need and interest. It also complemented other materials already available from other sources such as the American Cancer Society, the National Cancer Institute, and commercial companies. The two booklets developed for testing in this study were: 1) Hand and Arm Care, 2) Chemotherapy and Hormone Therapy. These two booklets focused on the patients' most immediate educational needs. Based on the success of this study's developmental methodology, four other booklets on Nutrition, Feelings, Pain Control, and Looking Good were to be developed at a later date following the same patient participation process.

VII. QUESTIONNAIRES ACCOMPANYING BOOKLETS

As the two pamphlets were developed they were given to Oncology Service members (two physicians, two nurses, and

the social worker) to check for accuracy. The patients were then given the booklets along with an accompanying questionnaire for the patient's review and comment. The questionnaires asked the patient: 1) what information was not clearly written, 2) if any part of the booklet was not useful, 3) what part of the booklet was most useful, 4) what additional information was needed, 5) if the art work needed changing, 6) were additional drawings needed, 7) what did the patient like best about the booklet, 8) what the patient did not like in the booklet, 9) what additional suggestions would the patient like to make (Appendix F).

If there was a negative reaction to any part of the text, the patient was asked to tell why. The information from the questionnaires was compiled in tabular form and guided the revision of the pamphlets.

VIII. BOOKLET MANUSCRIPTS

Each patient was given a packet to take home containing both pamphlet manuscripts, two questionnaires, a blue ballpoint pen, a yellow felt marker pen, and a letter containing the following instructions:

> As you read through the booklets, use the blue ballpoint pen to cross out any information you do NOT want. Also circle any word or part of the booklet that you do not understand.
>
> Please feel free to change any wording and make any comments anywhere in the booklets. Tell us where more information is needed. Tell us what you do not understand. Tell us if you want the drawings changed or new drawings added.

> Go through the booklets again. This time use the yellow felt tip pen. Draw a yellow line through all the information you did NOT KNOW OR WERE UNSURE OF BEFORE you read this booklet. This will tell us what new information the booklet taught you.
>
> Complete the questionnaire which accompanies each booklet (Appendix G).

A self-addressed stamped envelope was supplied to each patient for returning the booklets and questionnaires. The use of the blue ballpoint pen to cross out unwanted sections permitted the patients to delete threatening or offensive material without requiring them to verbalize their objections. There was a particular concern for providing a non-threatening mechanism for editing materials in highly sensitive topics such as psychological reactions and the proposed booklet on feelings and sexuality.

Use of the yellow felt marker not only identified which sections of the pamphlet provided needed information and should be stressed, but also gave insight into areas about which patients and their families felt uncertain and confused.

Following the Mayo Clinic's methodology, the patients' comments in the booklets were utilized three ways. The comments guided revision in language. The comments resulted in new sections being added to the booklets. (For example, a section on follow up was appended to the Chemotherapy and Hormone Therapy booklet.) The comments also pointed to the need for additional booklets (e.g., Looking Good).

IX. DATA ORGANIZATION

Data were collected from four sources: descriptive data about each patient from the Oncology Service records, information from the needs assessment instrument, the questionnaires, and the comments from the pamphlet manuscripts.

Since the Oncology Service served a very diverse clientele, descriptive data were gathered to profile the study's population. Patient characteristics are presented in Appendix A and in Tables I through V, pages 41-44.

Data from the needs assessment were organized into subject areas and then further subdivided into cognitive, behavioral, and affective categories. Thus the research investigator was able to identify not only what topics were of interest but also along what dimensions was help needed: cognitive, affective, behavioral. Particular attention was paid to identifying patterns of response since some questions elicited several reactions. For example, one question was: "How do you feel when you look at yourself undressed in a mirror?" The 20 respondents identified six areas of affective content which, when clustered and analyzed fell into these areas: 1) acceptance, 2) denial, 3) sense of impaired body image, 4) loss of femininity, 5) loss of self worth, 6) depression.

Data collected from the questionnaires accompanying the booklets were tabulated according to the eight

dimensions previously mentioned plus a category labeled "other" for miscellaneous comments. The categories were:

1. information not clearly written
2. information not useful
3. most useful part of book
4. additional information needed
5. art work changes
6. additional art needed
7. best part of booklet
8. part disliked in booklet
9. miscellaneous

Any section identified as needing revision by any patient was altered. Any section eliciting requests for more information was expanded if the topic was relevant to the objectives of that unit. Alterations in the art work were made in keeping with the patients' requests.

Information gathered from the markings and comments on the pamphlet manuscripts was tabulated page by page in three columns: reword, more information needed, miscellaneous. Again, any section identified as needing change was revised in keeping with the objectives for that unit.

X. PRINTING AND DISTRIBUTION

The revised booklets were rechecked by members of the Oncology Service for accuracy and then printed and made available to all breast cancer patients being served by the Hematology-Oncology Consultation Service (Appendix H).

XI. SUMMARY

For the development of new breast cancer patient education materials, this study followed a model used by the Mayo Clinic which recognized the patient as the educational "expert." Breast cancer patients participated throughout the developmental process. First patients were interviewed using a 75-item needs assessment questionnaire to ascertain their educational needs and interests. Then the patients were asked to critique the two booklets which had been written to meet the patients' most immediate educational needs. Finally, the booklets were revised in accordance with the patients' comments. All materials were checked for accuracy by the Oncology Service staff before being distributed to the patients.

CHAPTER IV

ANALYSES AND INTERPRETATION OF DATA

Data in this study were gathered formally from four sources: descriptive information about the patient population, the needs assessment instrument, the questionnaires accompanying the booklet drafts, the drafts of the booklets. Additional information was acquired informally through the many personal discussions between the investigator, the patients, and members of the Oncology Service. This informally derived information was used to help interpret patient responses.

I. PATIENT CHARACTERISTICS

Patient characteristics were obtained primarily to describe this study's population so that results could be compared with other studies. For example, there was some question as to whether clients with lower educational levels would participate effectively in the evaluation process. It was assumed that the patients in the Mayo Clinic study for the most part were well educated. However, it was found that patients from all four employment groups and both educational groups contributed extensively to this study. All patients followed directions correctly in reviewing the booklet manuscripts, making notations and in completing the accompanying questionnaires. Moreover, all

patients stated that the information in the booklets was clearly written and easily understood.

II. NEEDS ASSESSMENT INSTRUMENT

The needs assessment instrument, after being revised according to the comments of the nine jury members, was pilot tested on five breast cancer patients who had recently finished a course of chemotherapy. The instrument was revised again in line with this trial experience and then administered to the first 15 patients recruited to the study. Since a major portion of the instrument remained the same after the pilot testing on the five patients, their answers were included in the results whenever possible.

In the case of questions with multiple choice answers, the patients were first allowed to respond at will after which the investigator read the list of choices as a reminder of other options. For reporting purposes in this chapter, affirmative responses include both spontaneous answers and affirmative answers to suggested options. In many instances (especially those questions dealing with psychosocial issues) the responses added up to more than 100 percent. This was because patients often gave several answers.

Arm Care and Prostheses

DID THE DOCTOR (SURGEON) OR NURSE TELL YOU ABOUT TAKING PRECAUTIONS TO PROTECT YOUR OPERATED ARM?

YES 25% NO 70% NA 5%

One patient responding negatively said the doctor, however, made sure that she received this information from the Reach to Recovery Program. One patient said the surgeon spoke only about exercises and not using deodorants. Most patients not receiving arm care instructions from their surgeon subsequently received this information from the protocol nurses of the Oncology Service. At the time of the needs assessment interview, the patients knew about the following precautions:

Blood pressure not taken in affected arm--30%

No injections, laboratory work, vaccinations, etc. in the affected arm--35%

Protect affected arm from sunburn--10%

Protect affected arm from infections, pricks, burns--30%

Special clothing--5%

Exercise affected arm--30%

Do not carry heavy objects--15%

Carry purse on unaffected arm--10%

AFTER YOUR OPERATION DID YOU DO ANY SPECIAL EXERCISES FOR YOUR AFFECTED ARM AND SHOULDER?

YES 70% NO 25% NA 5%

Two patients responding negatively said they substituted normal housework for the special exercises.

IF YOU DID SPECIAL EXERCISES, HOW DO YOU THINK THEY HELPED YOUR ARM AND SHOULDER?

Reduced swelling--5%

Helped mobility--55%

Reduced pain--20%

Two patients had full mobility after the mastectomy even without exercising.

WERE YOU VISITED BY A REACH TO RECOVERY VOLUNTEER?

YES 70% NO 25% NA 5%

IF YOU WERE VISITED, DID THE VOLUNTEER'S VISIT HELP YOU?

YES 100%

The volunteer's visit helped in the following ways:

Moral support--93%

Shopping information about prostheses and bras--71%

Gave patient interim bra and prosthesis--100%

Taught special exercises--50%

IF NOT VISITED BY A REACH TO RECOVERY VOLUNTEER, WOULD YOU HAVE LIKED TO HAVE BEEN VISITED?

YES 60% NO 40%

The two patients responding negatively explained that they thought they had received the same kind of assistance from a friend who had recently undergone a mastectomy.

AFTER A MASTECTOMY, DO YOU THINK THAT FOR SOME WOMEN THE AFFECTED ARM WILL SOMETIMES SWELL?

YES 95% NO 5%

ARE YOU RESTRICTED NOW FROM DOING ANY OF YOUR USUAL CHORES?

YES 35% NO 65%

Most patients responding negatively admitted later in the interview that they did less around the house because they had diminished energy and tired easily.

HAVE YOU FOUND A SATISFACTORY PROSTHESIS?

YES 60% NO 35% NA 5%

Two patients responding negatively explained that since their surgery was so recent, they had not had time to heal properly yet.

DO YOU WEAR YOUR PROSTHESIS?

YES 65% NO 30% OCCASIONALLY 5%

Reasons for not wearing their prosthesis included: lost a great deal of weight recently, double mastectomy was difficult to fit due to uneven surgery, one patient could not afford a proper fitting prosthesis, two patients were still sore from recent surgery.

DID YOU HAVE ANY TROUBLE SHOPPING FOR BRAS AND CLOTHING?

YES 31% NO 69%

Shopping problems included:

Did not know where to shop--6%

Did not like selection--6%

Difficulty in proper fit--25%

WHO FIRST GAVE YOU INFORMATION ABOUT PROSTHESES?

Reach to Recovery volunteer--44%

Doctor--11%

Friend with mastectomy--19%

Other responses included: nurse in hospital where surgery was performed, salesperson, reading, found out by self, American Cancer Society.

WHAT FEATURES DO YOU LOOK FOR WHEN SELECTING YOUR PROSTHESIS?

The responses included: comfort, durability, natural look, attractiveness, wanted a special bra, did not want a special bra, easy care, proper fit, a prosthesis that feels like skin and has a nipple.

DID YOUR INSURANCE COVER THE FULL COST OF YOUR PROSTHESIS?

YES 40% NO 60%

Most patients responding negatively did not even try to get reimbursement. One patient deducted the cost off her income tax (which was allowable). Patients with special cancer insurance pointed out that their insurance did not cover the cost of prostheses and bras.

DID YOU NEED A WIG BECAUSE OF CHEMOTHERAPY?

YES 80% NO 20%

DID YOUR INSURANCE COMPANY COVER THE COST OF THE WIG?

YES 0% NO 100%

Most patients did not even think about asking for reimbursement for this expense. Most insurance companies and Medicare will not cover this expense although the insurance representatives urged the patients to try to collect and felt that the rule would eventually be changed.

ARE THERE ANY DRESS HINTS YOU WOULD LIKE TO PASS ON TO OTHER PATIENTS?

Responses were quite diverse and included: fiberfill is an excellent fill in for small busted women and can be used in a variety of ways to fill in bras, swimming suits, sleepwear, etc.; some breast forms will stick to the skin easily and do not present a problem of riding up or needing special pockets in bras to keep them anchored in place; patients named their favorite store for securing prostheses and bras; use the "18 hour" longline bra to prevent riding up--it is a cheaper choice than bras made specially for mastectomy patients; use tank top and gym shorts for bathing suit.

Arm care and prosthesis summary. Most patients did not learn about special care of the affected arm from their surgeon, most patients were visited by a Reach to Recovery volunteer (and all patients who were visited were appreciative of the help and information), most patients had found and wore a prosthesis, however, most patients did not recover the cost of the bras and prosthesis from their insurance companies, most patients needed a wig because of chemotherapy, but no patient received reimbursement for the cost of the wig, and most patients were eager to share their shopping and dressing hints with other patients.

Facts and Myths

WE ALL LEARN ABOUT CANCER FROM MANY DIFFERENT SOURCES, FROM WHOM OR WHERE DO YOU GET YOUR INFORMATION?

Doctor--55%

Nurses--15%

Scientific literature--5%

Nonscientific literature (books, magazines, etc.)--75%

Radio, television--50%

Family and/or friends--15%

American Cancer Society--0%

Hospital work--20%

Many family members with cancer--10%

Two patients specifically pointed out that their doctor told them very little; one patient stated that she was afraid to bother the doctor; one patient said she did not want to know too much; most patients said they were eager to read as much as possible to find about cancer.

The intent of the question was to find out where patients received information in general about cancer. However, most patients interpreted this question to mean, how did they find out about the status of their cancer.

WHAT IS THE MAIN SOURCE OF YOUR INFORMATION?

Books and magazines--50%

Doctor--20%

Other responses were: family experience with cancer, television. However, one-fifth of the patients complained

that they did not have much information.

DO YOU THINK SURGERY CAN SPREAD CANCER?

YES 50% NO 30% DO NOT KNOW 20%

DO YOU THINK YOU CAN CATCH CANCER FROM ANOTHER PERSON?

YES 0% NO 100%

DOES CANCER RUN IN FAMILIES?

YES 75% NO 5% DO NOT KNOW 20%

WHAT DO YOU THINK CAUSES BREAST CANCER?

Blow to the breast--15%

Pollutants in food--10%

Emotional stress--15%

Do not know--55%

Nobody knows--65%

Hormones--15%

Other responses were radiation from x-ray, gland plugged up. No patient identified viruses, air pollution, or heredity as being a possible causative agent.

IS BREAST CANCER--THE ILLNESS ITSELF NOT THE TREATMENT--SOMETIMES PAINFUL?

YES 75% NO 20% DO NOT KNOW 5%

Patients interpreted this question as meaning any pain other than breast pain was not due to the breast cancer. In actuality, pain is often due to the cancer metastasizing to other parts of the body, especially to the bones. It may be that the patients felt that if the pain were not due to breast cancer, then the cancer was not serious.

HAVE YOU BEEN TOLD ABOUT BREAST SELF EXAMINATION?

YES 94% NO 6%

WHAT WERE YOU TOLD BREAST SELF EXAMINATION CONSISTS OF?

All patients knew that they must palpate around the breasts and under the arms, look for dimpling or changes in the nipple, and that the check should be done monthly.

IS IT STILL NECESSARY TO PRACTICE BREAST SELF EXAMINATION?

YES 93% NO 7%

The patient responding negatively felt that the check up was the physician's responsibility.

DO YOU PRACTICE BREAST SELF EXAMINATION?

YES 72% NO 17% OCCASIONALLY 11%

One patient responding negatively explained that her breasts were so granular that it was impossible for her to check them herself.

HAS THE DOCTOR OR NURSE TALKED WITH YOU ABOUT A SPECIAL DIET WHILE YOU WERE ON CHEMOTHERAPY?

YES 40% NO 60%

Two patients were given pamphlets about nutritional needs. However, since the inception of this study, there has been a marked increase in nutritional counseling by the nurses on the Oncology Service. Additionally, patients with obvious nutritional problems were being seen by the nutrition consultant and received much help in obtaining proper dietary supplements.

IF YOU WERE COUNSELED AS TO DIETARY NEEDS, WHAT WERE THE INSTRUCTIONS?

Patients could not answer this question very well. One patient responded, "eat a balanced diet," another patient mentioned eating plenty of protein, still another patient suggested lots of fruits and vegetables. Two patients had special problems because they were diabetic and overweight but still could not give satisfactory answers.

DO YOU MAKE AN EFFORT NOW TO EAT A BALANCED DIET?

YES 50% NO 50%

In response to the following question asking what foods they ate, the patients listed fattening foods, fruits and vegetables, fish and chicken, vitamins, and five patients mentioned a well-balanced diet.

HAVE YOU LOST YOUR APPETITE FOR FOOD?

YES 44% NO 56%

One patient stated that radiotherapy caused greater food problems than chemotherapy.

ARE THERE ANY FOOD HINTS WHICH YOU HAVE FOUND TO MAKE THERAPY EASIER?

Many patients mentioned potatoes, soup, and dairy products as being helpful. Other hints included: salty foods, bland foods, sweets, instant breakfast drinks, lots of liquid, clams and shrimp, cereal, and marshmallows.

WERE YOU TOLD THAT YOU MIGHT HAVE TROUBLE MAINTAINING YOUR WEIGHT?

YES 35% NO 65%

HAVE YOUR SLEEPING HABITS CHANGED?

YES 45% NO 55%

Five patients stated that they felt more restless and awoke several times during the night. One patient said that she had trouble for a few nights after treatment.

Facts and myths summary. Most patients liked to read and received a majority of their information about cancer from magazines, newspapers, and books. Several patients also received information from their doctor but some patients specifically pointed out that their doctor did not supply them with enough information. A majority of the patients felt that surgery could spread cancer but no patient believed that cancer could be caught from another person. Most patients did not know what causes cancer and the vast majority believed that nobody knew the causative agent. Almost all patients knew about breast self examination and the majority practiced it regularly. Most patients do not remember receiving nutritional information, yet many patients have lost their appetite due to chemotherapy. Many patients have also reported sleep disturbances.

Psychosocial Factors

HAS ANYTHING HAPPENED TO YOU IN THE PAST YEAR (OTHER THAN THE CANCER) THAT HAS CAUSED EMOTIONAL STRESS FOR YOU?

YES 66% NO 34%

Stressful factors included:

Death of a spouse or child--17%

Serious illness of spouse or child--13%

Death of relative or close friend--22%

Serious illness of relative or close friend--17%

Loss of job--13%

Family trouble--13%

Other responses included: marital trouble of child, housing problems, husband of patient being away from the home much of the time.

HOW DID YOU FIRST DISCOVER YOU HAD CANCER?

Ninety-three percent of the patients stated that they felt the lump themselves but only 40% went right to the doctor. Two patients were told by their doctors at first that the lump was nothing to worry about.

DID YOU EXPECT THE DIAGNOSIS TO BE CANCER?

YES 60% NO 40%

HOW DID YOU FEEL WHEN YOU WERE TOLD THE DIAGNOSIS?

Since time from surgery varied from within the past month to having been performed eight years previously, all the responses may not have been accurate. The responses included: 20% stated that they expected the diagnosis, 13% said it was the Lord's will, 13% admitted they were shocked. Other answers were: wished family had been there for support, sorry for family, numbness, terrible--wondered how far it had spread, do the best you can, anger, fright, and disappointment over the postponement of a long-planned trip.

HOW DO YOU FEEL NOW?

The responses included: 20% admitted periodic depression, 20% felt very uncertain, 20% admitted that they were anxious, 20% said their mood depended upon their physical condition, 13% looked to the Lord to decide their fate, 13% stated that they did not dwell on their cancer, and one patient each mentioned that she was distressed, that she was thankful for each day, that she worried if it would recur, that she was fine--"there were lots worse things."

DO YOU KNOW ANYONE ELSE WITH BREAST CANCER?

YES 100% NO 0%

DO YOU TALK WITH SOMEONE SOMETIMES ABOUT YOUR ILLNESS?

YES 93% NO 7%

The patients discussed their illness with the following people:

Husband--100% of those married

Children--60%

Other relatives--60%

Friends--87%

Other cancer patients--40%

Health care worker--7%

Minister--14%

Two patients stated that their husband got very anxious when they discussed their illness. One patient stated that her children really did not want to hear anything about her illness.

IN WHAT WAY(S) ARE THESE PEOPLE HELPFUL FOR YOU?

Moral support--67%

Listening--27%

Other responses were: praying for patient, physical help.

Several patients mentioned the fact that they were helping their friends in discussing their illness. They were teaching their friends about the value of early detection and diagnosis and were helping their friends understand what happens physically and emotionally to a breast cancer patient. The patients seemed to get much satisfaction out of sharing their experiences and hoped their friends would heed their advice to learn the early warning signs of cancer.

IS THERE ANYONE YOU WOULD NOT TELL THAT YOU HAD CANCER?

YES 10% NO 90%

One patient stated that she would not tell her relatives or work associates and the other patient stated that she would not share the knowledge with a new acquaintance.

WHO ARE THE PROFESSIONAL PEOPLE IN THE COMMUNITY WHO ARE AVAILABLE TO HELP WITH EMOTIONAL STRESS? I AM ASKING YOU TO NAME RESOURCES IN THE COMMUNITY THAT ANYONE CAN TURN TO FOR ASSISTANCE IN COPING WITH STRESS.

Patients interpreted this question to mean--who would they use--and most patients felt it was a sign of weakness

to use anybody professionally to help cope with the stresses of cancer. Moreover, nobody, except patients who were in the health professions themselves, could name any professional mental health resource in their community. Seventy-three percent of the patients said they would use their ministers to help them cope with emotional problems although 13% of the patients wondered if the minister was skilled and 6% specified skilled pastoral help. Thirty-three percent would turn to their doctor for help but 6% did not think the physician was capable of handling problems. The four patients who were associated with the health professions named the social worker, mental health agencies, and family service agencies as resources.

WOULD YOU OR HAVE YOU USED ANY MENTAL HEALTH PROFESSIONAL?

YES 25% NO 75%

Again, those patients responding affirmatively were those who were associated with the health professions. The other patients stated that they felt the problems had to be worked out by themselves alone. Twenty percent stated they would call upon friends for help, 10% looked to their church for aid, 10% used family members for help, and 5% admitted asking the unit's social worker for assistance.

HOW OFTEN DO YOU THINK ABOUT YOUR ILLNESS?

OFTEN 63% NEVER 5% OCCASIONALLY 32%

This question was purposefully left vague to let the

patients interpret the frequency in their own way. It was meant to measure the patients' perception of how often their illness intruded upon their thoughts. Several patients responded: "when it's there, it's there, how can you ignore it." Other patient reactions were: "try not to think about it" and "still on my mind since I am receiving chemotherapy."

WHAT WERE YOUR REACTIONS THE FIRST FEW MONTHS AFTER SURGERY?

Shock--25%

Disbelief--15%

Anger (why me)--30%

Fear--15%

Depression--35%

Fatalism--15%

Other responses included: acceptance, God's will to test patient, numbness, loneliness, concern for children, and well prepared since husband had died of cancer recently. Almost all patients listed several reactions.

WHEN DO YOU FEEL BLUE, LONELY, DEPRESSED, ANGRY OR ANXIOUS NOW?

When feeling poorly physically--25%

Bad weather--20%

Pain--20%

Often anxious--15%

Occasionally--10%

Middle of the night--10%

Boredom--10%

Other responses were: thought of impending death, coming in for treatment, fate of small children, cost, little things in general, loss of husband, and try not to get upset.

WHAT PARTICULAR TIME OR EVENT IN YOUR ILLNESS NOW IS STRESSFUL FOR YOU?

Coming for treatment--40%

Thinking about the future--40%

Physical disabilities--40%

Pain--33%

Side effects of treatment--20%

Not knowing how long treatment will be and what it will accomplish--13%

Other responses included: starting chemotherapy, ending chemotherapy, and none--patient is convinced she is cured.

HAVE YOUR RELATIONSHIPS WITH YOUR FAMILY CHANGED IN ANY WAY?

YES 30% NO 70%

All patients responding affirmatively stated that their family had drawn closer together.

HAVE YOUR RELATIONSHIPS WITH YOUR FRIENDS CHANGED IN ANY WAY?

YES 35% NO 65%

Most patients stated that their friends have become closer and very supportive. However, two patients stated that they have withdrawn from social contacts.

HAS HAVING CANCER CHANGED YOUR PARTICIPATION IN SOCIAL ACTIVITIES?

YES 50% NO 50%

All patients responding affirmatively stated that the slow down was due to diminished energy and pain.

HAS HAVING CANCER CHANGED YOUR ACTIVITIES IN THE HOME?

YES 40% NO 60%

Again, the change was due to diminished energy and pain. The prohibition from lifting heavy objects also curtailed activities.

DO YOU EXERCISE REGULARLY?

YES 33% NO 67%

Two patients were recent mastectomees and were still doing arm exercises every day. One patient took little walks every day and one patient jogged with her husband in nice weather. Two patients spoke of returning to regular exercise classes.

WHAT THINGS DO YOU REALLY ENJOY DOING MOST?

Socializing--47%

Crafts--40%

Reading--27%

Television--27%

Church--27%

Volunteer activities--20%

Other responses were: playing the organ, cooking and canning, shopping, puzzles, attending plays and concerts.

HOW OFTEN DO YOU HAVE A CHANCE TO DO THESE THINGS?

EVERY DAY 47% OFTEN 41% WHEN NOT FEELING POORLY 12%

ARE THINGS FINANCIALLY HARDER NOW SINCE YOU GOT CANCER?

YES 47% NO 53%

ARE YOU NOW MARRIED?

YES 70% NO 30%

HOW DO YOU FEEL WHEN YOU LOOK AT YOURSELF UNDRESSED IN THE MIRROR?

Impaired body image--45%

Acceptance--35%

Loss of femininity--30%

Loss of self worth--20%

Denial--15%

Loss of body hair is worse--10%

Only one patient stated that it made her depressed.

WILL (WOULD) YOU LET YOUR HUSBAND SEE YOU UNDRESSED NOW?

YES 75% NO 25%

One patient mentioned that her husband was more ready to face the scar than she was. One patient stated that she had never let her husband see her undressed.

DOES YOUR HUSBAND TREAT YOU DIFFERENTLY NOW?

YES 50% NO 43%

Those patients responding affirmatively all said that

their husband treated them more tenderly after their operation.

HAS THERE BEEN A CHANGE IN YOUR INTIMATE MARITAL RELATIONSHIPS SINCE THE MASTECTOMY?

YES 36% NO 64%

Reasons for the change included: two patients said their sexual activity decreased because the husband was afraid of hurting the patient, one patient attributed the decrease in activity to age, one patient stated sexual activity had stopped before the operation, one couple's activity had decreased due to other gynecological problems of the wife, one patient stated that her husband was as interested in sexual activities as before the mastectomy but that the patient was rebuffing him due to feelings of loss of self worth. On the other hand, one patient advised resuming sexual relations as soon as possible after the mastectomy.

IS A WOMAN LESS FEMININE AFTER A MASTECOMY?

YES 30% NO 70%

Fifteen percent of the patients stated that the operation would be much more devastating to a younger woman. This was interpreted to mean that the patients felt it was inappropriate to have negative feelings about her own sexual image if she were a "senior citizen." Ten percent of the patients admitted that they felt less desirable. Other responses were of similar ilk: "breast is pretty

important," "man wants a whole woman," "probably feel a little less attractive," "proud of my body--whole people don't know what it feels like," Since only 30% said that a mastectomy made a woman less feminine, it can be seen that patients gave conflicting answers and had difficulty admitting to negative feelings about their body image and worth as a sexual being.

Psychosocial summary. Almost two-thirds of the patients had experienced a stressful event in the preceding year. The majority of the patients discovered a lump in their breast themselves but less than one-half went immediately to the doctor for diagnosis. The most prominent reason for the delay was pressing duties at home (often illness of spouse). The reaction to the news of the diagnosis covered the usual spectrum--from anger, shock, and anxiety to a fatalistic acceptance of the diagnosis. All but one patient shared her concerns about the disease with other people, usually spouse, children, other family members, and friends. All patients, except those in the health professions, were totally ignorant of mental health resources in the community. Moreover, most patients felt it was a sign of weakness to seek help from anyone other than family members, friends, or their ministers.

The most common reasons for experiencing depression or anxiety were poor physical status, bad weather, and pain.

The most stressful factors about cancer were treatment, thinking about the future, pain, and physical disabilities. Many patients drew closer to their family and friends after their operation. Few patients exercised regularly although exercise is an excellent way of preventing depression. Crafts, socializing, and inactive pastimes of reading and television were the patients' favorite activities. Almost one-half of the patients found cancer to be a great financial burden.

Over two-thirds of the patients were married. One-third of the patients stated they felt comfortable with their new body image; the other patients reported feelings of loss of self worth, loss of femininity, and impaired self image. Over one-half of the patients stated that their husbands treated them more tenderly after the operation. One-third of the patients reported a decrease in sexual relationships since the mastectomy. Many patients had difficulty admitting that the mastectomy caused them to feel less worthy as a sexual partner and mother.

General Information

DO YOU STILL SEE YOUR FAMILY PHYSICIAN?

YES 65% NO 35%

Patients continued seeing their family physicians for the following reasons:

Other illnesses--61%

New signs and symptoms--23%

Checkups--31%

Two patients responding negatively explained that they could not afford to see the family physician, one patient did not like her family doctor and had not chosen a replacement, and one patient felt there was no need for a family doctor since she was seeing the oncology physicians very frequently.

DO YOU THINK LAETRILE IS A GOOD CANCER TREATMENT?

YES 0% NO 50% DO NOT KNOW 50%

One patient had never heard of laetrile despite extensive recent newspaper and television coverage.

DO YOU HAVE A PARTICULAR MEMBER OF THE HEALTH CARE TEAM THAT YOU WOULD PREFER TO GIVE YOU YOUR TREATMENT?

YES 40% NO 60%

This question was suggested by members of the Oncology Service who felt that patients often had preferences but were very reticent about expressing them. This perception was correct as can be seen by the following questions.

DO YOU ASK FOR A PARTICULAR MEMBER OF THE HEALTH TEAM TO GIVE YOU YOUR CHEMOTHERAPY?

YES 13% NO 87%

IF THERE WAS A PARTICULAR PERSON ON THE ONCOLOGY SERVICE THAT YOU JUST DID NOT LIKE, WOULD YOU ASK ANOTHER PERSON TO HELP YOU?

YES 37% NO 63%

WHAT ARE THE POSSIBLE SIDE EFFECTS OF CHEMOTHERAPY?

Nausea and vomiting--100%

Hair loss--100%

Loss of appetite--70%

Tiredness--85%

Fever--25%

Pain--20%

Chills--20%

Diarrhea--35%

Constipation--15%

Weakness--10%

Sore gums--10%

Other responses included: sores, rapid heart beat, gastroenteritis, loose teeth, watering of eyes, allergic reactions, burning eyes, and inflamed mucous membranes. One patient stated that she felt as though she was being pulled apart.

It was obvious that the patients were very familiar with the general side effects of chemotherapy. However, no patient mentioned precautions for specific drugs. For example, it was very important that patients receiving cytoxan or methotrexate drink several glasses of liquid for two days following treatment to prevent kidney damage.

DO YOU THINK DOCTORS CAN CONTROL ANY PAIN THAT MAY BE ASSOCIATED WITH CANCER?

YES 75% NO 5% DO NOT KNOW 10% FOR A WHILE 10%

Most affirmative responses were given with some hesitancy.

HOW DO YOU EXPECT YOUR TREATMENT TO AFFECT YOUR ILLNESS?

Prevent recurrence--30%

Remission--18%

Cure--12%

Help--12%

Other responses included: not cure, prevent spreading, live longer, shrink tumor, do not know, and one patient was pessimistic about outcome. However, since only 20% of the patients were receiving drug therapy as a preventive measure, it can be seen that there was considerable confusion as to the objective of treatment.

IF YOU CAN THINK BACK TO THE VERY BEGINNING OF YOUR ILLNESS, HOW WOULD YOU HAVE LIKED TO HAVE BEEN GIVEN INFORMATION?

One-to-one teaching by the doctor--70%

Books, pamphlets, posters, etc.--70%

Films, videotapes, etc.--45%

Group discussions--40%

One-to-one teaching by the nurse--25%

Audiocassettes in the clinic--25%

Audiocassettes at home--25%

Classroom style lectures--15%

Several patients emphasized that they would like as much information as possible presented in as many different ways as possible. Some patients even specified the order of teachings: first one-to-one teaching by the doctor, then

group discussions, then audiovisuals. Little booklets were preferred; the patients feeling that they were "less overwhelming and easier to read." Two patients stressed the need for group discussion to "exchange ideas" and explore different viewpoints. Two patients pointed out that they did not understand the doctor; there were too many confusing medical terms used. One patient (unsolicited) was adamant that there should be a patient educator to organize a patient education program since "the doctor didn't have the time to teach."

WHAT COULD WE HAVE DONE TO HAVE HELPED YOUR ADJUSTMENT TO YOUR ILLNESS?

Twenty percent of the patients were very insistent that they wanted complete explanations of just what were the therapy options, how the therapy would affect the course of the disease, and what would be the probable outcome of treatment. They complained that they had not been given this information. The investigator was not sure whether indeed the patients had a valid complaint or whether the patients were using a form of denial (i.e., they had been told this information in so far as it was medically feasible to predict probable outcomes but the patients did not like the information). Verwoerdt has pointed out that quite often requests for information are really pleas for reassurance and support (70). Since these three patients did not have favorable prognoses, it was likely that additional emotional support was needed to help the patients cope.

Other responses were: a reiteration of the desire to have the family present when the doctor told the patient the diagnosis, give sympathy and hope, patients should know all the options and be able to try anything that may be preventative, unfavorable information should be given at a time when the patient is feeling physically and emotionally able to cope with the news, nothing--the patient must do all the adjusting by herself.

WHAT INFORMATION FROM YOUR OWN EXPERIENCE WOULD YOU LIKE TO SHARE WITH OTHER PATIENTS?

Again, there was an assortment of responses. Since religion plays a major role in east Tennessee, it was not surprising that the most common suggestion was to have faith in the Lord. The patients were also eager to encourage other women to seek early diagnosis and to heed the warning signs of cancer. Other responses included: surround yourself with humor, avail yourself of family support, retain social contacts, have faith in the doctor, keep busy as long as possible, keep to yourself when feeling poorly, have faith in yourself and your ability to cope, and learn to accept help graciously.

At the conclusion of the needs assessment interview, all patients were handed a sheet of paper listing 23 patient education topics plus one "other" category for miscellaneous patient requests. The patients were requested to check off ALL topics in which they had an interest. Finally, they

were asked to go back and circle those patient education topics which they felt were most important. The responses are presented in Table VI. A specific request was made for information about common emotional reactions to cancer. The patient wanted to know "how other patients feel."

General information summary. Two-thirds of the patients still utilized their family physician, primarily for other illnesses. One-half of the patients did not feel laetrile was an effective cancer drug; the other one-half of the patients could not decide as to its efficacy. Almost one-half of the patients preferred being treated by a specific team member, but patients rarely expressed this preference. Patients were quite well informed about the general side effects of drug therapy, but no patient mentioned special precautions for the particular drugs they were being given. A majority of patients felt that pain could be controlled although most affirmative answers were given with some hesitancy. Almost one-half of the patients gave an inappropriate answer or did not know what to expect when asked about the purpose of her drug therapy. Overwhelmingly, patients wanted information from the physician and from written materials. There was great interest in receiving as much information as possible in as many formats as possible. Encouragement, hope, and emotional support were critical factors for helping the patients adjust to their illness. There was also a strong demand to

TABLE VI

PATIENT EDUCATION NEEDS AND INTERESTS

Topic	% of Patients Stating Interest in Topic	% of Patients Stating Topic is Very Important
Origin of cancer	70	40
Diagnostic procedures	60	15
Kinds of surgical procedures	60	25
Radiotherapy explained	65	25
Chemotherapy explained	80	50
Immunotherapy explained	55	15
Future trends in treatment	65	20
Side effects of treatment	80	55
Pain control	65	20
Nutrition	60	25
Prostheses and dress hints	60	15
Breast self examination	60	30
Arm care	85	35
Dos and don'ts for daily living	55	10
Important signs and symptoms	85	40
Cancer myths	50	15
Exercises	65	15
Anxieties and stress	70	20
Sexuality	50	15
Depression	75	30
Dictionary of terms	45	5
Description of duties of health team members	40	10
Capabilities of UT Oncology Service vs. other cancer centers	50	30

"know all the options." Patients were eager to share their experiences and had a variety of suggestions for helping others to cope with the disease.

Finally, there was substantial interest in all patient education topics listed in the needs assessment questionnaire. However, the topics of greatest interest seemed to be: side effects of treatment, arm care, chemotherapy explained, important signs and symptoms, origin of cancer, and depression.

III. BOOKLET QUESTIONNAIRES

Fourteen out of twenty-two patients returned their questionnaires and booklets. This group of patients who did return the materials represented a broad spectrum of educational level and social class. Of the group of eight patients who did not return the materials, it was known that the condition of at least one patient had deteriorated very badly. The reactions to the arm care booklet were very similar to those expressed about the drug therapy booklet.

Hand and Arm Care

WHAT INFORMATION WAS NOT CLEARLY WRITTEN?

WHAT PART OF THE BOOKLET WAS NOT USEFUL?

In response to questions 1 and 2 all patients replied that all the material was clearly written and that all the material was useful.

WHAT PART OF THE BOOKLET WAS MOST USEFUL?

Regarding question 3 which asked the patient to identify the most useful part of the booklet: two patients selected blood work and blood pressure information, two patients chose protective measures when gardening, avoidance of insect stings, proper care of injuries, use of deodorants and shaving restrictions, and avoidance of sunburn. The remaining 10 patients could not identify any one part that was more useful. The typical comment was, "it is all useful."

WHAT ADDITIONAL INFORMATION WAS NEEDED?

Question 4 asked the patient what additional information was needed. Two patients desired information about post-surgical arm exercises. One patient suggested further information about the causes of arm swelling, and one patient made suggestions more appropriate for inclusion in other booklets.

WOULD YOU LIKE THE ART WORK CHANGED? HOW?

ARE ADDITIONAL DRAWINGS NEEDED? WHERE?

Questions 5 and 6 concerning the art work drew positive reactions from all patients except one. One mastectomee felt that the cover illustration of the arm depicted a plea for pity.

WHAT DID YOU LIKE BEST ABOUT THE BOOKLET?

Question 7 asked the patients to identify the best part of the booklet. Responses included: Five patients

commented on the clarity of the writing, seven patients commented on the usefulness of the information. Several patients took the occasion to again emphasize the need for comprehensive information at all stages of diagnosis and treatment.

WHAT DID YOU NOT LIKE ABOUT THE BOOKLET?

Question 8 probed the negative reactions to the booklet. All comments were complimentary except one patient questioned the brevity of the booklet and wondered if the topic should be incorporated with another subject. However, since 70% of the patients do not remember being taught these crucial precautions by their surgeons, it was deemed very important by the health care team that this information be supplied in a concise, easy-to-read format. Moreover, many patients themselves stated that short booklets were preferable and easiest to read.

WHAT ADDITIONAL SUGGESTIONS WOULD YOU LIKE TO MAKE?

Question 9 asked the patients for general suggestions. One patient took the opportunity to plead for distribution of the booklets as soon as possible after surgery. Two patients were interested in help with psychological issues.

Chemotherapy and Hormone Therapy

WHAT INFORMATION WAS NOT CLEARLY WRITTEN?

WHAT PART OF THE BOOKLET WAS NOT USEFUL?

In response to questions 1 and 2, again all patients replied that all the material was clearly written and useful.

WHAT PART OF THE BOOKLET WAS MOST USEFUL?

Question 3 asked the patients to select the most useful part of the text. Here, several patients gave more than one answer although the tables were the overwhelming choice with six patients opting for Table I (special precautions that accompany drug therapy), three patients selecting Table II (other medications which may conflict with drug therapy), and three patients selecting Table III (general side effects of drug therapy). Other responses were: two patients selected the portion on important signs and symptoms, one patient selected the information about bloodcounts, one patient selected the portion which cautioned against mixing other medications with chemo-therapy, and four patients stated that, "the whole booklet was useful."

WHAT ADDITIONAL INFORMATION WAS NEEDED?

Question 4 asked what additional information was needed. Two patients asked for the inclusion of the drug 5FU in Table I.

WOULD YOU LIKE THE ART WORK CHANGED? HOW ARE ADDITIONAL DRAWINGS NEEDED? WHERE?

Questions 5 and 6 asked about the artwork. Thirteen patients liked the art work and wanted no change; one patient felt that the expression on a drawing of a patient should portray hope. However, since the intent of that illustration was to depict puzzlement (to match the

accompanying text), the drawing was not altered.

WHAT DID YOU LIKE BEST ABOUT THE BOOKLET?

Question 7 asked what the patient liked best. Four patients stated that it was the clarity of writing, two patients selected the usefulness of the information, two patients specified the tables, one patient chose the section on important signs and symptoms, and five patients "liked it all." There was a comment about how the text's discussion of side effects of treatment would be "helpful and reassuring to patients starting treatment."

WHAT DID YOU NOT LIKE ABOUT THE BOOKLET?

Question 8 asked what the patients did not like. All patients were complimentary about the booklet except the one patient who reiterated her dislike of the expression on the drawing.

WHAT ADDITIONAL SUGGESTIONS WOULD YOU LIKE TO MAKE?

Question 9 gave the patients an opportunity to make general suggestions. Again, there were pleas for distribution of written materials to reinforce and complement one-to-one teaching by the physician. One patient asked for an explanation of immunotherapy and another patient requested an explanation of how the physician determined the impact of the treatment on the course of the illness. Other comments included: a need to stress the importance of exercise, the finding that only cotton clothing was comfortable next to the skin after surgery, an insistence on

the need for hospitalization during the first chemotherapy treatment, and a demand for basic information from the health care team.

In summary, the booklets appear to have been clearly written and the contents appropriate to the needs of this particular population. The few critical comments were made by one patient. The majority of patients could not select any one section of the arm care booklet which was most useful. However, in the drug therapy booklet, the patients selected the tables as being of greatest interest.

There were several suggestions as to the inclusion of additional information but the predominant theme was the plea for adequate patient education early in the course of the illness.

IV. BOOKLET MANUSCRIPTS

In general, comments and markings on the rough drafts of the booklets approximated the responses given on the accompanying questionnaires. All patients identified with the yellow marker those sections of the text which presented new information or clarified ideas about which they had previously been confused. As expected, these sections primarily were the same topics selected by the patients on the questionnaires as being of the most use.

With the exception of a portion of the art work, no part of the texts was identified as being unclear or

undesirable. However, one can never rule out the possibility that this lack of criticism may be due to the extreme reticence of the patients to give any negative feedback. The patients were willing to provide positive feedback and most booklets contained numerous comments on the text and the sharing of personal experiences. These comments aided revision and resulted in several new sections being added to the booklets. The booklet on arm care was amended to include information on exercise, instructions for double mastectomees, clothing alteration hints, an explanation on the mechanism for drainage of excess arm fluid, and an illustration showing where the lymph nodes and channels were located.

Additions to the drug therapy booklet included: explanations of immunotherapy and protocol, inclusion of the drug 5FU into Table I, an expansion of the discussion about the length and outcome of drug therapy (including a section on how the physician monitors the patient's status), and a long section discussing the physical and emotional aspects of follow up at the conclusion of drug therapy.

Hand and Arm Care

According to the patients' markings in the arm care booklet, the following information was new or clarified:

Use an insect repellant--46%

Manicuring procedures--23%

Reasons for specific precautions--23%

Length of time for observing precautions--23%

Carry purse on unaffected side--23%

Check dishwater and bath water temperature--23%

Loss of sensation in affectes arm--23%

Avoid injections, vaccinations, bloodwork, etc.--15%

Avoid taking blood pressure in affected arm--15%

Wear loose sleeves, jewelry, etc.--15%

Suntan slowly--15%

Check on use of deodorants--15%

Prompt care of cuts--8%

Raise arm to alleviate swelling--8%

Use precaution when gardening--8%

The written notations of the patients fell into three categories: points needing clarification, personal experiences, suggestions for new topics. Under the category of points needing clarification, the patients were looking for an expansion of the discussion of a particular topic. What was already written was clearly understood but they wanted more information about the subject.

Points needing clarification.

* There were two questions about the length of time precautions had to be observed.
* There was a request for the reasoning behind the stricture to raise the arm above shoulder level when swelling occurs. (This is so the excess fluid can be drained away by the lymph nodes located

behind the chest wall.)

* What is a lymph channel?

Suggestions for new topics.

* Inclusion of a section on arm exercises since exercises are very important for regaining strength and mobility.
* Wear watch on the unaffected arm.

Personal experiences.

* There was a comment that the patient did not know most of these precautions until a few months preceding this study. That is, the oncology nurse and not the surgeon supplied the information.
* Two patients concurred with the need to protect oneself from insect stings. One patient recounted her problems because of a severe reaction to an insect sting.
* Patient's reiteration of the need to suntan slowly and a comment about the patient's personal experience apropos this point.
* One patient discussed the preference of older women for long sleeved clothes. She shared several suggestions on altering clothes and shopping hints.
* There was a suggestion on how a patient can ease arm swelling on long automobile trips.

Finally, there were several expressions of pleasure with the booklet.

Chemotherapy and Hormone Therapy

According to the patients' comments in the drug therapy booklet, the following information was new or clarified:

Table I (special precautions with drug therapy)--57%

Drink several glasses of liquid daily--50%

Eat lightly before treatment--42%

Important signs and symptoms--42%

Use of other medications--42%

Detailed explanation of side effects--42%

Restrictions if low bloodcount--29%

Explanation of what hormone therapy is--21%

Explanation of how hormone therapy works--21%

Explanation of how chemotherapy works--21%

Explanation of what chemotherapy is--21%

Emotional impact of cancer--14%

Restrictions in use of alcohol--14%

How chemotherapy is given--7%

Current forms of treatment--7%

The written notations of the patients, again, fell into the same three categories as with the arm care booklet: points needing clarification, personal experiences, suggestions for new topics.

Points needing clarification.

* There were two requests as to the reasoning behind the suggestion to eat lightly on the day of treatment.

* A request for an explanation about how the physician determines the efficacy of treatment.
* There was a plea for a "better understanding between doctor and patient" about the length of treatment.
* A question about the use of tea and coffee.
* A request for an explanation of immunotherapy.
* A question about the mixing of pain pills and alcohol.
* A request for an explanation of the drug Leukovorin.
* Several comments about the absence of the drug 5FU from Table I. Patients assumed (incorrectly) that 5FU was excluded because its use was rare. In fact, it was excluded because there were no special precautions with its use.

Suggestions for new topics.

* An observation about the loss of bladder control and the suggestion that "light days" sanitary protection be utilized to take care of involuntary expulsion of urine during coughing, sneezing, laughing, etc.
* An observation about the feelings of security one has during treatment and the fears one has when treatment is finished. There was a question about how frequently follow up visits were scheduled.

Personal experience.

* A remark that the patient had never been told about the dangers of mixing medications.

* An observation that reimbursement for a wig was not possible through Medicare or Blue Cross.
* The utilization of the booklet by one patient to express her profound psychological distress and plead for help.
* An observation that hormonal treatment can cause vaginal bleeding in women with no ovaries.
* A comment that patients should never be afraid to ask questions of the health care team. It was suggested that patients make a list of points that the patient wants discussed and also that patients should request written materials.
* An observation that chemotherapy often causes an aversion to sweets.
* A suggestion that it might be useful to drink most of the additional fluid early in the day to avoid bathroom trips during the night.
* An expression of relief at finding out certain symptoms were temporary and due to treatment and not due to other infirmities or old age.

Finally, there was an expression of pleasure with the whole booklet and the observation that the text matched the patient's personal experience.

CHAPTER V

SUMMARY, FINDINGS, AND RECOMMENDATIONS

I. SUMMARY

This chapter presents a summary of the study's methodology and the findings of the study. The chapter is divided into three sections: 1) study purpose, study methodology, collection of data, and methods used to analyze the data, 2) findings, 3) recommendations.

Purpose of the Study

The purpose of this study was to demonstrate the use of patient participation during the development of breast cancer patient education materials. The resulting booklets were geared to a specific population--i.e., post-surgical breast cancer patient receiving drug therapy from the Hematology-Oncology Consultation Service, The University of Tennessee Center for the Health Sciences/Knoxville. There were two questions posed and answered by the study:

1. What are the educational needs and interests of the breast cancer patients receiving drug therapy from the Hematology-Oncology Consultation Service?
2. Will patients from varying educational and economic groups participate meaningfully in the process of developing the patient education materials?

The study was funded in part by an institutional grant from the American Cancer Society.

Methodology of the Study

The procedures used in this study were adapted from a model developed by the Mayo Clinic. Patients were kept involved throughout the developmental process, from the initial needs assessment to the final printing and distribution. A pool of patients meeting certain criteria were identified (breast cancer patients who were being seen at least monthly to receive drug therapy from the Oncology Service). Very ill patients were eliminated from the pool and the remaining patients were given a letter explaining the study's purpose and methodology by a member of the Oncology Service. All patients then met with the investigator who described the study in greater detail and answered questions from the patients. The 22 patients who agreed to join the study signed letters of consent.

Based on input from the Oncology staff and the literature, a 75-item semi-structured needs assessment questionnaire was constructed. The questionnaire was validated by two methods. It was submitted to a jury of nine local health and social science professionals. The questionnaire was revised in light of their recommendations and pilot tested on five breast cancer patients who had recently completed a course of chemotherapy. In light of this pilot test experience, the questionnaire was revised again. The first 15 patients recruited to the study were then interviewed using the last version of the needs assessment questionnaire.

The results of the needs assessment plus staff input guided the development of the first two booklets in a projected series of six pamphlets. The two booklets tested in this study focused on the patients' most immediate educational needs and interests: Hand and Arm Care and Chemotherapy and Hormone Therapy. After the booklets were checked for accuracy by the oncology staff, the patients were given packets to take home containing the following materials: drafts of the two booklets, a questionnaire about each booklet, yellow and blue pens, a letter describing what to do with the booklets and questionnaires, a self-addressed stamped envelope. The patients were encouraged to use the blue pen to make any comments or revisions they felt were appropriate. They were also asked to indicate those portions of the text they liked and disliked, what information was useful and not useful, and what information was confusing or unclear. They were instructed to use the yellow pen to indicate those protions of the text which contained new information.

Based on the patients' responses, the booklets were revised, rechecked for accuracy by the oncology staff, and then printed and made available to all breast cancer patients served by the Oncology Service.

Study Population

Three types of data were collected: descriptive data about the patients, information from the needs assessment

survey, comments and notations on the booklet drafts and accompanying questionnaires. The 22 study patients were white, ranged in age from 35-70 years, slightly over one-half were married (most of the remaining patients were widowed), and 10 of the 22 patients came from a rural area. Only four patients had more than a high school education and only five patients (or spouses) had professional training. On the other hand, seven patients (or spouses) were engaged in unskilled jobs and five patients (or spouses) in semi-skilled jobs.

One patient had undergone her mastectomy only one month before entering the study; at the other end of the spectrum, one patient had had the mastectomy performed eight years previously. Two-thirds of the patients had received radiotherapy. Four patients were receiving chemotherapy as a preventive measure; the remaining patients were receiving drug therapy for metastatic disease. Time since the inception of drug therapy varied from one month to 30 months.

Data Analyses Methodology

The data from the needs assessment questionnaire, booklet drafts, and accompanying questionnaires were simply tabulated as a percent of patients giving a particular answer. Responses to some questions from the needs assessment survey were analyzed additionally to determine along which dimension(s) (behavioral, cognitive, affective) the patients were requiring assistance. All responses were

utilized in some way in determining content of the projected series of six booklets. However, those topics which evoked the greatest interest and about which the patients seemed most confused formed the basis of the two booklets included in this study.

All patient comments and suggestions on the booklet drafts and accompanying questionnaires which were in keeping with the goals and objectives for that particular booklet were adopted. The patients' responses resulted in either an elaboration of a particular point, the addition of a new section in a booklet, or a whole new booklet.

II. FINDINGS

Based on the results of the needs assessment survey and oncology staff input, the educational needs and interests of the breast cancer patients who were being treated by the Hematology-Oncology Consultation Service can be deduced from the following findings:

1. Almost three-fourths of the patients did not remember receiving arm care instructions from their surgeon.
2. However, three-fourths of the patients did do arm exercises after surgery.
3. Almost three-fourths of the patients were visited by a Research to Recovery volunteer. All patients who were visited stated that the volunteer supplied emotional support and an interim bra and

prosthesis.

4. The majority of women did not utilize the Reach to Recovery volunteer to learn about selection and source of bras and prostheses. Nor did any patient request a volunteer to accompany her shopping; a practice recommended by many experienced breast and cancer patients.
5. Almost one-half of the patients had not found a satisfactory bra and prosthesis and one-third of the women encountered shopping difficulties. The biggest difficulty was improper fit. Each woman had different criteria for selecting bras and breast forms and was willing to share her experience with other patients. Most patients found out about bras and breast forms by trial and error.
6. A majority of women did not try to get reimbursed from their medical insurance for the bras and prostheses. Just one woman tried to get reimbursed for a wig needed to cover hair loss due to chemotherapy.
7. There were many dress hints and shopping hints the women were willing to share with each other if given the opportunity.
8. Nonscientific literature (newspapers, women's magazines, books, etc.) was the major source of

information about cancer. The physician was the next most common source although many patients complained that the physician did not supply enough information nor was he always understandable.

9. One-half of the patients erroneously thought that surgery could spread the cancer. Three-fourths of the patients felt that there was a family disposition to cancer.
10. Most patients did not know the causative agent(s) for cancer nor did they think the "experts" knew the cause.
11. Three-fourths of the patients thought that breast cancer could be painful but most patients were not quite sure if the doctor could control the pain.
12. Almost all the patients knew about breast self examination and practiced it regularly.
13. Most patients did not remember receiving nutritional counseling although drug treatment can cause serious disturbances in taste and appetite. Moreover, good nutritional practices are critical for helping the patient to tolerate the treatment and to combat the ravages of the disease.
14. Almost one-half of the patients had sleep disturbances due to treatment and/or the disease.
15. Two-thirds of the patients had undergone a

stressful event (other than their own disease) in the past year.

16. All but one patient discovered the lump in her breast herself yet less than one-half of the patients were checked immediately by a physician.
17. The disease was causing severe emotional stress for the majority of patients. Yet almost all patients were totally unaware of community mental health resources and, moreover, almost all patients felt that they must deal with the stress by themselves.
18. Two-thirds of the patients stated that the illness had not changed their relationships with friends or family. The remaining one-third of the patients stated that they had grown closer to family and friends. No patient admitted that a strain had been placed on relationships.
19. Almost one-half of the patients stated that the illness was causing severe financial stress.
20. Almost one-half of the patients had stated that her home and social activities had decreased due to fatigue and pain.
21. Two-thirds of the patients did not exercise regularly despite the fact that exercise can be therapeutic emotionally and physically.
22. Loss of a breast caused feelings of impaired body

image, loss of femininity, loss of self worth, and depression. A few patients felt that the loss of their hair was more devastating. Several patients still had not worked through their grief process over the loss of their breast and were denying the loss.

23. A majority of patients stated that their husbands treated them more tenderly since the operation.

24 One-third of the patients admitted that their sexual activity had decreased since the onset of the illness.

25. Two-thirds of the patients stated that the loss of a breast did not make a woman less feminine yet a majority of patients expressed negative feelings about an altered body image. Older women tended to feel that it was inappropriate to worry about an altered sexual image. Several patients remarked that "the operation would be more devastating to a younger woman."

26. One-third of the patients did not have a family physician for check ups, other illnesses, etc.

27. One-half of the patients did not think that laetrile was a "good" cancer drug; the other one-half were unsure of its efficacy.

28. Almost one-half of the patients had a favorite health team member yet almost no patient expressed

a preference for a particular member to help her. Only one-third of the patients would request a change in personnel if they particularly disliked the person treating her.

29. All patients were aware of the common side effects of drug treatment yet no patient mentioned a precaution for the specific drug(s) they were being given. For example, no patient was aware that kidney damage could occur with the drugs cytoxan and methotrexate if copious amounts of liquid were not ingested for two days following each treatment.

30. Almost all patients were unclear as to what the drug therapy could accomplish for them.

31. All but one patient wanted as much information as possible in as many formats as possible. Three-fourths of the patients specifically desired one-to-one teaching by the physician and a variety of written materials. Little booklets were preferred since they were "easier to read and less over-whelming." Almost one-half of the patients desired group discussions to exchange ideas and give peer support. Some patients complained that the physician was not always understandable in his explanations. One patient insisted that there should be a patient educator to organize an

educational system since "the doctor didn't always have the time to teach."

32. All patients were eager to share their experiences with other patients and a majority of patients felt that the exchange of information would be beneficial. The patients used a variety of mechanisms to cope with the stresses of the illness. These mechanisms included panic, denial, hyperactivity, withdrawal, depression, faith in the Lord, faith in the doctor, humor, anger, and resumption of normal activities. Some patients were able to draw much support from family and friends. Patients rarely came to the clinic alone.
33. A majority of patients felt that 22 out of a preferred list of 23 patient education topics were of great interest. The topics designated as being of the most interest included an explanation of chemotherapy, side effects of treatment, arm care, important signs and symptoms, and depression. All but the last topic were included in the two booklets developed for this study. Depression will be dealt with in one of the projected four other booklets.

Patient Participation

The second question posed by this study concerned whether in fact patients of varying educational and social

backgrounds would participate meaningfully in the developmental process. Results indicated that the poorer educated patients participated in the same way and to the same extent as did better educated patients. This was evidenced by the consistency in the quality and quantity of patient responses to the needs assessment interview. All 15 patients interviewed adequately answered all 75 questions and, moreover, all patients were very willing to share personal feelings, concerns, and experiences with the investigator. It was also evidenced by the fact that the 14 patients who returned the booklet drafts and accompanying questionnaires represented a broad range of educational and economic levels. Three patients came from an unskilled job background, three patients from a semi-skilled background, three patients from a skilled job background, and five patients from a professional job background. The respondents included the two patients considered by the investigator to be the most literate and the least literate in the group. All respondents correctly followed directions by: answering the questionnaires, identifying with the yellow pen those portions of the text which presented new information, making numerous comments in the booklets. The conclusion, therefore, was that this patient participation process was appropriate for use with populations that include poorly educated and low income persons.

III. RECOMMENDATIONS

On the basis of the findings of this study and an extensive review of the literature, the following recommendations are made:

1. All patients should be educated. (Information which is too threatening is screened out by the patient until or unless she/he is ready to cope.) Patient education should include information about diagnosis and treatment, rehabilitation, self-care instructions, and effective use of the health-care system. Being informed is seen by the patient as an essential factor in keeping control over his/her life.
2. There should be a planned, comprehensive coordinated patient education system with clearly defined roles and responsibilities delegated to the members of the health care team.
3. A comprehensive patient education system is dependent upon continuity of care as well as continuity of the educational system. All community health-related agencies and institutions should be involved in a planned system.
4. Patient education programs should be presented in a variety of formats to appeal to differing patient needs and interests. Also, multiple exposures reinforce teaching.

5. Patient education should be individualized to meet the needs and interests of the individual patient.
6. Group sessions should be incorporated into the patient education system. Many patients can utilize the group process to realize the universality of feelings engendered by illness and disability. Group sessions also present a less threatening opportunity to gain medical information from the health team members.
7. Much more attention should be paid to the psychosocial impact of the disease on the patient and family. Psychologically-oriented patient education materials as well as intervention by mental health professionals should be available early in the disease process to help the patients learn to cope with the various stresses of illness. Patients turn to charlatans and quackery when health care workers are insensitive to patients' needs for encouragement and support.
8. More studies need to be undertaken to better elucidate the psychological disturbances caused by illness and disability.
9. More and better intervention strategies should be derived to assist the patient to achieve optimal emotional as well as physical functioning. Very few hospitals employ adequate numbers of mental

health professionals.

10. This study should be replicated using a larger population to determine if, in fact, patients from differing backgrounds and educational levels have significantly different patient education needs and interests.
11. To ascertain the most efficient method for producing patient education materials, this patient participatory method should be compared with other methods for developing patient education materials.
12. Research should be undertaken to determine the method most suitable for developing the most effective patient education materials.
13. More research is needed for finding ways of persuading people to adopt better health habits. For example, this study showed that almost one-half of the women delayed going to the physician after they discovered the lump in their breast.
14. Patient education should receive greater attention and more support in the health care system. Few hospitals allocate enough resources or place enough emphasis to develop an adequate patient education system. Yet Green and others (17, 16, 14, 11) have shown that patient education is cost effective and can decrease health care costs.

CHAPTER VI

EPILOGUE

I. THE SETTING--APPALACHIA

The Knoxville-Oak Ridge complex contains one of the highest concentrations of sophisticated scientific talent in the United States. Yet the two cities are surrounded by the region called Appalachia--an area of striking contrasts. Appalachia has been alternately discovered, exploited, and forgotten since it was first settled in the eighteenth century. The geographical configuration has made communication and transportation difficult and has tended to keep much of the region isolated. The inhabitants of the area are a proud people with close family ties and fundamentalist religious beliefs. The outlook of many citizens is traditional rather than progressive, and fatalistic rather than self-controlling. In the rural areas the general level of education, while markedly improving over recent years, is still low and unemployment levels are high.

The beauty of the mountains is world renown. Yet the ubiquitous ugly scars of strip mining have served as a focal point of conflict between the forces concentrating on economic development and those forces desiring the preservation of the area's integrity. Adding to the bitter struggle is the fact that the economic benefits from the recovered coal have seldom been shared with the local inhabitants.

However, a new sense of social awareness has arisen in Appalachia and civic groups such as S.O.C.U.M. (Save Our Cumberland Mountains) have been formed to apply political pressure.

This, then, was the setting for this study. The patients utilizing the Hematology-Oncology Consultation Service were about evenly divided as to residence. About 50% resided in the Knoxville-Oak Ridge-Alcoa area; the remainder in Appalachia--in sections of east Tennessee or the neighboring states of Kentucky, Virginia, and North Carolina. Therefore, the values which many of the patients brought to the study had their roots in the ancient customs and beliefs of the region.

II. PATIENT CONCERNS

Within the past two years, some of the Oncology Service patients have been the object of two psychologically-oriented studies: Lefebvre's 1977 study The Cancer Patients and their Spouses: A Study by Self Report (56), and Harrison's 1978 study An Exploratory Study of the Relationships Between Psychological Variables and Chemotherapy Side Effects From Cancer Treatment (66). These two studies produced some very interesting insights which, in the long range, should be of great value to health care workers struggling to provide better service to oncology patients. However, the studies contributed very little of immediate

value to the participants in the study. Therefore, there were very strong feelings by this investigator that any new study include an immediate "payoff" to the population participating in the study. These feelings were strengthened by the remarks of several patients who stated that they were "tired and angry at being used as guinea pigs" and they wanted someone to pay attention to their needs. Thus, although an extensive assessment of the patients' needs and interests would have been an interesting study unto itself, it was deemed necessary to go one step further and develop the patient education booklets based on the results of the needs assessment. There also was great interest in ascertaining whether patients of widely varying educational levels would participate meaningfully in the booklet developmental process.

The Mayo Clinic patient education developmental process which utilized extensive patient participation, provided an interesting model to emulate. In essence, the Mayo model was based on the premise that the patients knew better than anyone else what their educational needs and interests were and it recognized the patient as the educational "expert." Following the Mayo methodology, this study not only relied upon the patients for determining the content of the patient education booklets, but it also used the patients to critique the booklets once they were written. Medical accuracy was assured by submitting the

booklets to the oncology staff for their review and comment. Patient relevancy was assured by submitting the booklets to the patients for their review and comment.

III. NEEDS ASSESSMENT INSTRUMENT

The construction of the needs assessment instrument presented the classical dilemma: optimum length versus comprehensiveness. Since the study population was small, only one instrument could be easily utilized. Yet it was impossible to incorporate into one instrument an adequate in-depth probe into many areas of the patients' concerns and needs. As a compromise, it was decided to touch upon several areas briefly and utilize knowledge gained from informal discussions with the patients and staff to help fill in informational gaps. This proved to be a satisfactory solution since the investigator found that the patients were always eager to talk about their concerns whenever they came into contact with a "good listener."

IV. THE REMAINING BOOKLETS

Six primary areas of patient education needs and concerns were identified by the patients and oncology staff. This study concentrated on developing the booklets focused on the two most pressing informational deficits. However, it was anticipated that the remaining four topics would be developed into separate booklets in the very near future

making a total of six booklets in the series. An overview of the projected contents of the four remaining booklets follows. The two completed booklets are found in Appendix H.

Good Food Is Good Medicine

Cancer puts extraordinary demands upon a person's nutritional status. The illness itself causes the body to burn up calories faster than normal. Treatment, whether it be surgery, radiotherapy or drug therapy, places an additional burden upon the body in order to repair damaged tissues and organs. Thus, it is imperative that at the very least cancer patients undergoing drug therapy adopt a properly balanced diet. However, for some patients, a normal, well-balanced diet is not sufficient and nutritional supplements and/or new eating patterns must be utilized.

It may be remembered that possible side effects of treatment produce a variety of gastrointestinal disturbances such as nausea, vomiting, loss of appetite, taste changes, diarrhea, constipation, and mouth ulcers. These unpleasant symptoms complicate the patient's task to maintain a good nutritional status. However, there are a number of simple methods available for combating these obstacles. Some helpful hints include:

1. Eating small amounts frequently.
2. Choosing soft foods rich in calories and protein.
3. Setting an attractive table.
4. Eating with pleasant company.

5. Avoiding stress at mealtime.
6. Engaging in mild exercise one half hour before eating.
7. Reinforcing the nutritional content of foods by using extra butter, cream, cheese, and powdered milk.
8. Choosing bland, easily digested foods.
9. Substituting eggs, cheese, beans, and fish for meats (which often taste rotten to patients on drug therapy).
10. Preparing foods that look and smell appetizing.
11. Using commercial nutritional supplements.

Some substance such as alcohol, salt, and other medications may be contraindicated and patients should be urged to check with their physicians concerning their use. Likewise, use of megavitamin supplements should first be cleared by the physician.

Looking Good

The American Cancer Society Reach to Recovery program is an excellent service which provides new mastectomees with invaluable information. However, since the surgeon must specifically order a Reach to Recovery visit, many patients never receive this service. Moreover, the vast majority of breast cancer patients who are seen by the Reach to Recovery volunteer only have one contact with the program. The result is, as the patient recovers, she finds

she still has many unanswered questions, especially those dealing with breast forms and clothing.

Prostheses and bras come in all sizes, shapes, materials, and price ranges. Unfortunately, few stores in general carry an extensive selection. Therefore, the patient is forced to shop around in many places in order to find the breast form and bra best suited to her needs and pocketbook. The Reach to Recovery program strongly urges that every mastectomee have an experienced breast cancer patient accompany her when shopping to help ensure proper fit. Yet most patients are unaware that Reach to Recovery volunteers are eager to perform this function. Nor are most patients aware that the volunteers annually compile a new list of bras and prostheses available in the Knoxville area. The list includes a good description of the breast forms and bras, prices and sources.

Many patients are also not aware that prostheses and special bras are recoverable medical expense under many insurance policies. Those special clothing expenses not reimbursed by insurance companies are then legitimate deductions from the federal income tax. In 1979 most insurance companies would not reimburse patients for wigs needed due to hair loss from drug therapy. However, there was some indication that in the near future, the cost of wigs needed because of treatment would be a recoverable expense. In any event, wig costs, again, are a legitimate

federal income tax deduction.

An attractive appearance goes a long way towards restoring the self confidence of a breast cancer patient. Fortunately, there are many aids now available to help the mastectomee dress flatteringly.

Pain Control

Most people equate cancer with severe pain, especially during the terminal stages. In reality, a minority of patients experience more than mild discomfort and frequently pain, if it is present, is due to other causes such as arthritis, etc. The main points that cancer patients should realize about pain are:

1. There are many medications available to help ease the discomfort.
2. The medications are usually in pill or liquid form; medications seldom need to be injected.
3. Pain medication should be taken at the first sign of pain. The patient should NEVER wait until the pain is severe before starting medication.
4. The best pain control with the smallest total amount of medication is usually achieved if the patient takes the medication at the first sign pain and then as often as needed thereafter.
5. Patients rarely become addicted to pain medication.
6. Anxiety usually intensifies pain.
7. There are many mechanical and psychological

techniques the patient can employ to help control pain. Mechanical measures include heat, massage, and mechanical stimulation. Psychological techniques include distraction, hypnosis, relaxation, music, and waking imagined analgesia.

8. A combination of medicinal and psychological/mechanical methods is probably the most effective means for achieving pain control for many patients.
9. Cancer patients need good emotional support and should seek professional counseling, if needed, to help them cope with the many stresses of the disease.

Feelings

The findings of many oncology workers as to the psychological impact of the disease have been reaffirmed in this study. Cancer assaults the patient's emotional, social and economic as well as physical stability. The problem is that too few patients reach out to seek the assistance that would make resolution of these issues infinitely more easy and less traumatic.

There are several key concepts which patients should realize. First, there is a universality to most of the emotions experienced by the cancer patient. All patients experience a range of psychological reactions to the disease. Second, there usually is a temporal quality to the psychological reactions. For most patients the periods of anger,

depression, fear, guilt, grief, etc. will be time limited. Third, there is a grief process that accompanies the loss of a body part just as with the death of a whole person and that grief process must be worked through. Many patients who have lost a breast share feelings of being ugly and deformed, of loss of femininity, of no longer being a whole person. These feelings are not restricted just to the younger woman. Fourth, reaching out to seek professional help is not a sign of weakness but rather a sign of strength. It indicates that the patient is able to utilize appropriate resources effectively to help work towards optimal mental as well as physical health. Moreover, patients who improve their emotional status often improve their physical status.

This study indicated that almost all patients were totally unfamiliar with the professional mental health resources available in the community. In Knoxville these resources include: the social worker and psychology intern who were part of the Oncology Service; mental health and social service agencies such as Child and Family Services, Catholic Social Services, Overlook Mental Health Center, Helen Ross McNabb Center, Family Crisis Center; mental health professionals in private practice such as social workers, psychiatrists and psychologists and skilled pastoral counselors.

One of the most difficult aspects of cancer is the

many unknowns the patient must face. There is the question of the extent of spread of the disease. How well will the patient respond to treatment? What will the treatment entail and how long will it be administered? What will be the side effects of treatment and the disease? Will the cancer recur? Will the patient die? How soon will the patient die? How will she die? Will there be pain and loss of control? Will there be disability? How well will the family be able to cope? How will the family and friends respond to the illness? Some of these issues could be resolved relatively easily. Other questions such as the possible recurrence of the disease may never be answered. People can deal with uncertainties much more effectively if they know that within a certain time span the questions will be clarified. How the patient copes with the albatross of possible recurrence is an important task that the patient must master in working towards emotional stability.

The alteration of self worth and self image profoundly affects the person's view of herself as a desirable sexual partner. If the breast cancer patient is married or has established a close relationship with another person, both partners should realize that time may be needed to adjust to the new body image. However, a warmly supportive sensitive mate who demonstrates that the patient is still a valued sexual partner will be an excellent morale booster.

All people are sexual beings and there are many ways

of expressing sexuality. Sexuality is often disturbed by profoundly stressful situations such as cancer. The patient may have diminished energy and pain. She may be preoccupied with fear, anxiety, worry over family functioning and finances. All of these factors can adversely influence sexual relationships. Additionally, feelings about sexuality tend to be very intense and personal, closely tied to religious and moral beliefs. The subject is not one that most people can discuss easily. Moreover, many physicians and nurses feel uncomfortable with the topic although there is a growing realization that attention to the patient's sexual concerns is an important aspect of total health care.

All patients including older patients should be encouraged to work towards obtaining a satisfying expression of their sexuality. Good communication with the partner will be helpful for exploring options for mutual pleasure and skilled counseling should be sought whenever needed.

V. CONCLUSION

The majority of patients in this study had metastatic disease. That means that for most of the patients, the prognosis was not very favorable. The emotional status of the patients seemed to vary from very good to very poor. At least two patients were literally paralyzed with fear; other patients (who by medical odds should have died long ago)

were aggressively fighting and succeeding in living a seemingly near normal existence. However, all patients had a great need for emotional support from the health care team and from their family and/or friends.

Patient education as well as skilled mental health counseling can make an important contribution to the cancer patients emotional status. When patient education needs and interests are appropriately met, more than just information is exchanged. A "good" patient education program aims at keeping the patient actively involved in his/her own health care. It implies that the patient is an important member of the health care team, that she/he has options and that she/he has the right to make choices. It permits the patient to retain some control over his/her life. The time is long overdue for the routine inclusion of comprehensive coordinated individualized patient education into the health care system.

LIST OF REFERENCES

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1. American Medical Association. "Statement on Patient Education." Adopted by the A.M.A. House of Delegates, June 1975.

2. American Hospital Association. "Statement on the Role and Responsibilities of Hospitals and Other Health-Care Institutions in Personal and Community Health Education." (S83) Chicago, Illinois: American Hospital Association, May 1974.

3. Savlov, Edwin. "Breast Cancer." In Clinical Oncology. Rochester, N.Y.: American Cancer Society, 1978.

4. Ulrich, Marian and Kenneth Kelley. "Patient Care Includes Teaching." Hospitals 46(8):59-65, April 16, 1972.

5. Young, Marjorie. "Patient Education." Health Education Monograph 26, 1968.

6. Patient Education Workshop: Summary Report. Proceedings of a Workshop sponsored by the U.S. Department of H.E.W., Bureau of Health Education, Atlanta, January 26-27, 1976.

7. Harper, Lilah, "Developing and Evaluating a Patient Education Program." Patient Education. New York: National League for Nursing, 1976.

8. Miller, Marian. "Patient Education--A Growing Concern of Many." Patient Education. New York: National League for Nursing, 1976.

9. Reiser, Mary. "Patient/Family Education: Its Value and Some Issues to Consider on How It Is To Be Accomplished." Patient Education. New York: National League for Nursing, 1976.

10. Shaw, Jane. "New Hospital Commitment: Teaching Patients To Live With Illness and Injury." Modern Hospitals 121(4):99-104, October 1973.

11. Hulka, Barbara, John Cassell, Lawrence Kupper, and James Burdette. "Communication, Compliance and Concordance Between Physicians and Patients with Prescribed Medications." American Journal of Public Health 66(9):847-853, September 1976.

12. Komaroff, Anthony. "The Practice and The Compliant Patient." American Journal of Public Health 66(9): 833-835, September 1976.

13. Blackwell, Barry. "Drug Therapy-Patient Compliance." New England Journal of Medicine 289(5):249-252, August 2, 1973.

14. Gabriel, Martha, Jean Paul Gagnon, and Candance Bryan. "Improved Patient Compliance Through Use of a Daily Drug Reminder Chart." American Journal of Public Health 67(10):968-969, October 1977.

15. Francis, Vida, Barbara Korsch, and Marie Morris. "Gaps in Doctor-Patient Communication: Patient's Response to Medical Advice." New England Journal of Medicine 280 (10):535-540, March 6, 1969.

16. Hertz, Philip and Paula Stamps. "Appointment Keeping Behavior Reevaluated." American Journal of Public Health 67(11):1033-1036, November 1977.

17. Green, Lawrence. "The Potential of Health Education Includes Cost Effectiveness." Hospitals 50(9):57-61, May 1, 1976.

18. Benson, Harriet, Louis Gordon, Constance Mitchell, and Virgil Place. "Patient Education and Interuterine Contraception: A Study of Two Package Inserts." American Journal of Public Health 67(5):446-449, May 1977.

19. Korsch, Barbara, Ethel Gozzi, and Vida Francis. "Gaps in Doctor-Patient Communication: Doctor-Patient Interaction and Patient Satisfaction." Pediatrics 42 (5):855-871.

20. Schwartz, Marc. "An Information and Discussion Program For Women After Mastectomy." Archives of Surgery 112(3):276-281, March 1977.

21. Rollins, Betty, First You Cry. Philadelphia: Lippincott, 1976.

22. Lasser, Terese. Reach To Recovery. New York: Simon & Schuster, 1972.

23. Keeling, Wayne. "Live The Pain, Learn The Hope: A Beginner's Guide To Cancer Counselling." Personnel and Guidance Journal 54:502-506, June 1976.

24. Klagsbrun, Samuel. "Communications In The Treatment Of Cancer." American Journal of Nursing 71(5):944-948, May 1971.

25. Kirscht, John. "Communication Between Patients and Physicians." Annals of Internal Medicine 86(4):449-500, April 1977.

26. Schmale, Arthur. "Principles of Psychosocial Oncology." In Clinical Oncology. Rochester, N.Y.: American Cancer Society, 1978.

27. Easton, Richard, Melinda Easton, and Maurice Levy. "Medical and Educational Malpractice Issues in Patient Education." Journal of Family Practice 4(2): 273-279, February 1977.

28. American Law Review 23(2):411-416, 1957.

29. Simmons, Jeanette. "An Overview of Patient Education." Presented at Patient Education Workshop sponsored by the U.S. Department of H.E.W., Bureau of Health Education, Atlanta, January 26-27, 1976.

30. Kucha, Deloros. "The Health Education of Patients: Development Of A System." Supervisory Nurse 5(5): 8-21, May 1974.

31. A Model for Planning Patient Education. Report of the Committee on Educational Tasks In Chronic Illness, Public Health Section, American Public Health Association, 1977.

32. Mager, Robert. Preparing Instructional Objectives. Belmont, California: Fearon Publishers, 1962.

33. Morrisey, George. Management By Objectives and Results. Reading, Massachusetts: Addison-Wesley Publishing Co., 1970.

34. Deeds, Sigrid. "Overview of Evaluation." Presented at the Patient Education Workshop jointly sponsored by the U.S. Department of H.E.W., Bureau of Health Education and the American Hospital Association, Chicago, August 1976.

35. Brown, Andrew J. "Evaluation's Role in Patient Education." Health Education 8(1):6-8, January-February 1977.

36. Kucha, Deloros. "The Health Education of Patients: Assessing Their Needs." Supervisory Nurse 5(4):26-35, April 1974.

37. Fylling, Carelyn. "Patient Education In The Outpatient Department." Presented at the Patient Education Workshop jointly sponsored by the U.S. Department of H.E.W., Bureau of Health Education and the American Hospital Association, Chicago, August 1976.

38. Suchman, Edward. Evaluation Research. New York: Russell Sage Foundation, 1967.

39. Scriven, Michael and Jane Roth. Evaluation Thesaurus. Pt. Reyes, California: Edgepress, 1977.

40. Webster, William. The Evaluation of Instructional Materials. Washington, D.C.: Association for Educational Communication and Technology, October 1976.

41. Baker, Eva. "Formative Evaluation of Instruction." In Evaluation of Education. James Popham (ed.). Berkley: McCutcheon Publishing Corp., 1974.

42. Tyler, R., R. Gagne, and Michael Scriven. Perspectives of Curriculum Evaluation. AERA Monograph Series on Curriculum Evaluation No. 1. Chicago: Rand McNally, 1967.

43. Pretesting in Cancer Communications. U.S. Department of H.E.W., DHEW Publication No. (NIH) 78-1493.

44. Cox, Barbara and Arlene Wentworth. "An Evaluation Model for the Development of Patient Education Literature." Bioscience Communication 2:333-341, 1976.

45. May, Candance. "Using Evaluation In The Development of Patient and Professional Education Materials." Mimeographed copy of a speech given November 9, 1977, from the Mayo Clinic, Rochester, Minnesota.

46. Bryant, Nancy. "Practical Consideration in Evaluating Patient/Consumer Health Education Programs." Presented at the Patient Education Workshop jointly sponsored by the U.S. Department of H.E.W., Bureau of Health Education and the American Hospital Association, Chicago, August 1976.

47. Green, Lawrence. "Evaluation and Measurement: Some Dilemmas for Health Education." American Journal of Public Health 67(2):155-61, February 1977.

48. Green, Lawrence and Howard Kalmer. "Selecting an Evaluation Design for a Patient Education Program: Options for the Practitioner Without Research Funds." Proceedings from the Patient Education Workshop sponsored by the Maryland State Department of Health and Mental Hygiene, Health Education Center, Baltimore, 1976.

49. Pritchett, Sue. "Financing Patient and Family Education At The Hospital Level." Presented at the Patient Education Workshop jointly sponsored by the U.S. Department of H.E.W., Bureau of Health Education and the American Hospital Association, Chicago, August 1976.

50. Klein, Roberta. "A Crisis To Grow On." In Rehabilitation Of The Breast Cancer Patient. American Cancer Society, 1971.

51. Bard, Morton and Arthur Sutherland. "Adaptation To Radical Mastectomy." In The Psychological Impact of Cancer. American Cancer Society, 1974.

52. Barckley, Virginia. "What Can I Say To The Cancer Patient?" Nursing Outlook 6(6):316-318, June 1958.

53. Cancer Source Book for Nurses. American Cancer Society, 1975.

54. Creech, Richard. "The Psychologic Support of the Cancer Patient." Seminars in Oncology 2(4):285-292, December 1975.

55. Bahnson, Claude. "Psychologic and Emotional Issues in Cancer: The Psychotherapeutic Care of the Cancer Patient." Seminars in Oncology 2(4):293-309, December 1975.

56. LeFebvre, Kenneth. The Cancer Patients And Their Spouses: A Study By Self Report. Knoxville: University of Tennessee Thesis, 1977.

57. Mantell, Joanne and Cecily Green. "The Need for Management of the Psychosexual Aspects of Mastectomy." Presented at the American Public Health Association Meeting, Washington, D.C., October 30-November 3, 1977.

58. Mantell, Joanne and Cecily Green. "Enhancing Sexuality: A Humanistic Approach To The Mastectomee." Presented at the American Public Health Association Meeting, Washington, D.C., October 30-November 3, 1977.

59. Chemotherapy and You. Washington, D.C.: DHEW Publication No. 77-1136, 1977.

60. Watson, Goodwin. "Resistance to Change." In The Planning of Change. Bennis, Benne, and Chin (eds.). New York: Holt, Rinehart & Winston, Inc., 1969.

61. Barckley, Virginia. "Families Facing Cancer." Cancer News. American Cancer Society, Spring-Summer, 1970.

62. Brauer, Paul H. "Should The Patient Be Told The Truth?" Nursing Outlook 8, December 1960.

63. Breast Cancer Network Guidelines. The Fox Chase Cancer Center, Philadelphia, 1976.

64. Cox, Barbara. Living With Lung Cancer. The Mayo Clinic, Rochester, Minnesota., 1977.

65. Davies, Robert, Donald Quinlin, Patrick McKegney, and Chase Kimball. "Organic Factors and Psychological Adjustment in Advanced Cancer Patients." Psychosomatic Medicine 35(6):464-471, November-December 1973.

66. Harrison, Diana. An Exploratory Study Of The Relationships Between Psychological Variables and Chemotherapy Side Effects From Cancer Treatment. Knoxville: University of Tennessee Thesis, 1978.

67. Holden, Constance. "Cancer And The Mind: How Are They Connected?" Science 200(4348):1363-1369, June 23, 1978.

68. Rabkin, Mitchell. "The Needs of Patients." New England Journal of Medicine 288(19):1019-1020, May 10, 1973.

69. Robinson, Leola. "Patient's Information Base: A Key To Care." Canadian Nurse 70(12):34-37, December 1974.

70. Verwoedt, Adrian. "Communication With The Fatally Ill." Ca 15:105-111, 1965.

APPENDICES

APPENDIX A

PATIENT DEMOGRAPHIC DATA

TABLE VII

DEMOGRAPHIC DATA

Subject	Age	Marital Status	Urban or Rural	Educ	Months Since Surgery	Months Since 1st chemo	Stage	Type of Treatment	Radio-therapy	Occupation of Patient or Spouse
A	57	M	R	HS	54	26	III	chemo	yes	unskilled
B	72	M	R	C	98	24	III	chemo horm	yes	prof
C	47	M	U	C	30	31	III	chemo	no	prof
D	48	M	U	HS	26	16	III	chemo	no	semi-sk
E	48	M	R	HS	?	23	III	chemo	yes	prof
1	53	M	R	C	50	30	II	adj t	yes	prof
2	52	M	U	HS	8	8	III	chemo	no	semi-sk
3	71	M	U	HS	96	17	IV	chemo	yes	prof
4	55	M	U	C	15	9	II	adj t	no	prof
6	62	M	R	C	42	4	III	chemo	no	prof
8	69	M	R	HS	20	7	III	chemo horm	yes	skilled
9	48	W	U	HS	8	8	III	chemo	yes	semi-sk
10	35	M	R	HS	8	8	III	chemo	no	semi-sk
11	68	W	R	HS	3	2	III	chemo	no	skilled

TABLE VII (continued)

Subject	Age	Marital Status	Urban or Rural	Educ	Months Since Surgery	Months Since 1st chemo	Stage	Type of Treatment	Radio-therapy	Occupation of Patient or Spouse
12	61	W	R	HS*	--	8	IV	chemo horm immun	yes	unskilled
13	58	W	U	HS	6	6	II	adj t	no	unskilled
16	40	M	R	C	60	15	IV	chemo horm	yes	prof
17	61	M	R	HS*	61	13	IV	chemo horm	yes	unskilled
18	36	S	U	HS	1	1	II	adj t	no	semi-sk
19	56	W	U	HS*	52	19	III	chemo horm	yes	semi-sk
21	55	D	U	HS*	47	29	III	chemo horm	yes	unskilled
22	69	M	R	HS	29	30	III	chemo horm	yes	skilled
24	52	M	U	HS	60	14	III	chemo	yes	skilled
26	70	M	U	HS	9	9	IV	chemo	yes	unskilled
27	59	S	U	HS*	24	1	IV	chemo	no	unskilled

TABLE VII (continued)

Subject	Age	Marital Status	Urban or Rural	Educ	Months Since Surgery	Months Since 1st Chemo	Stage	Type of Treatment	Radio-therapy	Occupation of Patient or Spouse
28	54	M	U	HS	12	1	IV	chemo	yes	skilled
29	58	W	R	HS*	39	1	III	chemo	yes	unskilled

C = College

HS = High school or less

HS* = Poor reading skills

Subjects A through E used to pilot test Needs Assessment instrument.

Subjects 1 through 29 used for study.

APPENDIX B

PATIENT INTRODUCTORY LETTER

1924 ALCOA HIGHWAY
KNOXVILLE, TENNESSEE 37920

THE UNIVERSITY OF TENNESSEE
MEMORIAL RESEARCH CENTER

Hematology-Oncology Consultation Service
and
University of Tennessee/Knoxville
Division of Health and Safety

Dear Mrs.

For most people cancer is a very mysterious disease. That is why the Hematology-Oncology Service is always looking for better ways to provide patients with the information they need.

A series of short booklets is going to be written expressly for women who have had breast cancer. Since we are aware that patients know better than anyone else what information should be included in the booklets, we are asking your help with this educational project. First we will be asking you to help us in determining what topics should be included in the booklets. Secondly, we also will be needing you to give us advice about the booklets as they are written.

We would be very grateful if you could participate in this project. However, we would like to emphasize that you are under no obligation to do so. You will receive the same treatment regardless of your decision. You also have the right to withdraw from the project at any time and for any reason. Please talk this over with your family. I will be contacting you very shortly to see how you feel about joining the project. At that time I would be very happy to answer any questions you might have.

Thank you for your time and consideration.

Very sincerely yours,

Muriel Levin
Health Educator

APPENDIX C

PATIENT CONSENT FORM

I, _____,
(name of patient)

agree to participate in the Breast Cancer Patient Education Research Project. This will include being interviewed to identify content for the patient education materials, helping to edit the rough drafts of the patient education booklets, and answering a questionnaire for each booklet.

The nature and purpose of the research project, the risks involved, and possible side effects have been explained to me. I understand that the procedures are part of a patient education research project which will be published upon completion. I further understand that patient confidentiality will be respected and that all data will be presented in such a way that no one patient can be identified.

I have been informed that I may withdraw from the study at any time, and that my withdrawal will in no way jeopardize my care.

Date_____ Signature_____

Date_____ Witness_____

APPENDIX D

LETTER TO JURY AND LIST OF JURY MEMBERS

University of Tennessee
Division of Health and Safety
and
University of Tennessee Center
for the Health Sciences/Knoxville
Hematology-Oncology Consultation Service

October 10, 1978

Dear

Thank you for consenting to serve on the jury which will help validate a patient education needs assessment instrument. The questionnaire will be administered orally to patients in a private interview. When there are multiple choice questions, the patients will be allowed to respond at will first before the list of choices is read off as a reminder of other possible answers. The symbol DK = don't know, and the symbol NA = not applicable.

Results from the needs assessment questionnaire will guide the development of a series of breast cancer patient education booklets. The booklets are being written specifically for local post surgical breast cancer patients receiving chemotherapy.

You are asked to do three things:

1. Alter the wording of any question to suit your preference.

2. Indicate which questions you think should be deleted.

3. Add any questions you think should be included.

A self addressed stamped envelope is enclosed for your convenience. Your help is much appreciated.

Sincerely,

Muriel Levin

JURY FOR NEEDS ASSESSMENT INSTRUMENT

Jennifer Crossland, R.N.
Head Nurse, Oncology Unit
East Tennessee Baptist Hospital

Joyce Diftler, M.S.S.W.
Oncology Social Worker
Hematology-Oncology Consultation Service
University of Tennessee Center for the Health Sciences/
Knoxville

Lois Doane, M.S.N.
Head Nurse, Oncology Unit
University of Tennessee Memorial Hospital

James Lewis, M.D.
Associate Professor of Surgery
University of Tennessee Center for the Health Sciences/
Knoxville

Paula McMorran, M.S.N.
Head Psychiatric Nurse
St. Mary's Medical Center

Joyce Milner, M.S.S.W.
Head, Social Services
East Tennessee Baptist Hospital

Doris Moore, R.N.
Head Nurse, Oncology Unit
St. Mary's Medical Center

Margaret Pierce, M.S.N.
Assistant Professor of Nursing
University of Tennessee/Knoxville

Jemey Webster, M.S.N.
Former Chief Protocol Nurse
Hematology-Oncology Consultation Service
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APPENDIX E

NEEDS ASSESSMENT QUESTIONNAIRE

No._____

BREAST CANCER PATIENT EDUCATION NEEDS
ASSESSMENT QUESTIONNAIRE

An Oral Interview

Thank you for agreeing to help us with our breast cancer patient education project. This questionnaire is the first step and is very important for helping us to identify the needs and interests of breast cancer patients. The interview will take between 45 minutes to 1 hour, and I will be asking you questions on several topics. Our intent is to learn what patients have been told and what they want to know. You know only what information has been shared with you. Therefore, there are no "right" or "wrong" answers. We also want to know what aspects of your illness are more difficult in order to provide better information for all patients. Your individual answers will NOT be shared with anyone in the clinic or hospital. But, based on your responses and the responses of other patients in the project, a series of booklets will be written. We will want you to read the rough copies of the booklets and comment on them before they are printed to make sure we have presented the information in a way that is useful for you.

The first part of this questionnaire is about some general topics.

ARM CARE AND PROSTHESES

1. Did the doctor/nurse tell you about taking special precautions to protect your operated arm? Yes___No___
   If yes, what precautions?
   a. Blood pressure not taken in affected arm.
   b. No injections, lab work, vaccinations, etc. in affected arm.
   c. Protect from sunburn
   d. Protect from infections, pricks, burns.
   e. Special clothing
   f. Other (specify)

2. After your operation did you do any special exercises for your affected arm and shoulder? Yes___No___

3. If you did special exercises, how do you think they helped your arm and shoulder?
   a. Reduced swelling
   b. Helped mobility
   c. Reduced pain
   d. Other (specify)

4. Were you visited by a Reach to Recovery volunteer, that is, a woman who had had a mastectomy herself and came to talk with you and share with you some hints on dressing, protheses, exercises? Yes___No___

5. If yes, did her visit help you? Yes___No___
   If her visit helped, in what way did she help?
   a. Moral support
   b. Shopping information
   c. Prostheses and bras
   d. Exercises
   e. Other (specify)

6. If not visited by a Reach to Recovery volunteer, would you have liked to have been visited? Yes___No___

7. After a mastectomy, do you think that for some women the affected arm will sometimes swell? Yes___No___

8. Are you restricted now from doing any of your usual chores? Yes___No___
   If yes, what chores?

9. Have you found a satisfactory prosthesis? Yes___No___NA___

10. Do you wear your prosthesis? Yes___No___Occas___
    If not, why not?

11. Did you have any trouble shopping for bras and clothing? Yes___No___Occas___
    If yes, what were the problems?
    a. Did not know where to shop
    b. Too expensive
    c. Did not like selection
    d. Unpleasant salespeople
    e. Embarrassment, shame, modesty
    f. Difficulty in proper fit
    g. Other (specify)

12. Who first gave you information about prostheses?

    Where to shop?

    What to look for?

13. What features do you look for in selecting your prosthesis?

14. Did your insurance cover the full cost of your prosthesis? Yes___No___

15. Did you (do you) need a wig because of chemotherapy? Yes___No___

16. Did your insurance company cover the cost of the wig? Yes___No___NA___
If yes, any hints on how to get reimbursed by the insurance company?

17. Are there any dress hints you would like to pass on to other patients?

FACTS AND MYTHS--FOOD

18. We all learn a lot about cancer from many different sources and people; from whom and/or where do you get your information about cancer?
    a. Doctor
    b. Other health team members (specify)
    c. Scientific literature
    d. Nonscientific literature (books, magazines, newspapers, etc.).
    e. Radio, television
    f. Other cancer patients
    g. Family and/or friends
    h. American Cancer Society
    i. Other (specify)

19. What is your main source of information?

20. Do you think surgery can spread cancer? Yes___No___NA___

21. Do you think you can catch cancer from another person? Yes___No___NA___

22. Does cancer run in families? Yes___No___NA___

23. What do you think causes breast cancer?
    a. Radiation from too many x-rays.
    b. Viruses (bugs, germs)
    c. Blow to breast
    d. Pollutants in the air
    e. Pollutants in food
    f. Heredity
    g. Emotional stress
    h. God's will
    i. Don't know
    j. Nobody knows
    k. Other (specify)

24. Is breast cancer--the illness itself NOT the surgery or medications--sometimes painful? Yes___No___NA___

25. Have you been told about Breast Self Examination? Yes___No___NA___

26. What were you told BSE consists of?
    a. Palpate around breast and under arm
    b. Look for dimpling, change in nipples
    c. Check monthly

27. Is it still necessary to practice BSE? Yes___No___NA___

28. Do you practice BSE? Yes___No___Occas___

29. Has the doctor, nurse, or anyone else on the health care team talked with you about a special diet while you were on chemo-therapy? Yes___No___

30. If yes, what is the diet?

31. Do you make an effort now to eat an enriched diet? Yes___No___
    If yes, what foods?

32. Have you lost your appetite for food? Yes___No___

33. Any food hints which you have found which have made therapy easier?

34. Were you told that you might have trouble maintaining your weight? Yes___No___

35. Have your sleeping habits changed? Yes___No___
    If yes, how?

PSYCHOSOCIAL

This next part of the questionnaire has some questions about feelings. It is very common for people with cancer to go through periods of time when they feel depressed, or anxious, or angry. Sometimes we can deal with a particularly stressful situation by ourselves and sometimes it is more effective if we get some help from another person.

36. But first I'd like to ask you whether in general in the past year or so has anything happened (other than the cancer) that has made you worried, unhappy, or otherwise caused emotional stress to you and/or your family? Yes___No___
    If yes, what?
    a. Death of spouse or child
    b. Serious illness of spouse or child
    c. Death of relative or close friend
    d. Serious illness of relative or close friend
    e. Loss of job (patient or spouse)
    f. Financial trouble
    g. Marital trouble
    h. School trouble
    i. Family trouble
    j. Housing problems
    k. Legal trouble
    l. Other (specify)

37. How did you first discover you had cancer?

38. Did you expect the diagnosis to be cancer? Yes___No___

39. How did you feel when you were told the diagnosis?

40. How do you feel now?

41. Do you know anyone else with breast cancer? Yes___No___

42. Do you talk with someone sometimes about your breast cancer? Yes___No___

If yes, whom do you talk with?
a. Husband/partner
b. Children
c. Other relatives
d. Friends
e. Other cancer patients
f. Health care team members
g. Professional counselors (social workers, psychologists, psychiatrists, etc.)
h. Minister
i. Other (specify)

43. In what way is this person (are these people) most helpful for you?

44. Is there anyone that you wouldn't tell that you have breast cancer? Yes___No___
If yes, whom?
a. Husband/boyfriend
b. Children
c. Parents
d. Relatives
e. Friends
f. Work associates
g. Employer
h. Other (specify)

45. Who are the PROFESSIONAL people in the community who are available to help with emotional stress? I am asking you to name resources in the community which people can turn to for assistance in coping with emotional stress?
a. Social worker on unit
b. Psychologist on unit
c. Family service agency
d. Mental health agency
e. Social worker, psychologist, psychiatrist in private practice
f. Minister
g. Doctor/nurse
h. Other (specify)

46. Would you or have you used any of these people? Yes___No___
If no, why not?
a. Don't need outside help
b. Too expensive
c. Hard to get to
d. Embarrassment
e. Other (specify)

47. How often do you think about your illness? Oft___Nev___Occas___

48. What were your reactions the first few months after surgery?
    a. Shock
    b. Disbelief
    c. Anger
    d. Fear
    e. Depression
    f. Loneliness
    g. Other (specify)

49. When do you feel blue, lonely, depressed, angry, anxious now?

50. What particular time or event in your illness now is stressful for you?
    a. Treatment
    b. Thinking about the future
    c. Impact on the family
    d. Financial drain
    e. Physical disabilities
    f. Pain
    g. Other (specify)

51. Have your relationships with your family changed in any way? Yes___No___
    If yes, how?

52. Have your relationships with your friends changed in any way? Yes___No___
    If yes, how?

53. Has having cancer changed your participation in social activities? Yes___No___
    If yes, how?

54. Has having cancer changed your activities in the home? Yes___No___
    If yes, how?

55. Do you exercise regularly? Yes___No___
    If yes, what do you do and how often?

56. What things do you really enjoy doing most?

57. How often do you have the chance to do these things?

58. Are things harder financially now since you got cancer? Yes___No___

It has been reported that quite often cancer affects marital relationships. Some of the next questions are delicate and you may prefer not to answer. However, we hope you will participate since sharing your experience will be helpful for other women trying to handle similar situations.

59. Are you now married? Yes___No___

60. How do you feel when you look at yourself undressed in the mirror?

61. Will (would) you let your husband see you undressed now? Yes___No___

62. Does your husband treat you differently now? Yes___No___
If yes, how does he treat you differently?

63. Has there been a change in your intimate marital relationships since the mastectomy? Yes___No___NA___
Why has your relationship changed?

64. Is a woman less womanly after a mastectomy? Yes___No___
If yes, in what way?

We are about at the end now. This last part of the questionnaire will deal with some general information topics again.

65. Do you still see your family physician? Yes___No___
If yes, for what reasons?
a. Other illnesses
b. Side effects of treatment
c. New signs and symptoms
d. Cancer treatment
e. Other (specify)

66. Do you think laetrile is a good cancer treatment? Yes___No___

67. Do you have a particular member of the health care team that you would prefer to give you your treatment? Yes___No___

68. Do you ask for that person? Yes___No___

69. If there was a particular person on the health care team that you just did not like, would you ask another person to help you? Yes___No___

70. What are some of the possible side effects from chemotherapy?
    a. Nausea/vomitting
    b. Hair loss
    c. Loss of apetite
    d. Change of taste
    e. Fever
    f. Chills
    g. Pain
    h. Tiredness
    i. Do not know
    j. Other (specify)

71. Do you think doctors can control any pain that may be associated with cancer? Yes___No___NA___

72. How do you expect your treatment to affect your illness?

73. If you can think back to the very beginning of your illness, how would you have liked to have been given information?
    a. One to one teaching by doctor
    b. One to one teaching by the nurse
    c. Group discussion
    d. Classroom style lectures
    e. Films, videotapes in the clinic
    f. Audiocassettes in the clinic
    g. Audiocassettes in the home
    h. Books, pamphlets, posters, etc.
    i. Other (specify)

74. What could we have done to have helped your adjustment to your illness?

75. What information from your own experience would you like to share with other patients?

76. I have here a sheet with a number of patient education topics on it. Would you please check off ALL the topics that would interest you in a patient education booklet. (After patient completes this check off.) Now will you go back and circle those topics that you think are the MOST important.

Thank you for your help. I realize that this may not have been easy for you. If you feel you would like to discuss anything further, I know Joyce Diftler will be glad to talk with you. What you have shared with me will be very useful for helping us provide better information for breast cancer patients. I look forward to working with you these next few months to develop some really helpful and meaningful patient education booklets. Are there any questions? If I can be of service to you, please do not hesitate to call upon me.

BREAST CANCER PATIENT EDUCATION TOPICS

Which of the following topics would you like to see included in the breast cancer patient education booklets? Please check off ✓ ALL the topics you are interested in.

1. Origin of cancer
2. Diagnostic procedures
3. Kinds of surgical procedures
4. Radiotherapy explained
5. Chemotherapy explained
6. Immunotherapy explained
7. Future trends in treatment
8. Side effects of treatment
9. Pain control
10. Nutrition--advice on food
11. Prostheses and dress hints
12. Breast self examination
13. Arm care
14. Do's and don'ts for daily living
15. Important signs and symptoms
16. Cancer myths
17. Exercises
18. Anxieties and stress
19. Sexuality
20. Depression, feeling blue
21. Dictionary of terms
22. Description of duties of health care team members
23. Capabilities of the UT Oncology Service versus other cancer centers
24. Other (specify)

Now, please circle those topics you think are MOST important.
THANK YOU!

APPENDIX F

QUESTIONNAIRES ACCOMPANYING BOOKLETS

CHEMOTHERAPY AND HORMONE THERAPY QUESTIONNAIRE

In order to end up with a series of booklets which will truly be useful for the breast cancer patients of the Hematology-Oncology Consultation Service, we need your help. The rough drafts of the booklets now have a blank page opposite each printed page. These blank pages are for your comments about the booklets. The booklets will be revised according to your comments and then professionally printed and distributed. In the final printing, there will be blank pages at the end of each booklet. These blank pages will be for your own personal notations about your medication, dietary needs, etc.

In addition to making comments in the booklets themselves, will you please help us by completing the short questionnaire accompanying each booklet.

1. What information was NOT clearly written?

2. What part of the booklet was NOT useful?

3. What part of the booklet was MOST useful?

4. What additional information is needed?

CHEMOTHERAPY AND HORMONE THERAPY (continued)

5. Would you like the art work changed? How?

6. Are additional drawings needed? Where?

7. What did you like best about the booklet?

8. What did you not like about the booklet?

9. What additional suggestions would you like to make?

HAND AND ARM CARE QUESTIONNAIRE

In order to end up with a series of booklets which will truly meet the needs of breast cancer patients of the Hematology-Oncology Consultation Service, we need your help. The rough drafts of the booklets now have blank pages opposite each printed page. These blank pages are for your comments about the booklets. The booklets will be revised according to your comments and then professionally printed and distributed. In the final printing, there will be blank pages only at the end of each booklet. These blank pages will be available for your personal notations about your own medication schedule, dietary needs, etc.

In addition to making comments in the booklets themselves, will you please help us by completing the short questionnaire accompanying each booklet.

1. What information was NOT clearly written?

2. What part of the booklet was NOT useful?

3. What part of the booklet was MOST useful?

4. What additional information is needed?

HAND AND ARM CARE (continued)

5. Would you like the art work changed? How?

6. Are additional drawings needed? Where?

7. What did you like best about the booklet?

8. What didn't you like about the booklet?

9. Do you have additional suggestions?

APPENDIX G

INSTRUCTIONAL LETTER TO PATIENTS

1924 ALCOA HIGHWAY
KNOXVILLE, TENNESSEE 37920

THE UNIVERSITY OF TENNESSEE
MEMORIAL RESEARCH CENTER
Hematology-Oncology Consultation Service
and
University of Tennessee/Knoxville
Division of Health and Safety

Dear Mrs.

Thank you for helping us with the patient education booklets. We are depending upon your guidance to make sure we are including the kind of information you are interested in having. Our purpose is to write a group of six booklets which will be useful for all breast cancer patients---both new patients and old patients.

In this envelope I have enclosed the rough drafts of the first two booklets. You will also find a blue ballpoint pen, a yellow felt underliner pen, two questionnaires, and a self-addressed, stamped envelope. I would like you to do three things with the booklets.

1. As you read through the booklets, use the blue ballpoint pen to cross out any information you do NOT want. Also, circle any word or part of the booklet that you do not understand.

   Please feel free to change any wording and make any comments anywhere in the booklets. Tell us where more information is needed. Tell us what you do not understand. Tell us if you want the drawings changed or new drawings added.

2. Go through the booklets again. This time use the yellow felt tip pen. Draw a yellow line through all the information you did NOT KNOW OR WERE UNSURE OF BEFORE you read this booklet. This will tell us what new information the booklet taught you.

3. Complete the questionnaire which accompanies each booklet.

After you have finished with the two booklets and questionnaires, please put both booklets and questionnaires in the enclosed self-addressed stamped envelope and mail them back to me. The booklets will be rewritten according to your comments and then they will be professionally printed and available to the patients of the Hematology-Oncology Consultation Service. Keep the pens for the next set of booklets which I hope to have ready in about a month. The topics of these next booklets will be: Feelings; Pain Control; Your Husband and You; Looking Good.

Your help with this project is invaluable and I am very grateful for your time and interest.

APPENDIX H

PATIENT EDUCATION BOOKLETS

1

HAND AND ARM CARE

one of a series of booklets for breast cancer patients





in a series of six booklets designed
especially for breast cancer patients.

Materials developed by
Muriel Levin, Ed.D.

Illustrated by
Terry Kelly

Copyright © 1979 by Muriel Levin

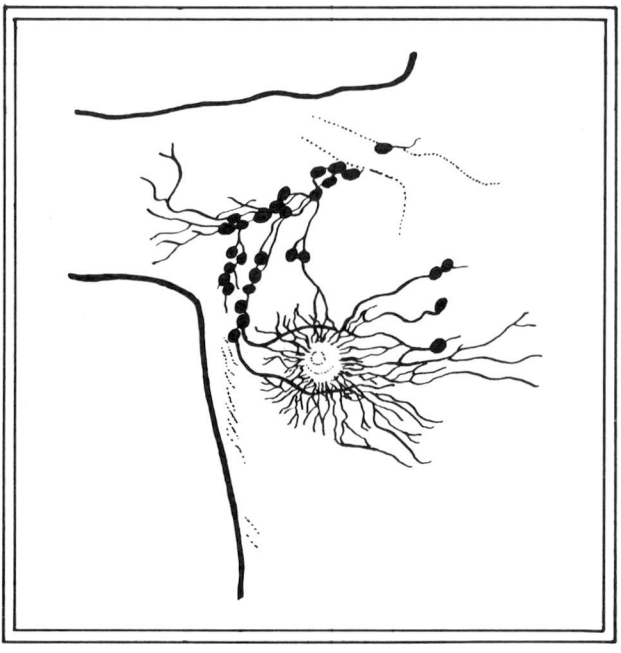
The author gratefully acknowledges
the invaluable assistance and
cooperation of the many breast
cancer patients who participated in
this project.

This booklet was made possible by an institutional grant from the American Cancer Society. Thanks are due to the staff of the Hematology-Oncology Consultation Service, The University of Tennessee Center for the Health Sciences/Knoxville, the Division of Health and Safety, and the Graduate School of Social Work, The University of Tennessee/Knoxville, who generously donated much time to guide and assist in this project.

HAND AND ARM CARE

HAND AND ARM CARE

During your mastectomy operation, some of the lymph nodes and channels were removed from under your arm. Because these nodes were removed, your arm on the operated side is less able to combat infection. Therefore, for the rest of your life it is necessary to always take some simple precautions to protect your arm. A list of these simple precautionary steps follows.



Lymph nodes and channels

KEEP THIS IN MIND AND REMEMBER

Make a special effort to avoid cuts, scratches, pinpricks, hangnails and insect bites. Any break in the skin can lead to an infection and swelling.

- Avoid injections and vaccinations in the operated arm.
- Do **NOT** have blood work taken from the operated arm if at all possible.
- Be careful when manicuring your nails. Use cuticle cream and remover instead of a scissors. Apply a lanolin handcream several times a day to your hand.
- Wear canvas gloves when gardening and avoid cuts, thorn pricks, scrapes, etc.
- Wear a thimble when sewing.
- Take prompt care of cuts and scrapes. Wash the area well with soap and water and cover with a clean protective dressing.



Protect your hand and arm.

- Bee and wasp stings are very inflammatory. Consult your doctor. Always use a good insect repellent if you think you might be exposed to insect bites or stings.

Avoid wearing anything on your affected arm that is tight. Too tight clothing, jewelry, etc. may cause swelling.

- Do **NOT** have your blood pressure taken on your affected arm.
- Wear your watch on your unaffected arm.

- Carry your purse on the other arm.
- Always wear loose jewelry and loose dress sleeves. In this day and age with men wearing fancy clothing, you may find men's shirts with their wider sleeves and insets a comfortable and attractive alternative to specially altered women's clothing.

If you have had a double mastectomy, blood work and blood pressure should be taken from the side of the oldest mastectomy. However, if this arm has had much swelling, check with your doctor for special instructions.

Avoid burns as they can lead to infection. Also remember that you may have lost some sensation in your operated arm and hand and may not be able to feel very hot things.

- If you must smoke, hold your cigarette in your unaffected hand.
- Always use a padded glove when reaching into the oven or handling hot dishes.
- Get a suntan slowly. Be very careful to avoid getting sunburned.
- Check your bath water and your dish water with your unaffected hand.

Miscellaneous

- Consult your doctor about using deodorants and shaving under your affected arm.
- Do not lift or move heavy objects. Get someone else to move the furniture, carry heavy bundles, or do other tasks which need strenuous activity. The rule with heavy objects is- if it hurts, don't do it!

- If your arm swells for no apparent reason, raise your arm above normal shoulder level. For example, on long car trips, arm swelling may be relieved by fastening home made cloth loops onto the side of the sun visor and/or the car ceiling. This is so excess fluid can be carried off by the lymph nodes located behind your chest wall. If the swelling persists, see your doctor.

A swollen arm is often due to infection. By following these simple rules, you can protect your arm against unnecessary discomfort.

Exercise

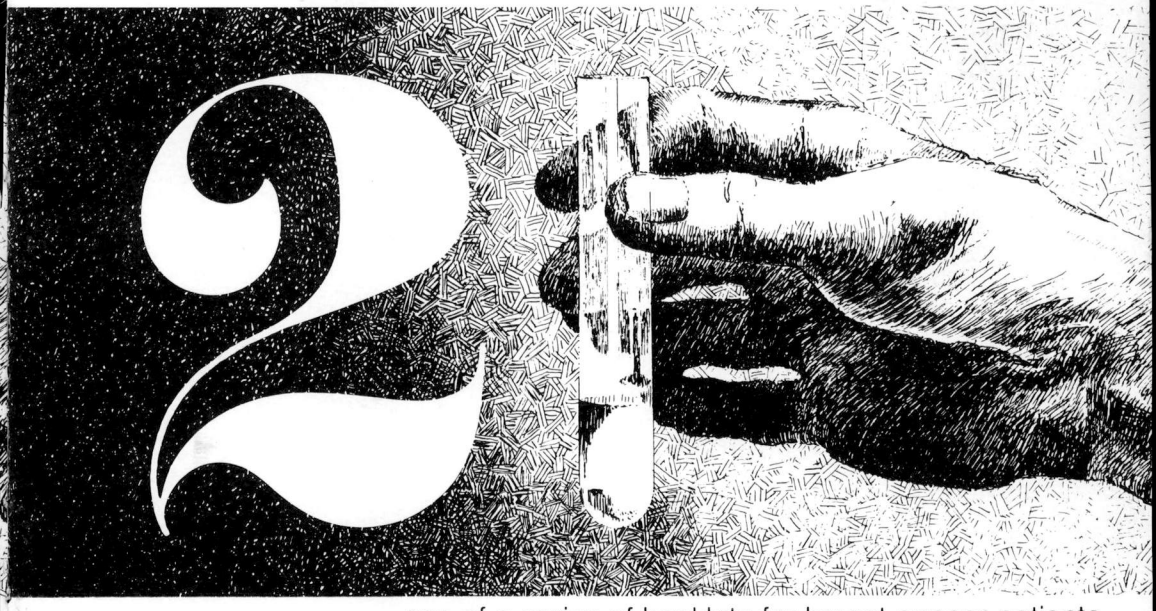
After a mastectomy operation, exercise is very important for regaining full range of motion in your arm and shoulder and for preventing pain and stiffness. Check with your doctor to see when he wants you to begin exercising. The doctor or nurse will give you instructions for specific exercises or they may suggest following the information provided in the *Reach to Recovery* booklet. Simple grooming and household chores like brushing your hair, drying your back, and sweeping the floor can also be helpful.



Simple grooming can be helpful exercise.



CHEMOTHERAPY AND HORMONE THERAPY



one of a series of booklets for breast cancer patients



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CHEMOTHERAPY AND HORMONE THERAPY

CHEMOTHERAPY AND HORMONE THERAPY

This booklet was written to help you understand the basics of chemotherapy and hormone therapy. Its purpose is to provide a little extra support and information for you and your family by answering some common questions many people have about their treatment. It is not meant to be a substitute for a good, open relationship between you and your doctor, nurse and clinic staff. You may have many other questions, problems, fears that need to be discussed. It is only natural that you have some anxieties, doubts, mood swings or other emotional reactions to your illness and its treatment. It is very important that you talk about these concerns with people you can trust, such as your doctor, nurse and social worker. All these people are



You may have many questions.

trained to understand these problems and are truly concerned with helping you to be as comfortable as possible. If you have other matters that need attention such as financial needs, medical equipment needs, home assistance needs or family problems, be sure to discuss these issues too.

What are the current forms of treatment for breast cancer?

The four most widely used types of treatment are surgery, radiation therapy, chemotherapy and hormone therapy. Immunotherapy, another form of treatment, is being used in a small number of special cases together with the other forms of treatment.

What is chemotherapy?

The word chemotherapy is taken from a combination of "chemical" and "therapy" (chemo-therapy). Simply, it means the use of drugs or medications for the treatment of cancer. Currently there are over two dozen different chemotherapeutic agents in use to treat different kinds of cancer.

What is hormone therapy?

Hormone therapy is the use of natural or synthetic hormones to treat cancer. Currently there are about a dozen different hormones being used to treat different kinds of cancer.

What is immunotherapy?

Immunotherapy is a form of cancer therapy which stimulates the body's own defense mechanisms to fight the disease.

What is a protocol?

A protocol is a treatment plan which specifies which

drugs a patient will receive, in what doses, and how frequently. The purpose of the protocol is to compare two or more treatments for the same kind of cancer. Doctors use protocols to develop new and better treatments for cancer.

How are people assigned to protocols?
Your doctor will recommend that you be entered into a protocol if it is appropriate in your case. Before being assigned to any new form of cancer therapy, you will be asked to give your "informed consent." This means that your doctor will explain the drugs you will receive, their potential benefits, the known side effects, and the reason for giving you these specific drugs.

How are chemotherapy and hormone therapy given?
The drugs may be given in one of three ways:

- by mouth
- by injection into a muscle (a "shot")
- by injection into a vein. This is done by putting a tiny needle into the vein under the skin and then slowly injecting the drug or drugs. Some drugs might be mixed in a bottle of fluid and allowed to drip in over a period of about 15 minutes. (Some drugs may take slightly longer.) During this time you may watch television, read or talk with your family.

The way in which you will have your drug given to you will depend upon the kind of drug that has been prescribed for you. You may be given one drug or several drugs at the same time, or different drugs at different times. Your doctor or nurse will explain your drug regimen to you but you should always feel free to ask questions.

Be sure to check if there are special instructions you should follow during your treatment. Certain drugs may require special attention. Table I (see pp 8,9) lists some of these special precautions.

Is drug therapy painful?

Usually not. Intravenous administration of a very few drugs can cause a burning or itching sensation in the veins. You will be told if you are getting one of these drugs. In all cases however, always report any pain or unusual sensations promptly so that the cause can be checked and corrected.

How does chemotherapy work?

Drugs enter the bloodstream—either directly by intravenous injection or indirectly by absorption through the stomach or tissues—and are distributed to all parts of the body. Those cells that divide rapidly, such as tumor cells, take up most of the drug. In the tumor cell the drug acts by interfering with the reproduction and growth of the cell, and the cell is eventually destroyed. The successful destruction of the tumor is dependent upon a number of factors, including the type of tumor and the drug itself.

Unfortunately, anticancer drugs affect normal rapidly dividing cells as well as tumor cells. Normal cells that might be affected include those in the bone marrow, the gastrointestinal tract, the reproductive system, and the hair follicles. Normal cells however, have a tremendous capacity to regenerate themselves and return to the normal state. The effect that the anticancer drugs have on your blood and on your normal cells will be carefully watched.

TABLE I

DRUG THERAPY—SPECIAL PRECAUTIONS

If you are taking this drug	Watch out for these signs	You must take this action
Adriamycin	red urine	normal for a day
Adriamycin	veins in arm getting drug may turn bright red	normal reaction seen occasionally; will eventually disappear.
Adriamycin Vincristine (Oncovin)	infiltration of drug into area around the intravenous injection site	When you get these drugs the nurse will stay with you; she will take proper measures to help counteract the effects of the drug seeping into the skin; this is very important to help prevent harmful skin ulcers; always tell the nurse if the drug burns or feels uncomfortable.
Vincristine (Oncovin)	constipation	Ask your doctor or nurse to suggest a stool softener or laxative.

Methotrexate (all doses)	kidney damage	Always drink several glasses of liquid daily and urinate often for two days after treatment; if you have trouble urinating, call the doctor promptly.
Methotrexate (high dose only)	nausea	ALWAYS make sure you take your leukovorin as directed by the doctor; if you vomit these pills, call the doctor promptly.
Cytoxan	cystitis (inflammation of the bladder- urgency, pain, bloody urine)	ALWAYS drink several glasses of liquid for two days after you get this drug; make sure you drink several glasses of liquid between the time you receive your treatment and bedtime and have urinated several times; if you have trouble urinating, call the doctor.
Hormones DES, TACE Tamoxifen Prednisone Megace	edema (retention of fluid, swelling)	Call the doctor promptly.
5 FU		no special precautions.

How does hormone therapy work?

Some cancers of the breast occur in tissues influenced by hormones. Some of these cancers tend to appear at a time of life when the normal hormonal activity in your body has changed, such as around menopause.

While chemotherapeutic drugs act on all rapidly dividing cells, hormones act on specific cells, tissues and organs. Treatment with hormones may affect cancers by changing the hormonal imbalance in your body which encouraged the cancer cells to grow. Only certain types of cancer can be treated with hormones. Your doctor will have special laboratory tests done to determine if hormone therapy is appropriate for the treatment of your cancer.

How long and how often will I receive drug therapy?

The length of time and the frequency of your chemotherapy or hormone therapy depends upon a number of factors including the type of cancer you have, the type of drugs necessary for your treatment, how long it takes your body to respond to the drugs, and how well you tolerate the drugs in terms of the potential side effects.

Generally, medications are given at one to four week intervals, and occasionally on a daily basis for short periods. Finally, and only generally speaking, the duration of your treatment may vary from six months to two years. Your doctor and nurse will explain the exact course of treatment that has been designed for you. However, you should remember that since it is very difficult to predict each patient's individual response to treatment, the doctor will not be able to tell you exactly how long each particular treatment will last.

Will I have to be hospitalized?
Usually patients are hospitalized for the first treatment so that reactions to the drug can be carefully watched. After that, most chemotherapy and hormone therapy programs can be given in the outpatient department (clinic). For some programs, a short period of hospitalization may be necessary in order to watch the effects of the drug more carefully.

Will I be able to continue working?
Most people find that they are able to work and perform the physical activities to which they are accustomed. This includes housekeeping, church activities, swimming, hiking, etc. How much you will be able to do will depend upon your own individual response to your illness and to the treatments. Talk with your doctor about your activities—most times your doctor will encourage you to be as active as possible.


Will I be able to continue normal activities?

Will I be able to have wine, beer or cocktails?
Alcoholic drinks may be taken in small amounts, probably not more than one or two drinks daily. In some cases it may be absolutely essential that you NOT drink ANY alcoholic beverages, so ask your doctor about its use for you.

What about taking other medications with these drugs?

It is **VERY IMPORTANT** that you **NOT** take **ANY** pills or liquid medications before you check with your doctor. It would be very helpful if you would bring a list of medications which you have been taking on your next visit to the doctor. Remember to include those drugs which you use only once in a while and also those drugs that you can purchase without a prescription. A list of drugs which might possibly interfere with or in some way affect your drug therapy is given in Table II. If you are taking any of these drugs, tell your doctor about the dose, frequency and use of the drugs.

TABLE II

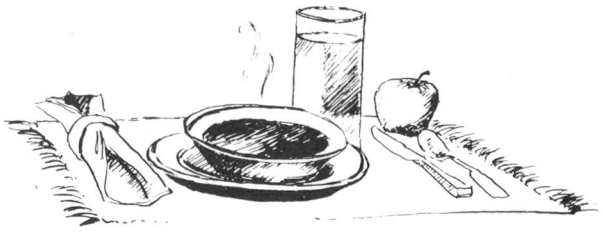
MEDICINES WHICH MAY AFFECT DRUG THERAPY

Tell your doctor if you are taking any one or more of these medicines.

ANTIBIOTICS (pills for infection)
ANTICOAGULANTS OR BLOOD MEDICATIONS (blood thinners)
ANTICONVULSANTS (seizure pills)
ASPIRIN
BARBITURATES (Seconal, Nembutal)
COUGH MEDICINES (including Robitussin)
DARVON
DIABETIC PILLS (sugar pills)
HORMONES (birth control pills, menopause pills)
SLEEPING PILLS
TRANQUILIZERS (nerve pills)
DIURETICS (water pills)
ANTIDEPRESSANTS

Should I restrict my diet in any way?

Generally speaking no. In fact, good food is good medicine. The person getting drug therapy needs to be sure that her body gets adequate vitamins, minerals, protein and calories. Proteins and calories are particularly important because they maintain a person's strength and prevent body tissues from breaking down. This is especially true when a person is recovering from surgery or undergoing drug therapy or radiotherapy. Both kinds of treatment can take a lot out of a patient and good nutrition is essential to rebuild the normal tissues that have been affected.



Good food is good medicine.

On the day of your treatment you should eat a light breakfast. It is also advisable for you to increase your fluid intake before and for one to two days after your treatment. Try to drink about 6-8 glasses of liquid each day. Do not forget that fluids include not only water and juice but also Jello, clear soups, and ice cream. You may want to drink most of the additional fluid early in the day. This will help eliminate getting up during the night. Also, if you find you are having bladder control problems, you might try using "light days" sanitary pads for protection against involuntary leaking of urine during coughing, sneezing, and laughing.

It may also be best to check with your doctor to see if he wants you to limit your use of salt.

If you have problems with your diet, if you find you

are not eating much, if you have lost your appetite, or if you are nauseated, be sure to talk with the doctor or nurse. They can help you plan menus which are appealing to you. Eating small amounts more often, eating favorite foods, and using high-protein supplements may help. You are urged to eat a well-balanced diet since good nutrition is a very important part of your treatment. For more information on nutrition, see the booklet in this series entitled, "Good Food Is Good Medicine."

How does the doctor determine the effects of the drugs?

Your doctor will use physical examinations, laboratory tests, scans and x-rays to help measure your response to treatment. All patients receiving drug therapy must have certain laboratory tests on a regular basis. Blood counts are very important for helping the doctor adjust the dosage of the chemotherapy so that your blood cell counts won't fall too low. If your blood counts are lower than normal, your doctor will reduce your drug dosage or postpone treatment until your blood count returns to normal. Other chemical tests follow your blood sugar level, and your kidney and liver functions. Scans and x-rays help your doctor to determine if the treatment is working.

What are the possible side effects of drug therapy?

Anticancer drugs have side effects in *some but not all* patients. Each drug can produce different effects in different people. These effects can be extremely variable in severity. Whether or not you experience these reactions is a very individual matter and has nothing to do with how well the drug is working to combat the cancer.

The side effects which may be seen in patients treated with some of the more commonly used cancer drugs are listed in Table III. A detailed explanation of side effects according to body system affected is reviewed below. Also included are the types of treatments commonly used to reverse the side effects.

TABLE III

SIDE EFFECTS OF COMMONLY USED ANTICANCER DRUGS

Gastrointestinal effects	nausea, vomiting, diarrhea, heart burn, constipation, indigestion, mouth ulcers
Muscle and Nerve effects	weakness, lethargy, tingling or numbness
Bone Marrow effects	bruising or bleeding, infection secondary to decreased white blood cells, anemia
Hair effects	partial or complete loss of facial, scalp and body hair
Ovarian effects	temporary partial or complete cessation of menstruation, inability to become pregnant (sterility)
Skin effects	variety of rashes, local or all over body, occasional itching
Heart and Kidney effects	swelling, shortness of breath

Gastrointestinal Effects

Nausea and vomiting are side effects which you might experience. However, pills, suppositories or injections to reduce the nausea will be given to you by your doctor. These will help ease much of the problem. The nausea may be mild or in extreme cases may be complicated by vomiting. The vomiting usually starts 1-2 hours after you get your drug and may continue for several hours. There are methods of sedation which will help you to sleep during this period and help you avoid the discomfort. Other less prominent and much less frequent gastrointestinal effects include constipation and diarrhea. These latter effects clear very rapidly, generally over a two to four day period.

Some people develop stomatitis, which is a soreness and ulceration of the lining of the mouth. Again this problem will last only a few days, but here are some hints to keep you more comfortable should it occur. Do **NOT** use commercial mouthwashes. They often contain alcohol and can further irritate your mouth. Instead, rinse your mouth with a mouthwash made up of ½ cup of hydrogen peroxide, ½ cup of water and a ¼ teaspoon of salt. Use cotton swabs instead of a toothbrush if the brush hurts your mouth. Try to eat foods that are easy to chew. Report any soreness in your mouth to your doctor or nurse at its first occurrence.

Muscle and Nerve Effects

Weakness and lethargy sometimes occur. They may be related to anemia, but can also be a direct effect of some of the drugs on the muscles and nerves themselves. In addition, the effect on nerves may result in a tingling or burning sensation in the hands and feet. This feeling is similar to having one's hands

"fall asleep" and may be associated with some clumsiness of movement. These effects are reversible in most cases and are only temporary.

Bone Marrow Effects.
Blood cells are produced in the bone marrow. White blood cells fight infection, red blood cells prevent anemia and carry oxygen to all the tissues, and platelets help to clot the blood and promote healing of breaks in the skin. As mentioned earlier in this booklet, anticancer drugs act to prevent cancer cells from replicating and sometimes act on normal cells as well. Because your bone marrow cells reproduce themselves rapidly in order to maintain blood counts, these cells are particularly sensitive to the drugs. The potential adverse effects of the blood are usually temporary and transfusions are available if needed to counteract these effects. A blood count will be taken frequently to watch out for:

- a decrease in your white count which might result in the development of an infection. If your white count is low you should avoid crowds or people with colds or other contagious diseases.
- a decrease in the number of your red blood cells which might cause anemia and result in shortness of breath or weakness and fatigue.
- a decrease in your platelet count which might result in the development of bruising, or a skin rash of small blisters under the skin, or actual bleeding in the internal organs such as the stomach and kidneys. Be careful to avoid injuring yourself since even a small cut may bleed for a long time. If you have a low platelet count your

doctor will tell you **NOT** to drink any alcoholic beverage or take aspirin or any other medication without his approval.

You should watch out for the following symptoms and report the signs to your doctor promptly:

- fevers (temperature over 102°)
- colds
- rashes
- cuts that get infected
- itching and burning in the genital or rectal area

Hair Effects

The hair follicles of the scalp and beard particularly, but also of the eyebrows, eyelashes, armpits, pubic and leg hair are rapidly growing cells. Thus they are sensitive to a few of the chemotherapy drugs. Loss of scalp hair commonly accompanies treatment, but complete loss of all body and facial hair occurs only rarely. Remember all hair will return when the drugs are discontinued, and may even return during treatment. You will probably want to wear a wig until your hair grows back. Wigs are a tax deductible medical expense or in some cases may be reimbursed by your medical insurance.

Ovarian Effects

It is very common for women who are still having menstrual periods to develop irregular periods or to cease menstruating altogether during drug therapy. In women close to menopausal age, hot flashes may occur. Women who do not have ovaries and are receiving hormone therapy may experience bleeding from the vagina.

During drug therapy, pregnancy generally will not

occur but still might be possible. Birth control measures are advisable since the potentially hazardous effects of anticancer drugs on the fetus makes pregnancy unwise at this time.

It is important to remember that while drug therapy may affect your fertility, it should have no effect on your ability to have and enjoy sexual relations with your mate.

Skin Effects

There are a variety of skin rashes that may develop although this happens infrequently. Localized or generalized rashes are usually red and sometimes itch. Occasionally the skin might peel, but blister formation is rare. Drugs will sometimes irritate the veins, making a coloration that develops along the pathway of the vein.

When should I call the doctor?

You should not hesitate to call the doctor if you have any symptoms that worry you, but especially in the following circumstances:

- fever (temperature over 102°)
- shaking or chills
- development of any rash
- marked pain or soreness at the drug injection site
- mouth soreness or ulceration and/or pain that persists when swallowing
- any bleeding that persists
- any pain of unusual intensity or distribution including a headache
- shortness of breath
- severe constipation or diarrhea

FOLLOW UP

After you have concluded your course of chemotherapy, you will be checked at regular intervals by your doctor. The frequency of these checkups is a very individual matter. Very generally though, you may be asked to return monthly for three or four months and then asked to come in four times a year. You are also urged to maintain regular checkups with your family physician.

Some patients talk about a "let down" feeling at the end of their treatment. The patients have likened being in chemotherapy to a security blanket. While they are taking treatment, they take comfort in the fact that they are doing everything possible to fight their cancer. When the treatment is finished, they wonder if the cancer will come back. These fears and anxieties about the future are very normal and should be discussed with your doctor. Cancer patients do have to face the possibilty of a recurrence. However, how you deal with this uncertainty is crucial for your physical and emotional health. The best approach is to take a positive attitude and look upon the end of your chemotherapy as a chance for a new beginning. Make each new day count.

If you have concerns, we urge you to talk about them with someone you can trust—your family, friends, clinic staff (especially the social worker and psychological intern), or a mental health professional in your community. You may also find helpful the booklet in this series entitled "Feelings" which deals more extensively with the emotional reactions to cancer and cancer treatment.



Talk with those who can help.

CONCLUSION

We hope that this booklet has helped you to understand some of the general effects of chemotherapy and hormone therapy and helped you to plan your daily activities. This booklet is not a substitute for the discussion of concerns and questions between you and your doctor, and the clinic staff (doctors, nurses, social worker, nutritionists). All of these people are concerned with your welfare and are dedicated to doing everything possible to help you. However, you play an important role in your treatment too. The successful long term treatment of any patient depends to a great deal upon her attitude. If you can strive for and maintain a positive attitude, very often you will respond better to treatment. This means you must be willing to fight for your life and believe you can live longer by doing so.

NOTES

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VITA

Muriel Ann Baggish Levin was born in Boston, Massachusetts, on March 12, 1932. She attended elementary schools in that city and Germantown High School in Philadelphia, Pennsylvania, graduating in 1949. In 1953 she received a Bachelor of Science degree in chemistry and bacteriology from The Pennsylvania State University. She spent the next seven years in the medical sciences, first in a clinical laboratory at Mountainside Hospital, Montclair, New Jersey, and then in basic medical research at Harvard Medical School, Boston, and Oxford University, England.

The next 11 years were spent in family activities and in a variety of community volunteer activities. In 1971 she entered graduate school, receiving a Master of Science of Social Work degree from The University of Tennessee in 1974. From 1973 to 1975 she served as Assistant Director of the Area Health Education Center, The University of Tennessee Center for the Health Sciences/Knoxville, and from 1975 to 1977 as Associate Director for Education and Community Programs, the East Tennessee Cancer Research Center, The University of Tennessee Center for the Health Sciences/Knoxville.

She reentered graduate school in 1977 and from 1977 to 1978 she held a graduate assistantship with the Bureau of Educational Research and Service. In 1979 she received a

Doctor of Education degree in health education. Her particular interests focus on the psychosocial impact of illness and disability and in the development of extended learning opportunities for health professionals, patients, and the public.

She is the widow of the late Dr. Alfred P. Levin and has two daughters.