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# Developing a Community-Based Oncology Patient Education Program

Marjorie N. Jenkins & Joseph Halperin

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# Developing A Community-Based Oncology Patient Education Program

by Marjorie N. Jenkins, B.S.N., M.B.A., R.N., C.N.N.A., and Joseph Halperin, M.D.

*Although interventions such as cancer educational and support programs may increase costs, creative program planning and management can help contain resources as well as improve quality of life and patient satisfaction. Here staff at two cancer centers outline model programs to help patients and their families respond to the medical, psychological, and social demands associated with cancer diagnosis and treatments.*

Seamless multidisciplinary oncology care for patients in the community requires development of an integrated plan for delivery of patient education. The plan must involve a collaborative team of professionals who can bridge programs housed within hospital walls to be inclusive of community services and physician office practices. To that end, the Moses H. Cone Regional Cancer Center in Greensboro, N.C., involved all program components into the planning process of its community-based oncology patient education program.

The need for an integrated patient education program arose when we realized that patients often presented for first treatment unprepared and in need of educational support, which affected their ability to provide full informed consent. Workload demands constrained staff from teaching patients. Furthermore, staff were frustrated by the fact that patients often received mental status-altering medications as part of their therapeutic regimen, making the first teaching session difficult. Patients were lost among various collateral channels of the health care system: hospital, doctor's office, ambulatory chemotherapy facility, and radiation therapy.

While the traditional model holds the physician as the major coordinator for all patient services, the evolving health care delivery system in managed care imposes time constraints and mandates less costly methods, including alternative avenues of patient education. Physicians are being asked, for example, to share their role as coordinator of all patient teaching and to work closely with an education "team."

Because today's medical environment demands cost savings,[1] our program development began with a requirement that there be no increase in resources. At the same time, we worked on the premise that empowering patients with knowledge would reduce use of health care resources by 1) improving their ability to respond more rapidly to evolving medical symptoms, 2) helping them anticipate therapy-related complications, and 3) reducing anxiety and the resultant increase in urgent-care requests.[2]

## THE PLANNING PROCESS

The first step was to form a Patient Education Planning Committee, a multidisciplinary team that included physicians and their staff and representatives from nursing (inpatient and outpatient), radiation oncology, gyn-oncology, medical oncology, surgery, nutrition services, social services, the IV team, and pharmacy. The committee developed a strategic business plan that included such program elements as individual responsibilities, teaching materials, and cost. Subcommittees were established to represent operational planning units vested in bringing ideas back to the Patient Education Planning Committee for discussion and consensus. The various subcommittees included:

- educational process
- physician referral/follow-up
- department-specific teams
- materials development
- flow sheet development
- program assessment.

The chairpersons of the planning process kept the Oncology Executive Committee and Cancer Committee fully informed during the process with periodic reports that served to develop program support and broad-based approval.

## THE EDUCATIONAL PROCESS

A flow diagram (Figure 1) was developed and became a working operational planning schema as well as the origin for designation

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*Marjorie N. Jenkins, B.S.N., M.B.A., R.N., C.N.N.A., is director of nursing at the Moses H. Cone Regional Cancer Center in Greensboro, N.C. Joseph Halperin, M.D., is medical director at the same institution.*

of various subcommittees.

A clinical nurse specialist was assigned the role of oncology care coordinator to facilitate the educational process. Her role includes collaborating with physicians, facilitating team issues, and supervising a clerical assistant who supports the movement of documents through the system. The clerical assistant creates an education folder for each patient and houses the permanent record. For Joint Commission purposes, documentation of the education folder's location is made in the patient's hospital record.

The education process begins with a physician referral to the oncology care coordinator. The physician or nurse fills out an Oncology Patient Education Form (Figure 2) that includes information about diagnosis, treatment, side effects, prognosis, and lifestyle issues. The form is sent to the oncology care coordinator for evaluation. The oncology care coordinator assigns the patient and/or family and friends to a nurse within the appropriate department based on the patient's primary therapeutic focus. The nurse then takes on the role of nurse education coordinator for that patient, initiating the disease-specific education, which includes information on the disease and treatment regimens, as well as possible complications and related side effects. Written education support information, such as fact sheets on specific anticancer drugs, are provided to reinforce the learning and to reassure patients by helping them distinguish normal side effects from those requiring immediate attention. For patients receiving multimodality treatment, the nurse educator coordinates teaching sessions with the appropriate departments.

The nurse education coordinator also performs a psychosocial and nutritional risk assessment and makes necessary referrals. Approximately 30 percent of patients with cancer experience significant emotional responses.[3] Patients are often unable to maintain adequate nutrition. These problems can significantly affect quality of life and lead to an increase in medical costs. Hence, anticipatory problem-solving is essential.

Oncology patients and their families, under duress during the time immediately after diagnosis, find it very difficult to assimilate the knowledge needed to exercise therapeutic options and respond to complications of the disease and/or treatment. The development of easily understood printed information provides access to a reliable reference. When patients are reassured by these tangible materials, as well as the educational efforts of staff, they are prepared for treatment and have less need to call or use

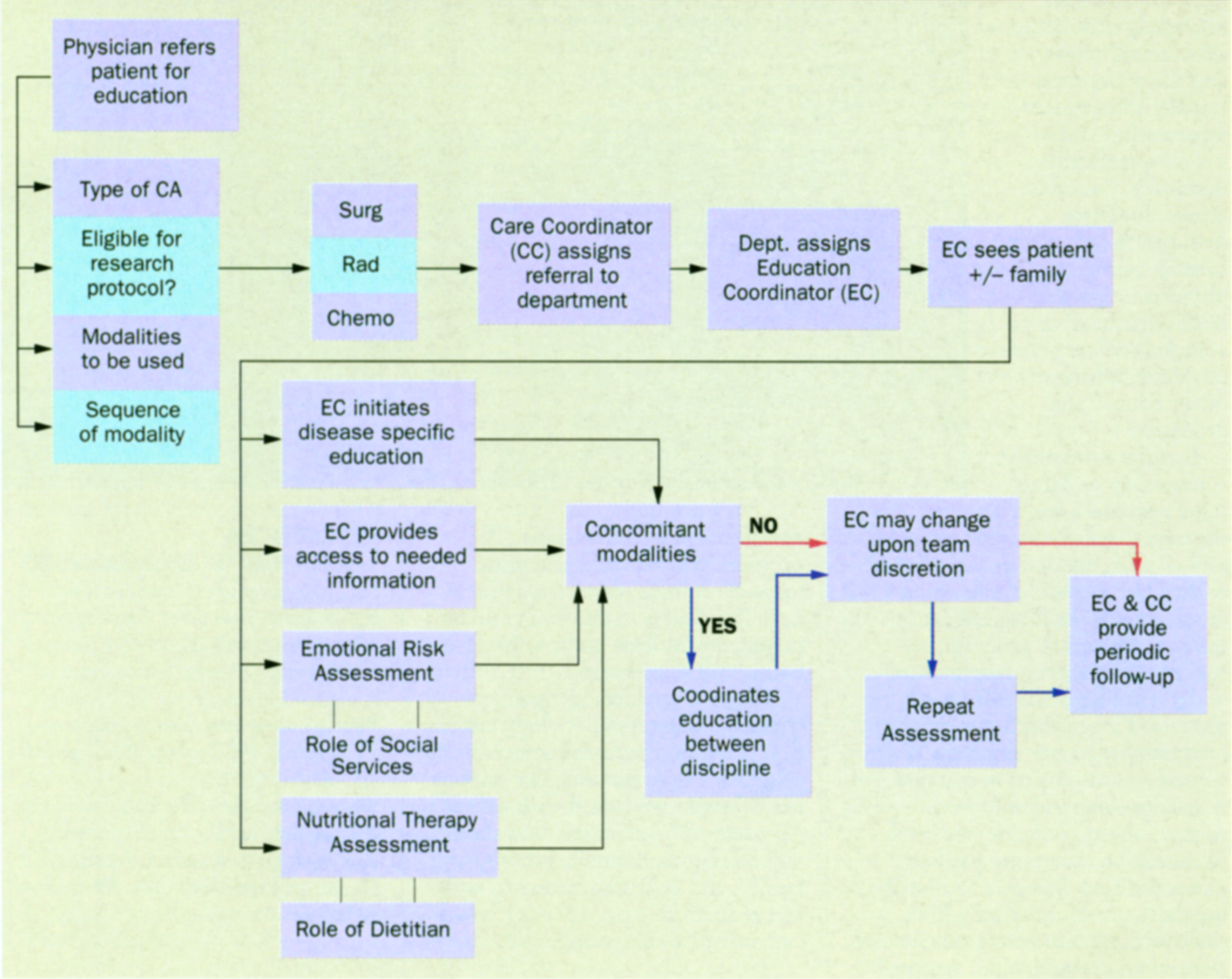
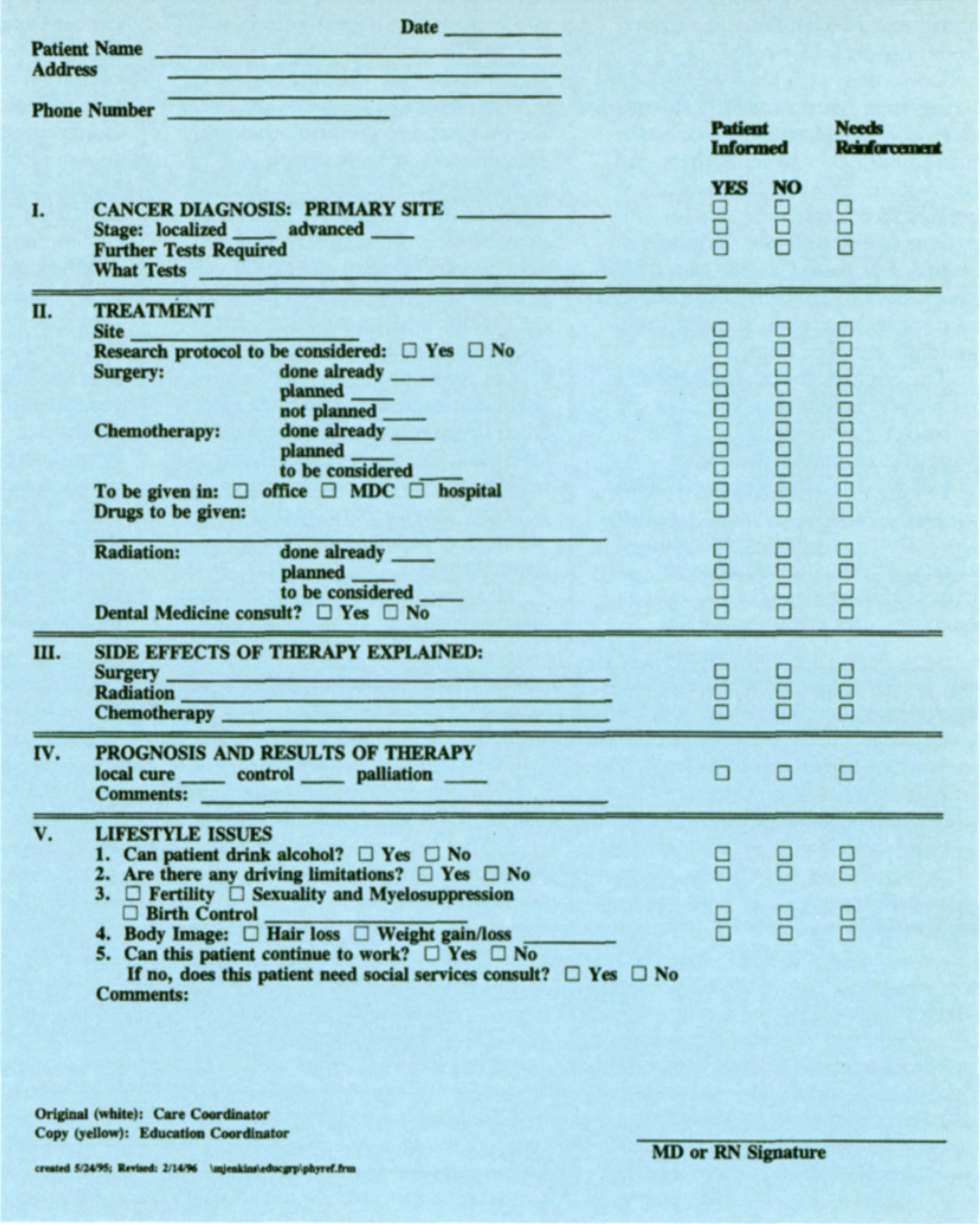


**Figure 1. Flow Diagram of Education Process**

emergency room services. To accomplish these goals, a subcommittee developed generic disease-specific and therapy-oriented printed oncology information.

Each department—medical oncology, surgery, and radiation oncology—developed department-specific educational processes to support the educational program and enhance patient outcomes. To integrate and document the education course, an oncology patient/family education flow sheet was designed to follow patients throughout their many visits to multiple settings. The flow sheet ensures that all team members are knowledgeable of the educational status and the patient has learned all pertinent information and, unless specifically necessary, does not attend duplicate sessions. A follow-up form is sent to the physician after the initial treatment is complete to keep the physician informed of the educational process.

**Figure 2. Physician Referral Form** Oncology Patient Education



Date __________
Patient Name ______________________________
Address ______________________________
Phone Number ____________________

| | | Patient Informed | | Needs Reinforcement |
|---|---|---|---|---|
| | | YES | NO | |
| I. | CANCER DIAGNOSIS: PRIMARY SITE __________ | ☐ | ☐ | ☐ |
| | Stage: localized ____ advanced ____ | ☐ | ☐ | ☐ |
| | Further Tests Required | ☐ | ☐ | ☐ |
| | What Tests ____________________ | | | |
| II. | TREATMENT | | | |
| | Site ________________ | ☐ | ☐ | ☐ |
| | Research protocol to be considered: ☐ Yes ☐ No | ☐ | ☐ | ☐ |
| | Surgery: done already ____ | ☐ | ☐ | ☐ |
| | planned ____ | ☐ | ☐ | ☐ |
| | not planned ____ | ☐ | ☐ | ☐ |
| | Chemotherapy: done already ____ | ☐ | ☐ | ☐ |
| | planned ____ | ☐ | ☐ | ☐ |
| | to be considered ____ | ☐ | ☐ | ☐ |
| | To be given in: ☐ office ☐ MDC ☐ hospital | ☐ | ☐ | ☐ |
| | Drugs to be given: ____________________ | ☐ | ☐ | ☐ |
| | Radiation: done already ____ | ☐ | ☐ | ☐ |
| | planned ____ | ☐ | ☐ | ☐ |
| | to be considered ____ | ☐ | ☐ | ☐ |
| | Dental Medicine consult? ☐ Yes ☐ No | ☐ | ☐ | ☐ |
| III. | SIDE EFFECTS OF THERAPY EXPLAINED: | | | |
| | Surgery ____________________ | ☐ | ☐ | ☐ |
| | Radiation ____________________ | ☐ | ☐ | ☐ |
| | Chemotherapy ____________________ | ☐ | ☐ | ☐ |
| IV. | PROGNOSIS AND RESULTS OF THERAPY | | | |
| | local cure ____ control ____ palliation ____ | ☐ | ☐ | ☐ |
| | Comments: ____________________ | | | |
| V. | LIFESTYLE ISSUES | | | |
| | 1. Can patient drink alcohol? ☐ Yes ☐ No | ☐ | ☐ | ☐ |
| | 2. Are there any driving limitations? ☐ Yes ☐ No | ☐ | ☐ | ☐ |
| | 3. ☐ Fertility ☐ Sexuality and Myelosuppression | | | |
| | ☐ Birth Control __________ | ☐ | ☐ | ☐ |
| | 4. Body Image: ☐ Hair loss ☐ Weight gain/loss ________ | ☐ | ☐ | ☐ |
| | 5. Can this patient continue to work? ☐ Yes ☐ No | | | |
| | If no, does this patient need social services consult? ☐ Yes ☐ No | | | |
| | Comments: | | | |

Original (white): Care Coordinator
Copy (yellow): Education Coordinator

____________________
MD or RN Signature

created 5/24/95; Revised: 2/14/96 \mjenkins\educgrp\phyref.frm

Regular assessment is necessary to determine outcomes and the overall value of a new program, as well as to document compliance with JCAHO patient education requirements. Prior to initiating the new education program, we surveyed patients to assess their understanding of the education process. Three months after the program began, we circulated a second questionnaire to patients. A results comparison of both surveys should indicate our level of success in increasing patient understanding. We plan to distribute these questionnaires, which patients complete anonymously and return in a pre-addressed stamped envelope, on a regular basis. The program was initiated as a pilot through a single physician's practice. The goal is to detect any unanticipated problems and resolve them before full implementation.

We have engineered a patient-friendly, integrated oncology education program that is transportable to other oncology centers. The process has been accomplished with existing resources. We anticipate that there will be improvement in patient, family, and staff satisfaction as well as a reduction in unnecessary health care resource utilization.

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# Developing Successful Cancer Support Groups

by Mary Gerbracht, R.N., M.S.N., A.O.C.N.; Laura Potts, Ed.D., C.H.E.; and Alan Munoz, M.D.

Since 1994, a support group for women with cancer has been successfully integrated and funded within the existing resources of a teaching hospital oncology program at St. Paul Medical Center in Dallas, Tex. The program is called RENEW (Relaxation, Education, Nutrition, Exclusively for Women). Because of staffing and funding concerns, a program was offered to both breast and gynecological cancer patients. We anticipated that the need for information and support would be similar in the two groups. Members of the breast center staff were added to the multidisciplinary planning team, which included the gynecological oncologist, the oncology clinical nurse specialist (OCNS), the oncology social worker, and the administrator of cancer services.

The mingling of breast and gynecological patients in the same group has been moderately successful. Many of the core members of the group received multimodal therapy of surgery, chemotherapy, and in some instances, radiation therapy. Patients who received only one modality of treatment, such as surgery for small breast cancers or surgery for cervical cancer, seemed to find less in common with members of the group. However, issues related to multimodal therapy such as fatigue, alopecia, role conflict, and concerns about relationships were common, regardless of the women's cancer diagnosis.

## TWELVE STEPS TO SUCCESS

*Be patient.* Successful support groups don't form overnight. Our women's cancer support group was three years in the planning stage.

*Encourage physician referrals.* Physician support drives attendance. Although many patients come to their first meeting only because their doctor strongly recommends attendance, patients will often come back because they want to.

*Listen to the needs of participants.* Be flexible enough to change plans in response to group requests. For example, after discussions about the optimal timing for the group, we scheduled RENEW meetings from 11:30 a.m. to 1:00 p.m., and served a complimentary lunch. This allowed some group members who are employed to attend during their lunch break.

*Be creative with funding.* Let's face it, in a world of capitated risk-based reimbursement, the financial resources to fund "soft" patient education programs are scarce. If your institution or community has a foundation, the most efficient means for obtaining start-up funding is through grants. From there, if the program is meeting patient needs, monetary and in-kind donations begin to follow. Your priority should be to establish a realistic budget before requesting support. Always monitor your expenses and report the outcomes.

*Honesty is the best policy.* Dealing directly with issues related to poor prognosis or recurrence is more helpful than denying such concerns. Encourage expression of feelings. Invite surviving group members to reflect on how relationships with the deceased have enhanced their own lives.

*Maintain contact with absent group members.* If a member misses a group meeting, call him or her in the interval. When a group member is hospitalized, the OCNS and oncology social worker at St. Paul Medical Center see her daily. Close communication provides group members with an enhanced sense of connectedness.

*Facilitating a group requires teamwork.* At St. Paul Medical Center, staff from the breast center, cancer services, and social work all contribute to the group design, implementation, and ongoing maintenance. A team approach fosters commitment to the group and helps ensure its success. Moreover, a team approach allows everyone to share the work and helps avoid staff burnout.

*Be consistent.* At St. Paul Medical Center, the psychologist, the oncology social worker, and the OCNS are the primary facilitators at each group, and at least one if not all three attend every group meeting. Having the same staff at each group meeting provides consistent support for participants and facilitates ongoing evaluation.

*Create a respite for participants.* Make participants feel special and pampered. Our meeting room at the hospital, for example, is beautifully furnished, private, and comfortable. The dietitian plans luncheon menus that are typical of a tea room.

*If it doesn't work, try something else.* Our support group bears little resemblance to what the planning committee had envisioned. That's fine. The bottom line is that the participants' needs are being met.

*Involve cancer survivors in group activities.* Group members who are post-treatment should be encouraged to stay involved. They can help by making reminder phone calls and planning events. They serve as living inspirations to those group members still in treatment.

*Evaluate the program.* Poll participants informally for feedback. Participants may find a didactic portion informative and helpful, or they may prefer more group interaction. We decided, for example, to stop group relaxation exercises at the end of each session at the suggestion of several group members; participants were primarily interested in group sharing.

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*Mary Gerbracht, R.N., M.S.N., A.O.C.N., is an oncology nurse specialist at St. Paul Medical Center in Dallas, Tex. Laura Potts, Ed.D., C.H.E., is cancer program administrator and Alan Munoz, M.D., is a gynecologic oncologist at the same institution.*