

Pathways to Care for Cancer Patients

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THE HEALTH PROFESSIONS pride themselves on technological advances in care of cancer patients. Yet, in today's environment in which the public is continuously being urged to watch for the "seven danger signals of cancer" and to consult a physician for frequent "cancer checkups," the health professional may easily lose sight of the difficulties the cancer patient encounters in getting to the proper person or facility for definitive care.

Few scientific publications are available regarding the socioeconomic impact of cancer. Grosse (1) examined the cost-benefit ratios of several cancer control programs and found a cost to society of \$2,217-\$46,181 for each cancer

death averted. Grosse's study, however, was not concerned with the structure of the system for care of cancer patients, only with the cost within the present system.

Other studies have dealt with social factors in

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the genesis of cancer (2) and their effect on outcome of treatment (3). Suchman (4) studied the relationship between stage of illness and the seeking of medical care. Kutner and associates (5) reviewed many studies on delay in diagnosis and treatment of cancer; their concern was with patient and physician factors leading to delay. No detailed studies are available concerning pathways a patient might follow to obtain definitive care in a particular community and obstacles to progress along those pathways.

With the preceding considerations in mind, I conducted a study to trace the pathways by which cancer patients reach definitive care in North Carolina. For the purpose of this study, I assumed that any hospital having more than 150 beds was a definitive care facility and that the ideal pathway to care for cancer patients consisted of three steps: (a) primary care physician, (b) secondary care consultant, and (c) hospital.

Study Methods

An interview guide was designed for collection of certain demographic and clinical information, including degree of satisfaction with care received. The guide consisted of the following questions:

1. How did you react to therapy?
2. What did you get from your therapy in the way of sickness, improvement, pain, shortness of breath, or other reaction?

3. Trace the pathways of care for the illness: Who noticed the first symptom? Places of subsequent treatment or consultations: (a), (b), (c)

4. Where did you receive most of your treatment? (in-State medical center, local hospital, other)

5. Were you satisfied with this arrangement? Would you have preferred the majority of your care elsewhere? If so, where?

After the guide was developed, a corps of experienced interviewers was recruited. Each was instructed concerning the purposes of the interviews, methods of eliciting responses to the standard format, and alternative interpretations of questions to be used if respondents failed to understand the original ones.

A request to the North Carolina Cancer Registry (6) for the names of 1970-71 registrants and their physicians yielded a list of 2,730 names. From this list, 426 patients with bronchogenic and epidermal carcinomas were eliminated. Skin cancer is rarely life threatening and thus does not elicit the same emotional response from patients as does cancer of other sites. Since the survival rate among lung cancer patients is so low, its treatment can hardly be called "definitive" (7). Thus, this large group of 426 patients was thought to be unsuited to a search for pathways to definitive care.

The physicians caring for the remaining registrants were then contacted for permission to inter-

Table 1. Distribution of 660 patients by race, sex, age, and diagnosis

Race, sex, and age group	Type of malignant disease						Total
	Ovarian	Hematologic	Lymphomas	Colon	Breast	Other	
Total patients.	25	16	82	154	355	28	660
<i>Race</i>							
White.	12	11	64	122	322	19	550
Nonwhite.	6	4	6	17	33	4	70
Not specified.	7	1	12	15	0	5	40
<i>Sex</i>							
Male.	0	4	29	56	0	15	104
Female.	25	12	45	98	355	11	546
Not specified.	0	0	8	0	0	2	10
<i>Age group (years)</i>							
Under 20.	0	1	1	0	0	0	2
20-29.	0	0	10	2	1	3	16
30-39.	5	0	20	2	34	1	62
40-49.	6	4	18	18	56	4	106
50-59.	4	4	6	28	58	3	103
60-69.	2	4	5	45	57	7	120
70-79.	1	1	3	21	32	5	63
80 and over.	1	0	0	6	6	0	13
Not specified.	6	2	19	32	111	5	175

Table 2. Expressed satisfaction with care of 660 patients with malignant disease treated in North Carolina

Diagnosis	Number	Satisfied		Preference if not satisfied	
		Yes	No	In-State medical center	Other
Carcinoma of ovary.	25	20	5	1	4
Carcinoma of breast.	355	343	12	5	7
Carcinoma of colon.	154	147	7	2	5
Malignant lymphoma.....	82	74	8	4	4
Hematologic malignancies.....	16	14	2	2
Other ¹	28	22	6	2	4
Totals.....	660	620	40	14	26

¹ Excludes skin and bronchogenic cancers.

view their patients. Patients of physicians who refused or failed to respond were also eliminated, leaving a final total of 646 patients and families of 41 deceased patients available for interview. The interviewers then completed 660 interviews from July 1, 1971, through June 30, 1972. A few respondents were interviewed at physicians' offices, but the majority were interviewed at home. Each interview averaged 45 minutes.

Data collected from the 660 interviews were punched into specially coded McBee® cards. Demographic and clinical variables were then tabulated by manual card sorting.

Results

The distribution of interviewed patients, as recorded by tumor registry diagnosis, is shown in table 1; skin and bronchogenic cancers are not represented, as explained earlier.

The respondents' answers to the questions about satisfaction with care revealed that a surprisingly small proportion were dissatisfied (table 2). Among the 40 respondents (6 percent) who expressed dissatisfaction, no single locus was favored overwhelmingly. Fourteen (35 percent of the dissatisfied) would have preferred treatment at one of the university medical centers in North Carolina.

The remaining 26 (65 percent) would have preferred treatment in a different local facility or in one outside the State, such as the National Cancer Institute, M. D. Anderson Hospital, or Memorial Sloan-Kettering Cancer Center. The reasons most often given for failure to reach the desired site for care at a medical center were

financial limitations or lack of transportation. The major stated reasons for failure to go to the local facility of choice were absence of suitable facilities in small communities and closed-staff hospitals in the larger ones.

Of the 355 breast cancer patients, 306 or 86 percent discovered the first evidence of their disease, a percentage somewhat lower than in other studies (8). The first observers of evidence of disease in all 355 patients were as follows:

Observer	Number	Percent of total
Patient.....	306	86.20
Internist.....	9	2.53
Family physician.....	24	6.76
Gynecologist.....	9	2.53
Surgeon.....	2	.56
Orthopedist.....	1	.28
Husband.....	3	.84
Medical center physician.....	1	.28
Total.....	355	99.98

Examination of the sequence in which the breast cancer patients obtained subsequent care revealed some interesting features (fig. 1). Not surprisingly, the family physician or a surgeon was most frequently consulted as the first step. It was of interest that the gynecologist was the next most important source of initial care, being consulted more frequently than the internist.

Additional observations concerning the pathways followed by breast cancer patients are shown in figure 1. Particularly noteworthy is that 38 patients (11 percent) of the original cohort of 355 required four steps before reaching definitive care. More than half the patients, however, had reached a community or medical center hospital by the third step in the care pathway.

More than 90 percent of the 154 colon cancer patients noticed the first evidence of their disease. Here the family practitioner and the internist were the most frequent sources of initial care, although the surgeon was consulted in a significant number of instances, as shown in the following table:

Source of care	Number	Percent of total
Family physician.....	63	40.91
Internist.....	57	37.01
Surgeon.....	20	13.00
Local hospital.....	7	4.55
Gastroenterologist.....	2	1.30
Chiropractor.....	2	1.30
Hospital emergency room.....	1	.65
Minister.....	1	.65
Osteopathic physician.....	1	.65
Total.....	154	100.00

Figure 1. Steps on the care pathway for 355 patients with breast cancer, North Carolina

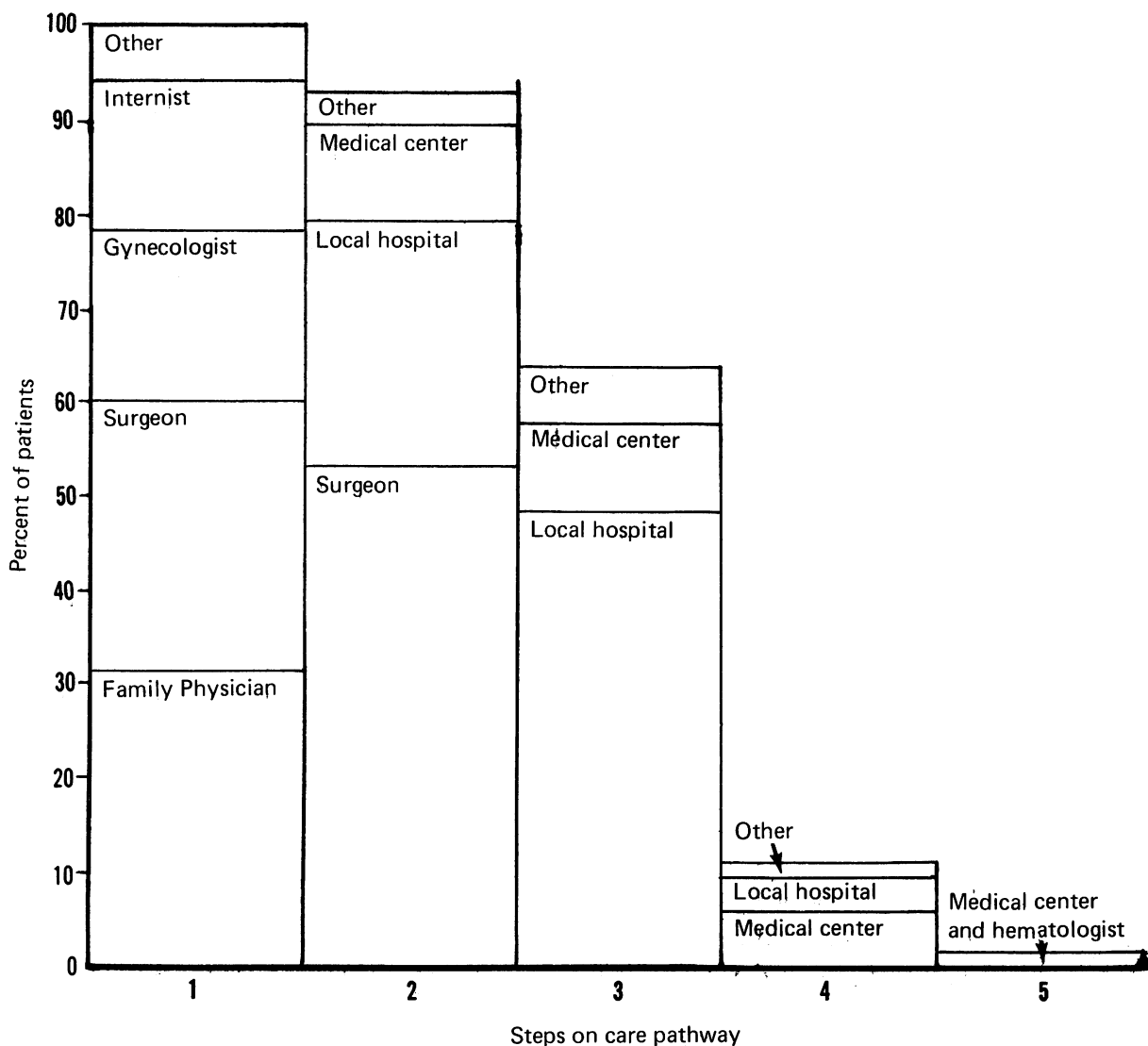
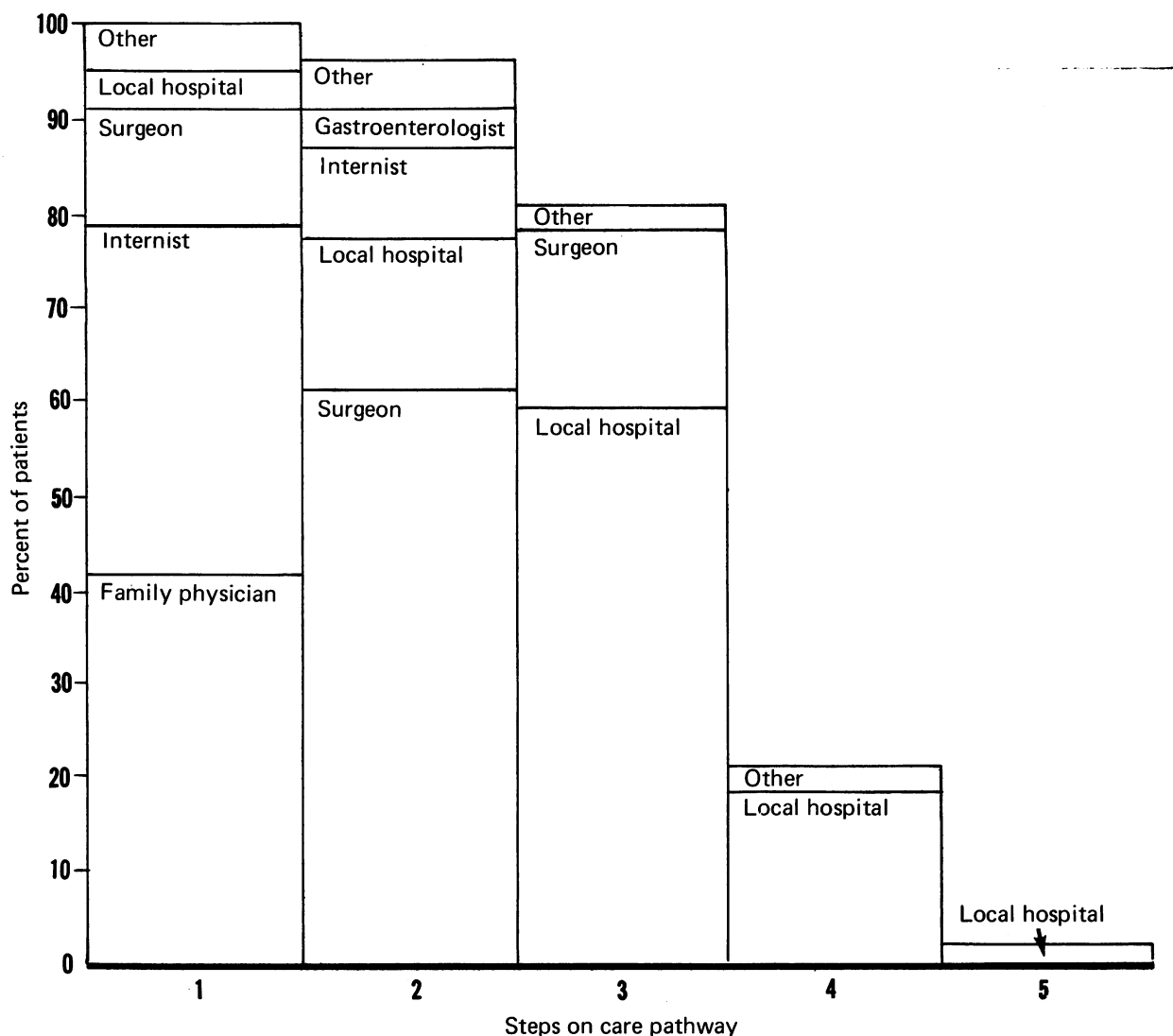


Figure 2 shows that the care pathway for colon cancer patients in North Carolina was apparently somewhat more difficult to traverse than that for breast cancer patients. Although the final step in the two pathways was the same, and the majority of patients reached definitive care in four steps, 20 percent of the original cohort of 154 colon cancer patients apparently did not reach definitive care until the fourth step. In contrast, only 11 percent of the breast cancer cohort required the fourth step to reach definitive care.

The first observers of evidence of malignant lymphoma in 82 patients were as follows:

Observer	Number	Percent of total
Patient.....	76	93.66
Internist.....	3	2.66
Surgeon.....	1	1.22
Family physician.....	1	1.22
Other.....	1	1.22
Total.....	82	99.88

Figure 2. Steps on the care pathway for 154 patients with colon cancer, North Carolina



For this group, as for the colon cancer group, the family practitioner or internist was the most frequent source of initial care. As shown in figure 3, of the original cohort of 82 patients 34 percent did not reach definitive care until the fourth step on the care pathway. Not surprisingly, the hematologist played a larger role in the treatment of patients with malignant lymphomas than in the treatment of patients with colon or breast cancer.

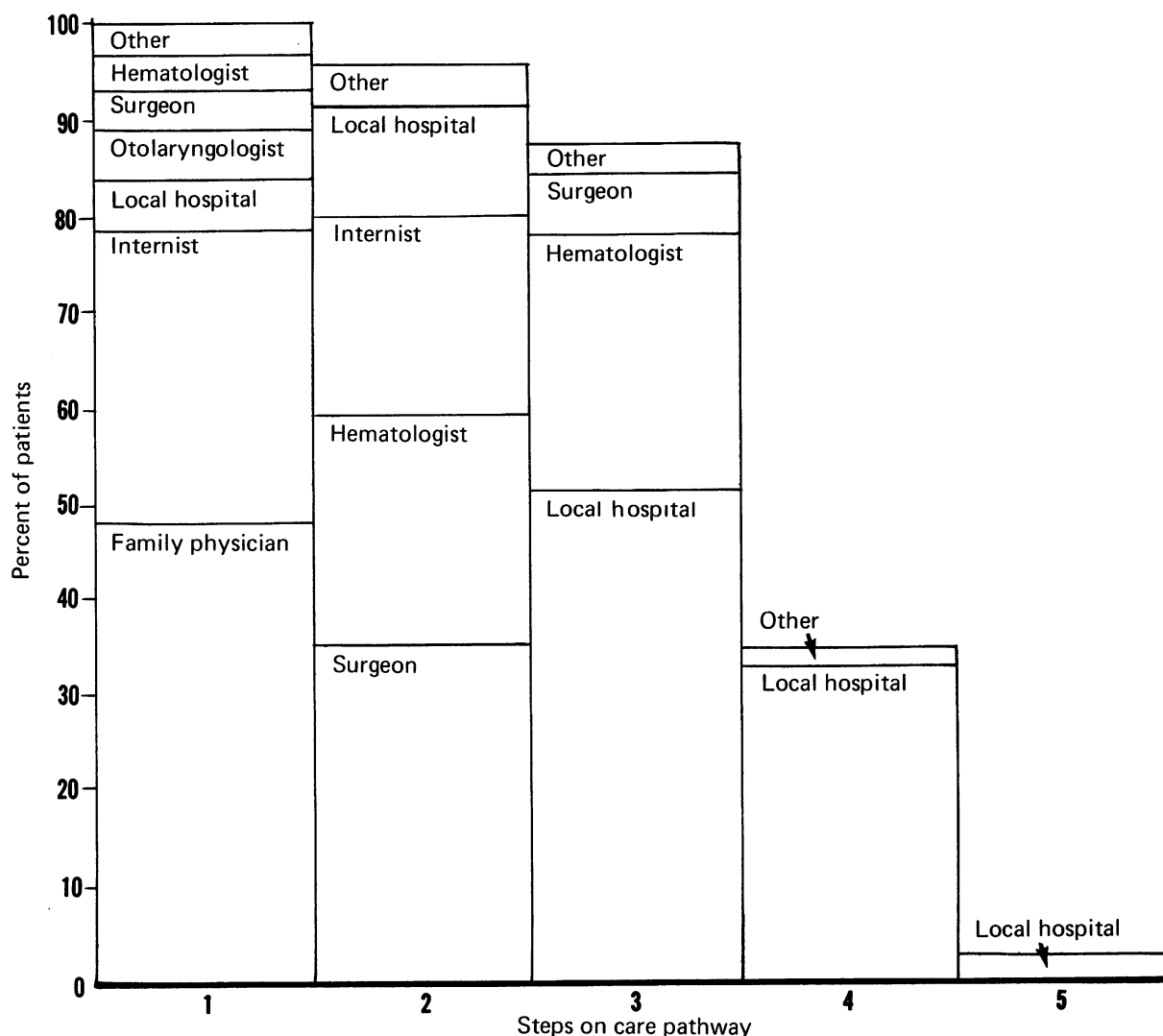
The ovarian cancer group consisted of only 25 patients. Although the number of patients was small, it is worth noting that 12 of the 25 apparently did not reach definitive care until the fourth step on their care pathway.

There were 16 patients with hematologic malignancies such as leukemia and multiple myeloma. Again, this group was too small for detailed analysis. An additional miscellaneous group of 28 patients consisted of 21 with stomach cancer, 4 with malignant melanoma, and 1 each with kidney cancer, prostate cancer, and spindle cell sarcoma. No significant data concerning pathways of care were generated from these groups because of their heterogeneity and small size.

Discussion

There are at least five uncontrolled variables which could determine whether a given patient

Figure 3. Steps on the care pathway for 82 patients with malignant lymphomas, North Carolina



appeared in this study or not. These are:

1. Whether he or she got into the medical care system before death from malignant disease,
2. Whether he or she was entered into the North Carolina Cancer Registry,
3. Whether his or her physician agreed to allow his patients to be interviewed,
4. Whether he or she could be located for interview, and
5. Whether he or she agreed to be interviewed.

Recognizing that there are at least as many more uncontrolled variables which have not been identified, I do not claim that the study sample is truly representative of the population of cancer patients in North Carolina.

The data from this study yield three areas for discussion: (a) patient satisfaction, (b) finder of initial evidence of disease, and (c) pathways to definitive cancer care in North Carolina.

Among patients queried about the quality of their medical care, usually about 10 percent are highly critical (9). In all categories of the present study, the dissatisfaction rate was considerably lower than 10 percent. From this observation, it may be inferred that relationships between cancer patients and their physicians in North Carolina appear to be good. It should be mentioned in this connection that the mechanisms for delivery of medical care to patients in this study were strictly traditional, that is, fee-for-service care in physi-

cians' offices or in hospital outpatient departments.

Initial evidence of disease. Only 86 percent of the breast cancer patients first observed evidence of the disease themselves. Since other reports show that up to 95 percent of breast cancer patients detect their own disease (10), there may be a difference between the patients reported here and those elsewhere. Assuming that the patients in the present study are reasonably representative of North Carolina patients in general, this difference is subject to two alternative explanations: (a) breast cancer awareness is lower among women in North Carolina than elsewhere and they do not examine their breasts as frequently, thus their disease is detected by someone other than themselves, presumably later in its natural history, or (b) cancer awareness is higher among women in North Carolina than elsewhere, and the availability and accessibility of medical care is so high that they consult physicians frequently enough for breast cancer to be detected by physicians before it is detected by the patients. Breast cancer mortality statistics, availability of health manpower, and patients' attitudes about cancer in North Carolina (10) suggest that the first explanation is more likely to be correct.

If one accepts the first explanation, this points to a need for intensified educational programs about cancer care among North Carolina women. Other studies have shown that women who conscientiously examine their breasts do so as a result of demonstrations of the procedure by their physicians rather than as a result of being exposed to educational programs of other sorts (11). This finding and those in the present study add emphasis to the need for further patient education by physicians and also suggest a specific task for physician's assistants or nurse practitioners in the cancer care portion of the system for delivery of medical care.

Regarding the first observer of disease in the colon cancer and lymphoma groups of patients, it was not surprising that the patients with lymphomas most often (94 percent) noted the first evidence of their disease. In patients with colon cancer, contrary to externally manifested disorders such as breast cancer and lymphomas, the first observation of evidence of disease by the patient may be less than optimal. Since colon cancer may exist in occult form for long periods of time, early detection by the physician could predate considerably the onset of symptoms noticeable by

the patient. The inclusion of screening for occult blood in the stool as a portion of "routine" examinations could improve the early detection rate for colon cancer (12).

Pathways to definitive cancer care. As pointed out by Whitted (13), formidable obstacles block the use of cancer care services. Among these are the educational level of the people to be cared for, the structure of our society, and the fear of detection of a disease known to be associated with hopelessness and suffering in many instances. To these, based on the present study, a further obstacle should be added: the difficulty experienced by the uninitiated consumer in traversing the proper pathways through the cancer care system itself.

A comparison of the pathways to definitive care for the three large groups of patients is shown in figure 4. Since there are no data available concerning pathways a patient might follow in an optimal system, there are no standards against which one might compare pathways. Although there are differences in the diseases represented, and certainly there are dimensions of care other than the number of steps involved in achieving it, the differences in these pathways should be explored. Why, for example, have 98.5 percent of the breast cancer patients reached definitive care in three steps while only 70 to 80 percent of the colon cancer and lymphoma patients have done so? Why are lymphomas and breast cancer, both externally manifested diseases, not more nearly alike in the pathways to care followed by affected patients? These are merely a few questions raised by these statistics.

Ideally, it would seem that the pathway to definitive care for each of these diseases should consist of no more than three steps: (a) primary care physician (family practitioner, internist), (b) secondary care consultant (surgeon), and (c) hospital. That many patients required more than these three steps may be due to the complexity of the cancer care system.

The first steps on the care pathways may represent particularly fertile ground for improving efficiency. Of 355 breast cancer patients, 124 who found a breast mass went first to either an internist or gynecologist. While consideration, therefore, should be given to intensified training in evaluation and management of breast masses in residency programs for medicine and gynecology, a less obvious implication may relate to patient

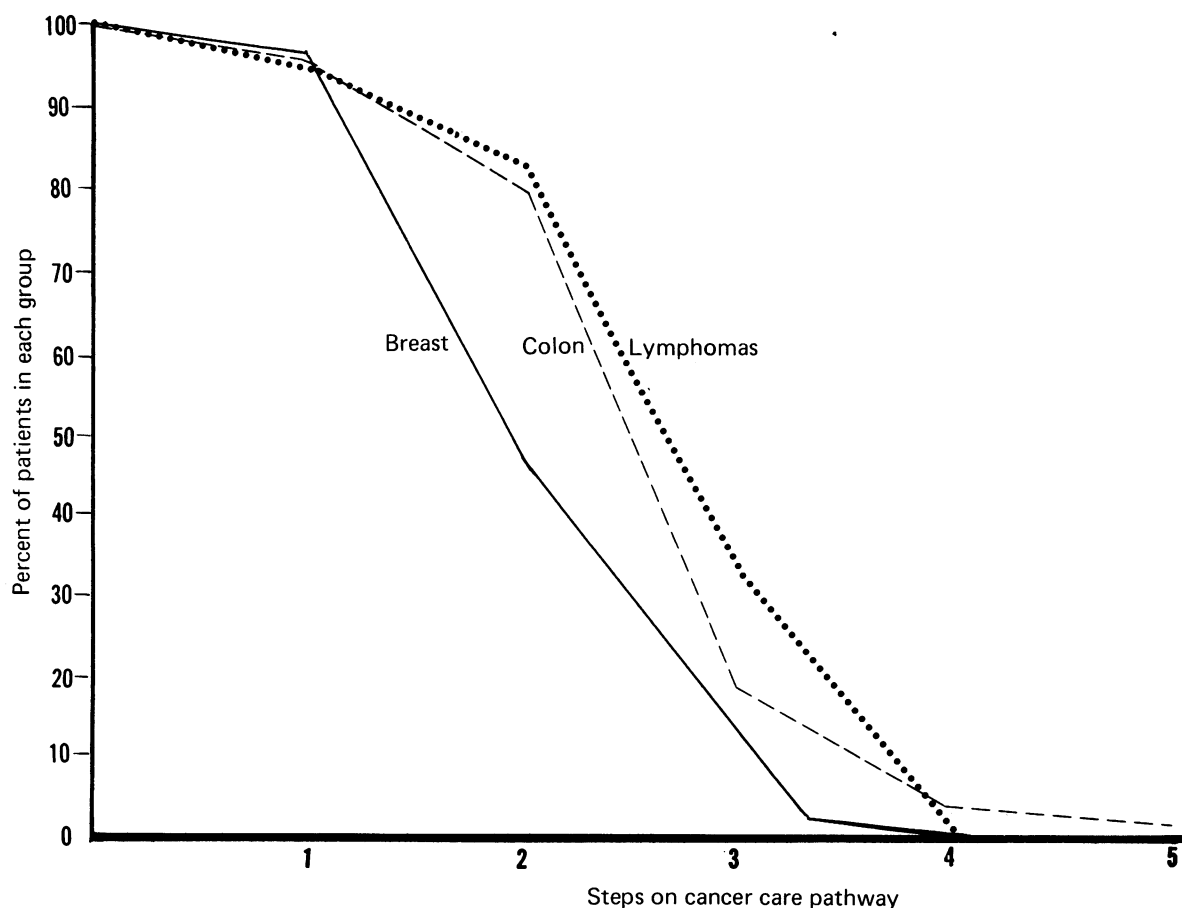
education. Perhaps patients should be encouraged to go directly to a surgeon on finding a breast mass. This would eliminate a step on the care pathway for many patients, shorten the timespan of diagnosis and therapy, and perhaps improve the outcome of the disease. At the same time it would place a greater burden on surgeons for careful nonoperative evaluation of such patients. An alternative which might shorten time spent would be a continuous community screening program for high-risk women, so that a breast mass could be evaluated quickly by physician's assistants or nurse practitioners and the patient referred quickly. Analogous programs for other types of malignant disease could be created without great difficulty (14).

With the exception of the small number who required a fifth step to arrive at definitive care, most of the colon cancer patients seemed to get

to definitive care with reasonable dispatch. It is disturbing to note, however, that 2 of the 154 patients, both of whom had rectal bleeding, elected to consult a chiropractor for their symptoms. A third such patient first consulted an osteopathic physician (in many areas this might be appropriate, but North Carolina law limits osteopathic physicians to the use of nonoperative and non-prescriptive methods). The first steps taken by these three patients suggests a need for better public education about the symptoms of colon cancer and the practitioners best equipped to deal with them.

One extremely important variable not considered in this study is that of time. The data are simply not available to answer certain pertinent questions such as: What is the total time elapsed from initial observation of signs or symptoms to completion of definitive care? What is the time

Figure 4. Cumulative percentages of patients arriving at definitive care, by steps on the care pathway, North Carolina



required for each step on a particular pathway? With this kind of information in hand, it should be possible to design or modify programs which will allow cancer patients to reach effective care in the most efficient manner.

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A study was conducted to trace the pathways by which cancer patients in North Carolina reach definitive care. It was assumed that any hospital having 150 or more beds was a definitive care facility and that the ideal pathway to cancer care consisted of three steps: (a) primary care physician, (b) secondary care consultant, and (c) hospital.

From the names of 1970-71 registrants in the North Carolina Cancer Registry, a list was compiled of 687 patients or families available for interview. Trained interviewers using a standardized format conducted 660 personal interviews of cancer patients or families of deceased cancer patients. Data tabulated from these interviews showed that 25 patients had carcinoma of the ovary, 16 had malignant hematologic disorders, 82 had malignant lymphomas, 154 had carcinoma of the colon, 355 had carcinoma of the breast, and 28 had miscellaneous malignant disorders. All patients had received their cancer care in North Carolina. Only 40 patients (6 percent) expressed

dissatisfaction with their care. First evidence of disease was noted by 86 percent of the breast cancer patients, 91 percent of the colon cancer patients, and 94 percent of the lymphoma patients.

Tracing the care pathways followed by patients in the three largest groups showed that 4.21 percent of the breast cancer, 4.5 percent of the colon cancer, and 4.9 percent of the lymphoma patients reached definitive care in one step. The majority of patients in all three groups (69.5 to 98.5 percent) reached definitive care in two or three steps, although substantial numbers required four, and some colon cancer patients required five steps.

Compared with the hypothetical system of three steps, it was concluded that many patients do not arrive at definitive care for cancer in the most efficient possible manner. Further data are needed, with particular attention to the time variable, before the medical care system can be modified to provide the cancer patient with the most effective care in the most efficient manner.