

**Clinical Research and Methods**

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# Physicians' and Patients' Views of Cancer Care by Family Physicians: A Report From the American Academy of Family Physicians National Research Network

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**Background and Objectives:** *There has been little research describing the role of family physicians in the care of patients with an active diagnosis of cancer. **Methods:** Using qualitative methods, we interviewed 15 family physicians and 15 of their cancer patients. We asked physicians about care of cancer patients in general and of the specific patient included in this study. Patient interviews focused on the role their family physician played in their care and their satisfactions and frustrations with that care. **Results:** The physicians reported coordinating referrals, providing general medical care, helping with decisions, and providing emotional support. Their involvement was more intense at the time of diagnosis and near death. The patients gave similar responses and also said they valued clear explanations and spending time with and feeling comfortable with their family physicians. **Conclusions:** Family physicians fulfill a number of important roles in caring for their patients with an active diagnosis of cancer. More research using representative samples is needed to determine the generalizability of these findings, but this study gives us some preliminary insight into the role family physicians play in cancer care.*

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Family physicians have many responsibilities in cancer care, including prevention, screening, diagnosis, and general medical care of cancer survivors. However, the role of family physicians in providing care for patients with an active cancer is less well defined. In the United States, medical and radiation oncologists, surgeons, and their care teams deliver curative and palliative cancer treatments, usually without direct involvement of family physicians. Care for cancer patients under active treatment is nonetheless regularly provided by family physicians in the form of emotional support and advice about treatment alternatives, as well as ongoing care for chronic and acute conditions not directly related to the cancer. Additionally, many family physicians resume primary medical management of cancer patients near death, directing hospice and palliative care.

In 2002, the American Academy of Family Physicians published *Family Physicians and Cancer*, a monograph for family physicians containing important information about cancer.<sup>1</sup> Discussion of the role of family physicians in the care of their cancer patients during active treatment is conspicuously absent from this monograph. This omission is not surprising, given the paucity of publications on this topic. A MEDLINE search from 1966 through September 2005 for original research regarding the role of family physicians in caring for cancer patients during active treatment yielded only 17 studies from the United Kingdom, Europe, and Canada,<sup>2-18</sup> and none from the United States. We found studies of the incidence of cancer in general practices,<sup>2</sup> the frequency of cancer-related office visits,<sup>3</sup> the potential role of general practitioners in follow-up of breast cancer patients in remission,<sup>4-8</sup> family physicians' perspectives on cancer care services,<sup>9,10</sup> patients' perspectives on the appropriate roles of specialist and generalist physicians in cancer care,<sup>11-14</sup> the effect of family physician continuity and rate of emergency department visits for end-of-life cancer care,<sup>15</sup> com-

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munication between cancer specialists and family physicians,<sup>16,17</sup> and psychological dilemmas of generalists in caring for cancer patients.<sup>18</sup> The absence of studies of the role family physicians play in cancer care in the United States was striking. To begin to address this gap, we undertook a qualitative study designed to explore the role of family physicians in providing care for their patients with an active diagnosis of cancer.

## Methods

### *Physician and Patient Selection*

In January 2002, physicians were invited to participate in this study through a notice posted to the 95 family physicians subscribed to the listserv of the American Academy of Family Physicians National Research Network. The notice sought family physicians willing to be interviewed about their care of patients with cancer and who could recommend one of their cancer patients to be interviewed as well. The first 15 physicians who responded were sent a consent form and project description via e-mail, and each one consented and participated in the study. Next, they were asked to specifically identify one of their patients in active treatment for cancer as a potential interviewee. The patients were then telephoned and invited to participate in the study. All but one of the 15 patients we contacted agreed to participate. The one patient was not enthusiastic about participating, and the physician identified a replacement.

All interviews were conducted by one interviewer, and all were conducted by telephone. Each subject gave written informed consent to be interviewed. Interviews were open-ended following a semi-structured interview guide. Not all physicians and patients were asked all questions. Rather, due to the exploratory nature of this study, we were interested most in what the physicians and patients offered spontaneously.

Each interview took 25 to 45 minutes and was tape-recorded and transcribed. Physicians' interviews focused on their role in diagnosis and treatment of their patients with cancer and included questions about the availability of cancer health care services in their area. The interviewer told each physician: "We want to focus on your role in caring for your patients with cancer, starting with the time of diagnosis until the patients' death and even after if you like. I would like you to answer the questions in general first and then as they pertain to your patient who has agreed to be interviewed, too." Patient interviews focused on the role their family physician played in their care as well as their satisfactions or frustrations with that role. The University of Missouri-Kansas City Social Sciences Institutional Review Board approved the study protocol.

## Data Analysis

We established a method for standardizing and displaying interview data, as illustrated in Miles and Huberman,<sup>19</sup> and conducted content analysis as described by Bernard.<sup>20</sup> Analysis took place in several steps. First, one researcher organized blocks of text (quotations and summations) into display tables of the main topical areas covered in the interviews for each subject. Next, two other researchers reviewed these tables and identified thematic patterns, such as types of roles reported or types of goals and strategies discussed. Finally, all three researchers cross-checked all phases of analysis in conference sessions in which they reviewed emerging findings and analysis strategies, discussed specific cases, and reached consensus about how to apply coding categories. Anomalies or discrepancies in coding procedures were addressed and resolved during these sessions, and case material was reviewed to spot-check for consistency in coding and classification procedures.

## Results

Table 1 summarizes the characteristics of the physicians we interviewed. All of the physicians were white. Some characteristics of the 15 patients we interviewed are summarized in Table 2. Most were older, white, middle-class women with health insurance.

Table 1

Selected Characteristic of the 15 Family Physicians Interviewed

<i>Characteristic</i>	<i>Number</i>
Gender	
Male	12
Female	3
Age	
30–40	1
41–50	8
51–60	6
Years in practice	
1–10	4
11–20	8
21–30	3
Community size	
< 10,000*	6
10,000–25,000 <sup>†</sup>	4
25,000–100,000	3
>100,000	2
Medical oncologist in community	10
Radiation oncologist in community	9
Hospice (or similar) program in community	15

\* One community in this category was within 25 miles of a major city.

<sup>†</sup> One community in this category was within 25 miles of a major city.

Table 2

Selected Characteristics of the 15  
Cancer Patients Interviewed

<i>Characteristic</i>	<i>Number</i>
Gender	
Male	3
Female	12
Age	
40–55	3
56–70	8
71–85	4
Race/ethnicity	
White	14
African American	1
Diagnosis	
Breast	6
Colon	2
Brain, melanoma, ovarian, prostate, rectal	1 each
Multiple cancers	2
Cancer treatment at time of interview	
Active	11
Complete	4
Years of education	
>11	1
12–14	11
15 +	2
Data missing	1
Insurance	
Private	8
Medicare, Medicaid, or other public	3
Both private and public	4
Annual household income	
< \$25,000	4
\$25,000–\$49,000	6
> \$49,000	2
Data missing	3

*Family Physician Interviews*

**Types of Care Provided.** The range of responses provided by the physicians is listed in Table 3. Seven physicians commented that they provide general care and treatment of problems unrelated to the cancer. Examples included monitoring chronic medical conditions such as diabetes and high blood pressure. They provide and coordinate referrals, are involved with their cancer patients' hospitalizations, and two family physicians assist in surgery of their cancer patients. Several physicians in rural areas commented that the distance to the hospital prevented them from having regular involvement with hospitalized patients.

Table 3

Their Role in Care of Cancer Patients Mentioned  
by 15 Family Physicians During Loosely  
Structured Phone Interviews, From Most  
Frequently to Least Frequently Cited\*

<i>Role</i>	<i>Number of Physicians Who Mentioned This Issue</i>
Assist in pain management	15
Involved in terminal care	15
Coordinate referrals	11
Provide general care	7
Involved at the beginning and the end	7
Help with decisions	6
Provide emotional support	5
Explain	4
Degree of involvement varies	4
Work with subspecialists	2
Handle complications and follow-up	2

\* The physicians gave these responses spontaneously. They were not questioned about each area.

Almost all of those we asked (12/13) said they made home visits to their patients with cancer. One physician gave an example of a patient with lung cancer whom he visited two or three times per week and then daily for the last few days of life. He said that he visited to “see how things were going, if there were any medications needed or to discuss with the family, and how they felt he [the patient] was doing.”

All 15 physicians indicated they play some role in pain management, but they reported doing so to varying degrees. One physician pointed out that his involvement in pain management tended to increase toward the end of the patient's life. Another noted that he managed pain for 90% of his cancer cases. All 15 said they were involved at some level in the terminal care of their cancer patients. Eight said they directed terminal care, and 10 mentioned that they were involved with hospice care. Seven physicians noted that their involvement with cancer patients was greatest in the beginning stages of the disease and again toward the end of life.

**Emotional and Supportive Care.** In response to our question about how often physicians break the news about a cancer diagnosis to their patients, the majority (14/15) responded that it was not possible to break the news themselves in all cases. Several physicians

(6/15) indicated that the news about cancer is related to patients by the doctor who makes the diagnosis. One doctor reported that he always informs the patient of the diagnosis. Six explained that their role included helping patients make decisions, particularly regarding cancer treatment options. In contrast, three physicians said that their patients rarely or never sought their advice in treatment decisions.

When we asked the physicians what questions their cancer patients typically ask them, most (12/15) commented that their patients frequently want information and advice about how to proceed and what to expect. One physician said, "It can be anything from what's the best choice to do, or should I or should I not have this done." Six noted that patients asked to have their disease explained, and five mentioned that patients asked about their prognosis.

When we asked the physicians to reflect on their philosophical views in caring for patients who have cancer, six discussed the importance of being realistic and honest with their patients who have cancer, especially regarding treatment options and the effectiveness and side effects of those treatments. Five discussed the importance of being hopeful and reassuring, and two indicated that they strive to be both hopeful and realistic.

*Patient Interviews*

When we asked the cancer patients to describe the role played by their family physicians in their medical care (Table 4), 12 said that they saw or communicated with their family physician regularly. The following comment illustrates the types of interactions patients described:

I have high blood pressure. So I usually go for that, and then after I had the surgery they had sent me back to him just for a check-up. And then, since that I've had radiation I go to him usually every 6 weeks for blood pressure . . . There's been a couple of times he hasn't seen me in so long that he would call up to the office and talk to my husband and ask him how I was doing.

Four said their family physician had played a role in the diagnosis of their cancer, and four mentioned that their physician managed symptoms or complications. For example, one patient explained that her physician treated side effects resulting from a medication.

Other patients explained that they saw their family physician for pain management, annual exams, or for post-surgery care. Four patients commented that their family physician was in regular contact with their specialists. Four commented that their family physician had been involved in their care while they were in the hospital, assisting with surgery, visiting, or calling. While most appreciated this involvement,

Table 4

Roles and Qualities of Their Family Physicians, as Described by 15 Cancer Patients in Loosely Structured Phone Interviews, From Most Frequently to Least Frequently Mentioned\*

<i>Patient Satisfied Because:</i>	<i>Number</i>
Understanding/caring/supportive	10
Patient comfortable with family physician	8
Explains things clearly	5
Takes time with patients	4
Skilled and knowledgeable	3
Went above and beyond the norm	2
Provided good referrals	2
Honest	1
Provides guidance and information	1
Physician has faith/spirituality	1
* Patients volunteered these responses spontaneously. They were not questioned specifically about each of these roles and qualities of their physicians.	

one found her family physician's hospital visits to be an unnecessary expense because the specialists were providing adequate care.

Five of the patients indicated that their family physician counseled them, discussed their disease and other concerns, or simply listened. One patient said:

Yes, in the beginning I went to him, and he said at my age, I could die with something else if I didn't want to proceed with this radiation treatment . . . So I talked to him extensively about whether to proceed with anything.

When we asked patients what made them satisfied or dissatisfied with the care provided by their family physicians, all expressed satisfaction with a number of issues (Table 4). At this point, patients began describing affective qualities of their physicians in addition to specific roles. Many pointed to the supportive, caring, or understanding nature of their physician. More than half (53%, 8/15) said they felt comfortable with their family physician, and some commented that, because of their history together, they knew each other well. Four said their physician's willingness to take time with them was especially satisfying. One noted:

Every time that I would go to him for my 4-month visit he would sit and talk with me the whole time and ask how everything was going and the treatments and

the side effects. He didn't just rush me in and out. He really, really was very concerned.

Other sources of satisfaction that patients mentioned included the family physician's skills and knowledge, giving good referrals, and going above and beyond what is normally expected. Patients also commented on their doctors' honesty, spirituality, guidance, and information sharing.

Only three patients expressed any dissatisfaction with the care provided by their family physician. One was displeased with being attended by students. Another patient was upset at not having been prepared for the diarrhea that occurred as a side effect of treatments. Two patients expressed dissatisfaction with the length of time taken to make the diagnosis. One patient talked about her frustration with herself and her family physician for the delay in diagnosis of her ovarian cancer and subsequent discovery of metastatic disease. The physician of this patient also mentioned the late diagnosis in her interview. She explained that the patient asked her if the late detection of the cancer was attributable to a mistake. The physician had discussed the difficulties in diagnosing ovarian cancer with the patient and listened to the patient's concerns. Still, the patient's comments clearly show that her frustration had not been assuaged by this explanation.

#### *Interview Pairs*

For the most part, patient and physician descriptions of physicians' involvement coincided. For example, a colon cancer patient and her physician both described their frequent contact, the general medical care provided by the family physician, and the physician's communication with the patient's family. In another case, a patient explained that her physician was always honest with her. This is consistent with her physician's comments about the need to discuss death honestly with patients. Similarly, one physician-patient pair emphasized spirituality, and the patient specifically referred to his physician's "strong faith." In some interviews, both the physician and the patient touched on aspects of the patient's personal life, such as the recent death of a family member.

In nearly all instances where they discussed the same issue, comments of patients and physicians were concordant. For example, there were no cases where physicians claimed to consider emotional support to be an important aspect of their role, while the patient indicated that the family physician was not supportive. One exception, however, was in communication with specialists regarding cancer treatment. While some physicians expressed a general concern regarding the challenge of staying "in the loop," most of their patients indicated that they thought their physician had regular communication with their cancer doctor. For example,

a breast cancer patient described her physician's communication with both the surgeon and the oncologist, while the physician expressed concern about his ability to stay updated regarding his patient's care.

#### **Discussion**

Despite the lack of empirical data to support their assertions, medical educators have described a role for generalist physicians in cancer management.<sup>21-23</sup> Brotzman recommends these roles and responsibilities for generalist physicians: be a case manager, maintain regular contact, be available, have knowledge of community resources, have knowledge of covered services, address ongoing health maintenance needs, manage pain appropriately, assess for pathologic depression, be aware of therapeutic options, and communicate with and support cancer patients and their families.<sup>23</sup> He calls on generalist physicians to provide comfort and emotional support, ensure continuity of care, monitor the status of the patient, and ensure that excellent communication occurs among various members of the medical team, the patient, and the family. He states that generalists must act as:

... a medical interpreter or as ambassador for patients in a foreign land. Primary care physicians need to encourage the creation of new relationships with other caregivers, supporting their credibility as players with clout in this new paradigm.

Our study provides some preliminary empirical evidence to support Brotzman's assertions. The family physicians we interviewed reported that they fulfill all of these roles and responsibilities, although not every physician did so for every patient. The role played by these family physicians in the care of individual patients clearly seems to be dictated by a combination of the particular patient's needs and the physician's inclination and availability. Our data also show considerable variability among these patients in their desire to have their primary care physician involved in active cancer care and in the level of family physician involvement they report. Yet, some aspects of care were addressed by nearly all of those we interviewed. Three fourths of the physicians provided and coordinated referrals to specialists. Half mentioned that they provided general medical care. All said they were involved in aspects of terminal care. We found family physician involvement to be more intensive at the beginning and end of treatment (diagnosis and referral and terminal care or resumption of regular care after cancer treatment.)

The purpose of this study was to begin an exploration of the landscape of care provided by family physicians in the United States for their patients with an active diagnosis of cancer. Understanding the role the family physician plays in cancer care is increasingly

important as health care delivery systems around the world reorganize to provide the best care possible with limited resources. In a critique of five different service delivery models for integrated cancer care, the “shared care” model was found most effective.<sup>24</sup> In this model, generalists play a central role in integration and direct provision of care. If we are to improve care delivery for cancer patients we must better understand the ways both patients and physicians view the family physician role and the interface between primary and specialty care. In a randomized trial, a shared care program in which general practitioners and patients were actively involved had a positive influence on patients’ attitudes toward the health care system of Denmark.<sup>25</sup>

### Limitations

Due to the small convenience sample we studied and the open-ended methodology used in this study, our findings are preliminary and cannot be generalized. We included no minority physicians, the patients were predominantly white and from middle-class households, and the communities included were relatively small. Further, because the physicians selected the patients we interviewed, they may be biased in favor of their physicians. Therefore, we were unlikely to elicit criticisms or areas of conflict between the patients and their physicians.

### Conclusions

Further systematic research with representative samples of physicians and patients is needed to test the generalizability of our findings. Future research also could explore what proportion of generalist physicians in fact fulfill the various roles we have described and for which Brotzman advocates. Finally, we do not know the optimal role of generalist physicians in caring for their patients with an active diagnosis of cancer. Our data suggest that one size does not fit all. Patients’ needs vary, and primary care physicians need to be flexible. The appropriate roles are likely to vary depending on the local health care system as well. Our data does suggest that cancer patients should expect to receive competent general medical care, advice regarding treatment, care coordination, pain management, and end-of-life care and emotional support from their primary care physicians.

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