

Views of Primary Care Providers on Follow-up Care of Cancer Patients

Mary Jo Nissen, PhD, MPH; Mary Sue Beran, MD; Martin W. Lee, MD;
Shubha R. Mehta, MPH; Donald A. Pine, MD; Karen K. Swenson, PhD, RN

Background and Objectives: Primary care providers (PCPs) are often involved in the care of cancer survivors. This study asked PCPs about their role in the follow-up care of breast and colorectal cancer patients and elicited opinions on improving the transfer of care from oncologists to PCPs. **Methods:** A total of 175 PCPs in a large health care system with an electronic medical record system were mailed a questionnaire that addressed (1) their comfort and confidence regarding surveillance for cancer recurrence, (2) when patients should be seen in primary care, (3) evaluation of the transfer of care, (4) potential problems with that process, and (5) suggestions for improving that process. **Results:** The response rate was 75.4%. Overall, 52% were comfortable having responsibility for surveillance of cancer recurrence, and 43% were confident they are following standard guidelines for cancer recurrence. Both of the aforementioned measures increased with years of practice. More than half rated the current transfer of care from oncologist to PCP as fair or poor. The most common problems identified were uncertainty regarding the type (62.6% for breast, 56.5% for colorectal), frequency (72.5%, 66.4%), and duration (74.8%, 67.2%) of surveillance testing. **Conclusions:** Levels of comfort, confidence, and satisfaction were generally low. PCPs need more specific guidance regarding surveillance for cancer recurrence.

(Fam Med 2007;39(7):477-82.)

The number of cancer survivors in the United States exceeded 10 million in 2002. Of these, more than 2 million were breast cancer survivors, and more than 1 million were survivors of colorectal cancer.¹ By 2050, the number of cancer survivors is expected to double due to population growth, the aging of “baby boomers,” improved detection of cancer through screening, and better cancer treatment.² Most survivors will need follow-up care to monitor for recurrences and second cancers.

The Institute of Medicine recently published a report that addressed the unique medical and psychological needs of cancer survivors and various models for their care.² The subtitle of the report, “Lost in Transition,” highlights the situation many patients face when they complete their cancer treatment. One of the four essential components of survivorship care outlined in

the report is the coordination of care between cancer specialists and primary care providers (PCPs) so that all health care needs are met.

In current practice, patients with early-stage breast and colorectal cancer are typically seen by oncologists for routine follow-up after completing cancer treatment. However, randomized trials showed that early-stage breast cancer patients who are followed instead by their family physician have equivalent medical and psychosocial outcomes.³⁻⁵ In addition, patients followed by a primary care physician as well as an oncologist are more likely to receive recommended preventive care for noncancer concerns than those followed by an oncologist only.⁶ These results suggest that primary care physicians should play a larger role in follow-up care for cancer survivors.

Views of PCPs regarding the current transfer of care are not well known. We sought to address three issues: (1) their comfort with and confidence in providing follow-up care, (2) how soon following cancer diagnosis such patients should return to primary care, and (3) problems PCPs perceive in the transfer of follow-up care

From Oncology Research (Drs Nissen, Lee, and Swenson, and Ms Mehta), Department of Internal Medicine (Dr Beran), and Department of Family Medicine (Dr Pine), Park Nicollet Health Services, Minneapolis.

from medical oncologists to PCPs. The survey focused on the care of breast and colorectal cancer survivors because they are large patient populations with good survival rates and thus seemed to be particularly likely to be seen by PCPs for follow-up.

Methods

Study Setting and Population

Park Nicollet Health Services (PNHS) is an integrated nonprofit health care system in the Minneapolis metropolitan area. It includes a 426-bed hospital and 25 urban and suburban clinics. Since 2001, PNHS has had an integrated electronic medical record (EMR) system, and providers throughout the system access patient records electronically to view consultation reports, progress notes, laboratory results, radiology results, and medication records.

The PNHS Cancer Center has on staff nine medical oncologists and three nurse practitioners (NPs). In 2004, 1,669 patients were diagnosed and/or treated for cancer at Park Nicollet; of these, 467 had breast or colorectal cancer. Patients are generally followed in the Cancer Center for more than 2 years following the end of chemotherapy regardless of stage of disease, although there is some variation in length of follow-up depending on the specific oncologists involved. The involvement of PCPs during this time period also varies, with some patients seeking primary care only as urgent care while others have regular primary care visits along with regular oncology follow-up visits.

Primary care is provided by 175 providers in the departments of family medicine (83 physicians, eight NPs, and nine physician assistants [PAs]) and internal medicine (67 physicians, five NPs, three PAs). All of these 175 providers were included in the study population.

Questionnaire

The questionnaire consisted of 25 items. Two items asked PCPs how comfortable they are in having responsibility for the surveillance of cancer recurrence in patients with breast or colorectal cancer. Two items asked how confident they are that they are following standard guidelines for surveillance. Each of those four questions used an ordinal 5-point scale anchored at both ends and ranging from 1 (very uncomfortable/not confident at all) to 5 (very comfortable/very confident). PCPs were also asked when the patient should be seen in primary care following cancer diagnosis (five multiple-choice alternatives) and to give a general evaluation of the transfer of care process (four multiple-choice alternatives).

The questionnaire included three lists of possible problems with the transfer of care, one applying to the care of patients with breast cancer, one applying

to patients with colorectal cancer, and one applying to patients with either diagnosis. PCPs were asked to check any of these 13 potential problems they believe exist with the current process.

Finally, the questionnaire included four demographic questions and two open-ended questions soliciting comments on ways to improve the process of transferring care from oncologists to PCPs. The content and format of the questionnaire were critiqued by a family physician, an internist, a medical oncologist, and an oncology nurse, and modifications were made before using the questionnaire for the study.

Survey Methods

The distribution of the questionnaire followed a modified Dillman⁷ procedure. A cover letter, the questionnaire, and a postage-free return envelope were mailed to all PNHS PCPs. Two weeks later, a modified cover letter, the questionnaire, and another postage-free return envelope were mailed to all nonrespondents.

The questionnaires were numbered so that nonrespondents could be identified and encouraged to reply, but respondents were otherwise anonymous. The Park Nicollet Institutional Review Board approved the study.

Statistical Analysis

Descriptive statistics included frequencies, median, and range. Percentages and 95% confidence limits were calculated for response variables. Responses regarding comfort and confidence in providing follow-up care were categorized as "yes" for responses of 4 or 5 and otherwise "no."

Associations between dichotomous response variables and demographic variables were assessed in univariate and multivariate analyses using logistic regression. Associations between multi-level response variables (preferred time of first appointment and evaluation of transfer of care) and demographic variables were assessed using chi-square.

Comparisons of PCPs' responses regarding breast versus colorectal cancer and surveillance for recurrence versus side effects of treatment used McNemar test. Qualitative data from the open-ended questions were categorized by content.

Results

Respondent Demographics

Of the 175 PCPs in the population, 132 (75.4%) responded. Demographic characteristics of those who responded are summarized in Table 1. PCPs indicating they provide follow-up care for breast or colorectal cancer patients were more likely to be a physician (MD) or an NP than a PA ($P < .0001$).

Table 1

Demographic Data on 132 Responding Primary Care Providers

Characteristic	#	%
Specialty		
Family medicine	80	60.6
Internal medicine	52	39.4
Credential		
MD	107	81.1
Nurse practitioner	13	9.8
Physician assistant	12	9.1
Provides follow-up care for breast or colorectal cancer patients		
Yes	108	81.8
No	19	14.4
No response	5	3.8
Years of practice		
Median	10	
Range	1–49	

Comfort and Confidence Regarding Surveillance for Recurrence

Results of questions about PCPs' comfort with and confidence in surveillance for cancer recurrence are shown in Table 2 as the percentage of respondents indicating they were comfortable/confident or very comfortable/confident. On average, 52.0% were comfortable or very comfortable in having responsibility for the surveillance of cancer recurrence, and 43.0% were confident or very confident they are following standard

Table 2

Primary Care Providers' Comfort and Confidence Regarding Surveillance for Cancer Recurrence

Question	Percent*	95% CI
Comfortable with having responsibility for surveillance		
• for breast cancer recurrence	48.8	40.3–57.4
• for colorectal cancer recurrence	55.1	46.4–63.5
Confident following standard guidelines for surveillance		
• for breast cancer recurrence	40.6	32.5–49.3
• for colorectal cancer recurrence	45.3	36.9–53.9

CI—confidence interval.

* Percent of respondents who indicated 4 or 5 on a scale of 1=very uncomfortable/not confident at all to 5=very comfortable/very confident.

guidelines for surveillance for cancer recurrence. These percentages did not differ significantly for breast versus colorectal cancer.

On univariate analysis, all four comfort and confidence measures were significantly associated with years of practice ($P < .03$ for all items). PCPs who have practiced longer indicated more comfort and confidence. None of these measures was significantly associated on univariate analysis with PCP specialty (family medicine or internal medicine), credential (ie, MD, NP, or PA), or with whether the PCP provided follow-up care.

Multivariate logistic regression analyses revealed significant effects of years of practice on all four measures (all $P < .015$). There were no significant effects of PCP specialty, credential, or whether the PCP provided follow-up care.

Preferred Time of First Primary Care Appointment

The time when PCPs would prefer to see patients for the first time following a diagnosis of breast or colorectal cancer was distributed across response alternatives as follows: 18.0% indicated during treatment, 36.1% within 3 months after treatment, 14.7% within 6 months after treatment, 17.2% within 1 year after treatment, and 13.9% between 1 and 2 years after treatment. This pattern did not vary with PCP specialty, credential, years of practice, or whether the PCP provided follow-up care.

Evaluation of Transfer of Care From Oncologist to PCP

When asked to evaluate the current process of transfer of care from the oncologist to the PCP, 8.4% described it as poor, 48.7% fair, 34.4% good, and 8.4% excellent. There were no significant associations between this evaluation and PCP specialty, credential, years of practice, or whether the PCP provided follow-up care.

A substantial majority of PCPs expressed uncertainty about the type, frequency, and duration of surveillance testing (Table 3). For both breast and colorectal cancer, uncertainty about potential side effects of treatment was substantially and significantly lower than uncertainty about the type, frequency, or duration of surveillance (all $P < .0001$). Responses to the items listed in Table 3 did not differ with PCP specialty on univariate analysis with two exceptions. First, PCPs in internal medicine were more likely than those in family medicine to indicate that patients contacted their oncologist for problems that should have been referred to the PCP ($P = .026$) and second, that patients contacted the PCP for problems that should have been referred to their oncologist ($P = .013$). Most responses did not differ with PCP credential, although NPs and PAs were more likely to express uncertainty about potential side effects of treatment for colorectal cancer than MDs ($P = .026$).

Table 3

Percentage of Primary Care Providers Who Perceived Problems With Transfer of Care From Oncologist

<i>Problem</i>	<i>Percent*</i>	<i>95% CI</i>	<i>Predictors**</i>
For patients with breast cancer:			
Uncertainty about what surveillance tests I should order	62.6	54.1–70.4	Years of practice
Uncertainty about how frequently I should order surveillance tests	72.5	64.3–79.4	Years of practice
Uncertainty about how long I should order surveillance tests	74.8	66.7–81.5	
Uncertainty about potential side effects of treatment	40.5	32.4–49.0	Years of practice
For patients with colorectal cancer:			
Uncertainty about what surveillance tests I should order	56.5	47.9–64.7	
Uncertainty about how frequently I should order surveillance tests	66.4	58.0–73.9	
Uncertainty about how long I should order surveillance tests	67.2	58.7–74.6	
Uncertainty about potential side effects of treatment	36.6	28.9–45.2	
For patients with either breast or colorectal cancer:			
Uncertainty about whether the patient's oncologist is providing preventive health care	42.7	34.6–51.3	
Concern about duplication of care by primary care and oncology	42.0	33.9–50.5	
Concern about missed care by primary care and oncology	48.1	39.7–56.6	Specialty
Patient contacts oncologist for problems that should be referred to me	21.4	15.2–29.1	Specialty
Patient contacts me for problems that should be referred to oncologist	39.7	31.7–48.2	Years of practice, specialty

CI—confidence interval.

* Percent of primary care providers who consider this a problem.

** Variables significantly ($P<.05$) associated with responses in multivariate model.

PCPs who had been in practice longer were less likely to express uncertainty about the frequency of breast cancer surveillance tests ($P=.017$) and potential side effects of treatment for breast ($P=.014$) and colorectal cancer ($P=.042$) and less likely to indicate that patients contacted them for problems that should have been referred to their oncologist ($P=.014$). None of the items varied with whether the PCP provided follow-up care.

The results of multivariate logistic regression analyses conducted on each of these items are summarized in Table 3, which notes any variable that was significantly associated with responses. Where indicated, the probability that the PCP identified the item as a problem decreased with years of practice and was higher for specialists in internal medicine than those in family medicine.

Qualitative Responses

The open-ended question “What would make this process better?” elicited written comments from 67 respondents (50.8%). All but 10 of the PCPs who addressed this question focused their suggestions on the need for more communication from oncologists and especially for much more specific information regarding the surveillance plan.

The second open-ended question, encouraging any other comments, elicited 26 responses. Responses to either question that focused on issues other than communication included: there should be a more formal transfer of care so that it is clear to patients that their care is being returned to their PCP, some patients might not be comfortable returning to their PCP for follow-up, the availability of new treatments (eg, letrozole or anastrozole) would necessitate a revisit to the oncologist, and PCPs need to be more aware of supportive services available to cancer patients.

Discussion

We found that more than 84% of PCPs at our institution indicated uncertainty regarding the type, frequency, or duration of surveillance tests for breast or colorectal cancer. These uncertainties were reflected in their relatively low confidence that they are following surveillance guidelines and their relatively low comfort in having responsibility for surveillance of cancer recurrence. Further, more than half of respondents rated the current transfer of care from oncologist to PCP as fair or poor, even though they practice in a health system that uses a fully functioning EMR in which all patient notes including consults, progress notes, laboratory results, radiology results, and medications are

accessed electronically. The use of an EMR apparently does not entirely meet the need for better communication between specialists and generalists regarding their patients, a need which has been a persistent theme in the literature.⁸⁻¹¹

Many respondents indicated in replies to the open-ended questions that they would be willing to provide follow-up care if given specific guidelines from the cancer specialist, a response also reported in other studies.^{12,13} Providing PCPs with specific written follow-up plans to guide their surveillance of their cancer patients might improve provider satisfaction as well as patient care.

PCPs who had been in practice longer were more comfortable being responsible for cancer surveillance, more confident they are following surveillance guidelines, and less uncertain about some of the specifics of surveillance. This finding contrasts with a recent review of studies showing that health care quality tends to decrease with years in practice,¹⁴ perhaps due to the difficulty in staying up to date on therapies and standards of care. The reasons for the increase in PCP confidence with years of experience are not clear but could indicate that providers grow overly comfortable with their custom of practice.

Two additional aspects of the results from the present study are worth noting. First, PCPs were much less likely to indicate uncertainty about potential side effects of treatment than about surveillance for cancer recurrence. Because empirical information on the possible late effects of treatment for breast cancer¹⁵ (arm lymphedema, premature menopause, osteoporosis, hot flashes, weight gain, cardiovascular disease, fatigue, cognitive impairment, psychosocial distress) and colorectal cancer (bowel dysfunction, sexual dysfunction, peripheral neuropathy, psychosocial distress) is limited,² the opposite result might have been expected. However, PCPs often deal with symptom-based problem solving in their daily practice but typically are involved less often with secondary cancer surveillance. Second, the two open-ended questions elicited no responses dealing with the patients' role in the transfer or coordination of care. Providing patients with a survivorship care plan outlining the timing and nature of necessary follow-up is one of the 10 recommendations for improving the health care of cancer survivors developed by the Institute of Medicine,² and active patient involvement is considered an important component of shared care programs.¹⁶

This study was conducted at a single institution, which limits its generalizability. However, because this health system uses an EMR, we suspect levels of satisfaction with the transfer of care might, if anything, be higher than in other organizations.

Conclusions

Follow-up care of a subset of breast and colorectal cancer patients by their PCP could, with adequate guidelines, support better care for survivors' noncancer concerns without sacrificing appropriate cancer care. Although PCPs and cancer specialists often suspect that patients prefer to receive their follow-up care by a cancer specialist,^{12,17} that view is not universally held among patients themselves.^{3,18} Regardless of what decision is made, it is important that individual patients understand who is in charge of their follow-up care.¹⁹

In addition, the Institute of Medicine report recommends that upon discharge from treatment, each patient (as well as his/her PCP) be given a survivorship care plan that includes a record of care received, important disease characteristics, and a follow-up care plan outlining the nature and timing of recommended surveillance. The availability of this plan to both patients and their PCP could facilitate the transfer of care from oncology back to primary care.

Acknowledgments: Financial support for this study was provided by Park Nicollet Foundation.

This paper was presented at the 2006 American Academy of Family Physicians Annual Scientific Assembly, Washington DC.

Corresponding Author: Address correspondence to Dr Nissen, Park Nicollet Institute, Oncology Research, 3800 Park Nicollet Boulevard, Minneapolis, MN 55416. 952-993-5286. Fax: 952-993-5235. mary.nissen@parknicollet.com.

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Editor's Note: This paper was selected as a research award winner at the 2006 American Academy of Family Physicians Annual Scientific Assembly.