

Cancer follow-up care

Patients' perspectives

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ABSTRACT

OBJECTIVE To assess family physicians' and specialists' involvement in cancer follow-up care and how this involvement is perceived by cancer patients.

DESIGN Self-administered survey.

SETTING A health region in New Brunswick.

PARTICIPANTS A nonprobability cluster sample of 183 participants.

MAIN OUTCOME MEASURES Patients' perceptions of cancer follow-up care.

RESULTS More than a third of participants (36%) were not sure which physician was in charge of their cancer follow-up care. As part of follow-up care, 80% of participants wanted counseling from their family physicians, but only 20% received it. About a third of participants (32%) were not satisfied with the follow-up care provided by their family physicians. In contrast, only 18% of participants were dissatisfied with the follow-up care provided by specialists. Older participants were more satisfied with cancer follow-up care than younger participants.

CONCLUSION Cancer follow-up care is increasingly becoming part of family physicians' practices. Family physicians need to develop an approach that addresses patients' needs, particularly in the area of emotional support.

RÉSUMÉ

OBJECTIF Examiner les rôles respectifs du médecin de famille et des spécialistes dans le suivi des cancéreux et la perception qu'en ont les patients

TYPE D'ÉTUDE Enquête auto-administrée.

CONTEXTE Une division régionale de santé du Nouveau-Brunswick.

PARTICIPANTS Un échantillon en grappes non aléatoire de 183 participants.

PRINCIPAUX PARAMÈTRES ÉTUDIÉS La façon dont les patients perçoivent le suivi du cancer.

RÉSULTATS Plus du tiers des participants (36%) ne pouvaient identifier de façon sûre le médecin responsable du suivi de leur cancer. Même si 80% d'entre eux souhaitaient recevoir des conseils de leur médecin de famille dans le cadre de leur suivi, seulement 20% en recevaient. Environ un tiers (32%) des participants étaient insatisfaits du suivi fourni par leur médecin de famille. Par contre, seulement 18% d'entre eux étaient insatisfaits du suivi par les spécialistes. Les participants plus âgés se montraient plus satisfaits du suivi que les jeunes.

CONCLUSION Le médecin de famille est de plus en plus appelé à fournir les soins de suivi du cancer. Il doit développer une approche qui répond aux besoins des patients, notamment dans le domaine du support émotionnel.

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Improved diagnostic methods and treatments have resulted in increasing numbers of cancer patients surviving and requiring follow-up care.¹ Consequently, cancer follow up is becoming an important issue in primary care. Cancer follow-up care is a broad concept with an ill-defined beginning and end, but it generally starts soon after acute treatment has been completed.² Depending on the type of cancer, patients can suffer from ongoing health problems ranging from physical discomforts to sociopsychologic problems, even years after acute treatment is completed.^{3,5}

With the increasing number of cancer survivors and lack of cancer specialists, especially outside large urban centres, family physicians will become more heavily involved in cancer follow-up care.⁶ Follow-up care for most types of cancer is not complicated. It generally involves history taking, physical examination, and perhaps blood tests or radiologic testing. Family physicians can well manage all these activities.

In the early 1990s, several Canadian studies indicated that family physicians were infrequently involved in their cancer patients' acute and follow-up care. Many oncology treatment teams do not include family physicians and, when the acute phase of cancer treatment has been completed, it is not easy for family physicians to re-involve themselves in their patients' care.^{7,9} Research has shown that general practitioners are capable of providing breast cancer follow-up care in a timely and safe manner.^{10,11}

Few studies have examined cancer follow-up care from patients' perspectives. One study examined patients' participation in decisions about cancer care,¹² and a Canadian study examined terminally ill patients' perceptions of their family physicians' role in their care.¹³ Canadian literature on cancer follow-up care is sparse and suffers from several limitations. Most studies were carried out in the early 1990s so results are dated, or the studies involved site-specific cancer or terminally ill patients. Also, all studies were based in urban centres. Results of past research, then, might not apply to rural cancer patients who have a variety of cancers and are not terminally ill.

Based on one of our research team member's experience with cancer follow-up care in family practice (this team member was under the impression that some cancer patients "fell between the cracks")

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of the primary and secondary health care system in rural areas), the team set out to assess, from patients' perspectives, where gaps exist in cancer follow-up care and to discover how satisfied patients were with the follow-up care they received from family physicians and specialists. Because health care systems are similarly structured in all Canadian provinces and because many areas of Canada are rural, we think the study results have national relevance, particularly for rural communities.

METHODS

River Valley Health (RVH) has one tertiary care regional hospital and several smaller hospitals in rural communities. The regional hospital has an oncology clinic that provides several cancer services, but not therapeutic radiation, which is provided outside the region.

Participants were recruited with the help of support groups, the media, advertisements, and notices in physicians' offices throughout the RVH area. Inclusion criteria for our study were age 19 or older, diagnosis of cancer at least 1 year before the study, and residence in the RVH area during the follow-up period.

Because no standardized survey instrument for cancer follow-up care had been developed, we generated a survey based on focus group discussions.¹⁴ Questions were based on themes that emerged from focus group and interview analyses, and were pilot-tested with 10 patients. The survey was divided into four sections: general health, cancer diagnosis and treatment, cancer follow-up care, and sociodemographic information. Questions on follow-up care asked about counseling and participants' satisfaction with follow-up care. The term "counseling" was not defined; the question simply asked: Did your doctor provide counseling about the emotional issues of cancer? The question concerning satisfaction with follow-up care read: Were you pleased with the follow-up care you received from doctors? Possible responses were very pleased, somewhat pleased, not pleased, or do not know. Both questions were asked regarding participants' family physicians and specialists separately.

Using sex and type of cancer as independent variables, we calculated descriptive statistics for each survey item, cross-tabulations, and measures of association (χ^2). A significance level of $P < .05$ was used to assess bivariate relationships. The study was approved by the Dr Everett Chalmers Regional Hospital Research Ethics Committee.

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RESULTS

Of 224 participants recruited and asked to fill out the questionnaire, 186 returned completed surveys (83%). Data from three participants with basal cell carcinomas were removed; analysis was, therefore, based on 183 cases. The internal reliability of the survey was measured using two items related to cancer treatment, giving a Cronbach's α coefficient value of 0.97. Average age of participants was 63 years (range 25 to 88), average age at cancer diagnosis was 55 years (range 19 to 81), and mean years between diagnosis and participation in the study was 6.7. Details of participants' sex, marital status, geographic location, education, and income levels are shown in **Table 1**,¹⁵ which also compares the study sample with findings of the 1998 National Population Survey (New Brunswick data).¹⁵ **Table 2** lists the cancer sites of study participants.

Table 1. Participant profile

CHARACTERISTICS	% OF STUDY SAMPLE	% OF NEW BRUNSWICK POPULATION*
Female	72	56
Married	77	66
Rural location	47	42
Secondary education or higher	48	28
Income <\$20 000	15	23
Income \$20 001 – \$59 999	61	55
Working full or part time	28	45

*Based on 795 New Brunswick people surveyed for the 1998 National Population Survey: health component.¹⁵ People younger than 25 years were excluded from this comparison.

Table 2. Cancer site of participants

CANCER SITE	%
Breast	46
Prostate	16
Colon or rectum	12
Other areas	26

Patients' perceptions of who coordinates care

More than a third of participants (36%) reported that, after acute treatment, they were somewhat or very uncertain which physician (family physician or specialist) was responsible for their follow-up care. Time since diagnosis was not significantly related to this uncertainty. Of those who felt certain who was in charge, 25% said family physician, 63% said specialist, and 12% said both. Income levels and education

were significantly related to feelings of uncertainty (**Table 3**). Participants with higher education and income levels were most uncertain of which doctor was in charge.

Counseling

Cancer follow-up counseling is complex and ill-defined. Specialists counseled 36% of participants. Sex was significantly related to having received counseling; more men than women reported having received it (**Table 3**). Only 27% of men and 17% of women, for an average of 20% of participants, reported having received cancer follow-up counseling from a family physician.

Most participants (80%) desired counseling from either their family physicians or specialists. More women (83%) than men (76%), and more breast cancer patients (83%) than prostate cancer patients (65%), expressed a desire for counseling from their family physicians. Counseling from a specialist was wanted by 84% of breast cancer patients and 73% of prostate cancer patients.

Table 3. Statistically significant relationships: Percentages, odds ratios with 95% confidence intervals, and P values.

ISSUE	% OF PARTICIPANTS	ODDS RATIO (95% CI)	P VALUE
Uncertain who coordinates cancer care			
• Less than high school education	26	2.4 (1.3-4.9)	<.001
• High school education or more	47		
• Income <\$40 000	30	2.1 (1.0-1.4)	<.05
• Income >\$40 000	47		
Received counseling from a specialist			
• Male participant	53	2.2 (1.1-4.5)	<.05
• Female participant	33		
Dissatisfied with follow-up care			
• Family physician provided care	32	19.5 (6.0-63.2)	<.001
• Specialist provided care	18		
• Patients currently younger than 64 cared for by family physician	58	2.2 (1.1-1.4)	<.05
• Patients currently older than 64 cared for by family physician	42		

Dissatisfaction with follow-up care

More participants reported dissatisfaction with family physicians' follow-up care than with specialists' follow-up care (Table 3). Age was significantly related to being dissatisfied with follow-up care: younger participants were more dissatisfied with their family physicians' care than older participants were. Sex did not have a statistically significant effect on satisfaction; 19% and 34% of women, and 17% and 27% of men, were dissatisfied with specialist and family physician follow-up care, respectively. Dissatisfaction and lack of counseling were not related.

Based on type of cancer, dissatisfaction with specialist care ranged from 12% to 21%, with highest dissatisfaction reported by prostate cancer patients. Dissatisfaction with family physician care ranged from 21% to 36%, with highest dissatisfaction reported by breast cancer patients followed closely by colorectal cancer patients (Figure 1).

DISCUSSION

Because the survey was grounded in focus group data, we are confident the questions reflect the issues pertinent to cancer follow-up care and, therefore, have high content validity.¹⁶ The variability between the demographic characteristics of the study sample and the findings of the 1998 National Population Survey (NPS): health component¹⁵ can be explained by age (Table 1). Although we have included only participants from the NPS who were 25 years and

older in order to better compare them with the study sample, our subjects were, on average, older. Average age of our study participants was 63, reflecting the fact that cancer often strikes older people. Therefore, the study sample slightly overrepresents women, married people, people with lower education levels, and those with higher incomes.

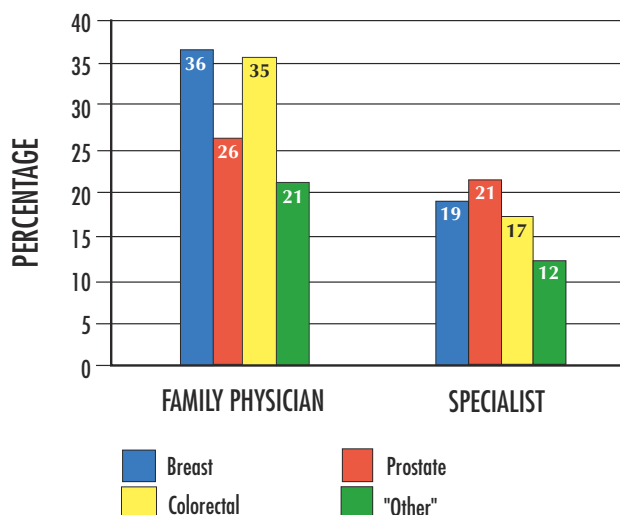
The urban-rural mix of the study sample is almost identical to that of the general New Brunswick population. The study sample had a higher proportion of retired people, so there were fewer people in the work force than in the general population.

Now that many cancer patients survive the acute phase of the illness, cancer is becoming a chronic illness.¹⁷ Family physicians will see an increasing number of cancer patients in need of follow-up care. Nevertheless, over the last decade, family physicians' involvement in cancer follow-up care has not increased. As Wood pointed out, the reasons for not becoming involved are often complex.¹⁸

Patients' dissatisfaction

Uncertainty about which physician was responsible for follow-up care, the desire for more counseling, and dissatisfaction with follow-up care are substantial issues that have emerged from this study. Patients need continuity of care and, therefore, gaps in care must be addressed. Cancer patients ought to be clearly informed who is responsible for their ongoing care after acute treatment has been completed; not knowing who to turn to could increase already high

Figure 1: Dissatisfaction with family physician and specialist follow-up care by type of cancer



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levels of anxiety. The fact that better educated and higher income participants reported greater uncertainty might reflect higher anxiety levels and a critical and more outspoken attitude than lower income and less educated participants would express.

Although counseling is poorly defined and could include formal and informal aspects, our data suggest that cancer patients want to talk to their physicians far more than physicians are able to accommodate. Research supports the benefit of counseling for cancer patients, and the Canadian Medical Association has confirmed that counseling is an important aspect of cancer follow-up care.^{19,20} Some cancer patients have further defined this as a need for "unrushed" consultations.²¹ Unfortunately, the fee-for-service structure does not always compensate family physicians adequately for long counseling sessions in their offices. This fact coupled with a national dearth of family physicians will only exacerbate the problem.

Family physicians' follow-up care was less well regarded than specialists' care. We speculate that cancer patients become emotionally attached to specialists because of the intense contact during acute treatment. It is also possible that the more negative assessment of family physicians' care was due to the limited involvement of family physicians in such care.

Dissatisfaction with family physicians' follow-up care is not universal. A randomized controlled trial assessing patients' satisfaction with transfer of follow up from hospital outpatient clinics to general practice showed that patients with breast cancer were more satisfied with general practice follow-up care than they were with care provided by hospital outpatient clinics.^{10,22} But there are important differences between that study and ours: only women with breast cancer were included in that trial, and family physicians' follow-up care was carefully designed and outlined by hospital consultants in "discharge" letters to general practitioners. Letters recommended a specific follow-up routine in addition to an education handbook on breast cancer follow-up care. Our study included a large number of women with breast cancer, but type of family physician care was not specified in any way. We could speculate that patients are more satisfied with family physician care when predetermined schedules are outlined by specialists or devised collaboratively by family physicians and specialists.

We believe that cancer follow-up care is an emerging issue that has been underestimated in importance. For example, in one resident training program outlining the eight stages of cancer management, a

scant two lines were devoted to cancer follow-up care.¹⁷ We have learned from patients that physicians should clearly communicate who is responsible for their cancer follow-up care. In addition, physicians clearly need to address patients' desire for counseling. Spending more time counseling, however, will increase the workload of family physicians already working an average of 51 hours a week.²³ More research is needed to better understand the issues in cancer follow-up care and to design follow-up care strategies that can accommodate patients' needs without overwhelming family physicians' practices.

The unique contributions of this study include the new knowledge that, even many years past acute treatment, patients still feel in need of cancer follow-up care (this need was expressed regardless of cancer site); and that family physicians are indeed "left out of the loop" concerning cancer follow-up care. Although the study was based on a nonprobability sample, we think the results highlight issues that are important for cancer patients and that are likely similar in rural communities across the country.

Limitations

As in most non-randomized studies, this one could be subject to self-selection bias; it is possible that cancer patients with strong views, either positive or negative, came forward to "tell their story." Some types of cancer might be overrepresented due to the recruitment strategies used. Therefore, we do not claim that results of this study are generalizable to all cancer follow-up care in New Brunswick or Canada. We do think, however, that they provide important and difficult-to-ignore insights into cancer follow-up care.

Conclusion

Cancer follow-up care is a relatively new area of inquiry, and we have documented perceptions and issues from patients' perspectives. Follow-up care is an important aspect of cancer care, but in our study, one third of patients did not know who was in charge of their care after they had completed acute treatment. Most participants (80%) would have liked counseling from their physicians, and one third were dissatisfied with their follow-up care. Specialist care was perceived more positively than family physician care. Better educated and higher income participants were most critical of follow-up care. ❀

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Contributors

Dr Miedema was involved in design and conduct of the study and analysis of the data, and was principal writer of all drafts of the paper. **Dr MacDonald** was involved in design and conduct of the study and analysis of the data, and reviewed all drafts of the paper. **Dr Tatemichi** was regularly consulted concerning design and conduct of the study, participated in analysis of the data, and contributed substantially to drafting the paper.

Competing interests

None declared

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Editor's key points

- This survey examined, from patients' perspectives, the availability of and satisfaction with cancer follow-up care in New Brunswick.
- About one third of patients were not sure who was responsible for their follow-up care: 63% thought specialists were in charge, 25% thought their family doctors were.
- About 80% of respondents wanted counseling, but only 36% of specialists' patients and 20% of family physicians' patients reported receiving it.
- More patients were dissatisfied with family physicians' follow-up care than with specialists' follow-up care.

Points de repère du rédacteur

- Cette étude voulait connaître l'opinion et le degré de satisfaction des patients concernant la disponibilité du suivi du cancer au Nouveau-Brunswick.
- Environ un tiers des patients ne pouvaient identifier de façon sûre le responsable de leur suivi : 63% croyaient que c'était le spécialiste et 25%, leur médecin de famille.
- Environ 80% des répondants souhaitaient recevoir des conseils, mais seulement 36% des patients des spécialistes et 20% de ceux des médecins de famille disaient en recevoir.
- Plus de patients étaient insatisfaits du suivi des médecins de famille que du suivi des spécialistes.

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