

Family physicians' roles in cancer care *Survey of patients on a provincial cancer registry*

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ABSTRACT

OBJECTIVE To describe cancer patients' experience of the role of family physicians (FPs) in their care.

DESIGN Mail survey of a random sample of patients from the Manitoba Cancer Registry.

SETTING Manitoba.

PARTICIPANTS Two hundred two adults, 6 to 12 months after diagnosis.

MAIN OUTCOME MEASURES Proportion needing different kinds of help from FPs and their rating of FPs' response; FACT-G quality-of-life score.

RESULTS Response rate was 56.6%; two thirds of the sample were in the follow-up phase. Most (91%) had an FP involved in their care, but FP involvement decreased after diagnosis. The most frequently needed kinds of help (with general medical problems, quick referrals, taking extra time, and quick office appointments) were well provided by FPs, but family support was not. Higher quality-of-life scores were associated with more help with general medical problems, more provision of cancer-related information, and more emotional support of patients and their families.

CONCLUSION Family physicians respond well to the most common needs of cancer patients and should be proactive in offering their support to both patients and families.

RÉSUMÉ

OBJECTIF Décrire ce que les patients cancéreux pensent du rôle du médecin de famille (MF) dans leur suivi.

TYPE D'ÉTUDE Enquête postale sur un échantillon aléatoire de patients du Manitoba Cancer Registry.

CONTEXTE Manitoba.

PARTICIPANTS Deux cent deux adultes, 6 à 12 mois après le diagnostic.

PRINCIPAUX PARAMÈTRE ÉTUDIÉS Proportion des patients requérant d'autres formes d'aide du MF et évaluation qu'ils font de sa réponse à leurs besoins; score FACT-G pour la qualité de vie.

RÉSULTATS Le taux de réponse était de 56,6%; les deux-tiers des répondants étaient dans la phase de suivi. Dans la plupart des cas (91%), un MF participait aux soins, mais son engagement diminuait après le diagnostic. Le MF répondait adéquatement aux types d'aide les plus fréquemment requis (problèmes de santé généraux, réorientation rapide, temps additionnel accordé et rendez-vous rapides), mais moins bien au support familial. Une association a été observée entre les scores de qualité de vie et le fait de mieux s'occuper des problèmes de santé généraux, de fournir plus d'information sur le cancer et d'apporter plus de support émotionnel au patient et à sa famille.

CONCLUSION Le MF répond adéquatement aux besoins les plus courants des patients cancéreux mais il devrait offrir davantage de support au patient et à sa famille.

This article has been peer reviewed.

Cet article a fait l'objet d'une évaluation externe.

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Providing care to people with cancer is an important part of family physicians' (FPs') work. In a family practice of 2000 people, about eight patients are diagnosed with cancer each year, and four patients die of the disease.¹ Such numbers will only increase in the future; large increases are predicted in the incidence and prevalence of cancer.² People with cancer visit their FPs about twice as often as other patients,^{3,4} and most say they turn to their FPs first rather than a cancer centre if their symptoms worsen.⁵

Caring for people with cancer presents a unique challenge to FPs. Mastery of cancer information and therapeutics is difficult,⁶ and patients and families have complex needs. Achieving continuity of care as patients move between FPs' offices, hospitals, and cancer clinics requires sharing patient information, coordinated management plans, and interprofessional communication (that is often lacking).⁷ A recent Canadian study demonstrated that a disturbing 36% of cancer patients were unsure who was responsible for their follow-up care.⁸

Previous research has explored FPs' perceptions of their role in caring for cancer patients.⁹⁻¹¹ Family physicians want to be more involved in all stages of cancer care and believe that their knowledge of patients and families is useful, particularly in making treatment decisions and in providing emotional support. Surveys of cancer patients have described relative dissatisfaction with FP versus specialist follow-up care,⁸ but also demonstrated that "family physician support" is an important contributor to patients' quality of life and mental health¹² and that FPs are viewed as supportive and open to discussing patients' fears and worries.¹³ None of these surveys have examined comprehensively what help

cancer patients need from their FPs, or the availability of that help. Further, all have relied on convenience samples drawn from the waiting rooms of urban cancer centres or through public advertisement, and these patients might not reflect the experiences of the general cancer population.

We sought in this study to paint a clearer picture of how cancer patients experience FPs' contribution to their care. Such an understanding is necessary if the role of FPs is to be understood and better integrated into the cancer care system. This study builds on the results of a qualitative study in which cancer patients described the roles of FPs under the themes of accessibility; support; and provision of triage, referral, and general medical care.¹⁴ Using a population-based sampling strategy, this study describes the kinds of help cancer patients say they need from their FPs, the extent to which FPs respond to those needs, and associations between patients' quality of life and provision of help by FPs.

METHOD

Design and measures

A survey was mailed in Manitoba to a random sample of 400 patients drawn in April 2000 from the Manitoba Cancer Registry, a provincial database that records all cases of cancer identified at time of biopsy, surgery, and hospital discharge. The Manitoba cancer population is similar to that of Canada as a whole.¹ Patients were included in the study if they were adults within 6 to 12 months of diagnosis, were diagnosed with their first cancer, and had a mailing address. Those with minor skin cancers and with carcinoma in situ were excluded.

Manitoba has one large urban centre that contains all the province's specialty cancer services. The sample was stratified to identify equal numbers of people from Winnipeg and from the rest of Manitoba to assess differences based on geography. Equal numbers of men and women were also selected. The sample frame was 5709 people.

In the survey, participants were first asked if an FP had been involved in their care since their diagnosis,

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and then were asked to describe the way their care was organized between their FPs and specialists. These patterns of medical care derive from our previous qualitative research (Table 1).¹⁴ Questions about diagnosis, treatment, and follow-up visits included questions about satisfaction with the level of FP involvement and about recent contact with FPs. Participants were then asked if they had needed each of 12 kinds of FP help, also derived from our previous study, since their diagnosis with cancer (Table 2).¹⁴ For each kind of help, respondents indicated on a 5-point Likert scale how often an FP had provided that help (always, often, sometimes, not too often, or never).

Table 1. Pattern of medical care reported by 180 participants cared for by FPs since diagnosis of cancer: *A further 18 respondents had no history of FP involvement and so did not answer, and four responses were missing.*

PATTERN OF MEDICAL CARE	N	(%; 95% CI)
Mainly specialist care: "Specialists take care of all my medical needs, so I rarely see a family doctor"	18	(10.0; 5.6-14.4)
Parallel care: "Cancer specialists look after everything to do with my cancer, and the family doctor looks after most of my other health problems"	80	(44.4; 37.1-51.7)
Shared care: "Family doctor and cancer specialists have both been involved in taking care of my cancer, and the family doctor looks after most of my other health problems"	70	(38.9; 31.8-46.0)
"None of the above describe my situation well"	12	(6.7; 3.1-10.3)

The survey included the Functional Assessment of Cancer Therapy—general scale (FACT-G), Version 4. This is a reliable and valid measure for evaluating health-related quality of life over the preceding 7 days, with higher scores indicating better quality of life.¹⁵ Last, demographic, disease, and treatment information was requested. Information about cancer stage and precise treatment regimens was not collected from patients and was not available from the cancer registry.

The survey was created with initial input from two cancer patients, two FPs, and two oncology nurses. It was then formally pilot-tested among four people with cancer recruited by a practice nurse at a Winnipeg clinic. Feedback about the face and content validity and about the organization of the survey was obtained, and the final version of

Table 2. Cancer patients' needs for different kinds of FP help since their diagnosis and their assessment of how frequently this help was provided

"THE FAMILY DOCTOR..."	N	RESPONDENTS NEEDING THIS KIND OF HELP FROM FPS % (95% CI)	RESPONDENTS NEEDING THIS KIND OF HELP WHO ALWAYS OR OFTEN RECEIVED IT % (95% CI)
Helps me with medical problems unrelated to my cancer	172	88 (83-93)	89 (84-94)
Gets me an appointment with a surgeon or other cancer specialist fairly quickly	172	85 (80-90)	88 (83-93)
Takes extra time with me during a visit	173	66 (59-73)	77 (70.7-83.3)
Sees me quickly in the office if I think it's necessary	172	56 (48.4-63.6)	77 (70.7-83.3)
Answers my questions about cancer and cancer treatments	168	49 (41.4-56.6)	59 (51.6-66.4)
Discusses how I am feeling about having cancer	170	44 (36.5-51.5)	51 (43.5-58.5)
Helps with common cancer-related problems, like pain, nausea, depression, and bowel problems	172	33 (26-40)	51 (43.5-58.5)
Speaks to me on the phone if I'm worried about something	172	32 (25-39)	60 (52.7-67.3)
Visits me when I am in hospital	168	30 (23.1-36.9)	78 (71.7-84.3)
Discusses with my family how they are feeling about my illness	170	29 (22.2-35.8)	38 (30.7-45.3)
Answers my family's questions about cancer and cancer treatments	170	29 (22.2-35.8)	38 (30.7-45.3)
Visits me in my home if it's necessary	167	10 (5.4-14.6)	37 (29.7-44.3)

the survey created. The Research Ethics Boards of the University of Manitoba and the University of Western Ontario approved the study.

Data collection and analysis

The Dillman Total Design Method¹⁶ was followed closely, and mailings were sent in May and June 2000. CancerCare Manitoba sent an initial invitation to participate, and those who agreed were then sent the survey. Reminders and repeat mailings were employed in both steps of recruitment. Data were entered into SPSS by a data-entry clerk; audits were done to ensure accuracy. Descriptive statistics were used, with χ^2 tests to explore associations

between categorical variables. Student's *t* test was used to test for associations between frequency of provision of each of the 12 kinds of FP help and patients' quality of life as reflected in FACT-G scores. For this analysis, the responses for each question were reduced to two groups: more frequent provision (those describing help as being "always" or "often" provided by the FP) and less frequent provision (help "sometimes," "not too often," or "never" provided).

A sample size of 237 was calculated based on using Student's *t* test (2-tailed test, $\alpha = .05$; $\beta = 0.20$) to detect a 10-point difference in FACT-G scores among those reporting more versus less frequent provision of a given kind of FP help. A difference of 10 points on the FACT-G scale is considered a clinically significant shift.¹⁷ This calculation included assumptions about likely response patterns and missing data. Previous surveys using the cancer registry had achieved an overall 60% response rate, so 400 patients were initially approached.

RESULTS

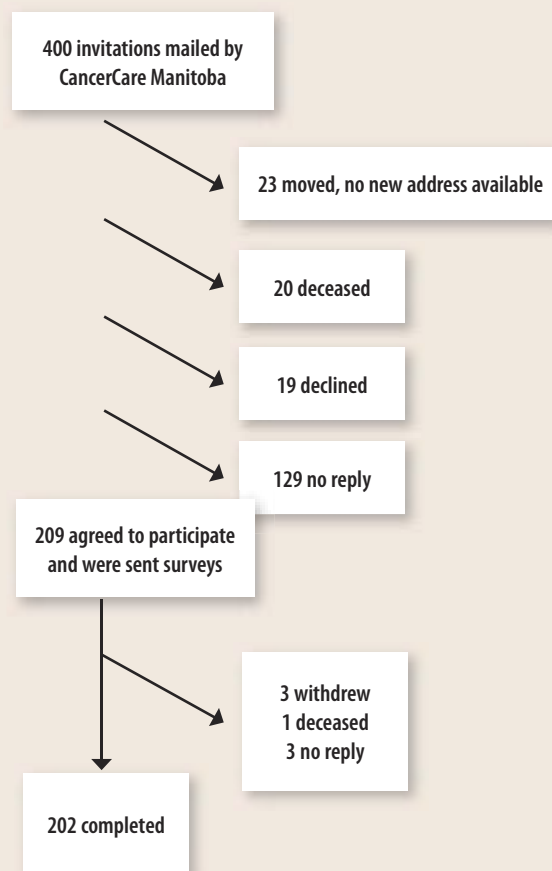
Participants

Overall response rate was 56.6% (202/357) among those who could be contacted (**Figure 1**). The sample (**Tables 3 and 4**) is somewhat younger than the general cancer population, and people with breast and prostate cancer are overrepresented. In comparison with the general Manitoba population, the sample is more likely to have completed high school, more likely not to be working, and more likely to have lower household incomes. Nonrespondents were more likely to be men (55%), were older than respondents (69.1 vs 63.5 years, $P < .001$), but were the same number of months from diagnosis.

Involvement of FPs

Most respondents (91%) reported that an FP had been involved in their care in some way since diagnosis of cancer. **Tables 1, 2 and 5** provide

Figure 1. Results of mailing



information about the nature of that involvement. Those who reported "mainly specialist care" were more likely to indicate they wanted more FP involvement than those with "parallel" or "shared" care ($P < .01$).

Respondents who described their FPs as being "very involved" during the diagnostic phase expressed more satisfaction with the speed of diagnosis than those who reported less involvement ($P < .05$). About 30% of respondents expressed the belief that their diagnosis should have been made sooner, and they were more likely to have changed their FPs than those who thought their diagnosis was made very quickly ($P < .05$). Most of these cancer patients (83%) had had at least one visit with their FPs in the previous 4 months, but almost half (47%) had no future appointments booked.

Table 3. Demographic characteristics of participants

CHARACTERISTIC	N (%)	% IN ORIGINAL SAMPLE
Sex (N = 202)		
• Male	90 (44.6)	50
• Female	112 (55.4)	50
Location (N = 202)		
• Winnipeg	102 (50.5)	50
• Rest of Manitoba	100 (49.5)	50
Age in years (N = 202)*		
		Estimated age (in years) distribution of cancer [†]
• 18-29	5 (2.5)	1.2
• 30-39	6 (3.0)	3.2
• 40-49	22 (10.9)	8.7
• 50-59	34 (16.8)	17.4
• 60-69	60 (29.7)	24.2
• 70-79	61 (30.2)	27.4
• 80+	14 (6.9)	17.0
Living arrangement (N = 199)[‡]		
• Live with spouse or partner	117 (58.8)	27.4
• Live with spouse or partner and children	35 (17.6)	29.6
• Live alone	37 (18.6)	28.1
• Other	10 (5.0)	14.9
Level of education completed (N = 198)[‡]		
• Junior high	42 (21.2)	38.2
• High school	86 (43.4)	22.7
• Technical or vocational training	40 (20.2)	23.8
• University degree	30 (15.2)	15.3
Employment status (N = 200)[‡]		
• In labour force, employed	76 (38.0)	63.3
• In labour force, unemployed	4 (2.0)	4.1
• Not in labour force	120 (60.0)	32.6
Gross household income (\$) (N = 176)[‡]		
• <20 000	41 (23.3)	12.1
• 20 000-39 999	57 (32.3)	24.2
• 40 000-59 999	41 (23.3)	24.1
• 60 000-79 999	20 (11.4)	17.7
• >80 000	17 (9.7)	21.9

*0.9% were younger than 18 and were not included in this study.

[†]Data from National Cancer Institute of Canada.¹

[‡]Manitoba data from 2001 Census of Canada. Available at www.statcan.ca, accessed 2004 April 14.

Table 4. Health characteristics of participants: Mean number of months since diagnosis was 9.8 (June 2000 was used as reference value).

DIAGNOSIS AND TREATMENT	STUDY POPULATION N (%) [*]	ESTIMATED NEW CASES, CANADA, 2003 [†] (%)
Site of primary cancer (N = 202)		
• Breast	54 (26.7)	15.1
• Prostate	39 (19.3)	13.4
• Colon or rectum	24 (11.9)	12.9
• Lung	15 (7.4)	15.1
• Reproductive tract	14 (6.9)	5.5
• Other	56 (27.7)	38.0
Phase of care (N = 170)[‡]		
• Active treatment (ongoing)	54 (31.8)	
• Active treatment (completed)	116 (68.2)	
Treatments received (N = 201)[‡]		
• Surgery	153 (76.1)	
• Chemotherapy	83 (41.3)	
• Radiation therapy	66 (32.8)	
• Hormone therapy	35 (17.4)	
Number of comorbid conditions (N = 199)		
• None	82 (41.2)	
• One to three	107 (53.8)	
• Four or more	10 (5.0)	

*Percentages might not add to 100% because of rounding.

[†]Participants with no FP did not answer this question.

[‡]Numbers do not add to 100% because more than one response was allowed.

Table 5. Levels of FP involvement in different phases of cancer care and patient assessment of that involvement

PHASE OF CARE	FP REPORTED AS VERY OR FAIRLY INVOLVED		LEVEL OF FP INVOLVEMENT REPORTED AS "ABOUT RIGHT" ^{**}	
	%	95% CI	%	95% CI
Diagnosis	63.3	56.3-70.3	--	--
Treatment	30.8	23.8-37.8	74.4	67.6-81.2
Follow up	39.8	31.0-48.6	75	67.3-82.7

^{**}The remainder expressed a desire for more involvement by FPs

Associations with higher quality-of-life scores

More frequent provision of four of the 12 kinds of FP help was associated with higher scores on the FACT-G. As well, participants reporting their FPs as "very involved" in their follow-up care had FACT-G scores that were 10 points higher than those whose FPs were viewed as slightly involved

DISCUSSION

Table 6. More frequent provision of four kinds of FP help is associated with higher FACT-G (quality of life) scores

KIND OF FP HELP	N	MEAN FACT-G SCORE	SIGNIFICANCE (STUDENT'S T TEST)	
			T	P
The family doctor discusses how I am feeling about having cancer	68		3.06	.003
• More frequent provision by the FP		87.5		
• Less frequent provision by the FP		76.5		
The family doctor helps me with medical problems unrelated to my cancer	140		2.83	.01
• More frequent provision by the FP		86.6		
• Less frequent provision by the FP		71.1		
The family doctor answers my questions about cancer and cancer treatments	73		2.32	.02
• More frequent provision by the FP		87.2		
• Less frequent provision by the FP		79.4		
The family doctor discusses with my family how they are feeling about my illness	43		1.98	.05
• More frequent provision by the FP		87.3		
• Less frequent provision by the FP		77.5		

or uninvolved ($P < .05$). The FACT-G scores were not found to be associated with either the pattern of medical care described by participants or the level of FP involvement during the treatment phase (Table 6).

Geographic differences

Participants from outside Winnipeg were more likely to be seeing a different FP than when diagnosed ($P < .05$) and were less likely to say that their FPs frequently took extra time during a visit when it was needed ($P < .05$). No other differences were seen between responses of those from Winnipeg and those from the rest of Manitoba.

This study is the first to paint a detailed picture of how people in the first year after diagnosis of cancer experience the role of FPs. Roughly equal proportions of participants reported “shared” and “parallel” care, and the four kinds of help most needed from FPs (general medical problems, prompt referrals, taking extra time during a visit, and prompt office appointments) were viewed as being well provided. Despite the common perception that FPs are hurried and fully booked, these participants generally viewed FPs as accessible and able to act as coordinators and providers of general health care. On the other hand, family support and home visits were less frequently provided, although fewer patients looked to their FPs for these kinds of help.

The decrease in FP involvement after diagnosis and the lack of planned follow-up visits is similar to that documented in an earlier survey⁵ and might reflect patients' and even FPs' preference as care shifts toward specialists. On the other hand, the decrease could reflect a lack of awareness of the important contribution FPs can make, particularly in follow-up care.¹⁸ Cancer centres are recognizing the need to develop new communication strategies to support the role of FPs.¹⁹

Four kinds of FP help were associated with higher quality-of-life scores when more frequently provided. Such associations do not represent causation, and other variables that we did not assess (such as extent of disease and treatment regimens) are likely more potent influences on quality of life. Nonetheless, these associations do point to roles that merit particular consideration as FPs reflect on the care they offer to their patients with cancer.

Help with general medical problems

Family physicians recognize the importance of attending to chronic health problems and preventive health care that otherwise could be overlooked in the preoccupation with cancer.^{9,20}

Talking about feelings

Although 84% of FPs reported in one survey that they always have a substantial role in emotional support of their cancer patients,¹¹ only 51% of participants in this study and 20% in another reported receiving such help from FPs.⁸ Distress and psychiatric illness are very common among people with cancer.²¹ The patient-centred clinical method,²² with its emphasis on understanding patients' illness experience, gives FPs the approach needed to assess their patients' emotional health.

Talking with families about feelings

That FPs infrequently provide family support is a concern, and this finding agrees with an Australian survey in which only 24% of cancer patients were satisfied with the support their families received.¹³ Spouses of cancer patients, particularly wives, experience distress that is equal to and more persistent than their ill partner's.²³ Attending to the needs of families is a natural role for FPs in cancer care.^{9,20} Family members need to be invited to be part of visits with FPs, signaling an interest in their health and allowing for assessment of family function.²⁴

Answering questions about cancer

Family physicians are trusted to give honest answers to questions about cancer,¹³ and patients sometimes look to their FPs to act as a "medical interpreter" because they feel confused by the information they have received from specialists.²⁰ Family physicians often rely on letters from oncologists in such discussions, but timeliness and content is often unsatisfactory.¹¹ Telephone discussions are likely to be more useful, and websites such as those of the BC Cancer Agency (www.bccancer.bc.ca) and the National Cancer Institute (www.cancer.gov) are good sources of cancer information for FPs.

This study has strengths and limitations. Sampling from a high-quality cancer registry enhances generalizability, but younger people and those with breast and prostate cancer are over-represented among respondents. The strengths of

EDITOR'S KEY POINTS

- This survey is the first in Canada to describe cancer patients' experience in obtaining care from their FPs after their cancer diagnosis.
- Only 18% of patients reported receiving "mainly specialist care." Roughly 40% each received "shared" (specialist and FP cancer care) and "parallel" (FPs did other medical care only) care.
- The four areas of most-needed help (general medical problems, prompt referrals, taking extra time during visits, and prompt office appointments) were well provided. In contrast, family support and housecalls were less frequently provided.
- Higher quality-of-life scores were associated with FPs being more involved in patients' care, particularly if FPs discussed how patients were feeling about their cancer, cared for non-cancer problems, answered questions about cancer and its treatment, and spoke to family.

POINTS DE REPÈRE DU RÉDACTEUR

- Il s'agit de la première étude canadienne à décrire ce que les patients pensent du suivi effectué par le MF après qu'ils aient eu un diagnostic de cancer.
- Seulement 18% des patients ont déclaré être suivis surtout par des spécialistes. Dans environ 40% des cas, le suivi du cancer était «partagé» (incluant spécialistes et MF) ou «parallèle» (le MF s'occupant des autres problèmes de santé).
- Les MF ont répondu adéquatement aux quatre besoins les plus criants (problèmes de santé généraux, orientation rapide en spécialité, temps additionnel accordé lors des visites et rendez-vous rapides), mais ils ont plus rarement apporté un support à la famille et fait des visites à domicile.
- Une association a été observée entre le score de qualité de vie et le niveau d'engagement du MF dans les soins, surtout s'il discutait avec le patient de sa façon d'envisager son cancer, s'occupait de ses autres problèmes de santé, répondait à ses questions concernant le cancer et son traitement, et en discutait avec la famille.

the standardized questionnaire and its derivation from previous qualitative research are offset by the barriers created by using a mailed survey. The study is also limited by its cross-sectional design, which does not permit causal interpretations, and by the retrospective nature of the data collected. Questions focused on participants' need for help from their FPs, but the survey did not clarify how these needs were communicated. Future research should assess patients' views of the role of FPs relative to other providers in the cancer system. How greater FP involvement affects patient, family, and provider outcomes should be studied prospectively, guided by the profile of FP involvement described here.

Conclusion

Family physicians are involved in the care of people with cancer. The most frequently needed kinds of help are well provided by FPs, but others, such as family support, are not. Higher quality-of-life scores were associated with more help with general medical problems, more provision of cancer-related information, and more emotional support of patients and their families. These findings will help FPs identify and value their role in cancer care, and will challenge cancer agencies to ensure that FPs are viewed as part of the cancer care team. Family physicians should be proactive in offering their support, booking follow-up visits, and bringing the healing resources of the patient-physician relationship to bear on the many challenges that cancer poses. ❁

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Contributors

Dr Sisler conceived and executed the study and prepared and revised all drafts of the manuscript. Dr Brown supervised the literature review, survey formulation, and data analysis, and revised all versions of the manuscript. Dr Stewart advised on formulating the research question and on data analysis strategies, and directed the final revision of the manuscript.

Competing interests

None declared

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