ORIGINAL RESEARCH

Patient, Primary Care Physician and Specialist Expectations of Primary Care Physician Involvement in Cancer Care

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BACKGROUND: In Canada, many health authorities recommend that primary care physicians (PCP) stay involved throughout their patients' cancer journey to increase continuity of care. Few studies have focused on patient and physician expectations regarding PCP involvement in cancer care.

OBJECTIVE: To compare lung cancer patient, PCP and specialist expectations regarding PCP involvement in coordination of care, emotional support, information transmission and symptom relief at the different phases of cancer.

DESIGN: Canadian survey of lung cancer patients, PCPs and cancer specialists

PARTICIPANTS: A total of 395 patients completed questionnaires on their expectations regarding their PCP participation in several aspects of care, at different phases of their cancer. Also, 45 specialists and 232 community-based PCP involved in these patients' care responded to a mail survey on the same aspects of cancer care.

RESULTS: Most specialists did not expect participation of the PCP in coordination of care in the diagnosis and treatment phases (65% and 78% respectively), in contrast with patients (83% and 85%) and PCPs (80% and 59%) ($p < 0.0001$). At these same phases, the best agreement among the 3 groups was around PCP role in emotional support: 84% and more of all groups had this expectation. PCP participation in symptom relief was another shared expectation, but more unanimously at the treatment phase ($p = 0.85$). In the advanced phase, most specialists expect a major role of PCP in all aspects of care (from 81% to 97%). Patients and PCP agree with them mainly for emotional support and information transmission.

CONCLUSION: Lung cancer patient, PCP and specialist expectations regarding PCP role differ with the phase of cancer and the specific aspect of cancer care.

There is a need to reach a better agreement among them and to better define PCP role, in order to achieve more collaborative and integrated cancer care.

KEY WORDS: cancer; primary care; cancer care follow-up; practice patterns; health care delivery.

J Gen Intern Med 27(1):8–15

DOI: 10.1007/s11606-011-1777-7

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INTRODUCTION

Cancer patients have to consult many health professionals, leading to fragmented care. Primary care physicians (PCP) involvement is frequently interrupted when patients are followed by oncology teams.^{1–5} At the treatment phase, patients often consider specialists as their regular physician,^{6,7} leading to a loss of continuity of care with their PCP.^{2,6,8–11} PCPs may feel disengaged in their role¹², making it difficult to take back the responsibility for patient care at the advanced phase¹³, especially without access to all relevant information.^{2,4,5,7,11,13–19}

As PCPs are recognized as key players in providing continuous and comprehensive care,^{20–23} many health authorities have recommended to keep them involved at all cancer phases^{11,24–26}. Information on PCP involvement in cancer care is scarce, especially at the treatment phase. Most studies have looked at PCP cancer survivorship care.^{6,7,27–32} Several surveys have documented PCP views on cancer care and they have consistently reported their willingness to be more involved.^{2,7,16,33,34} However, some PCPs feel that oncologists do not recognize their contribution.^{18,35} On their counterpart, oncologists would be willing to share patient care with PCPs,⁸ if their respective responsibilities were better defined³⁶. For patients, some prefer to consult oncologists,^{6,7} not always recognizing what role their PCP could play, especially if they do not have other health problems². However, others value their PCP involvement, particularly for their time, and emotional support.^{2,37} These studies emphasize the need to clarify the relative roles of PCPs and oncologists in cancer care and to better

Received April 19, 2010

Revised August 30, 2010

Accepted May 19, 2011

Published online July 13, 2011

understand each actor's expectations. No other research has looked at the variation in patients' relationship with their PCP according to the cancer phase. However, with the decrease in functional status experienced by patients with the cancer progression, it appears relevant to document changes in PCP patterns of care throughout the cancer care trajectory. This article reports results from a survey conducted in Quebec, Canada, where most patients (>80%) have a regular PCP. The survey included patients, PCPs and specialists involved in lung cancer care regarding PCP expected role at different phases of cancer.

METHODS

Study Design and Patient Selection

A prospective longitudinal survey of patients diagnosed with lung cancer was conducted between May 2005 and July 2008 in five hospitals in Quebec (Canada). Patients were eligible if they were diagnosed with lung cancer, regardless of type, stage and treatment. Lung cancer was chosen because of its high prevalence, its variable evolution and its diverse treatments. It provided the opportunity of documenting the change in patients' expectations regarding PCP involvement when they moved from one phase to another, while following them over a definite period of time. Eligible patients were informed of the study by the oncology team. Those who agreed to be contacted by the research team were invited to participate and signed an informed consent form. Basic information on non-participants was kept to compare them with participants.

Patients were followed for a maximum of 18 months, either at 3 or 6-month intervals, whether they had metastasis or not, in order to take into account their different survival. This strategy was chosen to ensure that patients with the most aggressive types of lung cancer would be followed closely enough to question them at different phases, without losing them to follow-up (if their condition deteriorated or if they died between two data collections); in addition, patients with the best prognosis would not be questioned too often during the same cancer phase (if their condition stayed stable). At baseline, patients were met during 45 minutes, either at the oncology clinic or at home, depending on their preference. Subsequent interviews lasted 20 to 30 minutes and took place at the oncology clinic, at home or over the phone. Their medical charts were reviewed at baseline and prior to each interview to determine if metastasis had developed and to ascertain the cancer phase.

When patients had a regular PCP, a letter was mailed to them to inform them of their patient's participation in the study and to invite them to complete a questionnaire. A mailed recall was sent to non-respondents three weeks later. If PCPs had more than one participating patient, they completed the questionnaire only once, but they were informed of each of their patients who participated. Specialists involved in lung cancer at the study hospitals (pulmonologists, hematologists/oncologists, thoracic surgeons) were also invited to complete a questionnaire. This study was

approved by the Research Ethics Committee of Laval University and of all study hospitals.

Patient Questionnaire

At baseline, patients completed questionnaires regarding their sociodemographics, lung cancer history, functional status (Eastern Cooperative Oncology Group Performance Status Scale- ECOG)³⁸⁻⁴⁰ (score 0 to 5; 0=normal activity; 1=Symptoms but ambulatory; 2=In bed<50% of time; 3=In bed≥50% of time; 4=100% bedridden), PCP expected role in coordination, emotional support, information transmission, symptom relief, and their PCP pattern of care (classified according to Norman et al's categories:² 1) sequential: virtually no PCP's involvement, patients receiving most of their care by the oncology team, 2) parallel: PCP involved mainly for non-cancer problems, 3) shared: involvement of both PCP and the oncology team in cancer care). The questionnaire on PCP role was adapted from Safran's⁴¹ and Starfield's⁴² validated primary care assessment tools and used 4-point Likert scales (1=not involved; 2=a little involved; 3=involved; 4=very involved). Subsequently, categories 1 and 2 were regrouped to indicate PCPs "not involved", and categories 3 and 4 were regrouped to identify those "involved". A test-retest analysis of this instrument was performed on 20 patients at two-week interval and, based on concordance testing, there was no significant difference between the two sets of response for all variables ($p=0.31$ to 0.99). At subsequent interviews, patients completed the same questionnaires on their functional status and their PCP expected involvement in the same aspects of care as those assessed at baseline. Data were classified according to three cancer phases: diagnosis, treatment and advanced/terminal. Determination of cancer phases was based on information from the medical chart, except for the advanced/terminal phase, which was defined as a score of 3 or 4 on the ECOG scale. This decision was made to avoid misclassification of patients, considering the lack of consensus in the literature to precisely define this phase from clinical predictors.

Physician Questionnaire

PCPs completed a questionnaire on their personal and professional characteristics and their actual and desired involvement at the same cancer phases and for the same aspects of care as those assessed with patients. The first part of the questionnaire was derived from the 2004 Canadian National Family Physician Workforce Survey⁴³ and, in the second part, questions were formulated to mirror patients' ones, in order to compare the two group responses. Similarly, specialists involved in participating patients care completed a questionnaire on their personal and professional characteristics and their expectations regarding PCP role at the same cancer phases, using the same questions than those asked to patients and PCPs.

Statistical Analysis

Baseline patient and physician characteristics were summarized with descriptive statistics. Statistical tests on

means (t -test) and proportions (χ^2) served to compare participants and non-participants. Patient and physician perceptions of PCP pattern of care and expectations regarding PCP role are presented as percentages of respondents who perceive each category of pattern of care and who expect PCP involvement at each cancer phase. When patients were questioned more than once per phase (i.e. extended period of treatment, or stability of cancer over time), a single response per patient per phase was used. For each continuous variable, a mean score was calculated from all responses provided by one patient per phase. For categorical variables (like PCP pattern of care), analyses were conducted alternatively using either the highest or the lowest score as the sole response per patient per phase. Since the results were found equivalent using either the highest or the lowest score, it was arbitrarily decided to present results obtained with the highest score. In most cases, patients questioned repeatedly in a cancer phase reported the same PCP involvement over time. Comparison of patient and physician perception of PCP pattern of care and of expectations, at each phase, of PCP involvement in different aspects of cancer care were assessed with Chi square (χ^2) analyses. Then, only for patients having a regular PCP, expectations from both patients and their PCP were matched regarding PCP role in cancer care. Agreement in expectations within these pairs was assessed with concordance rates (McNemar test). It was impossible to do the same with patients and oncologists since no oncologist was assigned to specific patients. Few PCPs (19%) have cared for more than one patient and contributed more than once to the analysis. For PCPs with more than one participating patient, a subset analysis was performed with only one matched patient-PCP randomly selected to limit the data set to one response per PCP. This analysis was compared to the one allowing for multiple patients matched to a PCP, and results were similar. An α level of 0.05 was used as significance threshold. All statistical analyses were performed using the SAS software, version 9.1 (SAS Institute Inc., Cary, NC).

RESULTS

From the 695 eligible patients, a total of 395 were recruited (participation rate 56.8%). No difference was found between participants and non-participants ($p=0.5$) for the type of lung cancer. More women refused to participate than men ($p=0.05$). Participants were slightly younger on average than non-participants (63.4 vs 65.5; $p=0.02$). Figure 1 shows patients' participation in the study. Over the study period, patients' condition did not progress similarly for everyone. Four scenarios of evolution were found: 1) patients died or dropped out before their second data collection, so they only contributed to the diagnostic phase ($n=75$); 2) patients were interviewed at baseline and during the treatment phase, but did not reach the advanced phase (either because they remained stable or died before reaching that phase), so they contributed only to the diagnostic and treatment phases ($n=281$); 3) patients were interviewed at all three phases ($n=27$); 4) patients were interviewed at

PATIENT PARTICIPATION IN THE STUDY

Figure 1. Patient participation in the study.

baseline, but their cancer progressed rapidly and their second interview was at the advanced phase ($n=12$).

Patient and Physician Characteristics

Table 1 shows patients' characteristics. Women were younger (61.7 vs 64.7; $p=0.002$) and lived more frequently alone (30.6% vs 19.9%; $p=0.01$) than men. Most patients received a treatment (92.9%), and a cumulative 42% had metastases at some point between the diagnosis and the end of the study (Table 1). Most patients had a regular PCP ($N=364$: 92.1%) and for 65.1%, they have been consulting this PCP for more than 5 years.

Table 2 shows physician characteristics. Of the 288 PCPs contacted by mail, 80.6% returned the questionnaire. Compared to Quebec PCPs surveyed in the 2007 National Physician Survey (NPS), participating PCPs reported a slightly higher number of years in practice⁴⁴. Most of them worked in private practice (82.7%) and approximately two thirds reported

Table 1. Patient Personal and Medical Characteristics

Variables	Patients N=395	
	n	(%)
Gender		
Female	170	(43.0)
Male	225	(57.0)
Mean patient age y (SD)	63.4	(9.5)
Mean education y (SD)	10.9	(3.9)
Delay (weeks) between investigation and Dx (SD)	5.6	(8.0)
Delay (days) between Dx and first Tx	29.0	(26.6)
Functional Status at Baseline		
Normal Activity	178	(45.1)
Symptoms but Ambulatory	150	(37.9)
Confined to Bed or Chair <50% of Waking Hours	44	(11.1)
Confined to Bed or Chair ≥ 50% of Waking Hours	20	(5.1)
Completely Disabled – 100% Bedridden	3	(0.8)
Type of Lung Cancer		
Squamous Cell Carcinoma	77	(19.5)
Adenomatous Carcinoma	164	(41.5)
Other Non-Small Cell Carcinoma	67	(17.0)
Small Cell Carcinoma	58	(14.7)
Unknown	29	(7.3)
Treatment		
Surgery with/without ChemoTx / Radiation Tx	113	(28.6)
Chemo Tx and/or Radiation Tx	254	(64.3)
No Treatment	28	(7.1)
Metastases		
Present at baseline	128	(32.4)
Found during follow-up	37	(9.4)
No	230	(58.2)
Staging of Lung cancer at Recruitment		
Stage I	56	(14.2)
Stage II	33	(8.3)
Stage III	119	(30.1)
Stage IV	133	(33.7)
Not Confirmed	54	(13.7)

participating to an on-call service for their patients. A large proportion (75.4%) was involved in palliative care and more than half were doing house calls (54.3%), which was more frequent than PCPs from the 2007 NPS.⁴⁵ Finally, a proportion of 70.3% of the 64 specialists involved in lung cancer care in the study hospitals completed the questionnaire. Almost half of them were pulmonologists. Compared to the 2007 NPS^{46,47}, participating specialists had slightly more years in practice.

PCP Involvement in the Follow-up of Patients with Lung Cancer

Throughout the cancer care trajectory, most PCPs reported being involved at the diagnostic (87.8%) and advanced (70.1%) phases of cancer, but fewer were involved at the treatment phase (43.7%). When questioned about their pattern of care with the oncology team during the treatment phase, 48.9% of PCPs reported shared care, while 45.4% mentioned a parallel pattern of care, and 5.7% felt left out (sequential care). These results differ from patients' perception of their PCP pattern of care at the same cancer phase. As shown in Figure 2, patients perceive less frequently a shared pattern of care between their PCP and the oncology team.

Table 2. Primary Care Physician and Specialist Personal and Professional Characteristics

Variables	Primary Care Physicians N=232		Specialists N=45	
	n	(%)	n	(%)
Gender				
Female	79	(34.1)	8	(17.8)
Male	153	(65.9)	37	(82.2)
Mean age y (SD)	51.1	(8.7)	49.3	(8.9)
Mean number of years in practice (SD)	25.8	(9.9)	24.5	(9.9)
Mean number of patients / week (SD)	NA		12.8	(15.8)
Speciality	NA			
Pulmonology			22	(48.9)
Hematology-oncology			17	(37.8)
Thoracic Surgery			6	(13.3)
Mean hours of work / week (SD)			NA	
Clinical practice	41.5	(10.6)		
Other professional work (n=72)	11.3	(8.9)		
Main Practice Site			NA	
Private clinic	192	(82.7)		
Long-term Care Center	3	(1.3)		
Community Health Care Center	12	(5.2)		
Family Medicine Teaching Unit	11	(4.7)		
Hospital/Emergency Room	14	(6.1)		
On-call system			NA	
None	83	(35.8)		
During office hours only	40	(17.2)		
24 hours per day / 7 days per week	80	(34.5)		
Other	29	(12.5)		
Involvement in palliative care *	175	(75.4)	NA	
At the clinic	148	(63.8)		
At home	126	(54.3)		
In Institutions (hospital, long-term care center, etc.)	72	(31.0)		

* Proportion of PCP involved in each setting calculated from the total number of participants (N=232), but globally, 175 (75.4%) of them reported being involved in palliative care; some physicians were active in palliative care in more than one setting

Expectations Regarding PCP Involvement in Lung Cancer Patients' Follow-up

Figure 3 shows certain discrepancies between patient, PCP and oncologist respective expectations regarding PCP role at the different cancer phases. Most patients would like a continuous involvement of their PCP at all phases, mainly for coordination of care and emotional support. A majority of PCPs wished to stay involved in all aspects of care, but, at the treatment phase, a lower proportion of them wanted to be involved in coordination of care. Oncologists recognized a role for PCPs mainly at the advanced phase. But, at the diagnostic and treatment phases, only a few saw PCPs involved in coordination of care, compared to patients and PCPs ($p<0.0001$). More than 80% of PCPs considered they could be involved in transmission of information to patients, but a smaller proportion of oncologists and patients shared that view, particularly at the diagnostic ($p<0.0001$) and treatment ($p<0.01$) phases. At all phases of cancer, emotional support was the aspect of care where the three groups

* p value corresponds to the comparison of patients' perception to PCPs' perception regarding patterns of care

* p value calculated with Chi square test to compare proportion of patients and PCPs who perceive each pattern of care by the PCP

† Sequential: Primary Care Physicians not involved when specialists are involved

‡ Parallel: Primary Care Physicians involved for health problems unrelated to cancer

Figure 2. Comparison of Patient and PCP Perceptions regarding Pattern of Care at the Treatment Phase.

agreed the most. There was also some agreement between them regarding PCP role in symptom relief, but mainly at the treatment phase ($p=0.85$).

Table 3 shows matched data between PCPs and their patients. Agreements in expectations between patients and their matched PCPs regarding PCP role in cancer care ranged from 26% to 72%, with generally the highest concordance rates found at the advanced phase.

DISCUSSION

This study shows a significant disconnect between patient, PCP and oncologist expectations regarding PCP involvement at all phases of cancer, but predominantly at the diagnostic and treatment phases. PCP participation in coordination of care and transmission of information seemed to be the aspects where the most significant discordance was found.

Figure 3. Comparison of Patient, PCP and Specialist Expectations regarding PCP Involvement at Different Phases of Cancer *: p value calculated with Chi square test at each phase to compare proportion of patients, PCPs and specialists who expect PCP involvement for each care aspect.

Table 3. Concordance Between Patients and their PCP on PCP Role in Cancer Care

		Patients Expectations		
		Involved	Not involved	Concordance
		n	n	%
PCP Expectations				
Diagnostic Phase				
Coordination of care (N=268)	Involved	69*	116	41.4
	Not Involved	41	42	
Emotional Support (N=265)	Involved	90	152	39.2
	Not Involved	9	14	
Information Transmission (N=266)	Involved	35	184	28.6
	Not Involved	6	41	
Symptom relief (N=253)	Involved	33	188	26.1
	Not Involved	3	33	
Treatment Phase				
Coordination of care (N=212)	Involved	23	28	63.2
	Not Involved	50	111	
Emotional Support (N=214)	Involved	90	64	55.6
	Not Involved	31	29	
Information Transmission (N=214)	Involved	45	64	58.9
	Not Involved	24	81	
Symptom relief (N=211)	Involved	43	188	54.5
	Not Involved	3	72	
Advanced/terminal Phase				
Coordination of care (N=29)	Involved	11	7	72.4
	Not Involved	2	10	
Emotional Support (N=29)	Involved	12	11	51.7
	Not Involved	3	3	
Information Transmission (N=29)	Involved	7	11	51.7
	Not Involved	3	8	
Symptom relief (N=29)	Involved	11	8	66.5
	Not Involved	2	8	

* Bold numbers indicate number of patient-PCP pairs with concordant expectations

While several surveys conducted with PCPs^{30,32-34} or patients,^{2,5,17} have described PCP role in cancer care, few have questioned both groups at the same time^{4,37} and even fewer have compared their opinions with those of oncologists^{31,48}. This research brings new knowledge that is necessary before introducing strategies to keep PCPs in the loop at all phases of cancer. As highlighted by Sussman and Baldwin⁴⁹, these results further emphasize the need to improve collaboration between PCPs and oncologists, and to better define their respective responsibilities.

Most patients, PCPs and oncologists were in agreement with the recognition of PCP role in emotional support. This result is concordant with other studies^{2,17,25,37} including Klabunde et al's⁴⁸, where 96% of PCPs reported being involved in evaluation/treatment of depression. The long-standing PCP-patient relationship puts them in a strategic position to provide emotional

support. Symptom relief is another area where almost 80% of the three groups expected PCP involvement.

Patient and PCP contrasting views regarding PCP role in cancer care are aligned with those related to patterns of care between PCP and the oncology team. PCPs perceived themselves more involved in shared care and patients considered that parallel care occurred more often. A potential information bias related to the definition given for each category of pattern of care may have contributed to this finding. Even though definitions presented to patients and PCPs were similar, the two groups may have understood them differently, leading to misclassification between the parallel and shared care patterns. Since many patients considered oncologists as the main responsible for their care, they probably turned to their PCP mainly for other health problems, which corresponds to a parallel pattern of care. So, the high proportion of patients perceiving a parallel pattern of care is not surprising. Hickner et al³⁷ found completely opposite results, with PCPs finding it challenging to stay in the loop and their patients having the impression that their PCP was regularly communicating with the oncologist. However, only a purposeful sample of 15 paired PCPs and cancer patients were interviewed in this qualitative study.

At all phases, PCPs expected to be involved in all aspects of care, which is consistent with results from other surveys^{2,7,16,33,34}. Contrastingly, oncologists expected PCP involvement mainly at the advanced/terminal phase. This also mirrors findings from other surveys where some PCPs felt that oncologists did not recognize their role in cancer care^{18,35}. In other studies, oncologists reported a willingness to share patient follow-up with PCPs,⁸ but they insisted on the need to better define their respective responsibilities.³⁶

Beside the potential information bias mentioned earlier, this study has some other limitations. Patient participation rate was rather low, but it compares well with other studies conducted with such vulnerable population^{5,31,50}. Moreover, few patients withdrew, their main reasons for dropping out being death or cancer recurrence, which were inevitable in this population. PCP and oncologist participation rates were higher than in other surveys^{5,30,31,34}, but their characteristics were slightly different from the ones found in the 2007 NPS, considered as representative of the Canadian medical workforce. However, since findings from this study are in agreement with those from other surveys^{31,37,48}, the situation described here is probably close to reality.

Another limitation relies on the exclusive recruitment of lung cancer patients, which makes uncertain the generalizability to patients with other types of cancer. However, since the cohort included patients with a varied distribution in age, gender, stage at diagnosis and treatment, it gives insights into patient preferences on cancer follow-up care that may also apply to other cancers. Also, while patients reported how they perceived their own PCP involvement in their care, PCP questions were not directed to one particular patient. It is possible that some of their answers might have been different if they were answering about a specific patient. Nevertheless, a minority of PCPs had more than one patient recruited in the study. Finally, this research focused only on four aspects of care, but they are key domains of cancer care.

In summary, this study highlights the existence of a large gap between patient, PCP and specialist expectations toward PCP involvement in the cancer care trajectory. It reinforces

the need to clearly outline PCP responsibilities in cancer care, taking into account oncologist role. These findings provide further support for the development of effective communication between PCPs and oncologists, in order to facilitate coordination and continuity of cancer care.

Acknowledgments: This study was supported by an operating grant of the Canadian Institutes of Health Research (CIHR), Grant MOP-68834.

The authors thank Mr Serge Simard, biostatistician, for his advices in data analyses and Mrs Lucie Misson and Danielle Marleau, for their role in patient interviewing and data collection.

Conflict of Interest: None disclosed.

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