RESEARCH PAPER

Towards Integrating Primary Care with Cancer Care: A Regional Study of Current Gaps and Opportunities in Canada

Vers une intégration des soins de santé primaires et des soins contre le cancer : étude régionale des lacunes et des occasions actuelles au Canada

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Abstract

Background and Objectives: Better integration between cancer care systems and primary care physicians (PCPs) is a goal of most healthcare systems, but little direction exists on how this can be achieved. This study systematically examined the extent of integration between PCPs and a regional cancer program (RCP) to identify opportunities for improvement.
Method: Cross-sectional survey of all practising PCPs in the region of interest using a study-specific instrument based on a three-tier conceptualization of integration.
Results: Among the 473 PCPs who responded (63% response rate), perceived role clarity and the desire for greater involvement in patient care varied across the care trajectory. Specific gaps were identified in PCPs' understanding of the referral process and patient follow-up after treatment.

Conclusion: Our novel survey of PCPs explicated the strategies that could improve their integration in cancer care, including mechanisms to support PCPs in the initial diagnosis of their patients and standardized post-treatment transition plans outlining care roles and responsibilities.

Résumé

Contexte et objectif : Une meilleure intégration entre les systèmes de soins contre le cancer et les médecins de première ligne (MPL) est un des objectifs de la plupart des systèmes de santé, mais il existe peu de guides d'orientation pour y arriver. Cette étude examine systématiquement l'étendue de l'intégration des MPL et des programmes régionaux contre le cancer afin de repérer les occasions propices à l'amélioration.

Méthode : Un sondage transversal, employant un instrument spécifique pour l'étude fondé sur une conceptualisation à trois volets de l'intégration, a été mené auprès de tous les MPL de la région étudiée.

Résultats : Parmi les 473 MPL qui ont répondu au sondage (taux de réponse de 63 %), la clarté du rôle perçu et le désir d'une meilleure participation dans les soins au patient varient le long de la trajectoire de soins. Des lacunes précises ont été identifiées quant à la compréhension qu'ont les MPL du processus d'aiguillage et du suivi des patients après le traitement.

Conclusion : Notre nouveau sondage auprès des MPL éclaire les stratégies qui pourraient permettre d'améliorer l'intégration entre les MPL et les soins contre le cancer, notamment des mécanismes de soutien pour les MPL dans le diagnostic initial ainsi que des plans standardisés de transition post-traitement qui définissent les rôles et responsabilités pour les soins.

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Introduction

The care of cancer patients is characterized by multiple, complex and often stressful interactions involving a wide range of care practitioners and settings, along the various stages from initial diagnosis to palliative care (Kristjanson and Ashcroft 1994). Cancer patients and their families frequently report feeling overwhelmed and lost in a system that is increasingly difficult to navigate (Institute of Medicine and National Research Council of the National Academies 2005; Sullivan et al. 2004). Primary care physicians (PCPs) report being isolated from the cancer care system and, therefore, less effective in helping patients cope with their diagnosis and treatments (Aubin et al. 2012; Kasperski and Ellison 2007). Furthermore, poor integration between the cancer system and PCPs results in reluctance by some patients to be referred back to primary care following cancer treatment (Hudson et al. 2012; Mayer et al. 2012).

Although there is a need for a significant proportion of cancer care to be provided through specialized centres, it is also clear that for comprehensive care, especially during the early healthcare diagnostic and post-treatment phases, community providers must be involved to help ensure that patients' supportive care and informational needs are met and their non-cancer-related health issues are managed (Klabunde et al. 2009; Roorda et al. 2012). A large study of cancer patients in the US illustrated that reduction in PCP involvement was associated with poorer overall care and health outcomes, especially in the management of non-cancer-related health conditions (Earle and Neville 2004). Major challenges to PCPs include lack of knowledge about cancer treatments, as well as insufficient communication and role confusion between PCPs and cancer specialists in the provision of care (Aubin et al. 2012; Dworkind et al. 1999).

In Ontario, Canada, cancer care is provided by regional cancer centres, community oncologists and PCPs. Integration of PCPs with cancer specialists and centres is largely informal (CCO 2015). Cancer Care Ontario (CCO) is the government's cancer advisor, directing and monitoring the funding for cancer services in the province. CCO integrates all specialized cancer care providers including overseeing nursing and allied health, but are not explicitly linked to community providers, including PCPs. To date, most cancer care system integration initiatives have only focused on specialized providers. CCO, as well as decision-makers elsewhere in Canada and in the US, has identified better integration between cancer care programs and PCPs as a key strategic objective; however, little direction exists on how this could be best achieved across the trajectory of illness (Dohan and Schrag 2005; Hudson et al. 2012; Salz et al. 2012; Sullivan et al. 2004). The purpose of this study was to systematically examine the extent of integration of PCPs with a regional cancer program (RCP) for the care of cancer patients and to identify opportunities for integration to be improved, from the perspectives of PCPs.

Methods

Design

A cross-sectional survey of all practising PCPs in the selected healthcare-planning region was undertaken. We assessed PCPs' perceptions of/satisfaction with integration between PCPs and the RCP according to the three domains employed by CCO's Cancer System Quality Index initiative: *Clinical, Functional and Vertical Integration* (Table 1) (Levitt and Lupea 2009). Ethical approval to conduct the study was obtained from the McMaster University Ethics Board, Hamilton, ON.

Setting and Sample

The study sample included all identified active PCPs with office addresses within the Hamilton, Niagara, Halton and Brant Local Health Integration Network (HNHB LHIN) area in Ontario (ON), Canada. This region extends over 7,000 km^2 and has a population of 1.4 million (Government of Ontario 2010). Over 200,000 seniors live in the HNHB LHIN, representing the largest proportion in all ON LHINs (LHIN 2009) The HNHB LHIN age-standardized rate per 100,000 for new cancer incidences is 592 (578 in ON) and for mortality 219 (202 in ON) (CCO 2016). The PCP to population ratio is 76 per 100,000 population in the HNHB LHIN, lower than the provincial rate of 85 per 100,000 population (LHIN 2009).

TABLE 1. Domains of integration measured and study findings

Domain of integration	Definition	Indicators measured	Findings
Clinical	Extent to which *patient care services* are coordinated across the various functions, activities and operating units of the cancer system.	• PCP knowledge of how to work up newly diagnosed patients for common cancers. • Clarity of PCP role across the care trajectory. • Self-reported care provision by PCPs across the care trajectory.	• PCPs indicated knowing how to initiate investigations of signs and symptoms and how to identify the appropriate referral, except in the case of neuro-oncology and, to some degree, head/neck cancer. • PCP role uncertainty indicated, particularly while patients are undergoing treatment. • Most PCPs indicated being involved in patient care across the care trajectory, but less so in the palliative care stage.
Functional	Extent to which key *support functions and activities* are coordinated across operating units of the cancer system.	• Communication between PCPs and the RCP. • Diagnostic tests are available in a timely fashion.	• Most PCPs were satisfied with the exchange of information between their practice and the RCP; however, some delays were indicated in patient information received from RCP. Few PCPs used the regional cancer centre's web portals for information. • PCPs reported problems obtaining MRIs and CT scans, as well as delays in obtaining biopsy results.
Vertical	Extent to which there is regional *collaboration, coordination and leadership* with respect to cancer services that is recognized as a "system."	• PCP understanding of referral to the RCP and system navigation. • PCP perception of RCP coordination.	• Many PCPs did not know the procedure for referring patients to the RCP. Strong need expressed for guidelines on when and how to connect their cancer patients to the RCP. Most PCPs agreed that a cancer system navigation program is required. • PCPs felt there was generally good coordination of care between their practice and the RCP. However, many PCPs felt coordination and access to services for cancer patients following diagnosis need to be improved.

CT = computed tomography; MRI = magnetic resonance imaging; PCP = primary care physicians; RCP = regional cancer program.

This setting includes a diversity of rural and urban communities with the full range of cancer care services at a regional tertiary care cancer centre, including surgery, radiation therapy and medical oncology, as well as supportive care for patients in treatment. There is no singular model of palliative care across the region; these services are highly variable and are fragmented in some communities (Bainbridge et al. 2011).

The wide spectrum of organizational and compensational models for PCPs is represented including fee-for-service, capitation and salary-based remuneration. The research team used multiple sources to construct and verify the study sample including databases from The Ontario College of Family Physicians (membership obligatory for PCPs practising in ON), The College of Physicians and Surgeons of Ontario, The Canadian Medical Directory and a current list of HNHB LHIN PCPs obtained from a physician recruitment agency.

Instrument

The data collection survey instrument was designed to assess key aspects of integration of PCPs with the RCP. While no single accepted definition of care integration exists in general medical care or specifically for cancer care, the concepts of role clarity and communication between providers are foundational (Ahgren and Axelsson 2005; Maslin-Prothero and Bennion 2010; Suter et al. 2009) and formed the basis of the instrument developed and used in this study. We used the CCO-defined constructs of functional, clinical and vertical integration to develop questions that are meaningful to system planners working towards the stated objective of improving the integration of all care providers during the care of cancer patients across the trajectory: from initial investigation of suspected cancer, to post-treatment follow-up, to palliative care once the cancer is deemed incurable (Levitt and Lupea 2009).

An existing questionnaire specific to the measurement of PCP integration in cancer care was not found, and therefore, we reviewed a number of instruments that contained questions on PCP involvement in cancer care to ensure inclusion of important content. These sources included the multidisciplinary Cancer Services Integration Survey (Dobrow et al. 2009), the Patient Navigation in Cancer Care Family Physician Questionnaire (Doll et al. 2005), the National Family Physician Survey (Woodward and Pong 2006) and the Family Physicians and Cancer Care Manitoba Survey (Sisler et al. 2004). Our survey was based on the salient content areas of these instruments, the relevant literature and input from experts in cancer care integration. Expert opinion was sought with respect to the instruments' coherence and comprehensiveness, and pilot testing was conducted with five clinicians outside the study area. Most items were dichotomous (yes/no) to improve ease of completion, with many of these items allowing for open-text elaboration when answered negatively, to further divulge issues. Questions were grouped by stage in the cancer trajectory (peri-diagnosis, active treatment, follow-up and palliative) following the nomenclature of CCO documentation (Cancer Quality Council of Ontario 2015). A core set of indicator items was repeated for each stage of the trajectory. The instrument was organized in this fashion for ease of flow and completion, to prime respondents for thinking separately about their interaction with the cancer system/patient at each stage, and to enable comparison in indicator items across the cancer trajectory.

Data collection

A Dillman Tailored Design Method with up to four mail contacts was used to administer the mail survey, with an added telephone contact stage for non-responders (Dillman 2000). A small incentive was included with the survey ($10 gift card). Completed surveys were returned via mail (stamped addressed envelope [SAE] provided) or toll-free fax.

Data analysis

Response data were analyzed using SAS version 9.1 (SAS Institute, Cary, NC) and SPSS version 21 (IBM Corp., Armonk, NY). Analysis was primarily descriptive, with item results presented as frequencies and proportions. Thematic analyses were completed on open-text comments and quantified (Creswell 2013). Confidence intervals for the binomial proportions were calculated using the Wald method. Cronbach's alpha as a coefficient of internal consistency between items within a trajectory stage and percentage of missing responses were calculated to provide measures of instrument validation.

Exploratory analyses were conducted using multivariate logistic regression to explore potential associative factors for high- or low-activity areas of integration and PCP involvement. Independent variables selected were years in practice, cancer education sessions attended (yes/no) and number of newly diagnosed cancer patients in the past year. Outcomes for this analysis included practitioner understanding of the process of referral to the RCP, role clarity and care provision across the trajectory of the patient's cancer experience and satisfaction with information provided by the RCP, considered as dichotomous variables (yes/no).

Results

Of 748 PCPs deemed eligible to participate, 473 (63%) completed a study survey. These practitioners represented a wide range of years in practice with a median duration of 25 years, and 69% having practised over 10 years in the study area (Table 2). A comparison of demographics between respondents and non-respondents revealed no significant differences (chi-square test, all $p < 0.05$) between these groups.

TABLE 2. Primary care physician characteristics ($N = 473$)

Respondent characteristics	Value
Male, *n* (%)	279 (59.0%)
Years since graduation, median (range)	25 (1–57)
Length of practice in region, *n* (%)	
0–4 years	72 (15.2%)
5–10 years	76 (16.1%)
11–20 years	111 (23.5%)
>20 years	213 (45.0%)
Solo practice, *n* (%)	177 (37.4%)
Practice setting, *n* (%)	
Private office	416 (87.9%)
Walk-in clinic	32 (6.8%)
Community health centre	20 (4.2%)
Academic teaching unit	23 (4.9%)
Other	57 (12.1%)
Primary source of income, *n* (%)*	
FFS	254 (53.7%)
CAP	103 (21.8%)
Mixed§	52 (11.0%)
Salary	18 (3.8%)
Other	47 (9.7%)
Size of practice, *n* (%)	
<1,000 patients	48 (10.1%)
1,000–1,999 patients	234 (49.5%)
≥2,000 patients	177 (37.4%)

CAP = capitation; FFS = fee-for-service. *Source >80% of income for family medicine. §FFS and either CAP or sessional pay each ≥20% of income.

Peri-diagnosis

A substantial proportion of the PCPs reported problems accessing the RCP for newly diagnosed patients. Only 61% of PCPs reported knowing the procedure for referring patients to the RCP. About one-third (35%) of respondents said that cancer-related diagnostic tests were not available in a timely fashion, with 27% of all respondents reporting delays in obtaining MRI results. Nearly half (48%) of the respondents felt that coordination and access to services for cancer patients needed improvement, and most (81%) agreed that some kind of a cancer system navigation program was required to help their patients access necessary medical and supportive care services (Table 3).

TABLE 3. Primary care physician perceptions throughout the stages of cancer

Cancer stage	Respondents' perceptions (agree)	*n* (%)	95% CI
Peri-diagnosis	Cancer-related diagnostic tests NOT done in timely fashion (*N* = 468)	163 (34.8)	(30.7, 39.3)
	MRIs NOT done in a timely fashion	125 (76.7)	
	CT scans NOT done in a timely fashion	107 (65.6)	
	Biopsy results NOT received in a timely fashion	82 (50.3)	
	Don't know procedure for referring patients to RCP (*N* = 461)	179 (38.8)	(34.5, 43.4)
	Where to call unclear	110 (61.5)	
	What tests to order prior to referral unclear	106 (59.2)	
	Who to call unclear	139 (77.7)	
	Coordination/Access to services for cancer patients needs improvement (*N* = 439)	211 (48.1)	(43.4, 52.7)
	Cancer system navigation program is required (*N* = 460)	371 (80.7)	(76.8, 84.0)
	Recommend a Coordinator model*	176 (47.4)	
	Recommend an Advisor model§	48 (12.9)	
	Recommend a Shared model¶	130 (35.0)	
	Unsure or recommend other model	17 (4.6)	
Active treatment	Manage patients' common symptoms related to cancer or its treatment as problems arise (*N* = 452)	348 (77.0)	(72.9, 80.6)
	Continue to manage patients' other medical issues (*N* = 469)	461 (98.3)	(96.6, 99.2)
	Provide patients with information about their cancer and cancer treatments (*N* = 461)	262 (56.8)	(52.3, 61.3)
	Involved with patients in decision-making process about cancer management (*N* = 458)	257 (56.1)	(51.5, 60.6)
	Know how to contact a provider within RCP involved in patients' care (*N* = 459)	345 (75.2)	(71.0, 78.9)
	Have difficulty reaching RCP providers to discuss patient (*N* = 457)	83 (18.2)	(14.9, 22.0)
	Feel inadequately informed by RCP regarding significant changes in patients' health status (*N* = 454)	99 (21.8)	(18.2, 25.8)
	Feel inadequately informed by RCP regarding changes in patients' medications or treatments (*N* = 460)	78 (17.0)	(13.8, 20.7)
	Feel inadequately informed by RCP regarding next steps in patients' care (*N* = 460)	87 (18.9)	(15.6, 22.8)

Cancer stage	Respondents' perceptions (agree)	*n* (%)	95% CI
Follow-up	Encourage cancer patients to follow-up at practice upon completion of cancer treatment (*N* = 468)	420 (89.7)	(86.6, 92.2)
	Easy to connect patients back to RCP if recurrence of initial cancer diagnosis is suspected (*N* = 434)	397 (91.5)	(88.4, 93.8)
	Feel adequately informed by RCP regarding what is involved in follow-up of cancer patients upon being discharged from oncologist care (*N* = 461)	362 (78.5)	(74.5, 82.0)
Palliative	Know who to contact to obtain palliative care services for patients (*N* = 461)	350 (75.9)	(71.8, 79.6)
	Refer to publicly funded home care (*N* = 473)	233 (49.3)	(44.8, 53.8)
	Refer to palliative care physicians (*N* = 473)	143 (30.2)	(26.3, 34.5)
	Refer to hospital palliative care (*N* = 473)	89 (18.8)	(15.5, 22.6)
	Refer to residential hospice (*N* = 473	74 (15.6)	(12.6, 19.2)
	Refer to palliative care team/network (*N* = 473)	50 (10.6)	(8.1, 13.7)
	Main resource used is Myself (*N* = 473)	31 (6.6)	(4.6, 9.2)
	RCP responsive to requests for advice (*N* = 374)	300 (80.2)	(75.9, 83.9)
General	Overall, felt there is good coordination of care between practice and RCP (*N* = 452)	389 (86.1)	(82.5, 89.0)
	In general, satisfied with the way information is exchanged between practice and RCP across trajectory of care (e.g., quality, timeliness, completeness, etc.) (*N* = 460)	398 (86.5)	(83.1, 89.4)
	Interested in attending multidisciplinary case conferences on patients (*N* = 456)	207 (45.4)	(40.9, 50.0)
	Accessed Cancer Centre's web portals as a source of information (*N* = 463)	39 (8.4)	(6.2, 11.3)
	Attended educational sessions to increase knowledge regarding cancer care (*N* = 469)	304 (64.8)	(60.4, 69.0)
	Current method of remuneration adequately compensates me for the care I provide to my cancer patients (*N* = 454)	244 (53.7)	(49.1, 58.3)

CI = confidence interval; CT = computed tomography; MRI = magnetic resonance imaging; PCP = primary care physicians; RCP = regional cancer program.
*Coordinator model – navigation program becomes responsible for coordinating appointments and the PCP practices are informed but not responsible for care.
§Shared model – navigation program helps coordinate patient appointments and the PCP practices coordinate care. ¶Advisor model – navigation program provides PCPs with advice, and physician practices coordinate care and appointments.

Active treatment

Most (77%) of the PCPs reported managing the common symptoms of their patients related to cancer or its treatment as problems arose. However, only about half (56%) reported that they are involved with their cancer patients in the decision-making process about their cancer management. Most (75%) PCPs reported that they knew how to contact a provider within the RCP to go over questions or concerns involving a patient. However, 22% of PCPs reported not being adequately informed by RCP providers about significant changes in patients' health status (Table 3).

Follow-up

Most (90%) PCPs reported encouraging their cancer patients to follow-up at their practice upon completion of treatment, and that it is easy to reconnect patients to the RCP if a recurrence is suspected. Fewer PCPs (79%) felt adequately informed by the RCP regarding what was required in the follow-up of their cancer patients upon being discharged from the oncologist's care (Table 3).

Palliative

Many (76%) PCPs knew who to contact to obtain palliative care services for their cancer patients, and most (80%) stated that the RCP was responsive to their requests for advice pertaining to this stage of care. The main resource PCPs reported using for their palliative care cancer patients was publicly funded homecare. Very few (7%) PCPs indicated being solely responsible for palliative care (Table 3).

PCPs' role across care trajectory

The majority of PCPs understood their role and felt it was valued at various stages of the cancer trajectory. This was most evident around the diagnostic, follow-up and palliative care phases and less so during active treatment (Table 4). Of note, PCPs advocated for more involvement in follow-up and palliative phases of care.

TABLE 4. Primary care physician role in cancer-related care

Cancer stage	PCP respondent role statement (agree)	*n* (%)	95% CI
Peri-diagnosis	PCP role clear (*N* = 463)	336 (72.6)	(68.3, 76.4)
	PCP role valued (*N* = 418)	314 (75.1)	(70.8, 79.0)
Active treatment	PCP role clear (*N* = 464)	300 (64.7)	(60.2, 68.9)
	PCP role valued (*N* = 420)	280 (66.6)	(62.0, 71.0)
	PCP involved in patient care (*N* = 466)	380 (81.5)	(77.8, 84.8)
	PCP wishes more involvement in patient care (*N* = 443)	118 (26.6)	(22.7, 30.9)
Follow-up	PCP role clear (*N* = 461)	312 (67.7)	(63.3, 71.8)
	PCP role valued (*N* = 425)	325 (76.5)	(72.2, 80.3)
	PCP involved in patient care (*N* = 468)	420 (89.7)	(86.6, 92.2)
	PCP wishes more involvement in patient care (*N* = 459)	219 (47.7)	(43.2, 52.3)
Palliative	PCP assumes responsibility for patient care (*N* = 460)	350 (76.1)	(72.0, 79.8)
	PCP wishes more involvement in patient care (*N* = 446)	207 (46.4)	(41.8, 51.1)

CI = confidence interval; PCP = primary care physician.

Major barriers to PCPs' involvement in cancer care for their patients that emerged from the open-text comments included limited access to patient information and/or the cancer treatment plan, lack of professional interaction with the RCP and direction as to the appropriate role of the PCP and limitations in their own knowledge and skill in oncology.

Care coordination, informational exchange, education and remuneration

Overall, most physicians (86%) reported that there is good coordination of care between their practice and RCP (Table 3). Despite some problems with communication, most PCPs (87%)

reported being satisfied with exchange of information between their practice and the RCP (Table 3). Just under half (45%) of the respondents expressed an interest in attending multidisciplinary case conferences (MCCs) on their cancer patients. If RCP referral guidelines were developed, most PCPs said that they preferred to receive these as a one-page summary sheet with key contact information, rather than in pamphlet form or on the Internet. Few (8%) reported having accessed the RCP web portals for information on treatments or referral processes.

Slightly over half (54%) of PCPs reported that they received adequate remuneration for the care provided to their cancer patients. The most frequently reported reason for dissatisfaction with compensation was that payment inadequately covers the time and effort spent with cancer patients and/or their families. PCPs on capitation payment arrangements also identified that their patients being seen by oncology associates at the RCP negated the fees the PCP would normally receive.

Factors associated with reported integration

Multivariate logistic regression was applied to explore the associations of PCP responses pertaining to their involvement and understanding of the processes in patient cancer care, RCP perceptions and other key factors of integration (Table 5). Physicians who had attended cancer education sessions (Table 3), had more years in practice or had seen more newly diagnosed cancer patients in the past year, tended to report better role clarity, being more involved in patient care across the disease trajectory and were more likely to understand referral procedures to the RCP. Cut points of effect for years in practice and number of cancer patients were not apparent.

TABLE 5. Multivariate regression of factors associated with system knowledge and role clarity at selected critical stages ($N = 473$)

Factor	Associated variables	OR (95% CI)	*p*-value*
PCP knows procedure for referring patients to RCP	Attends cancer education sessions	1.53 (1.01, 2.32)	0.047
	Years since graduation	1.03 (1.01, 1.05)	0.001
	Number of new cancer patients seen	1.88 (1.43, 2.46)	<0.0001
PCP role clear at follow-up	Attends cancer education sessions	1.52 (1.00, 2.32)	0.052
	Number of new cancer patients seen	1.33 (1.01, 1.74)	0.042
	Years since graduation	1.02 (1.00, 1.04)	0.019
PCP assumes responsibility for palliative care	Attends cancer education sessions	2.28 (1.40, 3.73)	0.001
	Number of new cancer patients seen	2.10 (1.52, 2.91)	<0.0001

CI = confidence interval; OR = odds ratio; PCP = primary care physician; RCP = regional cancer program. *p-values <0.05 are significant.

Item response psychometrics

Missing responses were relatively low (4.6%) for the 45 dichotomous scaled items. Binomial frequency distributions indicated a variable range of responses for items, most ranging between 20% and 80%, with few floor or ceiling effects noted, with the exception of items about management of patients' other medical issues during active treatment and ease of connecting patients back to RCP in case of recurrence, which most PCPs answered in the affirmative. Acceptable internal consistency was found within the items relating to each of the clinical–functional domains of integration, but less so for vertical integration.

Discussion

Although patterns-of-care research has shown that there is evidence of ongoing contact between PCPs and cancer patients across the care trajectory, there is little known about the nature of the encounters, to what extent providers work together and the types and extent of gaps in care (ICES 2006; Klabunde et al. 2009; Roorda et al. 2012). This study represents one of the first efforts to quantify these gaps, specifically in the context of PCP and RCP provider integration from the diagnosis stage to palliative care. Table 1 maps key response items to the three domains of integration (i.e., clinical, functional and vertical) and the main findings for each.

Studies have shown that clinical guidelines and navigational pathways in general are considered useful by PCPs in caring for cancer patients (Mayer et al. 2012; Papagrigoriadis and Koreli 2001; Zitzelsberger and Graham 2004). Our finding that many of these physicians do not understand the referral process to the RCP, and perhaps lack adequate guidelines, is important for planners to consider if PCPs are to remain involved in patient care at this initial transition. We found that basic information about where and whom to call and what diagnostic testing to have in place is not well understood. Emerging approaches to streamlining the patient transition into an RCP require mechanisms to ensure that PCPs are clear about referral processes. At the time of the study, tools to support the referral process had been developed for specialists, but were not systematically disseminated to PCPs. Web-based technologies seemingly have the potential to address PCP knowledge gaps in connecting patients to the RCP, but at this point, fewer than 10% of respondents report using RCP web resources. Systematic dissemination of referral guidelines in hardcopy, with reference to the RCP web portal, would likely have good uptake, particularly, given that respondents indicated overwhelmingly a need for a simple chart or card outlining referral procedures and key contact information for the RCP.

There is emerging evidence that targeted informational support to PCPs using a simple procedure that includes a faxed note of their patient's progress during the initial transition period best meets the information needs of these providers (Mansell et al. 2011; Ray et al. 1998). In an Australian study, it was observed that this basic procedure lead to significant improvements in physician confidence in the management of patients, with communications with the RCPs, and satisfaction in shared care (Jefford et al. 2008). The shared care finding is notable when considering that in the current study, over a third of respondents felt that their role was not valued across the trajectory of care, and many desired ongoing contact with the appropriate teams in the RCPs. Interventions to better support PCPs with specific information about the care of their patients and how to connect with the RCP would be expected to help improve this situation, leading to better care integration.

During active treatment, virtually all respondents indicated that they continued to be involved in the care of their patients' non-cancer medical problems and most indicated that they managed some of the side effects of treatment as well. This finding is reassuring in light of an Institute of Medicine review that suggested that PCPs' overall involvement in cancer care may be diminishing (Institute of Medicine and National Research Council of the National Academies 2005). Potential gaps remain in the provision of fully integrated care, in that almost half of the respondents reported not providing informational support to their patients about cancer and its treatment, and a similar proportion indicated having no involvement in their patients' cancer therapy decisions. Because PCPs are the preferred informational support across the trajectory of care for many cancer patients, methods to improve information sharing specific to the needs of these providers are essential for the realization of this patient preference (Whelan et al. 2003).

Although most PCPs knew who to contact during active treatment about issues specific to shared patients, over a fifth felt inadequately informed about changes in the condition or treatment trajectory of these patients. This would clearly impair PCPs' ability to provide appropriate care. Studies showing the benefit of standardized written communications between PCPs and cancer specialists would inform what interventions would be most helpful to address this gap. Finally, the interest expressed by some respondents in attending MCCs on their patients is important for system planners to consider the expansion of MCCs as part of quality improvement initiatives. Our findings suggest that it may be feasible to attempt to broaden the mandate of MCC attendance, perhaps using videoconferencing technologies, to facilitate attendance by PCPs. MCC participation by PCPs is possible using the RCP teleconference platform currently used by cancer specialists. PCP involvement in these MCCs would potentially support improvements in provider role clarity and patient care planning.

At the follow-up phase of cancer care, respondents indicated ongoing care provision for non-cancer-related problems, but there remained gaps in the provision of survivorship care. Only two-thirds of PCPs indicated that their role during this phase was clear, and a substantial proportion did not feel that their role was valued. These obstacles must be overcome to ensure that PCPs are well positioned to support and execute survivorship plans for the ever-increasing number of cancer survivors.

Palliative care for cancer patients remains problematic with well-described, chronic shortages of community-based services and continued high utilization of acute care services, especially emergency departments (Carstairs 2010; Henson et al. 2015; Hui et al. 2010). Most PCPs in our study indicated knowing how to arrange basic palliative care services, yet some perceived that the RCP was not responsive to their requests for advice on how to manage this care in their patients. Once again, guidelines were felt to be useful to support PCPs, especially in helping them navigate the resources available in the community for this phase of care.

In an exploratory multivariable analysis, we found that PCPs indicated higher rates of important integration parameters such as familiarity with processes of referral, role clarity and feelings of being valued, with both increasing years of practice and attendance at educational events that include explicit patient care and process best practices. These findings support the need for outreach and education by RCPs, especially for PCPs early in their careers. We also observed that regardless of the model, many respondents felt the compensation for care of cancer patients to be inadequate. This finding concurs with the finding of the work from other research groups studying models of care integration that have determined the importance of financial incentives as a key element of success in care integration and patient outcomes – a key consideration for health system planners (Shortell et al. 2000; Wagner 2004). However, greater remuneration on its own can have a negative impact on the internal motivation of providers and does not guarantee greater PCP integration or better-quality care (Gosden et al. 2001; Scott et al. 2011).

A limitation of this study using self-reported data is the potential for respondent bias. Some PCPs may have exaggerated their involvement in cancer patient care or their understanding of the transition processes, whereas non-respondents may be even more detached from cancer care and the RCP. Our findings almost certainly present a better scenario than the overall reality in PCP–RCP integration. Similarly, associations found between self-reported practice factors and involvement in care provision could be because of PCPs who perceive themselves as highly involved in cancer care, inflating the number of new cancer patients seen or the related education sections attended. We neither assessed integration from the perspective of the RCP, other cancer care providers or patients nor corroborated the PCPs' perspectives with administrative information, such as time to RCP intake, PCP service provision, etc. Input from non-physicians, service administrators and patients is also important in designing interventions to improve cancer system integration. This study did not directly assess the cost implications of poor integration and whether improvements would lead to changes in healthcare costs. Finally, our study-specific instrument requires further validation in different cancer care systems to test its reliability and validity.

There are two important preliminary observations to make when considering the overall results of this study. The first is that it is feasible to conduct this type of research with PCPs using a proven methodology for mailed surveys (i.e., clear study purpose, small incentive, SAE/fax return, targeted follow-up) (Vangeest et al. 2007) as shown by our response rate of 63%. The second observation is that the various aspects of care provision and integration between RCP and PCPs differ across the trajectory of care and that interventions are important to support gaps, especially in the peri-diagnostic and post-treatment surveillance phases of care. It is also evident that communication between community and RCP providers requires improvement, and that interventions need to incorporate clear guidelines about roles and responsibilities for patient care.

By identifying the specific aspects of caring for patients from the perspectives of a large and representative sample of PCPs within a regional planning structure, this study represents an important first step towards informing the design of system interventions to improve PCP satisfaction with/perception of integration with the RCP. The following strategies have been explicated: (1) Tools to support initial work-up at the cancer centre, such as diagnostic assessment and RCP navigation; (2) Mechanisms to facilitate PCP involvement in MCCs; (3) Other mechanisms that enable real-time communication between PCPs and the RCP during therapy; (4) Standardized post-treatment transition plans that include explicit statements about roles and responsibilities in care; and (5) Clear avenues for PCPs to connect directly with specialists at the RCP. These actions that are aimed at increasing PCP involvement need to regard the comfort levels of these providers and uphold patient care continuity. This study serves as a partial baseline for evaluating regional and provincial initiatives that are designed to improve system functioning and the patient care experience through enhancing RCP and PCP integration.

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