

Editor's key points

► This study provides important insights into the extent to which family health clinics provide primary-level palliative care in Ontario and eastern Quebec. The authors found that most of the responding clinics in both provinces reported that their patients who required palliative care had access to ambulatory and home care. A relatively small group of clinics in Ontario (28%) and most clinics in Quebec (91%) provided on-call palliative care services themselves.

► Factors that enabled clinics to provide palliative care included interprofessional communication within the team, access to specialist palliative care support teams, information exchange between hospital physicians and the primary care team, and palliative care training. Barriers included after-hours coverage, additional time required to provide palliative care, limited access to palliative care beds for patients with complex needs, and inadequate palliative care training.

► Strategies to address existing gaps (eg, after-hours care) included palliative care education, support from palliative care teams, and clinical aids and tool kits. Incentives such as adequate remuneration for family physicians to provide this care, do home visits, and undertake goals-of-care discussions are needed. Health care funders need to ensure that home-care resources and community-based palliative care teams are put in place.

Do family health clinics provide primary-level palliative care in Ontario and the eastern regions of Quebec?

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Abstract

Objective To explore the extent to which family health clinics in Ontario and the eastern regions of the province of Quebec provide palliative care.

Design A cross-sectional survey.

Setting Ontario and the eastern regions of Quebec.

Participants The clinic leads of a select group of family health clinics with patient enrolment models in Ontario and the eastern regions of Quebec.

Main outcome measures The types of palliative care services that the clinics provide, as well as the enablers of and barriers to providing palliative care within the 2 provinces.

Results The overall response rate was 32%. Clinics in both provinces reported providing palliative care to ambulatory patients (83% of Ontario clinics and 74% of Quebec clinics). Only 29 of 102 (28%) Ontario clinics provided on-call services themselves, compared with 31 of 34 (91%) Quebec clinics, with the resulting effect being that more patients were directed to emergency departments in Ontario. Access to palliative care specialist teams for support was higher in Ontario than in Quebec (67% vs 41%, respectively). In Ontario, 56% of practices indicated that they had access to palliative care physicians who could take over the care of their patients with palliative care needs, but a lower number (44%) actually handed over care to these physicians.

Conclusion A group of clinics are providing full palliative care services to their own patients with palliative care needs, including “on-call” services and home visits, and these serve as role models. In Ontario in particular, substantial gaps still exist with respect to clinics providing their own after-hours coverage and home visits; many rely on other services to provide that care. In Quebec, lack of access to palliative care specialist teams appears to be a key challenge in the areas included in this survey. This survey could help policy makers and funders of health care services ensure that appropriate conditions are put in place for optimal palliative care provision in these clinics, such as coordinating access to on-call coverage and support from palliative care specialist teams, as well as providing education to all physicians and adequate remuneration.

Les cliniques de santé familiale offrent-elles des soins palliatifs de qualité en Ontario et dans l'est du Québec?

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Résumé

Objectif Étudier la mesure dans laquelle les cliniques de santé familiale de l'Ontario et de l'est du Québec offrent des soins palliatifs.

Type d'étude Une enquête transversale.

Contexte L'Ontario et l'est du Québec.

Participants Les dirigeants d'un groupe sélectionné de cliniques de santé familiale de l'Ontario et de l'est du Québec qui fonctionnent selon un mode de recrutement des patients.

Principaux paramètres à l'étude Les types de soins palliatifs offerts par les cliniques de chacune des provinces ainsi que les facteurs qui facilitent l'offre de soins palliatifs ou qui y font obstacle.

Résultats Le taux global de réponse était de 32%. Les cliniques des deux provinces ont rapporté avoir dispensé des soins palliatifs ambulatoires (83% en Ontario et 74% au Québec). Seules 29 cliniques ontariennes sur 102 (28%) ont fourni elles-mêmes des services sur demande, comparé à 31 cliniques sur 34 au Québec (91%), ce qui signifie qu'en Ontario, un plus grand nombre de patients ont été dirigés vers des services d'urgence. En Ontario, il était plus facile qu'au Québec d'avoir accès au soutien d'équipes spécialisées dans les soins palliatifs (67% c. 41%, respectivement). En Ontario, 56% des cliniques ont indiqué qu'elles avaient accès à des médecins qui pouvaient prendre en charge des patients nécessitant des soins palliatifs, mais il y en avait moins (44%) qui confiaient cette tâche à ces médecins.

Conclusion Un groupe de cliniques offrent à leurs propres patients qui en ont besoin des soins palliatifs complets, incluant des soins sur demande et des soins à domicile, et ces cliniques servent de modèles. Particulièrement en Ontario, il existe encore des lacunes considérables du côté des cliniques qui offrent des services à domicile ou en dehors des heures normales; bon nombre se fient à d'autres services pour fournir ce type de soins. Au Québec, il semble que l'accès insuffisant à des équipes spécialisées dans les soins palliatifs constitue un problème important en ce qui concerne les domaines touchés par cette enquête. Cette enquête pourrait faire en sorte que les responsables des politiques et du financement dans les services de santé mettent en place des conditions optimales pour offrir des soins palliatifs dans ces cliniques, par exemple en coordonnant l'accès aux soins sur appel et au soutien d'équipes spécialisées dans les soins palliatifs, de même qu'en fournissant de la formation et une rémunération adéquate à tous les médecins.

Points de repère du rédacteur

► Cette étude fournit des données utiles quant à la mesure dans laquelle les cliniques de santé familiale de l'Ontario et de l'est du Québec offrent des soins palliatifs de qualité. Les auteurs ont observé que la plupart des cliniques ontariennes et québécoises qui ont participé à l'enquête ont déclaré que leurs patients qui avaient besoin de soins palliatifs avaient accès à des soins à la clinique comme à domicile. Une proportion relativement faible de cliniques de l'Ontario (28%) et la plupart des cliniques québécoises (91%) dispensaient elles-mêmes de tels services sur demande.

► Parmi les facteurs qui permettaient aux cliniques d'offrir des soins palliatifs, mentionnons la bonne communication entre les professionnels de l'équipe, l'accès au soutien d'équipes spécialisées dans les soins palliatifs, le partage d'informations entre les médecins hospitaliers et l'équipe des soins primaires, et une formation portant sur les soins palliatifs. Les obstacles incluaient la nécessité de travailler en dehors des heures normales, les heures supplémentaires nécessaires pour offrir des soins palliatifs, l'accès limité à des lits pour les patients présentant des besoins complexes et une formation inadéquate dans ce domaine.

► Les stratégies envisagées pour remédier aux lacunes existantes (p. ex. le fait de travailler en dehors des heures normales) comprenaient une meilleure formation sur les soins palliatifs, le soutien d'équipes de soins palliatifs ainsi que du matériel clinique et des trousseaux d'outils. Des incitations seraient nécessaires, telles qu'une rémunération adéquate accordée aux médecins de famille pour qu'ils offrent ce type de soins, fassent des visites à domicile et participent à des discussions éventuelles sur les objectifs des soins. Les organismes qui financent les soins de santé doivent s'assurer de la mise en place de ressources pour soins à domicile et d'équipes communautaires de soins palliatifs.

The need to improve access to palliative care for patients with malignant and non-malignant illnesses is increasingly being emphasized.^{1,2} This is accompanied by a growing body of evidence and experience that shows the benefits of implementing a palliative care approach earlier in the illness trajectory—not relegating it only to the end of life (EOL).³⁻⁶ Capacity in the health care system to address these needs is therefore paramount.

A case can be made for primary-level (first-line, non-complex) palliative care to be delivered by health care professionals who are not palliative care specialists; these include family physicians, other primary care providers, and professionals in specialty areas such as oncology, internal medicine, geriatrics, nephrology, and cardiology, among others.⁷⁻⁹ This might not be the situation in Ontario where palliative care specialists appear to provide the bulk of all palliative care.¹⁰

The main goal of this study was to explore the extent to which family health clinics in Ontario and Quebec provide palliative care to their own patients. The survey is part of a larger project called *INTEGRATE*, which aims to have palliative care initiated earlier in the illness trajectory and to improve transitions of care between the community and cancer centres. Although the *INTEGRATE* project has involved 3 health regions in Ontario and the eastern regions of the province of Quebec, this survey targeted clinics across all of Ontario's 14 health regions. In Quebec, the survey targeted 7 regions that represent the eastern part of Quebec, where the *INTEGRATE* project was conducted.

— Methods —

A cross-sectional survey was conducted of a select group of family health clinics in Ontario and the Quebec city region of Quebec.

Sampling

Several primary care team models exist in Ontario and Quebec. They vary in terms of the remuneration methods for physicians and funding for other professionals.¹¹ In Ontario we surveyed family health teams (FHTs), community health centres, Aboriginal health access centres, and nurse practitioner-led clinics (NPLCs). We chose these because they are mandated to provide continuity of care for the populations they serve and, with the exception of NPLCs, are multiprofessional, allowing comparison with the Quebec-based practices that are also multiprofessional. Approximately 27.5% of family physicians in Ontario are reimbursed by capitated enrolment models such as FHTs. At the time of the study, about 3 million Ontarians (22% of the population) were enrolled in the 185 FHTs across Ontario.¹¹ In comparison, 29% of family physicians are paid by non-capitated enrolment models such as family health groups and 35% by a traditional fee-for-service (FFS) model.

The funding mechanisms for the various patient enrolment models in Ontario, including FHTs, family health organizations, family health networks (FHNs), and family health groups, are complicated. The different models are based on capitation reimbursement for physicians, blended with varying degrees of FFS and incentives. Family health teams require that physicians be paid through one of the blended capitation models (FHNs or family health organizations) or a blended salary model; most FHT physicians are paid through the FFS model. In the case of FHNs, another blended model, payment is mostly based on capitation. Depending on the type of model, some palliative care-related services fall within the basket of services covered by the model while others do not, thus allowing the physician to bill them as incentives. Some of these incentives, depending on the model, include some palliative care home visit codes, palliative care outpatient case conferencing, palliative care support, and a weekly palliative care case management fee. There is also an annual palliative care special premium bonus for seeing more than 4 “palliative care” patients a year.

In Quebec, the survey focused on 3 primary care models, as these are also the predominant models in that province: family medicine teaching units, family medicine groups, and local community health centres (known as *centres locaux de services communautaires [CLSCs]*). All 3 models are multiprofessional. The CLSCs provide most of the home-based palliative care in the regions.¹²

During the time of the survey, home-based palliative care physician services in the community were generally provided by the family physicians using an FFS model. Some provided home visits. In the case of CLSCs, family physicians are paid on an hourly basis to care for “orphan” patients (ie, patients who do not have a family physician) at home.

The surveys targeted the clinics as a collective and not as individual physicians or staff members. In Ontario, invitations to participate in the survey were sent to clinical or administrative leads of clinics (including community health centres, Aboriginal health access centres, NPLCs, and community-governed FHTs) represented by the Association of Family Health Teams of Ontario and the Alliance for Healthier Communities (formerly the Association of Ontario Health Centres). In Quebec, invitations were sent to the clinics included in the Réseau universitaire intégré de santé de l'Université Laval.

Data collection and analysis

A survey was developed specifically for this study. An iterative process was used by a working group consisting of researchers and clinicians. Questions explored whether practices provided different types of palliative care services and identified enablers and barriers to providing palliative care. The survey specified that palliative care was not limited to EOL. The survey was translated

into French by Francophone members of the research team and adapted to reflect the Quebec health care system. It was available online via FluidSurveys.

Ethics approvals were obtained from the University of Toronto's Ethics Review Board in Ontario and both ethics boards of the Centres de santé et de services sociaux de la Vieille-Capitale et d'Alphonse-Desjardins in Quebec. The survey was administered from June to September 2014 in Quebec and in July and August 2014 in Ontario. Analyses were performed using the SAS, version 9.4., and SPSS, version 13.0, software systems.

— Results —

Table 1 shows the response rates for each type of clinic. The overall response rates for Ontario and Quebec were 31% and 33%, respectively, but rates varied among the different types of clinics (21% to 92%).

Table 2 describes the types of palliative care services provided. Most of the clinics in both provinces reported providing palliative care to ambulatory patients with palliative care needs (83% in Ontario and 74% in Quebec) and provided home visits for patients at the EOL (78% in Ontario and 92% in Quebec); however, fewer clinics in both provinces provided after-hours coverage for these patients (52% in Ontario and 62% in Quebec).

Only 29 out of 102 (28%) Ontario clinics provided on-call services themselves, compared with Quebec where out of the 34 clinics that answered the question, 31 (91%) of them provided this service (data not shown in tables). In Ontario, 43 of 102 (42%) clinics reported that they offered after-hours coverage for their patients but that this coverage was provided by other parties, including community palliative care nurse practitioners, home-care agency nurses, or palliative care services. In Ontario, 32 clinics (31%) indicated that no after-hours coverage was provided and patients were instead

directed to emergency departments (compared with 3 clinics [8%] in Quebec). In both Ontario and Quebec, few clinics kept a registry of their patients who required a palliative care approach (19 of 102 [19%] clinics and 12 of 39 [31%] clinics, respectively). In Quebec, this was done mostly by physicians attached to CLSCs in each district, as these entities provide on-call coverage 24 hours a day, 7 days a week.

Table 3 summarizes access to and use of palliative care resources by the clinics. In Ontario, 67% of practices reported having access to a palliative care specialist support team. This was lower in Quebec (41%). In Ontario, 56% of practices indicated that they had access to palliative care physicians who could take over the care of their patients with palliative care needs, but a lower number (44%) actually handed over care to these physicians. Access to palliative care units (42% in Ontario and 57% in Quebec) and residential hospices (48% in Ontario and 69% in Quebec) was relatively limited in both provinces.

Factors that enabled clinics to provide palliative care included interprofessional communication within the team, access to specialist palliative care support teams, information exchange between the hospital physicians and the primary care team, and palliative care training. Barriers included after-hours coverage, additional time required to provide palliative care, limited access to palliative care beds to admit patients with complex needs, and inadequate palliative care training.

— Discussion —

This study provides important insights into the extent to which family health clinics provide primary-level palliative care in Ontario and in eastern Quebec. Seen through a social accountability lens that values comprehensive and continuous care,¹³ some of the findings

Table 1. Number of responding primary care clinics and response rates

PROVINCE	TYPE OF PRIMARY CARE PRACTICE	CLINICS IN JURISDICTION, N	COMPLETED SURVEYS,* N	RESPONSE RATE, %
Ontario	Family health team	185	54	29
	Community health centre	108	23	21
	Nurse practitioner-led clinic	25	20	80
	Aboriginal health access centre	10	5	50
	Total	328	102*	31
Eastern Quebec	Local community health service centre (centre local de services communautaires)	50	13	26
	Family medicine group (groupe de médecine familiale)	55	15	27
	Family medicine unit (unité de médecine familiale)	12	11	92
	Total	117	39	33

*Partially completed surveys were excluded.

are encouraging. Most of the responding clinics in both provinces, for example, reported that they provided ambulatory and home care to their patients requiring palliative care (83% and 78% in Ontario, and 74% and 92% in Quebec, respectively). A relatively small group of clinics in Ontario (28%) and most clinics in Quebec (91%) provide on-call palliative care services themselves. These clinics serve as role models.

However, some substantial gaps are noted. Some clinics do not provide palliative care even to ambulatory patients with palliative care needs (17% in Ontario and 26% in Quebec) and only 53% and 62% in Ontario and

Quebec, respectively, provide after-hours coverage themselves. In Ontario, 42% of clinics reported that while they offered after-hours coverage for their palliative patients, this coverage was provided by other parties, in some cases only nurses. This is concerning, as only physicians may prescribe key medications such as opioids, with the exception of nurse practitioners. Almost 1 in 3 (31%) of responding Ontario clinics indicated that no after-hours coverage was provided; patients were instead referred to emergency departments. In the remaining 17%, after-hours coverage was likely provided by another entity such as a home-care service or palliative care service, on behalf of the clinic. In Quebec, medical care in long-term facilities, residential hospices, and palliative care units is provided either by full-time on-site physicians or part-time physicians who provide on-call coverage 24 hours a day, 7 days a week.

Differences in the health care systems of Ontario and Quebec explain some of the variation in the findings. In Ontario, for example, each of the 14 regions (referred to as *Local Health Integration Networks*) have a community care access centre (CCAC) that coordinates home-care services, including palliative care. The CCACs provide care coordinators to organize the care of individual patients; third party nursing agencies are engaged to provide direct care in patients' homes. There appears to be large variations in the level of primary-level palliative care training of the CCAC care coordinators and home-care nurses across the regions and even within regions. Each Local Health Integration Network also has, since 2013, 3 to 4 palliative care nurse practitioners. However, their role varies from region to region; in some regions they work alongside a palliative care specialist physician to support family physicians, community nurses, and long-term care homes in a consultation support role. In other regions, the palliative care nurse practitioners provide primary-level palliative care, often working with local palliative care specialists;

Table 2. Types of palliative care services provided by responding clinics

SERVICE OFFERED	ONTARIO (N = 102), N (%)	EASTERN QUEBEC (N = 39), N (%)
Care for ambulatory patients with progressive illness	85 (83)	29 (74)
Home visits to provide end-of-life care for patients	80 (78)	36 (92)
Care coverage provided outside of regular office hours	54 (53)	24 (62)
Advance care planning	78 (76)	26 (67)
Grief and bereavement support	68 (67)	9 (23)
Care for patients in long-term care facilities	43 (42)	20 (51)
Care for patients in residential hospices	18 (18)	22 (56)
Care for patients in palliative care units	16 (16)	16 (41)

Table 3. Clinics' access to and use of palliative care resources and services

PALLIATIVE CARE RESOURCES AND SERVICES	ONTARIO (N = 102)		EASTERN QUEBEC (N = 39)*	
	HAVE ACCESS TO, N (%)	ACTUALLY USE, N (%)	HAVE ACCESS TO, N (%)	ACTUALLY USE, N (%)
CCAC palliative care case management and contracted nursing services	91 (89)	88 (86)	NA	NA
Palliative care consultation team in community	68 (67)	65 (64)	13 (41)	12 (38)
CCAC palliative care nurse practitioners	55 (54)	43 (42)	NA	NA
Palliative care physicians (take over care as most responsible physician)	57 (56)	45 (44)	12 (39)	12 (39)
Residential hospice for patients at end of life	49 (48)	39 (38)	22 (69)	19 (59)
Community hospice programs (day hospice, hospice at home)	42 (41)	35 (34)	20 (63)	18 (56)
Palliative care unit (for complex cases across the illness trajectory)	43 (42)	34 (33)	17 (57)	17 (57)

CCAC—community care access centre, NA—not applicable.
*Only 32 of the 39 Quebec clinics answered these questions.

this approach does not necessarily build primary-level capacity among family physicians and other primary care providers. Capacity building can occur when these nurse practitioners support generalist family physicians, which does occur in some regions.

The remuneration model for palliative care physicians in Ontario might also influence access to primary-level palliative care. There is currently an overreliance on an FFS model for palliative care physicians; such a remuneration model might incentivize the palliative care specialists to take over all the care, including the primary-level palliative care. Quebec does not have regional palliative care nurse practitioners; however, it does have the CLSCs, which Ontario does not. There is also a relative dearth in Quebec of community-based palliative care specialist teams to support family physicians and community nurses.

Some of the factors contributing to these gaps are highlighted. They include lack of training and comfort providing palliative care and the lack of access to palliative care community teams for support. In a recent study of family physicians in 10 countries, including Canada, more than 50% indicated that they had not received adequate palliative care training and felt uncomfortable providing this care.¹⁴

Strategies exist to address these and other gaps. They include palliative care education, just-in-time support from palliative care teams, and clinical aids and tool kits.^{8,15-17} Incentives such as adequate remuneration for family physicians to provide this care, do home visits, and undertake goals-of-care and advance care planning discussions are needed. Health care funders should ensure that there are home-care resources and community-based palliative care support teams in place, and that these teams are funded to build capacity, not undermine the role of primary care providers—which might occur when they are funded by an FFS model. Conversely, family medicine clinics need to take ownership of this care and be held accountable.

The risks of a system that relies on specialist palliative care teams to provide all palliative care, including primary-, secondary-, and tertiary-level care, have been highlighted.¹⁸ It transmits an erroneous message that clinicians who are not specialized in palliative care are not capable of providing primary-level palliative care, including basic symptom management and psychosocial support, and undertaking advance care planning and EOL-related goals-of-care discussions. Long-standing therapeutic relationships between family physicians or other specialists with their patients are disrupted. If sidelined and neither supported nor given the opportunity to nurture their skills in this area, these clinicians will become de-skilled in the provision of primary- or generalist-level palliative care, thereby further reducing the capacity of the health care system to provide palliative care. The demand for palliative care is increasing and will

outstrip the supply of providers, particularly if the sole providers are seen to be a small number of palliative care specialists. In the case of family physicians, given the right conditions and support, there is evidence that family physicians can provide high-quality primary-level palliative care, and can reduce hospitalizations, hospital deaths, and emergency department visits.^{8,19-23}

Specialist physicians and nurses across a broad spectrum of specialty areas, including oncology, internal medicine, cardiology, pulmonology, neurology, critical care, emergency medicine, and geriatrics, if equipped with the necessary basic palliative care skills and supported by palliative care specialist teams, are also able to provide generalist-level palliative care. This includes identifying patients with palliative care needs earlier in the illness trajectory, initiating symptom management and psychosocial support, and engaging in more timely advance care planning and goals-of-care discussions. We therefore need a model that includes primary- or generalist-level palliative care capacity, as well as specialist palliative care, for managing more complex and difficult cases and helping advance the field. These 2 can coexist and support each other, and patients, in turn, have increased access to palliative care.

Limitations

There are several limitations to this study. The overall response rates were suboptimal. This, and the voluntary nature of the survey, might have introduced a selection bias in favour of practices that do provide palliative care. In the 2010 National Physician Survey of Canadian physicians, 45.7% of family physicians reported providing palliative care (43.1% in Ontario and 41.3% in Quebec).²⁴ It is possible that some clinicians in clinics providing palliative care might indeed not be providing this care themselves. The study did not explore palliative care delivery by other models in Ontario and the response rates precluded comparisons between urban- and rural-based practices and between clinic models. Although the study was conducted in 2014, the results remain relevant. The results of this survey are particularly pertinent today, as they inform the further development of palliative care and primary care in the 2 provinces. Finally, the study was not designed to explore the quality of palliative care provided.

Conclusion

This study provides valuable insights into the current provision of primary-level palliative care by a subset of family health clinic models in Ontario and Quebec. There exists a group of clinics that are providing a broad scope of palliative care services themselves, and these clinics serve as role models. However, considerable gaps exist and these need to be addressed; they include low rates of after-hours coverage by family medicine clinics and lack of community-based palliative care teams to support the primary care providers.

Leadership is going to be required by policy makers and funders to ensure that the health care system can adequately meet the growing palliative care needs of the populations they serve. To do this, the health care system must include the capacity to provide primary- or generalist-level palliative care, as well as specialist-level palliative care. While a specialized palliative care work force and specialized palliative care services across different settings are needed, the system must also provide the support and conditions to ensure that all health care professionals providing care to patients diagnosed with life-threatening and life-limiting illnesses are able to provide primary- or generalist-level palliative care. 🍁

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Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

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