

Mapping primary and generalist palliative care: Taking a closer look at the base of the pyramid

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Background

Universal and timely access to palliative care for patients with serious illnesses requires mobilization of communities and both specialist-level and primary- or generalist-level palliative care services.^{1–7} When equipped with core palliative care competencies and supported by palliative care specialists, health professionals in primary care and across several other specialties should be able to provide a *palliative care approach*.^{8–10} This includes identifying patients with palliative care needs early, undertaking advance care planning and goals of care discussions, identifying and addressing patients' needs, mobilizing resources, and referring to palliative care specialists when needed.¹¹

A pyramid is often used to depict the different levels of palliative care provision (see Figure 1(a)), where the base represents primary- and generalist-level palliative care—the former delivered by primary care providers and the latter by professionals across different specialties—and the apex depicts specialist-level palliative care. Both levels are further sub-divided in some jurisdictions.

Mapping and atlas approaches are used to study, report, and monitor the status of palliative care in different jurisdictions.^{12–15} While mapping specialist palliative care services has some challenges,^{14,16} assessing the state of primary and generalist palliative care is more complex and at times elusive.¹⁷

This paper highlights limitations of some indicators and methods of assessment of primary and generalist palliative care (referred to herein as *primary-generalist*), and proposes some additional mapping approaches. Ongoing work on a Canadian Palliative Care Atlas has informed this reflection.

Discussion

A strong specialist palliative care presence (apex) may not necessarily generate a robust primary-generalist palliative

care base (see Figure 1(b)).^{10,18} If, in any given jurisdiction, one were to draw back the curtain (figuratively) and look more closely, one may find varying levels of primary-generalist palliative care presence; undeveloped and weak (Figure 1(c)), partly present or present to varying degrees across different services and care settings (Figure 1(d)), or well established and vibrant (Figure 1(e)). Figure 1(e) would be characterized by the majority of primary care providers and health care professionals across different specialties equipped with core palliative care skills and providing a palliative care approach to the patients under their care. In jurisdictions with poorly developed primary-generalist palliative care, specialist palliative care services must provide all levels of palliative care, risking longer wait times for patients and excessive workloads and burnout of these teams.¹⁸

Many factors influence the presence and vitality of primary-generalist palliative care.^{18–20} To provide primary-generalist palliative care, for example, professionals and services require core palliative care skills, the presence of appropriate processes and funding models, support from specialist palliative care teams through consultation and shared care models, and access to resources such as home care services. Importantly, primary care providers and providers of care across other specialties need to take ownership of integrating a palliative care approach in their daily practices.²¹ Specialist palliative care teams in turn need to value the contributions of primary-generalist

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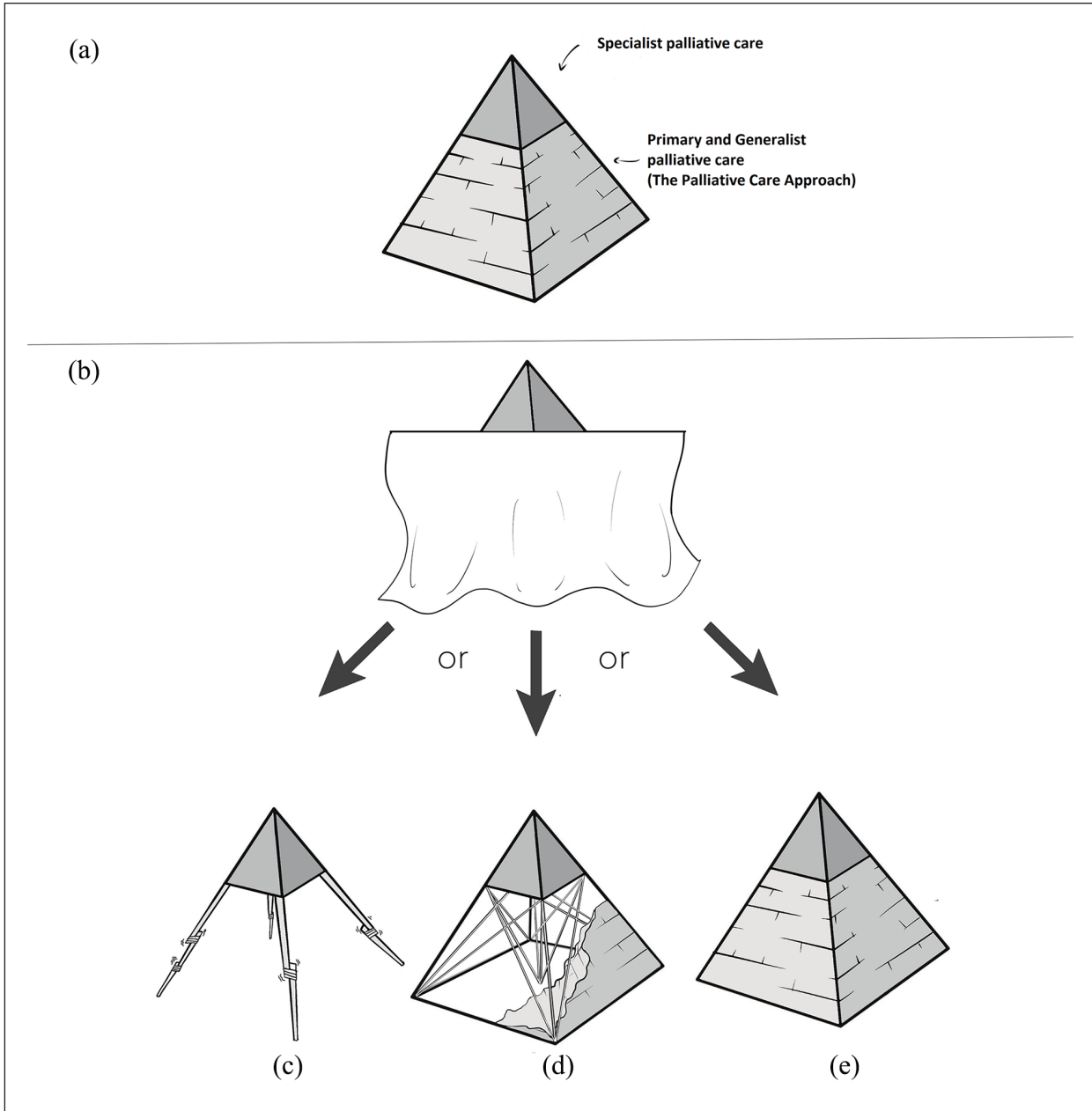


Figure 1. The status of primary and generalist palliative care in a health care system: Weak, under development, or well established.

palliative care, and support and nurture them.^{22,23} Appropriate remuneration models that incentivize collaboration are essential, as is the willingness and ability to take over the care of a small number of patients whose needs are complex.²¹

Micro- and macro-level indicators of primary-generalist palliative care currently include, among others, the percentage of patients identified as having palliative care needs in primary care and specialty services, early activation of palliative care including the number of months before death that patients were identified for a palliative

care approach, the presence of advance care planning, the proportion of patients who receive care from their primary care provider or other specialists in the last months of life, home visits by primary care providers, referral rates to specialist palliative care services, the presence of incentives to promote early identification of patients with palliative care needs, policies and funding that promote primary-generalist palliative care development, and palliative care training across the learning continuum from undergraduate and residency training to continuing education.^{16,17,24}

Understandably, some indicators have limitations and don't fully capture some important nuances. The presence of palliative care in medical undergraduate and postgraduate curricula, while essential, may not necessarily predict whether learners will practice it once they graduate.²⁵ In a longitudinal, multiyear study of Canadian family medicine residency programs, more than half of residents in some programs reported that they did not intend to provide palliative care after graduation, despite receiving that training.²⁶ A number of factors may explain this, including insufficient palliative care training opportunities or hidden curricula that undermine the role of primary palliative care.²⁷ Family medicine residents assigned to practices that do not provide primary palliative care, and who rotate through specialist palliative care teams that practice predominantly a takeover model, may be left with the impression that palliative care can only be provided by palliative care specialists.^{18,27,28}

In some regions of Ontario, a Canadian province, some family physicians and primary care clinics do not provide primary palliative care despite financial incentives, funding models and policies to encourage them to do so.²⁹ The reasons are multicausal, including a depleted and exhausted primary care workforce, absence of resources, convenience, and palliative care clinician remuneration models that incentivize takeover of care from primary care providers and other specialists, regardless of complexity.^{18,22,23} Over time this erodes the readiness and willingness of family physicians and other specialists to provide primary-generalist palliative care.¹⁸ In an Ontario survey of patient-rostered primary care clinics, 44% of clinics relied on specialist palliative care clinicians to provide all the palliative care to their patients.²⁹ Only 28% of clinics provided on-call palliative care coverage themselves.

Large population-level administrative datasets and data extracted from electronic health records are useful mapping tools.^{30–36} They may help facilitate the identification of patients with palliative care needs and those receiving it, care providers, and the timing of palliative care activation and advance care planning.^{31,33,37,38} A large administrative database was used in Ontario to retrospectively identify palliative care providers in the last year of life for persons with serious illnesses; 21.2% of persons received only primary or generalist palliative care from a physician, 14.7% received palliative care from non-palliative care clinicians supported by specialist palliative care physicians, and 11.1% received palliative care only from palliative care physicians.³¹ Just over half of patients received no physician-delivered palliative care in the last year of life.

These databases however have limitations, especially if their original purpose is not the mapping of palliative care services. In Ontario, for example, there is no specific code that allows a palliative care physician with a family

medicine background to be differentiated from a generalist family physician, requiring indirect and sometimes imperfect methods to identify providers.³⁷ Primary palliative care may be provided by nurses or nurse practitioners but this is not captured in physician billing databases, leading to under-reporting of primary palliative care. Clinician notes in electronic health records may not explicitly state “palliative care” or “advance care planning” even when these are provided. Conversely, the appearance of the word “palliative” in a patient record does not necessarily reflect its quality. Moreover, large databases are not available in many jurisdictions.

Important nuances may be missed.³⁹ A 2014 study on community-based specialist palliative care teams in Ontario found significant reductions in emergency department visits and hospitalizations across the eleven teams studied.⁴⁰ Unfortunately, the paper failed to explain that in the case of two teams studied the majority of palliative care was provided by primary care providers, supported by palliative care clinicians through a consultation model.

As a further example of some dissonance between indicator results and reality, building primary-generalist palliative care capacity across different settings and specialty areas appears in several Canadian federal, provincial, and territorial strategic plans and frameworks.⁴¹ While some jurisdictions are allocating the resources and policies to operationalize this, implementation has been piecemeal and suboptimal in others.⁴¹

Complementary mapping strategies

Complementary studies may be needed to corroborate information derived from population-level administrative databases and to explore the nuances of primary-generalist palliative care provision in and across jurisdictions. This includes the extent to which primary care providers and other specialists actually provide it across their services, and the number of months before death that early identification, assessment and advance care planning occur across different diseases. Complementary studies may include studies of electronic medical records of randomly identified practices,^{42–44} and surveys of primary care practices and specialty clinics in those jurisdictions.^{29,45} Standardized surveys could facilitate the collection of information.⁴²

Palliative care mappers and researchers could mobilize practice-based research networks (PBRNs) or surveillance sentinel practices that exist in several countries.^{46,47} These are groups of primary care practices, clinicians and researchers that collaborate to study various aspects of primary care in a region. Some routinely extract data from their respective electronic medical records for this purpose.^{48,49} Artificial intelligence may soon help these networks analyze the large data available to them.

Palliative care teams, in turn, may provide insights or signals into the state of primary-generalist palliative care in their respective regions by way of short, periodic, standardized surveys. The Consultation-Shared Care-Takeover Framework, for example, has been used by specialist palliative care teams and researchers to explore how these teams interact with primary care and other specialty services; a model that relies largely on taking over care from primary care teams may indicate underdevelopment or frailty of primary-generalist palliative care.^{18,22,23}

Conclusion

Given the pivotal role of primary-level and generalist-level palliative care to improve earlier and universal access to palliative care, strategies to improve them should be implemented and their state should be monitored and mapped.^{1,7,50–53} This includes the number of months before death that key steps are undertaken such as early identification, assessment and care planning for patients dying on different illness trajectories. Current mapping methods and indicators serve as important stepping stones, but ongoing work is needed to fine-tune them and to identify additional indicators—direct or proxy—that facilitate a better depiction of their state. In the interim, there are some strategies such as undertaking periodic surveillance through collaborations with sentinel practices or practice-based research networks and establishing networks of sentinel specialist palliative care teams that monitor the state of primary- and generalist-level palliative care in their jurisdictions. It is recognized that these strategies will require additional funds and resources to implement, and that the establishment of some of these networks may take time. Lastly, given the current strains on health care systems in many jurisdictions, innovative ways to support primary-generalist palliative care without increasing strain on them or on specialist palliative care teams are urgently needed.^{20,54–57}

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