Defining and measuring a palliative approach in primary care

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The most frequently cited statistic about palliative care in Canada, quoted in numerous publications from Canadian policy makers,[1] politicians,[2] academics,[3] advocates,[4] and the mass media,[5] is that "only 16-30% of those who need it receiv[e] palliative care."[6] The fallacy in this claim, of course, is the implication that all Canadians approaching the end of life should be cared for by specialist palliative care teams. The widely held perception is that primary care's role in providing palliative care is both minor and shrinking, and that the system's response should be to build webs of specialist palliative care to assume responsibility for the growing numbers of these patients.

Myth of 16%

In truth, family physicians provide the bulk of the medical care to community-dwelling patients approaching the end of life.[7,8] So if we know that primary care teams provide palliative care for most community patients, why is the myth of 16% so widespread? Confusion arises because *palliative care* is a term used to refer both to an approach to care, and to a specialized care team. As an approach to care, palliative care appreciates death as a normal life event, emphasizes good communication and clarification of goals of care, and focuses on quality of life including symptom management. However, the term is also used to identify the specially trained individuals whose work focuses exclusively on this patient population. As family physicians we recognize that all patients with life-threatening illness should receive palliative care as an approach, but this care does not always need to be provided by specialized physicians or teams. Continuity of care with primary care providers is valued by palliative care patients[9,10] and is cost-effective for the system.[11]

If we can so easily clarify this distinction between palliative care as an approach and palliative care as a discipline, why does the myth of 16% persist? One reason is that we have failed to clearly describe the contribution that primary care can, should, and does make in the treatment of patients with palliative needs. To do this we need to define, in the most concrete terms possible, exactly what a palliative approach in primary care entails. What does it mean to provide access to palliative care in our primary care practices? We need to be able to recognize and measure the degree to which our primary care systems are meeting patients' palliative care needs. It might be that only 16% to 30% of Canadians approaching the end of life are served by specialist palliative care teams, but is it not better to ask how many Canadians have their palliative care needs adequately met? Even more to the point for us as family physicians, how many Canadians have their palliative care needs adequately met in primary care?

Ensuring a palliative approach in primary care

The reality is that merely having a primary care provider does not guarantee access to a palliative approach in primary care. We all know a few family physicians who will not prescribe opioids under any circumstances, do not do home visits, and are unable to offer after-hours care beyond a telephone message directing patients to the nearest emergency department. To have one's palliative care needs met, one requires care that attends to those needs—in other words, care that is consistent with a palliative approach. While there is no formal definition of a palliative approach in primary care, the essential idea is that interprofessional primary care teams, regardless of the setting of care, should have in place the skills, resources, and processes necessary to recognize, assess, and manage basic palliative care needs in a timely fashion (24 hours a day, 7 days a week) in a community setting (office, home, or long-term care facility).

Ensuring patients have access to a palliative approach in primary care does not imply a one-size-fits-all policy, expecting each primary care team to offer an identical basket of services in the exact same manner. Access to a palliative approach in primary care need not be monolithic, but it must be universal.[12] We do not all need to do the same things the same way, but a palliative approach to care should be practised by all health care providers who look after patients living with life-threatening illnesses.

This conversation does not concern family medicine alone. The point is not that we, as family physicians, are the ones who must meet every need for every patient. Access to a palliative approach in primary care requires that in every primary care setting (outpatient offices, home care organizations, long-term care facilities, and elsewhere), providers of every discipline (family

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physicians, nurses, nurse practitioners, pharmacists, personal support workers, paramedics, social workers, and others) possess and implement the basic palliative care knowledge, skills, and attitudes pertinent to their discipline. This requires not just education,[13] but also an infrastructure, a policy environment, and a culture of care delivery that facilitates a palliative approach in primary care. A palliative approach in primary care also requires appropriate support from specialists for patients with complex needs. High-quality palliative care, like high-quality maternity care or mental health care, depends on cooperation and coordination between primary care and consultant specialist teams.

Conclusion

Canadians facing life-limiting illnesses expect their primary care providers to help address their palliative care needs. The responsibility to demonstrate that we are meeting this expectation is ours. To ensure that our patients are getting access to a palliative approach in primary care, we need to define it, describe it, support it, teach it, and measure it. Primary care's contributions to serving Canadians approaching the end of life is already well appreciated by those patients and their families, but only when we measure it can our role in the palliative care system be recognized by our colleagues and accounted for appropriately by system planners. Only then will be we able to counter the myth of 16%.

Our patients deserve to have access to a palliative approach in primary care. Let's make it explicit. Let's make it expected. Let's make it happen.

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