Advanced illness home care

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Palliative care has moved from historically focusing on dying patients to focusing on palliation any time in illness, suggesting palliative care can be appropriate for almost everyone entering their last years.[1,2] In 2017, the Framework on Palliative Care in Canada Act was passed, which mandates that in the subsequent 5 years, the Canadian government must define *palliative care*—its teaching, data collection, funding, and access.[3] Such an expansion of palliative care requires us to reconsider its provision—the character of this sort of palliative care, and the fact that some of this care needs to be provided to homebound patients. Increasing numbers of family physicians will be required as members of teams providing such care, which we have here called *advanced illness home care* (AIHC). So far, suggestions to address this need have focused mainly on training family physicians in clinical aspects of palliative care. While this training is beginning to be provided, we want to propose additional ways to develop AIHC in Canada.

Presenting the issue

It has been pointed out repeatedly that medical advances have prolonged the lives of those with chronic diseases and, so doing, have simultaneously created a larger group of persons living with morbidity. Inevitably, such patients reach a point that they cannot reasonably leave the place where they live (we have called this their *home*, acknowledging that some persons have temporary rather than stable shelter as their home). If provided with care that continues to treat their underlying conditions, these patients might live for months or even years.

While such home care appears at first glance like typical palliative care, it is different. In definitions of *palliative care* such as that of the World Health Organization, there are often suggestions that dying should be understood as a normal process; that death should not be hastened or postponed; and that symptom control can be added on to other forms of care.[4] But for patients requiring AIHC and their families, death and dying might be considered to be a disturbingly abnormal experience. Some will want their death hastened. Some will want to use many means to prolong their life. And in chronic disease, disease-directed treatments might be in themselves the most effective palliation. Consequently, the care of AIHC patients can be very complex, and might include not only treatments at home, but perhaps also both planned and unexpected treatments in acute care. Such care often involves uncertain or repeatedly shifting goals of care concerning whether to go to hospital, to receive aggressive treatments, or even to receive resuscitation attempts.

As it stands, this small percentage of the population, sometimes referred to as *the 5%*,[5] are among the highest users of health care resources, often receiving care in emergency departments and hospitals increasingly as their conditions worsen. For a minority who are identified and are receptive to palliative care, home palliative care programs can successfully provide care, simultaneously reducing emergency department visits and hospitalizations.[6] But others, especially those with noncancer diagnoses, might not receive this option if providers do not see the patient as a "long-term palliative" patient, or if remuneration is inadequate, or if patients and families have difficulty considering the patient to be entering the last part of his or her life. Many of these patients will need AIHC, and there is evidence to show that such care can be provided successfully, with a savings to the medical system.[7]

Alternative proposal

At this point, what is typically suggested is training in palliation and communication for practising family physicians.[1,8-10] And while family physicians seem well suited to the task, only a small proportion are currently able and willing to provide this type of "round-the-clock" care in the patient's home. The idea of AIHC has been presented for some time,[11] and here we are not attempting to reconceive the clinical character of such care; instead we are proposing the following ways to promote such care: by focusing on family physicians who are starting or are early in their careers; by focusing on the practicalities of creating the sort of comprehensive home-visiting practice that AIHC requires; and by presenting AIHC as a new, interesting, and challenging practice.

Early career family physicians. Early career family physicians stand to have the greatest effect on AIHC. They have most of their career ahead of them, meaning more clinical effect, but also more potential for future research, teaching, and administrative effects. They are more likely to bring the newest ideas to these aspects of AIHC. They might also be initially more flexible while establishing their careers, before clinical, family, and other commitments become entrenched.

Practicalities of practice. To attract early career family physicians to AIHC, more attention needs to be focused on the practicalities of practice. As with palliative care, the physicians most suited to providing AIHC are generalist physicians, with skills involved in managing advanced chronic disease (especially multimorbidity), but also with more specific skills in palliation

and communication. To this point, teaching has focused accordingly on disease management, as well as on palliation and communication skills.

However, a recent study has shown that these early-career physicians are deterred from pursuing AIHC as much as or more by a lack of understanding of the practicalities of home care.[12] They lack a sense of how to clinically practise complex medicine in a home setting, including the administrative needs of creating such a practice; how to achieve reasonable payment for AIHC; and how to set up office support, arrange on-call coverage, engage community support, and arrange for referrals, for example.

The more these skills of practice can be supported with established AIHC teams, the better. Advanced illness home care thrives under a team approach that—given the complexity of care, shifting goals, and abrupt fluctuations in patient condition—includes a variety of professionals. Although only a few of these teams currently exist, they present a promising possible model for future care—functioning regionally, and including physicians and other professionals specifically dedicated to the team as well as physicians who "opt in" as needed to provide shared care for their own patients. In this way, AIHC teams are closely linked with primary care but are not practice based. With the development of regional teams, early career physicians could join an existing program rather than each physician trying to develop his or her own model, as is usually the case now.

Advanced illness home care as an interesting and satisfying practice. Finally, the practice of AIHC should be introduced in its reality, as an interesting, challenging, satisfying, and balanced practice. Too often AIHC is presented as a moral obligation, in critical or castigating tones. Instead, AIHC should be presented positively: highlight its characteristics (eg, flexibility and variety) and promote that it is a necessarily shared practice that nonetheless permits independence; explain the challenges of relying heavily on history and physical findings and clinical judgment; emphasize the effects of physician presence and communication; and describe the rewards of partaking in a meaningful part of a person's life. For certain personalities, these opportunities will be highly attractive and provide both opportunities to help patients and the prospect of a satisfying career.

Conclusion

Palliative care is expanding to include a wider scope of patients living with chronic disease and aging. Some of this care includes AIHC, and the complexity of such care requires teams that include family physicians with particular training and skills. Some of this training is already beginning to be provided, but some is lacking. We propose that resources be devoted to the clinical and practical requirements of developing AIHC practices. Furthermore, we propose that AIHC be promoted in its fullest sense, as a fulfilling, growing type of practice; as a compelling practice for existing family physicians; and especially as a worthy choice for new family physicians building their careers.

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Competing interests
None declared

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References

1. Rocker G, Downar J, Morrison RS. Palliative care for chronic illness: driving change. *CMAJ* 2016;188(17-18):E493-8. Epub 2016 Aug 22.
2. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* 2015;373(8):747-55.
3. *Framework on Palliative Care in Canada Act.* S.C. 2017 c. 28.
4. World Health Organization [website]. *WHO definition of palliative care.* Geneva, Switz: World Health Organization; 2019. Available from: **www.who.int/cancer/palliative/definition/en/**. Accessed 2019 Jun 7.
5. Wodchis WP. *The concentration of health care spending: little ado (yet) about much (money).* Presented at: Canadian Association for Health Services and Policy Research 2012 Conference; 2012 May 30; Montreal, QC. Available from: **www.cahspr.ca/en/presentation/5244423937dee8014beea024**. Accessed 2019 Jun 7.
6. Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC, et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *BMJ* 2014;348:g3496.
7. Hotstetter M, Klein S, MacCarthy D. *Supporting patients through serious illness and end of life: Sutter Health's AIM model.* New York, NY: The Commonwealth Fund; 2018. Available from: **www.commonwealthfund.org/publications/case-studies/2018/jan/sutter-health-aim**. Accessed 2019 Jun 7.
8. *Palliative care. Canadian Medical Association's national call to action.* Ottawa, ON: Canadian Medical Association; 2015. Available from: **www.cma.ca/sites/default/files/2018-11/palliative-care-report-online-e.pdf**. Accessed 2019 Jun 7.
9. Canadian Hospice Palliative Care Association. *The Way Forward National Framework: a road map for an integrated palliative approach to care.* Ottawa, ON: The Way Forward Initiative; 2015. Available from: **www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf**. Accessed 2019 Jun 7.
10. Canadian Society of Palliative Care Physicians. *Backgrounder: palliative care medical education.* Surrey, BC: Canadian Society of Palliative Care Physicians; 2018. Available from: **www.cspcp.ca/wp-content/uploads/2018/02/Palliative-Care-Medical-Education-Feb-2018.pdf.** Accessed 2019 Jun 7.
11. Dechêne G. La fin de vie à domicile des malades non cancéreux: un défi pour l'omnipraticien! *Méd Qué* 2001;36(6):29-32.
12. Mahtani R, Kurahashi AM, Buchman S, Webster F, Husain A, Goldman R. Are family medicine residents adequately trained to deliver palliative care? *Can Fam Physician* 2015;64:e577-82. Available from: **www.cfp.ca/content/cfp/61/12/e577.full.pdf**. Accessed 2019 Jun 7.

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