



## Editorials

### Role of family physicians in end-of-life care *Rhetoric, role, and reality*

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**I**n family medicine we talk about providing comprehensive, continuing primary care almost as a mantra. As family medicine and the health care system change, however, are family physicians really providing that kind of care? In particular, what is a family physician's role in end-of-life care?

Are family physicians managing community care for dying patients and their families? Do family physicians have the skills to practise good community-based palliative care? What are the issues and challenges? The experience of many palliative care programs in Canada is that family physicians are not meeting the needs of their dying patients, particularly home-care patients, in an effective manner.

Three articles in this issue of *Canadian Family Physician* examine aspects of family physicians' role in caring for dying patients and their families. These articles describe patient expectations and family physicians' perceptions of their involvement in palliative care and some of the issues affecting that involvement. These articles provide some initial and intriguing insights into various facets of the issues.

Before looking at the articles themselves, however, some background issues need discussing. First, what are the goals of patients at the end of their lives? The only Canadian study in this area<sup>1</sup> defined some aspects of end-of-life care that were important to patients: adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, and relieving the burden on and strengthening relationships with loved ones. Other studies report similar findings.<sup>2,3</sup> Family physicians' role should be built around those needs.

How family physicians provide palliative care also has to be in synchrony with the Canadian Palliative Care Association's standards.<sup>4</sup> Family physicians must be part of interdisciplinary teams that concern themselves with all aspects of patient and family needs and expectations—physical, psychological, social, and spiritual.

#### **What family physicians do not say**

The article by Burge et al (page 1989) examines the issues of end-of-life care from the viewpoint of family physicians. The analysis of this qualitative study brought out several domains of concern: access to resources to support home care, family support, time and compensation for that time, and physicians' emotions. These are all important issues that might facilitate better home palliative care.

What is interesting is what is missing from the discussion. Family physicians did not seem to express commitment to home visits. They expressed concern about other community resources but not about the adequacy or inadequacy of the way they meet the need for home visits. They did not express concern about their ability to provide good palliative care. Yet experience in many Canadian palliative care programs has shown that physicians are not providing adequate palliative care, including adequate pain control.

Few Canadian family physicians have had more than minimal training in modern palliative care in either residency programs or in effective continuing education programs. The physicians interviewed did not directly address their own issues in dealing with death. They reflected on external forces as being most important. Is this lack of focus on their own skills or part of their own anxiety about death?

#### **What patients say**

The article by Norman et al (page 2009) looked at palliative care patients' perceptions of the family physician's role in cancer care. This small qualitative study of a selected group of inpatients on palliative care units offers us some areas for further inquiry, but should not be seen as giving definitive answers. It does raise the important issue for patients of interruptions in doctor-patient relationships that occur during cancer treatment. It does raise the problem of lack of effective communication between physicians and between family physicians and patients.

Family physicians were reported to be accessible, but home visits and even hospital visits were rare. Interestingly, these patients saw palliative care specialists as more of a resource than their own family physicians. This might be because they had been admitted to palliative care units. It would be interesting to repeat the study on a group of patients earlier in their illness being cared for at home.

**What physicians do**

The article by Aubin et al (page 1999) provides us with some glimpses of the actual involvement of family physicians in palliative care. This mail survey of family physicians in the Quebec city region of Quebec has some important biases in interpreting its results, the most important of which is recall bias.

There were some interesting findings, however. Only 62% of those completing the survey were providing palliative care. Physicians providing palliative care tended to be older, and, therefore, probably tended to have older patients and more patients requiring palliative care. They also tended to have more on-call coverage, a necessary ingredient of providing home palliative care.

Physicians saw on average two or fewer patients requiring palliative care. Although physicians interested in palliative care did home visits, no corroborating data indicate how many home visits or the circumstances and outcomes of patients wanting to stay at home as long as possible or wanting to die at home.

Most of the physicians surveyed thought they were hampered in providing palliative care by lack of knowledge about pain and symptom management and about how to counsel patients and their families. They described a lack of training in palliative care in residency programs and a need to provide such training to new family physicians. Even though expert help was available by telephone from well-known and well established palliative care resources in Quebec, few used such resources. This lack of consultation seems to be unique to palliative care and to affect both specialists and family physicians. Other barriers included lack of adequate remuneration for home visits and lack of 24-hour-a-day, 7 day-a-week on-call coverage.

**Questions remain**

These studies, therefore, provide some enticing glimpses into issues for patients and family physicians in end-of-life care. We come back to the original questions, however: What is the role of family physicians in providing palliative or end-of-life care? Do family physicians have a role? Should

they have a role? What information do we need still to make those decisions?


First, we need some accurate data. We need practice content data so that the number of these patients in an average family practice and the requirements for care that they place on physicians are understood. We need accurate data on family physicians' involvement in home visits. We need to enhance the data provided by these three studies by repeating them elsewhere in Canada. More data are needed on palliative care patients' perceptions of family physicians' role, both as to what patients want and as to what they actually see. We need more data on what family physicians see as their role and on their attitudes to end-of-life care. Unfortunately, at the moment, guesswork mostly guides decision making.

Second, the discipline of family medicine is going to have to decide whether the rhetoric we use about home care is realistic in practice. The various provincial governments in Canada seem to think that home care is family physicians' domain. Yet fewer and fewer family physicians are providing this service, and more and more care is being shifted to the community. Perhaps the best thing for patients and family physicians alike is to establish specialized regional home palliative care programs to provide home care to dying patients.

You cannot practise what you do not know. We need effective education in end-of-life care in family medicine residency programs. We also need to train residents effectively in providing home care. Many family medicine residents have limited, if any, useful experience in home care during their 2-year program. Also, effective continuing education programs in end-of-life care need to be offered to family physicians so that the palliative care they give addresses patient and family needs and expectations.

Most Canadians indicate they would like to die at home. There has been lots of rhetoric from federal and provincial health authorities on home care. Services available to support dying patients at home and access to home care, however, vary greatly between regions in Canada. Budgets for home care have not increased sufficiently to meet the demands of an aging population, the increasing prevalence of cancer and chronic diseases, and the downloading of services from hospitals to the community. Payment to physicians for home palliative care is inadequate in many provinces. Health care authorities and family medicine provincial and federal organizations, therefore, must work together to develop effective plans and funding to meet community care needs.

Finally, effective partnerships between family physicians and regional palliative care resources need to be established. Successful partnerships exist in some areas of Canada, such as Edmonton, Toronto, and Victoria, and such partnerships have led to improved end-of-life care for patients and their families.

If family physicians cannot meet the needs of dying patients and their families, perhaps it is time to dispose of the mantra of “comprehensive continuing ‘cradle to grave’ care” as an essential part of family medicine and allow other systems to be put in place so that the needs of dying patients and their families can be addressed in an effective and holistic manner. Maybe home palliative care is too important to be left in the hands of family physicians. 

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