

# A march of folly

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Folly, as defined by Barbara Tuchman, is “the pursuit of policy contrary to the self-interest of the constituency or state involved . . . folly is a policy that is counter-productive.”<sup>1</sup>

Current trends in cancer incidence and mortality rates, education, research, and societal mores and views combine to present a number of antithetical propositions. A review of these propositions highlights the need for ethical reflection and studies on end-of-life issues affecting cancer patients and their families, lest we also embark on a “march of folly.” Examples of these conflicted conditions occur in relation to cancer incidence and mortality, the shift from institutional to community care, education and research, communication and the health care workforce, and euthanasia and physician-assisted suicide. What follows are my own musings on these problems and the promising aspects of modern end-of-life care. My colleagues will have their own list.

## Cancer incidence and mortality

National age-adjusted death rates related to cancer are beginning to decrease slightly,<sup>2</sup> *but* it is the total number of deaths from cancer that is important for families and for the health care system, a number that is likely to rise. As the size and average age of the population increases we will need more coordinated services to help dying patients and their families.

## The shift from institutional to community care

Patients with advanced cancer are now more often expected to remain at home during the final stages of their illness, *but* several factors make this change difficult.

There are fewer caregivers at home as the number of traditional family units and the size of families decrease.<sup>3</sup> Family members are often dispersed, and all may be employed outside the home. For those who do become home caregivers, the technical responsibilities are often awesome and expensive; there is a substantial cost associated with moving ventilators, pumps and other equipment into the home, both financially, since our health care system is set up to “reward” primarily hospital care, and in terms of the technical and emotional demands placed on family caregivers.<sup>4</sup> Setting up a “hospital in the home” places unique demands on family members, who must be trained to carry out unfamiliar and complex tasks, which they may find frightening because of the possibility of making a mistake. Balancing conflicting demands can lead the caregiver into a state of exhaustion or anxiety.

Ethical considerations dictate that we not automatically expect the traditional caregiver, usually a female relative, to assume a role that may not be in her best interest. Selflessness is an admirable trait, but if we expect families to make heroic sacrifices we must ensure that they are supported and recognized for their generosity. At present, government health care resources are used primarily to fund institutions and to cover physician fees and inpatient medication costs. The *virage ambulatoire* (an increasing emphasis on home care) means that the family incurs additional costs: the caregiver may have to give up gainful employment; the services of health care professionals other than physicians (which may not be covered by a health plan) may be required; and medication, which is covered when a patient is in hospital, must be paid for by the family. Self-sacrifice must be leavened by a fairer distribution of health care resources to support caregivers.<sup>5</sup>

Although Canada’s economic situation, as reflected by corporate profits, is



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sound, the same cannot be said of the economic situation that many Canadian families face. In the current environment of high rates of unemployment and low wages, families may not be able to afford the increased costs associated with home care. The incomes of some have improved in step with corporate profits, but many families remain untouched or, because of layoffs, harmed by the corporate boom.

Traditional sources of support that families used to be able to rely on, such as churches and social organizations, are not as prominent in our increasingly secular society.

## Education and research

Several conflicting propositions can be identified in the areas of research and education. The community believes that physicians and other health care professionals are trained to manage pain and other aspects of suffering, *but* many studies have demonstrated that patients with advanced cancer often suffer unrelieved pain and that faculties of medicine devote only limited time and effort to palliative care.<sup>6-11</sup>

Excellent information about palliative care exists in specialty journals, textbooks and monographs *but* not in sources usually encountered by students, residents and practising health care professionals. The amount of space devoted to palliative care concerns in mainstream journals and major medical texts is minimal in proportion to the importance of the topic (A.T. Carron et al: personal communication).

The amount of resources devoted to clinical research should reflect the prominence of the problem in question and the probability that research can redress it.<sup>12</sup> Cancer pain, the cachexia-anorexia syndrome and other common symptoms of advanced cancer are research topics that hold particular promise,<sup>13</sup> *but* current patterns of funding and research funding agency and faculty encouragement for research into palliative care issues are disproportionately low.<sup>14</sup>

The limited number of oncologists, the expectation that they should be conducting clinical research and the pressures on diagnostic resources of hospitals may mean that patients who enter clinical trials are more likely to get access to oncologists and hospital resources, *but* if this hypothesis is correct, there may be undue pressure on patients to participate in research and those with advanced cancer who are unable or unwilling to participate in clinical trials may be at a disadvantage.

In the future, decisions that affect priority setting in medical care and the approval of new techniques and pharmaceutical agents will be increasingly evidence based,<sup>15</sup> *but* palliative care programs may be unfairly jeopardized if research in this area is not valued or supported and an evidence base for end-of-life therapies and initiatives is consequently lacking.

Support for cancer chemotherapy by the pharmaceuti-

cal industry continues to be welcomed, *but* backing for this line of enquiry could skew the involvement and interest of the limited number of people with clinical research skills in Canada, with the result that promising lines of research addressing end-of-life issues may not be encouraged or supported. A bias in the research agenda may occur if industry sponsorship for trials of potentially profitable drugs is not balanced with public agency (National Cancer Institute and Medical Research Council of Canada) or private foundation support for research on modes of care that generate no profit.

## Communication and the health care workforce

Several issues related to communication also encompass conflicting priorities. Reducing health care costs has been judged to be imperative and depends, in part, on decreasing the health care workforce and decreasing funding to its traditional centres of operation — health care institutions. The workloads of nurses are increasing, and in some instances nurses are being replaced with less-well-trained personnel. Enrolment in medical schools is at its lowest level since the mid-1970s,<sup>16</sup> and the overall physician supply is decreasing.<sup>17</sup> These trends suggest to health care professionals that they must be “lean and mean” in their interactions with patients and must operate in an efficient, highly technical manner, *but* in our training we learn a holistic approach to treating patients, an approach that emphasizes the development of communication skills and the need to spend time with patients to make full use of these skills.

Predictions that the burden of chronic illness will increase in the early years of the next century, primarily related to the aging of the population, have highlighted the importance of communication between the health care professional and the patient and family, *but* health care professionals may not have the time to practise what they preach. There is also the question of who will pay for the time needed for communication. Is the current “medicine as business” approach, with its emphasis on efficiency, compatible with the objectives we learn in medical school?

Communication demands time and commitment from the health care professional, sometimes without recompense, *but* because of their own family interests and nonprofessional time commitments, health care professionals may not be able to devote any more time to their work than they already do.

## Euthanasia and physician-assisted suicide

Most of the community supports the introduction of legislation that would allow euthanasia and physician-



assisted suicide,<sup>18,19</sup> but the closer the health care professional and the patient get to the point where such a step might be considered, the less likely either is to support it.<sup>18,20</sup> The views of physicians who seldom care for dying patients are similar to those of members of the community at large, but support for euthanasia among physicians decreases in direct correlation with their experience in caring for the dying.

There is community support for euthanasia, but the community may not appreciate the current inadequate status of palliative care. It is clearly an ethical abomination to actively take steps to kill someone who has not had access to relief of suffering.

## Conclusion

All of the above propositions have ethical implications. Some are simply wry observations, but others lend themselves to studies aimed at identifying the paradox and developing proposals to eliminate contradictions from the equation. Our medical faculties and granting agencies should heed the paradoxical environment in which we currently practise and give priority to research initiatives that provide data-driven proposals to resolve ethical dilemmas. If we fail to do so, we may find ourselves embarking on a march of folly into the 21st century.

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