

Commentary

Michael M. Burgess

In "Euthanasia and Health Reform in Canada," Michael Stingl argues that the legalization of euthanasia can be made reasonable social policy only in the context of healthcare reform to deliver primary- and community-based care.¹ Stingl accepts that euthanasia "is in effect a treatment for unbearable suffering caused by a patient's health condition" and that includes not only pain, but "a personal response to a medical situation that the individual finds unbearable given his or her beliefs and values about the meaningfulness of human life." He is not worried "about the reasonableness or validity of their request, but about the validity of the situation which leads to their request." The failure of the healthcare system to adequately respond to the needs of people who are suffering with chronic or terminal conditions may lead competent people to elect euthanasia. Stingl argues that it is the institutionalization of care for dying people that reduces their ability to find meaning in prolonged life, and thereby makes it more attractive to consider ending one's life sooner. Options such as palliative care at home that significantly improve quality of life and make euthanasia less attractive are currently only available to those who can privately subsidize healthcare services. If an emphasis is placed on community-based initiatives and well-supported self-help, then there would be less inequality of healthcare and the voluntariness of choices,

including euthanasia, would be more equal for all people under the healthcare system.

Stingl correctly locates the demand for euthanasia in the context of how we care for dying persons. Only by providing better opportunities for those who are suffering and dying to find meaning in their lives can we be relatively certain that requests for euthanasia are "choices."² Societies such as Canada have the responsibility to provide the basic conditions for personal meaning and the formation of communities. The difficult issues are how to fulfill this responsibility and what amount of resources should be dedicated to providing the basic conditions for meaning. I have four concerns with Stingl's analysis:

- 1) The healthcare system does not have the responsibility to provide contexts of caring for dying persons that support their finding meaning.
- 2) Healthcare reform is inadequate as a means of supporting attempts to find meaning by those who are dying and suffering.
- 3) Euthanasia for competent persons will probably reduce resistance to euthanasia for incompetent persons.
- 4) The same social changes required to support euthanasia for competent persons are required for persons who are incompetent and their caregivers.

The healthcare system as it has evolved in Canada, the U.S., and Europe was designed to deliver professional and institutional healthcare services. The Canada Health Act is intended to grant equal access to healthcare services. Diverse analyses have challenged the adequacy of equal access to healthcare services as a goal. The emphasis on

These reflections have benefited from the review of, and collaboration on previous manuscripts referred to in the text. I am particularly grateful to the comments of Margaret Battin, Patricia Baird, Michael Stingl, and Donna Wilson, and for the collaboration of Arthur Frank, Susan Sherwin, and Peter Stephenson.

delivering healthcare services is critiqued for many faults:

- 1) Promotes utilization of services irrespective of perceived or actual need.
- 2) Tends to neglect prevention of conditions that may lead to utilization of services.
- 3) Narrows the definition of health to the absence of need for health services (i.e., neglects other contributions to well-being, such as social conditions).
- 4) Healthcare professionals and institutions define health and what services are needed.

There has been a shift in emphasis to health, understood as an overall state of well-being, sometimes qualified by the limits on one's personal and social situation. The shift grants individuals and communities more control over what counts as a good state of well-being, emphasizes maintaining health, and recognizes the various determinants of health. Some versions of healthcare reform attempt to reconceptualize the healthcare system in order to support this decentralized notion of health.

Is it the responsibility of a healthcare system to support the broader notion of well-being promoted in this reconceptualization? Current insurance, institutional, and professional arrangements are the result of particular historic and social forces. It is clear that most Canadians, for instance, rank fair access to healthcare services as a defining feature of justice in Canadian society, only sometimes tempered with concerns about effectiveness and reasonable costs. The emphasis on health promotion and community-based care has gained momentum at a time of concern about the costs of the healthcare system. Health promotion is there-

fore inevitably perceived as a way of avoiding the costs of healthcare services. Community-based care is similarly perceived as a way of delivering care in less expensive settings. Regional health boards with the responsibility to manage community-sensitive healthcare systems now have no choice but to consider the specific community values and demands for health promotion. But due to shrinking budgets, the efforts directed toward health promotion must demonstrate cost-saving effects in terms of reduced utilization of services. Healthcare reform under reduced resources must prioritize its services, assuring equal access to those in need of whatever services are provided. Under current fiscal restraints, it may be unreasonable to place the burden of community and self-help initiatives for health promotion on the healthcare system.³

The healthcare system may also be an inappropriate institution in which to organize community and self-help initiatives. Although generally less expensive than U.S. private and semi-private arrangements, Canadian healthcare has managed the delivery of expensive professional, institutional, and technological healthcare services. Advances in understanding and technology have led to specialized skills and professionalization of the healthcare workforce. Despite a shift from physician-managed to administratively managed healthcare, the hierarchical organization and specialty-oriented categorization of services has been retained. Although new mission statements and objectives include community- and patient-based care, it is difficult to facilitate an emphasis on the general well-being and maintained health of the individual. Rather, the goals of health maintenance and promotion are to be pursued through the preserved hierarchy and specialized services. Ironically, even the general "caring" activities of nurses seem

to have a more difficult time being justified for purposes of efficiency evaluations than do “customer services” in private healthcare. So it is unclear that the healthcare system has the financial or organizational ability to meet the broader notion of reasonable access to health as “the conditions within with these basic human goods (i.e., meaningful life) might be developed or maintained.”

Perhaps healthcare reform should be directed to reorganize the healthcare service delivery system to deliver the full range of social goods that support the well-being of citizens and their ability to live meaningfully. Stingl recognizes that a health system can only provide the basic conditions for meaningful life, and cannot guarantee that each person will achieve meaningful life, and that there are limits to how much healthcare a society can afford. Achieving the best system of support for meaningful life that a society can afford, subject to limits of social spending and geography, would make reasonable the assumption that requests for euthanasia by competent patients are voluntary, and not based on the failure of the system to provide reasonable alternatives.

Healthcare reform, however, is not a reasonable approach to support dying and suffering persons’ attempts to find meaning. The basic needs for meaningful life under conditions of suffering and dying may be attainable only under conditions that are beyond the scope of healthcare reform. I have argued elsewhere that the primary needs for meaningful life for suffering or dying persons are the company of loved ones, attention to immediate needs, and the opportunity to revisit experiences.⁴ The institutionalization of dying is only one obstacle. The organization of domestic and vocational life in society is the major obstacle in providing these primary needs. Professional services delivered

in a hospital, a hospice, or a home may supplement or facilitate this kind of belonging and care, but it cannot replace it. Communities and cultures that organize vocational and domestic life to accommodate caring for dying and suffering persons do a better job of providing the opportunity for meaning in suffering and dying.⁵ What is required is not healthcare reform, but a restructuring of workplace and domestic life to accommodate and honor caring for suffering and dying persons. It is difficult to hope for such radical social reorganization in the short term, particularly under fiscal restraints that emphasize efficiency and productivity. Compassionate responses to persons who judge their lives to be unbearable and request euthanasia cannot wait for the revolution.

Legalizing euthanasia for competent persons who find their suffering unbearable will affect attitudes and practices toward incompetent patients. Stingl correctly argues for a strong distinction between euthanasia for competent and incompetent patients and views as unsustainable both the distinction between killing and letting die, and the doctrine of double effect. It may even be possible to separate the public policy about allowing competent persons to choose euthanasia from public policy about life-prolongation and euthanasia for incompetent persons. But policy and widespread acceptance that competent persons can choose euthanasia will lead to an increased acceptance of euthanasia by incompetent persons’ substitute decisionmakers. The fact that competent and incompetent patients are distinguishable as a class does not isolate incompetent patients from social attitudes that are stimulated by policies dealing with competent patients. Persons with disabilities and their spokespersons sometimes articulate this as a willingness of people without disabil-

ities to make judgments about the quality of life of persons with disabilities.

Finally, Stingl claims that a system that supports meaningful existence for those who are suffering provides a more reasonable context in which to support requests for euthanasia or cessation of treatment. This claim applies with equal force to persons who are unable to speak or act for themselves and to their caregivers. The provision of adequate support to caregivers and dependent people would reduce the concern that nontreatment or euthanasia is a choice of convenience or economy based on a devaluing of the dependent person. Healthcare reform is inadequate. Rather, widespread changes in attitudes and social reorganization are required.

Michael Stingl has correctly located the central concern about euthanasia policy in the context of inadequate support for suffering persons' meaningful existence. This concern exists for competent and incompetent persons and their caregivers. Individual requests to be assisted to end life are reasonable due to immediate practical limitations, and must be considered on that basis. A policy legalizing euthanasia must consider more than individual tragedy, but whether the policy sustains tragic social conditions. This is true whether the quality of life assessment leading to the consideration of euthanasia is for oneself or on behalf of another.

Notes

1. Stingl M. Euthanasia and health reform in Canada. *Cambridge Quarterly of Healthcare Ethics*, this issue, 348–62.
2. For further elaboration, see Burgess MM. Medicalization of dying. *Journal of Medicine and Philosophy* 1993;18:269–79.
3. Burgess MM. Health care reform: whitewashing a conflict between health promotion and

treating illness? In Stingl M, Wilson D, eds. *Efficiency versus Equality: Health Care Reform in Canada*. Halifax, Nova Scotia: Fernwood Publishing Company, 1996:153–62.

4. See note 4, Burgess 1993. This article extends to dying the notion of medicalization developed in the context of reproduction in Burgess MM, Frank A, Sherwin S. Medicalization and the new reproductive technologies. In Royal Commission on New Reproductive Technologies. *New Reproductive Technologies: Ethical Aspects*. Vol. 1, App. Ottawa: Royal Commission on New Reproductive Technologies, 1994:149–89.
5. Burgess MM, Stephenson PH, Ratanakul P, Suwannakote K. End of life decisions: clinical decisions about dying and perspectives on life and death. In Coward H, Ratanakul P, eds. *A Cross-Cultural Dialogue on Health Care Ethics*. Waterloo, Ontario: Wilfrid Laurier University Press, in press.

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Commentary

John Hubert and Susan Sherwin

According to the present argument, worries that some individuals might make premature or unnecessary choices for themselves regarding euthanasia should further motivate and help shape our discussions about healthcare system reform. The reason for this is that in some cases individuals with chronic or terminal illnesses may have their lives made more unbearable than they otherwise might have been by the failure of the healthcare system to respond appropriately to their needs. Until these apparent inadequacies are remedied, there will remain doubt about whether such individuals have made a free and reasonable choice in favor of euthanasia, or whether such a choice was in effect forced upon them by the effects of unjust gaps in the provision of health services. Thus, it is inferred that there is a deep connection between discussions regarding liberalizing euthana-