

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-

sia in Canada and the ongoing move to reform our healthcare system. Further, it is claimed that explicit recognition of these links in the context of public debate will better inform our decisions in regard to both.

Stingl's approach to these thorny issues is both novel and intriguing. The euthanasia debate in particular seems to have become mired in rhetoric and stalled by all-too-familiar arguments. In the case of health reform, there is little doubt that widespread change is both warranted and desirable. While the idea that there are important links between these debates is certainly plausible, we are not convinced that they are connected in the way Stingl proposes. Our response focuses on four areas of his account that we take to be problematic. The first difficulty is related to assumptions Stingl makes regarding the empirical motivation for the project. The second is the disquieting ambivalence about paternalism that runs through the paper and that threatens to undermine the otherwise laudable task of enhancing personal choices regarding end-of-life decisions. The third difficulty, assuming that sufficient motivation for linking the euthanasia and health reform debates can be found, is that Stingl may not have pushed the discussion regarding the social obstacles to free choice far enough. And the final difficulty is the 'chicken and egg' problem: worries about the still cloudy issue of whether healthcare system reform *must* precede the liberalization of euthanasia policy, and the impact waiting for reform would have on those now suffering.

Any acceptable public process of health system reform needs first to be motivated and informed by relevant empirical evidence suggestive of the fact that there is some demonstrable healthcare need that is not being met due to problems in the way the present system is structured. Stingl does not

offer any concrete support for his claim that there are numbers of chronically or terminally ill Canadians who would too hastily opt for euthanasia if it were to become immediately available in the present system. While admitting it is intuitively plausible that particular lives might be made more unbearable by an inadequate health system response, that health reform might ensure a better response, and that the current failure might in some cases precipitate untimely requests for euthanasia, we are uneasy about the paucity of empirical data available to suggest this is actually the case. Certainly, the mere possibility that there exist such cases is not enough to make the concern a major focus of an important and extremely complex public policy debate, especially given what we do in fact know: that there are people who currently find their lives unbearable because of illness or the intolerable sequelae of treatment and who seek a state-sanctioned remedy through assisted death (rather than better access to health services).

Certainly, the Sue Rodriguez case does not provide us with an example of the kind required to motivate the initiatives envisioned here. Her life was made unbearable in part by pain, in part by the frightening prospect of imminent physical and mental deterioration, and in part by the realization that she would soon no longer be the person she knew herself to be. These effects of her illness were compounded by the knowledge that there would be no one to help—unless they themselves assumed significant personal risk—if she decided that she could bear no more. In cases such as this, it is doubtful what positive effects could be brought about for the individual through system reform. Better access to better care, or even greater levels of social support, are not likely to carry much weight in decisions regarding euthanasia for many patients like Sue

Rodriguez who suffer what they judge to be unacceptably devastating and alienating effects of chronic or terminal illness. Ultimately, the only way in which the system failed Sue Rodriguez was by failing to honor her persistent and explicit request for assistance in taking her own life.

If we are, as Stingl suggests, to learn from the Dutch experience, it remains unclear exactly what lessons we should draw from the example. Consider the fact that in cases where physicians refused requests for euthanasia, the reason given for the refusal in 45% of cases was that the physician had determined that there was “no unbearable suffering.” One is forced to wonder on what possible basis such a determination could legitimately be made. We are hampered in our judgments about the suffering of others precisely because there are no objective criteria by which to judge unbearable suffering. The increase in the number of determinations of this kind made by physicians in the Netherlands between 1990 and 1995, may, as Stingl points out, suggest that physicians are becoming “more confident, rather than less confident, in the force of their own assessments of their patient’s health conditions.” However, it is not clear why we should think of this trend as a good thing. If being more confident in their assessments means that physicians are professing insight into the subjective judgments of their patients, then there is reason to worry about the degree to which this kind of paternalism might ultimately affect patient choice. Such paternalism seems to conflict with Stingl’s apparent support of informed, voluntary choice in euthanasia.

Consider, for instance, the situation of patients who have availed themselves of the kinds of supports that are available in the Dutch system, or in programs such as On Lok, and yet still request euthanasia. The evidence

he provides of experience in the Netherlands suggests that physicians and policymakers may assume that the lives of such patients are not as unbearable as they otherwise might have been, and, hence, that these lives are not sufficiently unbearable. It seems that the provision of the very kinds of health services that Stingl takes to be necessary in order to support real choice may in practice have the paradoxical effect of working to limit the extent to which such choices are acted upon by those who ultimately remain in control. Part of the point of extending the concept of ‘suffering’ beyond a focus on inescapable pain in the first place was to allow patients’ subjective judgments about their quality of life to be recognized by others as having a legitimate place in the nexus of reasons for their choice. This point seems to have been lost somewhere along the road in the Dutch experience with euthanasia, despite—or perhaps because of—the provision of an extensive support network.

The issue of ‘freedom of choice’ lies at the heart of the current debate about whether Canada ought to proceed with liberalizing current legal restrictions on euthanasia and physician-assisted suicide. Supporters of liberalized euthanasia legislation are typically found arguing that in a just society, control over one’s own life should include control over decisions regarding one’s own death, in circumstances where the life one leads is subjectively judged to be unbearable. A virtue of Stingl’s approach is that it presses the debate about euthanasia beyond traditional bounds concerning what the limits of free choice are, and moves it toward a much needed examination of the social conditions that are necessary for the exercise of free choice; a strategy that, as he notes, is familiar to us from the body of feminist literature on the subject of moral agency. But does he push these bounds far enough?

Other than a brief reference at the beginning of the paper to the importance of paying close attention to the “social determinants of health,” Stiglitz fails to take full account of factors that are widely known to have a significant impact on health, yet which fall outside the sphere of influence of the healthcare system. Indeed, many important Canadian policy documents have cited the need to take a broad understanding of the factors that affect health. For instance, the Ontario Premier’s Council on Health Strategy Report (1991) identifies position in a work hierarchy, unemployment, poverty, and social rank as significant factors governing personal health status; moreover, it observes that general social policy and the economic well-being of the nation also play significant roles in determining health. Not only do such factors affect people’s health status, they also affect their ability to adapt to illness and to live meaningful lives in the face of chronic or terminal illness. Any response to illness and suffering by the healthcare system, regardless of how appropriate it might be, may still leave many people unable to attain those things that might help to make living with a chronic or terminal illness more tolerable. This possibility seems sufficiently powerful to compel us to extend the boundaries of discussion even further. This is to say that we need to look beyond health reform and begin to address deeper issues of how peoples’ lives in general can be made better.

Granted, neither the healthcare system nor any other social service should be expected to provide individuals with everything that can fill lives with meaning. However, as attention to the social determinants of health illustrates, many services outside of those traditionally (or even plausibly) provided under the banner of a healthcare system may go a long way to making one’s life not

only healthier, but more bearable in the face of chronic or terminal illness. The degree to which these non-health system factors differentially impact the way people die is highlighted by the suggestion that “whether or not one is successful in obtaining a gentle and peaceful death of one’s own choosing will depend heavily on one’s social position and social connections.” This should come as no surprise. Our present experience with the ways in which social privilege confers certain advantages in respect to healthcare choice and access generally should leave us with little doubt that socially privileged individuals have a wider range of acceptable options available to them at the end of life as well. Deinstitutionalizing care for those with chronic illness and efforts to expand and improve services in the healthcare sector will have a limited impact so long as such reforms are put in place in isolation from a move to broader social reform. Healthcare reform is best understood as an important piece in a much larger puzzle.

Consideration of how health reforms and other social initiatives might impact the overall quality of our lives highlights the need to specify more explicitly the qualities that make up an acceptable life. On Stiglitz’s account, people with certain chronic or terminal illnesses sometimes choose to end their lives because they find those lives to be no longer bearable. To be worth living, however, it seems that a life should be more than just bearable; some would insist that life must also be desirable in some significant sense. For many who live a life severely hampered by illness, it may be the inescapable prospect of having to live a *merely* bearable life that motivates their request for assisted death. Society’s concern for those with all types of illness should include attention to the positive features of life that can give it meaning.

A final tension that runs throughout the paper is linked to the laudable, but perhaps incommensurable, goals of on the one hand trying to ensure that people who are suffering unbearably are able to escape their suffering when they so desire, and on the other hand wanting to create conditions within which the choice of an early death would need to be made less frequently and would be as free as possible when it is made. According to Stingl, this second goal requires that we begin by understanding that people may sometimes be compelled to make unnecessary decisions for early death when they do not have access to appropriate health services. Further, in order to prevent such deaths we need to improve community-based support services available to everyone “within the limits of what can reasonably be afforded.” Given present realities, however, Stingl seems to be faced with the following dilemma: First, with the current political climate in Canada, there is good reason to doubt whether such reforms are at all likely in the near or foreseeable future; and even if the requisite political will were in place, such reforms would not come about overnight. Thus, insisting that a policy legalizing euthanasia must wait for the implementation of such reforms means refusing requests from people who now judge their lives to be unbearable; such a requirement would undermine the first goal by needlessly prolonging these people’s suffering. Second, the only alternative to waiting for the implementation of reforms is to adopt a liberalized euthanasia policy now. However, if we do not wait for reform, we may thereby reduce the political pressure to improve services. To be fair, Stingl seems to recognize this tension

in his argument; however, he makes no move to resolve what we take to be a critical and worrisome implication of the present proposal.

Stingl has succeeded here in drawing our attention to some subtle and often overlooked issues in the debate about assisted death in Canada and elsewhere. He has first of all reminded us that pain is only one factor of many that can make a life with chronic or terminal illness unbearable, and that we have a moral obligation as a society to seek ways to reduce these factors where they may be amenable to public policy transformations. He has also reinforced the fact that individual choices are made within, and largely conditioned by, a set of socially determined circumstances and limitations. However, we believe he has failed to establish the central claim that “the question of euthanasia must be tightly linked to health reform initiatives.” It appears to us that this approach has it backwards. The primary goals of health reform—particularly if it is to “strengthen both primary and community-based care”—should be to promote health and to prevent and relieve illness. There seems something terribly odd about making issues around managing death a central focus of health reform initiatives. While enhancing the freedom and legitimacy of personal choices about euthanasia would be a welcome consequence of health system reform, concerns about the circumstances of such choices should not shape the move toward reform. Health system reforms are best motivated and informed by a broader concern for ensuring the social conditions that make peoples’ lives in general not only bearable, but healthier and more meaningful.