

Information Outreach Ltd. Tom Koch, PhD
Medical ethics, chronic disease, gerontology.

<http://kochworks.com> 2 Sept. 2009

I hesitate to submit a brief to a committee of the Quebec National Assembly considering the issue of euthanasia as a right that might require legislative protection. I am, after all, an Ontarian and the issues before the committee will not directly affect medical choices in my provincial domain. But Quebec has long been a social leader in Canada; its parliamentarians have led the way in advancing social programs and policies that affected and will affect all Canadians. Thus Quebec's decision in this area will affect all Canadians, partly by example and partly in the broader related legislative processes that are our Canadian system.

With your permission I would therefore like to make a brief submission on the issue of euthanasia and physician-assisted suicide, subjects I know something about. For almost 25 years I have been engaged in the care of the fragile, first as a familial caregiver and later as a gerontologist working with fragile seniors and their families. In the 1990s this work expanded into work with a general population defined not by age but by diagnosis and by disability. I thus have worked with persons with cancer, MS, with spinal cord injury, and other debilitating chronicities. I have consulted for hospital review boards and consult not only with patients and their families but also physicians.

Much of my work is published in books and articles listed on my website. In this brief submission I would like to speak not as an academic or a professional but as a Canadian who is concerned about the issue the honourable members are considering. Rather, I'm concerned with the way the subject is framed.

A "right to die"

There is not only a "right to die" but an inevitability to the fact of dying. Mortality is the human condition. To speak of a right to die is, in effect, to talk about something else entirely. It is to create a right for persons to insist upon physician assistance, compensated by provincial health care monies, in the premature termination of a life that might go on for weeks, months, or years.

To my way of thinking, consideration of such a right, one of state-supported, physician or other-assisted euthanasia, is premature. Until we first can guarantee to all a right to live without pain and with at least a modicum of dignity the "right to die" a fast death becomes the default solution, an answer to otherwise manageable clinical problems.

Mostly, people seek physician-assisted suicide because they have untreated pain or fear the prospect of being in untreated pain. And certainly, a person with chronic pain that is not well managed will be depressed and may wish to die. Everyone knows an aunt or uncle, a parent or loved one who died in pain, often twenty or thirty years ago.

Today pain can be well managed by competent professionals, if they are available, in over 90 percent of all cases. All Canadians, and all Quebecers, should have a right to a life free of pain, or as free of physical pain as possible. At present, too few of our Canadian physicians have been trained in pain relief tactics. Too few hospitals make this a priority. Nor in most provinces do we adequately compensate physicians and nurses for the intensive work this expertise requires.

Defining palliative care as a prior right, by which I mean the treatment of chronic pain as a healthcare principle—and assuring access for all citizens—would remove a major rationale for physician-assisted suicide. This would mean financial support for and access to the best palliative treatments available. Before a right to die can be honourably considered this right must first be enacted and made real. Advancing euthanasia as a “right” without this prior right is to create a context in which death may seem better than life because of a failure of treatment.

Depression and Fear

A life-changing diagnosis is ...fearful. A limiting injury is fearful. There is nobody who has had a spinal chord injury who has not thought of suicide. Indeed, there are few who have had any life-changing diagnoses that have not been depressed, perhaps to level of suicidal thoughts. The things that were are not; life seems...thinned. We are afraid that anything new will be less than what was and ask, “What’s the point?”

There is a vast literature here that says, with time, most people come to see in the life lived under new situations (cognitive limits, neurological limits, mobility limits) the potential of a life that while different is still good and certainly worthwhile. This takes time, and it takes good counselling and rehabilitation. To the degree that the life of the patient is lived not in an institution but in the community, with support and supportive aides (computers, access-modified cars, home care, etc.) it can become rich. A provincial health service that assures these things as a prior right will create for most the context of a life worth living irrespective of limits. A province that does not provide these things creates a context in which life’s potential is limited not simply by the condition or disease but by the lack of support.

The Burden of Being

Many are concerned about being a “burden” on loved ones who would be “better off” without them. Again, if the burden of care is solely a family’s then the effect may be considerable. To the extent we as a community provide support the tasks of daily care are lessened, the burden not personally or financially prohibitive. That, of course, is one reason why we have made national healthcare a priority.

But for some the burden is psychological, the sense that they because they can’t contribute and thus should be left to die. This is depression and will usually disappear over time and with treatment. Advancing a “right to die” for the fragile who are depressed will rob them, and us, of the potential life they have left and might surely enjoy were they to give it a chance. To do so without first assuring a range of supportive services is to create the context in which death is the medical option, not life in complex circumstances.

Slippery Slopes

Some say there is no “slippery slope” while others insist that once one permits this that its field expands. Certainly it expanded dramatically in Holland where the Dutch Right to Life Society was founded in the 1970s to address the needs of those, principally cancer patients, in physically untreatable pain. Over the years, Dutch have

permitted euthanasia to be deployed for depression (a famous legal case, here), anorexia, and old age where people are not terminal but fear their loss of abilities.

It is very difficult to craft a law that does not make of euthanasia a general response to chronic conditions. The idea of a general “right” once instantiated, is necessarily general.

Whose Choice is it?

In the famous case *Regina v Rodriguez*, the petitioner, Sue Rodriguez, insisted it was her right as an individual to seek death at the moment of her choosing. She wanted the state’s approval and the assistance of provincial physicians. The Supreme Court argued there is no “right” to assisted suicide. Further, there is a “life interest” in the continuity of each individual in the community, in his or her continued welfare.

By asserting the life interest, and the obligations of the health community to provide the palliative care, rehabilitation, and community living for persons with limiting conditions, that life interest is affirmed. It would be denied were a “right to die” without a right to live free of pain and with support to not first be enacted.

Similarly, in *Regina v Latimer* the accused, Robert Latimer, insisted he had the right to kill his daughter with Cerebral Palsy. He was her father, he knew best. The courts argued he did not and that in taking her life he violated the state’s prohibition. One may read this case technically as a failure to provide adequate palliative care, of the correct response to her hip dislocation. The transcript of the case also reveals a parent unwilling to engage fully the social services that the province was willing to make available. The Court was clear that death is not the reflexive right of any one person choosing for another: parent or physician. Nor, in *Rodriguez*, was it solely the individual’s right to choose for him or herself.

Here we have the notion of solidarity and fraternity, of the individual as a member of the community that legitimately seeks to foster his or her welfare. Certainly a person can refuse treatment. A person can refuse nutrition. But a “right to die” in the popular sense is more than individual choice. It seeks the community’s acceptance and active participation in the death of one of it’s own, a violation of the ideas of solidarity and fraternity that are crucial to our sense of community.

In answer to the question, “Whose choice is it?” I have always answered ... ours. Death is not an individual event. The death of an individual reverberates across the family and community in which that person resides. That is why this question is before a committee whose judgment is that of the community. To choose for euthanasia and assisted suicide is not to bring the ideal of community support forward. It denies our commonalities and the belief we are more than physical potentials. We are across our lives community members supporting and supported by others.

Let me say, here, I have several times been asked either to assist in a person’s suicide or to give my approval, to countenance it the idea if not participate actively in the fact. In each situation I have identified a failure of palliative care, a failure of supportive services, a failure of support for family caregivers at the root of the request. And

sometimes there has been pride, and a fear of a different life whose potential the person cannot see in the moment of distress. The latter are the most troubling to me and my greatest fear is that by encouraging this legislation you encourage fear, and the failure of the services fragile persons need to eliminate pain and maximize their place in the community. The result will be unnecessary deaths.

I write without all the footnotes, the academic arguments I normally include in such presentations. I write it as a man in his 60s whose academic positions are of far less consequence, in this discussion, than his experiences. I submit this in the belief that those members of the Assembly arguing for euthanasia do so in the belief they are asking in the best interests of their fellow citizens. I submit that on the basis of my experience they are wrong and those they seek to advantage will be the persons most disadvantaged should a euthanasia “right to die” bill be advanced in Quebec.

For me the question is the degree to which we believe all citizens important, all lives worth treating. It is a question of the nature of the society we create, one in which we seek the best advantage for everyone or whether we find the easy way to discard those who seem, to us, burdensome. Let me suggest as a Canadian that we are better than that and Quebec is better than that.

Thank you for your attention. Should members wish I would of course be willing to present myself to answer questions that arise from this brief. In June 2010 I submitted written briefs and an oral presentation on “compassionate care” to a Parliamentary Committee on “Compassionate Care” in Ottawa. Those materials can, of course, be made available to the honourable members in Quebec.

In short, as a Canadian engaged in these issues, personally and professionally, I will do what I can to advance this debate at the request and discretion of Committee members.

A handwritten signature in black ink that reads "Tom Koch" with a stylized flourish at the end.

Tom Koch, PhD

Current Appointments: 2010-2011

- Adj. Prof. Medical geography, University of British Columbia.
- Bioethicist, Canadian Down syndrome Society (Resource Council).
- Consultant in bioethics and gerontology, Copeman Healthcare, Vancouver, BC.
- Consultant in bioethics and gerontology, Alton Medical Centre, Toronto, ON.
- Director, Information Outreach, Ltd.
- Former professor (adj.), gerontology, Simon Fraser University, Vancouver, BC.

<http://kochworks.com>