

Catholic Health Alliance of Canada

Presentation to

All-Party Parliamentary Committee on Palliative and Compassionate Care

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October 19, 2010

Introduction

On behalf of the Catholic Health Alliance of Canada I want to thank the members of Parliament for leading this important discussion on palliative and compassionate care and for allowing us to present some insights.

The Catholic Health Alliance of Canada serves as the national voice of Catholic health care in Canada. It works to support the network of approximately 110 Catholic hospitals, long-term care centres, nursing homes, and community health centres located throughout Canada. This network includes smaller, rural centres as well as some of the largest health care organizations in the country: Providence Health Care, Vancouver; Covenant Health, Alberta; St. Boniface Hospital, Manitoba; St. Joseph's Health Care in Hamilton and London; and St. Michael's Hospital in downtown Toronto. The Catholic Health Alliance of Canada is committed to advocating with and on behalf of the most marginalized members of our society, most particularly those who are sick, suffering and dying. Many Catholic hospitals and homes are actively involved in the care of

those who are dying and offer palliative care services. The Alliance actively promotes palliative care and improved pain control through education and advocacy activities, and has articulated ethical norms for care of the dying person.

Contributions for Palliative End of Life Care from Some Catholic Traditions

Recognizing the importance of this discussion and debate for all Canadians, regardless of religious or cultural background, we believe there are at least three Roman Catholic traditions that can provide important contributions to the public discussion: the spiritual/moral tradition of a "good death"; Roman Catholic Social Justice teaching and the importance of reason –the intellectual tradition.

A "good death"

It is important for Catholics to contribute their understanding of a good death in the complex circumstances of dying today and to work with others to ensure all Canadians access to the benefits of palliative care which can provide support for a "good death". For modern medicine and indeed all contemporary society, death is the enemy; something to be denied, defied and avoided at all cost. Over the past few years especially, there has been much discussion and debate in Canadian society about assisted suicide and euthanasia. These represent a totally different conception of a "good death". At the same time, that debate revealed enormous confusion about the rights and duties of patients at end of life. It also demonstrated ignorance of the advances of modern medicine in palliative end of life care.¹

In the Catholic tradition, life and physical health are precious gifts entrusted to us by God. We must take reasonable care of them, taking into account the needs of others and the common good. Catholic morality requires respect for the life of the body; it does not make it an absolute value. Over centuries, the Catholic faith has developed principles for determining the meaning of "reasonable care". These principles direct that the obligation to prolong life is to be evaluated in light of one's medical condition and ability to pursue the spiritual goals of life. A judgment regarding acceptance or refusal of any intervention is based on *reasonable hope for benefit* and

acceptable risks and burdens as determined by the patient. This means that Catholics are morally obliged to use medical means that offer reasonable hope of benefit without imposing excessive burden. At the same time, it also means that Catholics are not obliged to use medical means when death is imminent and medicine only prolongs the dying; that is, when there is no reasonable hope of benefit, or treatment imposes excessive burden. It is important to understand this wise tradition clearly.

The dying process is often accompanied by pain and other physical symptoms such as breathlessness. Catholics have a duty to provide relief. A particular confusion has arisen around the use of morphine and other opiod medications in pain control. Their proper use in the alleviation of pain does not hasten death.^{2,3,4} Optimal palliative care can provide considerable relief for almost all symptoms. Dying can also be a time of great suffering; some of that suffering is in relation to physical symptoms but most comes from the experience of deeper spiritual and emotional issues. Persons of faith experience the same difficulties as others in acknowledging the limits of medicine to cure. Acknowledgment of dying is a precious time of grace, reconciliation and healing. An intentional shift to the goals of palliative care resonates with the Christian notion of the good death. The stated goals of palliative care are the relief of pain and other physical symptoms, together with assistance for the spiritual, emotional and familial issues at end of life. Palliative care has made major advances in achieving these two goals. Both recognize that pain and other physical symptoms and human suffering can be related but are distinct human experiences. Pain is a physical reality; it can be relieved well by modern medicine. However, suffering is a total, human, spiritual experience; it requires a spiritual remedy.

Today a "good death" is generally understood as a peace-filled acceptance of death where the dying person is surrounded by and reconciled with loved ones; farewells have been said and life tasks completed. Today, a good death is understood not as a frantic and fearful pursuit of a saving technology to the last breath. A good death instead is one that comes with well and peacefully made decisions about reasonable hope for medical benefit and acceptable burdens and risks; acceptance of the limits of medicine to cure; acceptance of dying; the prudent use of medicine to alleviate pain and other physical symptoms; a focus on respecting the dying person's values and life goals; and being supported by loved ones. Modern palliative care emerged to

improve the care for the dying in today's death-denying, death-defying world. Its fundamental philosophy is not to hasten nor prolong dying.⁵ It is not surprising that the roots of modern palliative care can be traced to religious beginnings, and that CHAC and its member organizations have been very active in the early and continuing development of palliative care in Canada. CHAC participates actively in the QELCC and supports the *Blueprint for Action 2010-2020* which outlines four priorities for the next decade:

- *Ensure all Canadians have access to high quality hospice palliative end of life care.
- *Provide more support for family caregivers.
- *Improve the quality and consistency of hospice palliative end of life care in Canada. Canadians should expect to receive high quality care in all parts of the country.
- *Encourage Canadians to discuss and plan for end of life. Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians.

Roman Catholic Social Justice Teaching

The provision of equitable, accessible, high-quality palliative care is a matter of justice. The gaps and inequities represent a real challenge for Canadians.⁶ The recent international ranking of Canada's end of life care as ninth is not good enough.⁷ It is, in a real sense, a failure to deliver on the promise of equity and solidarity underlying the Canada Health Act, a defining public policy.

The foundational principles of Catholic social justice teaching can provide strong motivation for improvement. These principles include:

- i. The dignity of each person
- ii. Social interdependence of persons and solidarity with the whole of creation
- iii. Subsidiarity in decision-making
- iv. Preferential option for the poor (and vulnerable)
- v. The promotion of the common good

Dignity, interdependence and solidarity are central notions in any national end of life strategy. The notion of the common good is crucial here. The common good is understood as the sum total of those conditions of social life which allow social groups and their individual members, relatively thorough and ready access to their own fulfillment.⁸ The whole of society, in fact, is

required through its health-care and civil institutions to respect the life and dignity of the seriously sick and the dying. As the Committee recognizes care of our most vulnerable is a test of the national character.

The Catholic Intellectual Tradition and Empirical Research

The Catholic intellectual tradition has always emphasized the importance of faith and reason. Reason requires respect for knowledge and the ability to analyze complex issues. There are three sources of information that are important for advancing palliative care. The first is an understanding of the philosophical and moral arguments for and against competing conceptions of a "good death"; the second is awareness of public understandings, fears and hopes as demonstrated in opinion polls; and the third is new and emerging information from the research on desires for hastened and assisted death and reasons for complying with requests for assisted death. Recognizing methodological flaws and the ethical complexities in research around end of life, empirical research is helping to clarify a number of issues about assisted death and palliative care. Some representative samples of the growing body of empirical evidence with relevance to palliative care are included here.

The first published study assessing the attitudes and experiences regarding PAS and euthanasia found that "...the key determinants of interest in euthanasia relate not to physical symptoms but to psychological distress and care needs (emphasis added)". ^{9:2466} A US study of how experienced physicians respond to not infrequent requests for assisted death, even where illegal, identified three categories of issues and physician responses:

Physical symptoms-responded to by increased pain and symptom management.

Psychological issues-responded to by attending to issues of depression and anxiety.

Existential suffering-which was most frequently responded to by assistance in death. 10

Here, physicians who were uncomfortable with not being able to 'fix' suffering were likely to respond by complying with the patient's request for hastened death.¹⁰

In a 2006 systematic review on understanding desire for die statements from patients with advanced disease, Hudson and colleagues categorized four issues:(1) feelings and current reactions to circumstances (fears regarding death and loss of control); (2) communication of distress and suffering or a communication of exploring ways to relieve distress; (3) asking for information regarding euthanasia and physician assisted suicide because of (1) or (2); and (4) a small number specifically seeking assistance with hastening death or acknowledging their intent to commit suicide. ¹¹ Zylicz identifies five main profiles of persons requesting assisted death: patients whose request is based on fear of the future (anxiety); patients who are exhausted by their disease course (burnout); patients who desire to control a disease process they experience as out of control; patients with depression; and patients whose main motive is based on a belief that it is their right to determine the circumstances of their death. ¹²

Other studies have now explored directly the reasons patients and their family members give for their requests. One such study of patients who were seriously considering PAS and their family members, recruited through advocacy organizations that counseled hastened death, identified seven issues in three major categories:

- 1) Illness-related experiences including feeling weak, tired and uncomfortable; pain and or unacceptable side-effects of pain medications and loss of function.
- 2) Sense of self and the desire not to lose control.
- 3) Fears about the future focusing on fears for future quality of life and dying and negative past experiences of dying.¹³

This same study noted "...that *pain is often not the most salient motivating factor* (emphasis added)". ^{13:239} Another Oregon study concluded.

"According to family members, the most important reasons for PAD were: wanting to control the circumstances of death and die at home, and worries about loss of dignity and future losses of independence, quality of life and self-care ability. *No physical symptoms at the time of the request were rated higher than a median of 2 (of 5) in importance* (emphasis added). Worries about symptoms and experiences in the future were". 14:154

A Norwegian study in advanced cancer patients at a palliative medicine unit focused on understanding wishes for and attitudes about euthanasia. They found that wishes were generally "fluctuating and ambivalent" and "... fear of future pain, rather than actual, perceived pain, was the predominant motivation for a possible future wish for euthanasia". A 2007 Canadian study surveyed patients receiving palliative care for cancer to determine attitudes toward the legalization of euthanasia and physician assisted death and personal interest in a hastened death. 62% of these patients endorsed the legalization of euthanasia and physician assisted suicide. They endorsed it as a future possibility. Only 5.8% said that if it were legal they would have used it. This study highlighted again the importance of physical and psychological findings. Over 50% had a sense of self perceived burden to others; 40% of those with a desire for euthanasia or physician assisted suicide met diagnostic criteria for major depression. Depression has been the subject of a growing and increasingly robust body of research. Chochinov et. al. found a strong relationship between the desire for hastened death and clinical depression. Breitbart and colleagues found that the "diagnosis of depression was significantly associated with desire for hastened death". This body of research for a treatable condition has important consequences for palliative care's response to requests.

Recognizing that many doctors have difficulty with death and dying, an Australian study explored the role of doctors' attitudes and experiences, particularly experiences of terminally ill patients and the doctor patient relationship in patients' wishes to hasten death (WTHD). It concluded that "Dissatisfaction with the level of care the patient had received for emotional symptoms was a salient theme among the doctors with patients in the high WTHD group". 19:383 Early after legalization of PAS in Oregon investigators reported that requests for assisted death affect physicians who receive and respond to the requests as emotionally intense, highly time-invested, and provoking feelings of discomfort. 20 In the Dutch experience, participating physicians believed that they had done the right thing but also believed that "ending a person's life was inherently an unnatural act and felt unacceptable". 21:229

The dilemmas encountered by palliative care workers when patients wish to hasten death have been identified: increased responsibility to adequately manage symptoms; challenges to beliefs regarding patient autonomy; concerns that physician assisted death is antithetical to the philosophy of palliative care; missed opportunities for spiritual transformation; conflicts over

when and how to help patients re-define quality of life and confusion regarding their advocacy role when patients and their families are in conflict over PAS.²² The recent Swiss experience at the Centre Hospitalier Universitaire Vaudois, the first hospital in Switzerland to allow Assisted Suicide within the hospital is instructive,

"Clearly, the decision to allow access to AS within the hospital has had a significant impact on the palliative care consult service which does not endorse the practice of AS or euthanasia. It has created tensions between the philosophy and beliefs of the palliative care team and the institution's directive on AS....It has prompted significant discussion within the team and a deeper understanding of the implications of principles such as non-abandonment, patient autonomy and caregiver values and positions, and larger impact on society as a whole". ^{23:665}

A set of important themes emerge strongly from the growing empirical literature. As exemplified in the Oregon experience, most patients who request PAS or euthanasia do not experience intractable pain or other physical symptoms. There is no significant association between desire for hastened death and either the presence of pain or pain intensity. Fear of future pain, rather than actual, perceived pain, is a strong motivation for a possible future wish for euthanasia. Rather, persons indicating desires for hastened death are concerned about loss of control, autonomy, being a burden and loss of dignity. Moreover, depression and hopeless are significant contributor to wishes/requests. The other hand doctors have "difficulty addressing patients" existential suffering 10:657 yet feel an obligation to 'do something'.

We also know now that AD takes a toll on physicians, even when they believe it was the right thing to do in a particular case. Finally, the experience of AD within palliative care has brought confusion and distress. AD is being provided most often for issues that extend far beyond the care of those who are at the end of life and those with terminal illness. They go beyond the medical issues of pain and other physical symptoms to an array of social and emotional circumstances which cause human suffering.

Lessons for Palliative Care

While there is a general perception that requests for assisted death arise from circumstances of intractable and unbearable pain and other physical symptoms, the evidence is clear that pain and other physical symptoms may generate conversation about hastening death but almost all of

these physical concerns can be alleviated with quality palliative care. The experience of unrelieved pain is not a significant factor in the actual requests for hastened and assisted death. The most common issues related to consideration of and requests for assisted death raised in the research are fears of *future* suffering: loss of control; loss of a sense of dignity and concerns about being a burden, especially to loved ones. There is strong uncertainty about what kind of care and support will be provided in the dying process. The growing evidence is clear that depression-a treatable disease- plays a large role in patient's requests.

Lessons for Education

This research raises serious issues about the general public's understanding of patients' rights to refuse unwanted medical intervention, the availability of palliative care and support in dying and the efficacy of quality palliative care, especially for pain. Despite advances in palliative care over the last twenty years, there is a great need for education into all aspects of palliative end of life care. This education is needed at all levels, for patients and their loved ones, for health care providers and for policy makers.

Lessons for Access

Fears of being a burden are strong are strong forces in requests for assisted death. Clearly, a national strategy to develop access to palliative care and programs to relieve the burden of caring for dying loved ones is urgently needed. Equitable access to a full range of palliative care services for rural and urban populations and for the full range of trajectories of dying is essential. Special attention must be given to improving the support for family caregivers with particular attention to respite care.

The complex issue of adequate funding for any effective national palliative care strategy must also be finally dealt with.

Lessons for Care

We are a death-denying *and* death-defying society. Intentionally shifting from the goals of cure and substantial improvement in symptoms and function to the goals of palliation at end of life is difficult for many patients, families and even some health care professionals. The importance of early introduction of palliative goals to all persons with serious, chronic and life-threatening conditions cannot be emphasized enough.

Quality standards for palliative care in all settings-rural and urban; home, hospice and palliative care unit are urgently needed. The experience of high quality palliative care at end of life is the most important factor in getting out the message that persons can be helped to a good death.

The literature is clear and compelling that recognition and response to issues of suffering-in contrast to issues of pain and other physical symptoms-is an essential element of care. Pastoral and spiritual care is a core component of palliative end of life care. Special attention needs to be given to the preservation of dignity in all care.

Research into the "tough cases" of end of life care is an ethical obligation of all committed to the improvement of end of life care.

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