Palliative Care and End of Life Therapies

We believe that life is a gift from God which should be respected and protected through all of its stages. Each human life has inherent worth, regardless of age or physical, mental or other abilities. Care for the sick and the elderly is part of God’s call for Christians. Palliative care and emotional support are necessary and appropriate responses to those who suffer from terminal illnesses and/or are near death. Set within the introductory context of a brief summary of current Canadian and international experience, this document reflects on two such innovative practices that have been found to offer dignity to and alleviate suffering for those who need it most.

Introduction

While patients may refuse consent to any medical treatment or procedure, under current law in Canada they cannot receive a treatment or procedure for the purposes of ending their lives. Canada’s Criminal Code (“Code”) does not contain a specific reference to “euthanasia”, but this practice is considered an act of murder and is captured by the Code.1

While the offender’s intention to murder is relevant for determining what charges are laid and what sentence is given, the motive for the offence (for example, compassion, anger, greed) is not taken into consideration. Consent to death does not affect the criminal responsibility of the one who inflicts death. Further, counselling someone to commit suicide or assisting suicide is also prohibited in the Code.2

The provisions have faced several challenges in recent years. In 1993, the Supreme Court of Canada (SCC) decided the Rodriguez v. British Columbia (AG) case. British Columbia resident Sue Rodriguez brought a challenge to the Code prohibitions after being diagnosed with a terminal illness. In 1993, the SCC ruled against Rodriguez with a majority of the judges affirming that the prohibition against physician-assisted suicide is rooted in the interest of the state to protect and maintain respect for human life. They went on to say that to effectively protect life and those who are vulnerable in society, a prohibition without exception on the giving of assistance to commit suicide is the best approach.3

On April 21, 2010, Bill C-384, Right to Die with Dignity, was voted down in the House of Commons 228 to 59.4 C-384 was the third private member’s bill in recent years concerning end of life treatment

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2 Ibid., s. 241.
introduced by Member of Parliament Francine Lalonde. Had the bill passed, euthanasia and assisted suicide would be legalized for any individual over 18 who, “appearing to be lucid,” requested death. The patients’ requests would not have been limited to those who are terminally ill and would include those who experience depression or other chronic medical conditions.5 Furthermore, while the bill required at least two medical practitioners to confirm the diagnosis of the patient in writing, the definition of practitioner was not limited to a physician, and the bill protected the practitioners by not requiring them to file a report until after death; this provision placed the patient at a heightened risk of having their wishes misinterpreted or being pressured while in a sensitive condition to choose euthanasia rather than try medical treatments.6

On June 15, 2012, a lower court judge at the British Columbia Supreme Court ruled that exceptions should be carved out of the existing Code provisions that prevent euthanasia and assisted suicide. The judge ruled, contrary to our highest court’s decision in Rodriguez and despite the demonstrated expressed will of Parliament in the Bill C-384 vote, that the Code’s provisions violated equality rights and the rights to life, liberty and the security of the person. The judge concluded the existing provisions discriminated, in particular, against persons with physical disabilities who are unable to commit suicide without assistance and therefore the state should be required to provide a means to assist those who want to commit suicide.7 The decision has since been appealed and will be heard by the British Columbia Court of Appeal in the spring of 2013.8

It is important to note that nations that have legalized assisted suicide have also experienced increasing rates of euthanasia. Life has become devalued. The lives of the elderly or infirm are not considered as worthy of protection or dignity as those of healthier, younger citizens.

In the Netherlands, the original criteria for euthanasia required that only terminally ill, suffering, competent adults who repeatedly requested and consented to death could seek voluntary euthanasia. Three decades later, none of those requirements remain. Individuals have been killed in hospitals without their consent:

In 30 years, the Netherlands has moved from euthanasia of people who are terminally ill, to euthanasia of those who are chronically ill; from euthanasia for physical illness, to euthanasia for mental illness; from euthanasia for mental illness, to euthanasia for psychological distress or mental suffering—and now to euthanasia simply if a person is over the age of 70 and “tired of

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6 Ibid.
living.” Dutch euthanasia protocols have also moved from conscious patients providing explicit consent, to unconscious patients unable to provide consent.9

The laws and official guidelines of the nation have been watered down and modified by judicial interpretation to the point where no physical suffering or even illness need be demonstrated. Children as young as 12 years old may request euthanasia without parental consent.10

According to a 2000 study on euthanasia and assisted suicide in the Netherlands, in 86 percent of so-called assisted suicides, the person assisting the suicide took a more active role, meaning assisted suicides actually became acts of euthanasia. The study also found that a third of legal injections were given without patient consent and that physicians frequently falsified death certificates.11 A 2010 study found that despite an approximate rate of under-reporting of 20-23%, there had been a 73% increase in deaths by euthanasia since 2003.12 Most disturbingly, has been the 50% increase of deaths by ‘terminal sedation’ between 2005 and 2010. Terminal sedation is distinct in from palliative sedation, which permits natural death to occur. Terminal sedation withdraws food and water from a sedated person. It ends the life of a person who is otherwise not dying. It is considered by many as “slow euthanasia” and some have argued that it is utilized in order to keep the rates of euthanasia deaths low.13

Belgium legalized euthanasia in 2002, despite opposition from many groups including the Belgian Medical Association.14 Trends similar to those in the Netherlands have been discovered. A recent study found that in one region, 32% of deaths by euthanasia occurred without patient request or consent. When physicians were asked why consent wasn’t obtained, they responded that the patients were comatose (70%) or suffered from dementia (21%); that euthanasia was in the patients’ best interest (17%); or that to discuss the issue with the patient “would have been harmful to that patient (8%).”15

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15 J. Pereira, “Legalizing euthanasia or assisted suicide”.
Abuses continue to occur with atrocities such as one labelled the “weekend clean-up” at one Belgian hospital where elderly and serious ill patients are routinely administered legal drugs at the request of family members burdened with their care.\textsuperscript{16}

While attempts to decriminalize euthanasia and assisted suicide can cause us to focus on legal principles and political manoeuvring, a fundamental question must be asked: Why do people request assisted suicide? Can something be done to meet their underlying needs, fears and concerns? Or is the third-party taking of lives the only response to their suffering? Additionally, how can we recognize and support the value of the lives of those who are facing disabilities and decreasing capabilities?

This document examines two recently developed forms of therapy that address those concerns in order to offer hope and healing for some of society’s most vulnerable citizens.

**Reasons for Euthanasia and Assisted Suicide Requests**

In response to the debates provoked by C-384, Quebec’s National Assembly established the Select Committee on Dying with Dignity to further explore the contested values and definitions of dignity, individual autonomy, compassion and respect for the sacredness of life. The Select Committee commenced its public hearings in September 2010.\textsuperscript{17} In one testimony delivered at a hearing, Monique David explained that the Canadian Association of Palliative Care distinguishes four main reasons patients request death: “pain and physical suffering; loss of control over their illness, their lives and their bodies; the desire to not be a burden; and depression and psychological distress linked to their illness.”\textsuperscript{18} David personally encountered the latter when her father, having suffered a debilitating heart attack, became depressive and suicidal.

However, anti-depressants significantly eased her father’s anxiety crises, eliminating his requests for death and reducing his perception of burdening the lives of his family members. As David related, “gradually, [my father] came to realize that he could continue to be useful— less physically, but more interpersonally. . . But if we had succumbed to his dark, recurring desires, supported by a doctor or a medical system that legalizes euthanasia, my father would no longer be among us.”\textsuperscript{19} David’s testimony reveals an insight that many key figures of the medical community also stress, the will to live is inextricably linked with maintaining a sense of meaning and connection to one’s world.

Medical experts have observed that with the advancement of pain management technology throughout the 20\textsuperscript{th} and into the 21\textsuperscript{st} century, psychological and emotional factors have surpassed physical pain as an influence on patients’ requests for assisted suicide or euthanasia. Studies in the state of Oregon, which legalized assisted suicide in 1997, have shown that the most common concerns of those who elect

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\textsuperscript{19} Ibid.
to die is the loss of autonomy, the inability to engage in activities that they have experienced make life enjoyable, the loss of dignity, and the loss of control of bodily functions. Furthermore, in the case of the Netherlands where both assisted suicide and euthanasia have been legal since 2002, requests for assisted suicide are often based on fear of the future, exhaustion or burnout, a desire to control an out of control process, depression, and the firm belief in a right to choose the manner and time of their death.

The will to live is correlated more with anxiety and depression than physical symptoms, studies reveal. Despite the fact that considerations related to a desire to die are both complex and multifactorial, the research is demonstrating that “psychological, existential and social reasons seem to be more prominent than those directly related to physical symptoms, such as pain.” And, the concern about loss of control, autonomy, and dignity “go beyond the medical issues of pain and other physical symptoms to an array of social and emotional circumstances that cause human suffering.” Euthanasia and assisted suicide are largely being requested on account of emotional and existential suffering, aligning the issue of “dying with dignity” with the issues of fear and anxiety that influence people to commit suicide. Canadian Association for Suicide Prevention (CASP) executive director Tim Wall states that “most people who die by suicide experience intense feeling of sadness and emotional pain, and feel hopeless about that pain ever diminishing.”

Palliative care is the most prominent alternative to the legalization of assisted suicide and euthanasia. As opposed to therapeutic obstinacy, aggressive treatment which might prolong a patient’s life to the detriment of his or her quality of living, palliative care aims to provide “better medical care for pain and symptom control and to attend more appropriately to the personal, emotional and spiritual issues at the end of life.” As an end of life treatment, it addresses the psychological and existential factors that influence requests for assisted suicide and euthanasia. Palliative care targets the sources of a patient’s anxiety, therefore renewing his or her will to live, the overall quality of his or her life, and ultimately, the quality of his or her death.

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21 Kathleen Foley and Herbert Hendin, Eds., The Case Against Assisted Suicide: For the Right to End of Life Care, (Baltimore: John Hopkins University Press, 2002).


25 Nuala P. Kenny, “Responding to Requests for Euthanasia...”.
Dignity Therapy

A significant advancement in palliative care is Dignity Therapy, a theory developed in 2007 by Dr. Harvey Max Chochinov of the University of Manitoba and his colleagues as a “novel therapeutic intervention for suffering and distress at the end-of-life.”

Dr. Chochinov explains that the preservation of dignity is directly connected to maintaining the will to live: “Loss of dignity is often associated with feelings of being a burden to others and not feeling worthy of respect of esteem. . . . Hope, or more specifically loss of hope, has also been connected to the construct of dignity, and is a highly significant predictor of suicidality.”

A team of doctors and nurses from the University of Manitoba and Edith Cowan University in Perth, Australia drafted an individual palliative care treatment that offered terminally ill patients the opportunity “to address issues that matter most to them or speak to things they would most want remembered as death draws near.”

The study involved asking a patient suffering from a terminal illness questions about his or her life, and transcribing and editing the patient’s responses into a final version that could be bequeathed to a friend or family member. The questions asked what the most important aspects of his or her life were, when he or she felt most alive, and of what accomplishments he or she is most proud. Building and remembering relationships with family and friends were also central to the study’s focus, and the patient was asked what his or her hopes for one’s family, and if there was any advice he or she would like to pass on to loved ones.

Results from the study reveal that given the opportunity to communicate their concerns and reflect over their lives, 91% of the patients found Dignity Therapy helpful, 76% said it increased their sense of dignity, their sense of purpose (68%), and meaning (67%). Furthermore, 47% of patients remarked that Dignity Therapy increased their will to live, despite the deterioration of their health, and the study highlights that the benefits were even higher in patients who initially indicated psychological and existential distress.

The final version of the patient’s transcript becomes a narrative that reminds the patient of the value of his or her life, and provides a lasting memento for family and friends. A 61-year-old woman suffering from recurrent cancer summarizes the renewed hope, purpose and dignity she experienced with the

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28 Harvey Chochinov et al, “Dignity Therapy”.
29 Ibid.
31 Harvey Chochinov et al, “Dignity Therapy”.
32 Ibid.
therapy: “This experience has helped me to delve within myself and see more meaning to my life. I really look forward to sharing it with my family. I have no doubt that it will be enlightening to them.”

Dignity Therapy provides a model for integrative palliative care that meets the emotional, psychological and spiritual needs of patients suffering from terminal illness. It enables patients to remember past experiences, express their present concerns, and prepare for death and the effect it will have on their families. Because existential suffering is the most prominent factor influencing terminally ill patients to request assisted suicide or euthanasia, the concept of dying with dignity is best defined to include and address this concern in the best interests of the patient. Mental health interventions successfully alleviate symptoms of depression and despair in patients with advanced disease. While interventions incorporate pharmaceutical aid including anti-depressants and pain relievers, far more significant is fostering an environment in which meaningful relationships with friends and family are continued, developed and resolved, spiritual or religious searching is encouraged, and end-of-life issues are discussed.

Validation Therapy

Unlike Dignity Therapy which focuses on meeting the needs of terminally ill patients, Validation Therapy addresses the mental, social, and existential needs of the aged who are suffering from various forms of dementia, Alzheimer’s disease or disorientation. The elderly suffering from these conditions are particularly vulnerable and marginalized because their needs are misunderstood by loved ones, and often, the medical community, and they no longer satisfy a role in society that the dominant culture deems valuable.

Naomi Feil, the originator of Validation Therapy, emphasises that the population is aging because of improved living standards and advancements in medical technology, but this trend has created a vacuum in medical and social care where the needs of the very old are often unmet. Canada’s Special Senate Committee on Aging produced a report in 2009 about Canada’s aging population that echoes Feil’s concerns and promotes a positive understanding of aging and the implementation of integrative programs that support the diverse needs of the elderly. One of the greatest barriers the Committee sought to address is that of ageism, or the discrimination on the basis of age that makes assumption about a person’s capacity, ignores an older person’s known wishes, or treats the older adult as a child. In promotion of the contrary, the Committee stated: “We strongly reaffirm that the frailest among us are much more than the sum total of their incapacities; that they contribute to society, not only in their past achievements, but in the dignity of who they are today.”

Validation Therapy presents a model of palliative care that is based on principles similar to those expressed by the Senate Committee on Aging. A Validation Therapist’s interactions with a patient begin from the premise that all people are unique and valuable, and that there is a reason behind the

33 Ibid.
behaviour of disoriented “old-old” people.\textsuperscript{36} By accepting behaviour non-judgmentally, the validation therapist aims “to understand the personal meaning underlying an individual’s behaviour,” and to aid the individual in restoring and reconciling aspects of one’s life that might be causing disoriented behaviour. \textsuperscript{37} Feil states that autopsies have shown that many elderly persons survive significant brain damage attributable to aging and stay relatively oriented, “whereas others become severely disoriented with the same amount of damage to brain tissue.”\textsuperscript{38} Feil hypothesised that each stage of life has a unique task that individuals must face at a prescribed time in the human life span, and an “ignored task” can cause adverse mental and emotional reactions. Therefore, disorientation or repetitive behaviour in very old age, while it does not seem to correspond with the person’s external reality, is relevant to the person’s overall integrity as an individual.

In one case study that reflects her hypothesis, a patient, Mrs. F, who was diagnosed with “senile dementia” stared frequently into space and shouted: “There’s Mother. She’s got my laundry. I have to help her carry it. She might trip and fall.”\textsuperscript{39} When a therapist tried to orient Mrs. F to reality by informing her that her mother was dead, Mrs. F responded by withdrawing from the therapist. On one occasion she muttered, “Well I know that. And you know that. But my mother doesn’t know that. She’s carrying too much laundry, and I have to help her, so get out of my way!” Two months later, the therapist affirmed Mrs. F’s need to help her mother rather than trying to orient her to reality. Mrs. F responded, crying, “She was a wonderful mother. I should have helped her more. She died when she was only 30 years old.”\textsuperscript{40} Feil reports that after four weeks of Validation Therapy, the patient’s facial muscles relaxed, her voice became less frantic, she no longer stared into space, and she began to interact with the therapist. Validation Therapy aided Mrs. F to express her grief and guilt and as her grief lessened through validation her behaviour became more oriented.\textsuperscript{41}

Feil concludes that an approach to interacting with the very old that does not insist on participation in present reality in many cases prevents the withdrawal inward to a vegetative state. While further medical studies are still being conducted to determine the overall efficacy of Validation Therapy, the current results suggest that affirming and validating the experiences of the very old enables some patients to reconcile tensions in their lives that, left unaddressed, might lead to increased symptoms of disorientation, dementia or vegetation. Furthermore, by reducing difficult behaviour through validation, such a therapy can relieve the stress of caretakers and dissemble existing prejudices against the very old that lead to obstinate geriatric care, therefore affirming the aging as part of the human development process.\textsuperscript{42}

\textsuperscript{36} Naomi Feil, “Validation Therapy,” adapted from her book The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer’s-Type Dementia, 1993, \url{http://archives.evergreen.edu/webpages/curricular/2000-2001/hhd2000/Mukti%27s%20Notes/VALIDATION%20THERAPY.htm}.


\textsuperscript{38} Ibid.

\textsuperscript{39} Ibid.

\textsuperscript{40} Ibid.

\textsuperscript{41} Ibid.

\textsuperscript{42} Ibid.
Conclusion

As studies of assisted suicide and euthanasia requests show, fear of death and anxiety about the dying process greatly influences the quality of a person’s life, and ultimately, the quality of one’s death. Palliative care therapies such as Dignity Therapy and Validation Therapy reveal that central to the dying process is a process of integrating one’s experiences into an understanding of life. Their studies reveal that patients suffering from terminal illness, the very old, and family and friends of the dying benefit from addressing one’s emotional and psychological end of life needs; while the assumption that a legal right to assisted suicide and euthanasia grants one dignity in death ignores the complexity of the human experience. As the 2009 Report of the Special Senate Committee on Aging emphasises, the medical community and legislative bodies need to explore more adequate ways to meet the needs of the aging and those with terminal illness. Further, “[t]hose committed to a philosophy of ‘neither hastening death nor prolonging dying’ must make a renewed commitment to understanding and facilitating dignity at the end of life.”  

For more information, please contact The Evangelical Fellowship of Canada’s Centre for Faith and Public Life at ottawa@theEFC.ca or visit our website at www.theEFC.ca. © November 2012

43 Nuala P. Kenny, “Responding to Requests for Euthanasia...”.