

UNDERSTANDING THE ACTIVE VOLUNTARY EUTHANASIA DEBATE

BY

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## ABSTRACT

The subject of active voluntary euthanasia is one of the most complex, deeply divisive and heart wrenching moral issues now being debated around the world. An understanding of both the key ethical issues and the social context of the debate is essential to the development of normative analysis and just social policies. In Chapter One, the terms utilized to conceptualize the debate, key topics related to active voluntary euthanasia, and the main themes of the dissertation are explored. In Chapter Two, I assess George and Sheila Grants' essay, "The Language of Euthanasia." Chapter Three considers some of the transformations in biomedicine that have lead to greater control over the body. The provision of diagnoses and prognoses more accurate than could be provided in previous eras of medicine is considered as an important factor in the current debate. Chapter Four considers changing attitudes toward the meaning of suffering. Chapter Five traces the development of individualism and the rise of patient autonomy. The relationship between an increased concern for patient autonomy and the active voluntary euthanasia debate is explored. In Chapter Six, I examine a specific proposal for the legalization of active voluntary euthanasia, the "California Death With Dignity Act." Finally, based upon the major points of the preceding chapters, Chapter Seven provides a normative analysis in support of active voluntary euthanasia under certain circumstances.

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## CHAPTER ONE

## INTRODUCTION: UNDERSTANDING THE ACTIVE VOLUNTARY EUTHANASIA DEBATE

The subject of euthanasia is one of the most complex, difficult, deeply divisive, and heart wrenching moral issues now being debated around the world. With the possible exception of the topic of abortion, there are few other subjects that have generated such deep rifts in the medical, legal, and theological communities. Nor is the controversy startling, since euthanasia is not a minor topic at the periphery of medicine or the other healing professions. Instead, the subject of euthanasia challenges all our intellectual and emotional resources, because it strikes at the root of our conceptions of selfhood and society, and raises questions about what constitutes the moral care of the most defenseless members of any society: the suffering and the dying.

My own research trajectory captures the difficulty of reaching any definite resolution to the debate. In an earlier version of this dissertation, I concluded by asserting that the legal barriers to euthanasia that exist in Canada, the United States, and most other nations should remain, while much greater attention should be given to hospice and palliative care. Since then, I have altered my position from opposition to euthanasia to a qualified support of the restricted practice of euthanasia, though my fears of

the dangerous possibilities of any social policy endorsing even the most carefully circumscribed form of euthanasia have never altogether abated. In part, my sense of uncertainty is a reflection of the constraints under which I investigated the subject of euthanasia.

Stanford anthropologist Renato Rosaldo, in a poignant essay about death written after his young wife died while conducting research in the Philippines, once wrote that one of the greatest shortcomings of the anthropological research on death and dying was that it was written by too many young scholars.<sup>1</sup> According to Rosaldo, these researchers, while adept at reporting rituals of lamentation, mortuary rites, and the concrete, material elements of the cultural appropriation of death and dying, tended to neglect the experience of the dying as well as the emotions of those closest to the dead. As a result, while a great deal of research examines the highly visible rites of death and dying, there is much less known about the interior and interpersonal human experiences of loss, and bereavement.<sup>2</sup> Rosaldo attributes this neglect by anthropologists of the experiences of suffering, loss, and deprivation to an inability on the part of young researchers to understand the existential elements of death and dying. Relatively untouched by a personal debilitating illness, living in industrialized, technologically oriented nations where death is supposed to come only to the aged, and still too young to have experienced the death of close family members, many of

these researchers could not comprehend the anguish of the embodied experience of death and dying, and instead diminished their research by attending to more superficial, yet manageable research issues.

Like the young researchers Rosaldo criticizes, I too find it difficult to address, or even face, the most personal, existential dimensions of the euthanasia debate. Admittedly, I am now familiar with the deontological and consequentialist arguments utilized to endorse or condemn the practice of euthanasia. I understand many of the historical transformations in society that have led to the development of the euthanasia debate. I am aware of most of the seminal books and articles that help to illuminate various elements of the debate. However, there is a limit to my understanding and experience. I have visited a hospital burn unit, but I cannot imagine what it is like to suffer from serious burns over most of the body. I know of several people with cancer, but I do not pretend to comprehend the experience of undergoing chemotherapy, radiation treatments, and surgery. Despite all of my reading, visits to hospital units, and conversations with others about euthanasia, I have never suffered from the nausea, diarrhoea, loss of hair, and mouth infections that can accompany cancer treatment. Likewise, I have seen patients dying of AIDS in Los Angeles, but I cannot pretend to have entered their experience. So, even though I possess a great deal of important, useful knowledge about the euthanasia debate, am familiar with the various arguments for

and against euthanasia, can recognize the names of the major players in contemporary medical ethics, and can trace the recent history of the debate, there is a key dimension of the subject that I have, perhaps inevitably, neglected. I do not know what it is like to have Multiple Sclerosis, AIDS, ALS, or to be quadraplegic. I am familiar with the percentages of those who suffer severe cancer pain in the final stages of terminal illness, but cannot comprehend what that suffering entails. Despite all of my research, I lay no claim to the role of "expert." Indeed, I am rather skeptical of those physicians, lawyers, and others, who feel content to play this role as the euthanasia debate is conducted in the popular media. Their pronouncements sometimes trouble me, as I question the profundity of the experiential dimension of their knowledge of pain and suffering. Many of those most qualified to write about terminal illness, severe pain, and euthanasia, tend not to be the author of the articles to be found in medical journals and law reviews.

I see this dissertation as near the beginning, rather than the culmination of my understanding of euthanasia. Perhaps the next time I write about the subject, I will not be so reticent about visiting people in hospices, palliative care units, and oncology wards. Perhaps I will take a more "journalistic" approach and try to interview individuals such as Sue Rodriguez, the woman from British Columbia whose request for the provision of medical assistance in suicide is being ruled upon by the Supreme

Court of Canada.<sup>3</sup> Such an approach could demonstrate the "multiple voices" in which the subject of active voluntary euthanasia is articulated in a pluralist society, and help to reveal the complexity of the debate. However, this dissertation is not the product of such research.

Nor, given my relatively good health and my unwillingness to invade the already limited privacy of the terminally ill, do I pretend to capture the most deeply personal elements of the subject of euthanasia. Instead, I have chosen to consider one rather traditional Christian view of the subject of euthanasia, because Christians have tended to play a significant role in supporting current prohibitions of euthanasia. I then proceed to examine the social context of the debate before exploring proposals for the regulation of active voluntary euthanasia.

Before considering the more obvious complexities of the debate, the language we use to frame the issues needs to be critically examined. Moral analysis of the subject is significantly complicated by the ambiguous, polyvalent meaning of the term, "euthanasia." Ordinarily, there needs to be a clear understanding of the terminology used to formulate reflection and discussion. However, the very meaning of the term, "euthanasia," is highly contested. For some individuals, active euthanasia, even the voluntary form that includes the consent of the dying subject, means the outright killing of one human by another and is morally equivalent to murder.<sup>4</sup> For other participants in the debate, "euthanasia"

is not a condemnatory moralistic term. Rather, it is the word used to describe the compassionate response of one human to a suffering individual who requests assistance in putting an end to unbearable suffering.<sup>5</sup>

I think some of the confusion is removed from the debate by considering a typology developed by Barney Sneiderman, Professor of Law and Bioethics at the University of Manitoba.<sup>6</sup> Within this typology, Sneiderman demarcates four distinctive forms of euthanasia. "Active voluntary euthanasia" is utilized to delineate situations in which an individual such as a physician participates in the deliberate, intentional, directly causal ending of the life of another human being, at the conscious, considered request of that individual. For example, if a physician provides a lethal injection to an alert, competent patient who had requested the doctor to do so, she would have performed "active voluntary euthanasia." In contrast, "active nonvoluntary euthanasia" would involve a similar act without the considered request of the patient. In Canada and the United States, as in most other nations around the world, active euthanasia, whether voluntary or involuntary, is illegal. In Canada, the Criminal Code prohibits the provision of active euthanasia, and the Law Reform Commission of Canada supported this prohibition in its examination of the subject of active euthanasia in 1982.<sup>7</sup>

In contrast, there are two forms of passive euthanasia. "Passive voluntary euthanasia" involves the cessation or

withdrawal of medical treatment with the consent of the patient. For example, a patient suffering from end stage renal failure can elect to cease to undergo dialysis even though this will lead to certain death. "Passive, nonvoluntary euthanasia" also involves the cessation or withdrawal of treatment, but occurs without the considered request of the patient. This typology helps to qualify our understanding of the meaning of "euthanasia." I think Sneiderman's typology can be further nuanced if nonvoluntary euthanasia, both active and passive, is further divided into two separate categories. Nonvoluntary euthanasia would involve the absence of the voluntary request of the patient. In contrast, "involuntary euthanasia" can be used to describe situations where decisions are made by medical personnel or family members that actually contradict the choices of the patient.<sup>8</sup> Thus, there is a spectrum of behaviour that can be labelled as various forms of "euthanasia."

Recently, participants in debates about "bioethics" have devoted considerable attention to the similarities and differences between active voluntary euthanasia and "physician assisted suicide." In physician-assisted suicide, a physician provides a patient with the means of death, such as a drink containing a lethal substance, but takes steps to ensure that the patient performs the fatal act of administration. I consider the distinction between physician-assisted suicide and active voluntary euthanasia

morally specious. While there may be psychological and interpersonal differences between the provision of active voluntary euthanasia and physician-assisted suicide, I do not think that a meaningful moral line can be established between physician assisted suicide and active voluntary euthanasia. Dan Brock supports this view in his observation that in both instances,

the choice rests fully with the patient. In both the patient acts last in the sense of retaining the right to change his or her mind until the point at which the lethal process becomes irreversible. How could there be a substantial moral difference between the two based only on this small difference in the part played by the physician in the causal process resulting in death?<sup>9</sup>

Thus, I do not attempt to further refine Sneiderman's typology in this respect by introducing a moral distinction between physician assisted suicide and active voluntary euthanasia.

It is the limited subject of "active voluntary euthanasia" that I address, and that is currently being debated in medical, legal, philosophical, and theological communities. In contrast to "active euthanasia," passive euthanasia is well-established within medical care in Canada, the United States, and many other regions of the world.<sup>10</sup> While a literal reading of the Criminal Code of Canada could lead to an interpretation of the illegality of "passive voluntary and nonvoluntary euthanasia," physicians are not prosecuted for ceasing or withdrawing medical treatment when this is directed by the request of the patient, or by surrogate decision-makers such as family members when the

patient is incompetent and cannot make decisions.<sup>11</sup> Furthermore, "passive euthanasia," is widely supported in medical ethics and medical law, and is no longer a significant source of moral controversy.<sup>12</sup> In Canada, patients have an established right to insist that treatment cease, and the court system has declared that physicians must abide with this request.<sup>13</sup>

"Active nonvoluntary" and "active involuntary euthanasia" are not significant sources of moral controversy in Canada and the United States, because very few individuals think there is a legitimate justification for deliberately killing individuals in the absence of the considered request of the individual.<sup>14</sup>

In contrast, there is enormous controversy surrounding the subject of "active voluntary euthanasia."<sup>15</sup>

The contemporary debate revolves around the "right" to self-determination.<sup>16</sup> Current discussions involve debate as to whether the provision of active voluntary euthanasia can be considered an autonomous, morally acceptable act. Few scholars can be found to be arguing for forms of "active euthanasia" in cases where this capacity for reflection and self-determination is lacking at the time of the request for active voluntary euthanasia.<sup>17</sup> Admittedly, there exist important differences between those who would support the provision of an advanced directive allowing the performance of active voluntary euthanasia once the patient reaches a particular stage of illness, and those who would not allow an

advanced directive to represent the request of a now-incompetent patient. However, there appears to be a general consensus that a patient ought to be competent, reflective, and able to understand the consequences of choices at the time of the decision to request active voluntary euthanasia. I do not consider the moral issue of active euthanasia involving infants because they are never "autonomous," rational, or competent. We may wish to justify euthanasia in such cases on the basis of mercy, or beneficence, but we are no longer being guided by respect for autonomy.

Admittedly, it is conceivable that if "active voluntary euthanasia" for "autonomous" individuals is legalized, individuals lacking this capacity for choice may one day be killed by physicians. However much this possibility of a descent down a "slippery slope" may inform our current consideration of active voluntary euthanasia, the contemporary debate dwells to an overwhelming extent upon reflective, competent individuals aware of the consequences of their choices.<sup>18</sup> Therefore, I think it is important to enter the dialogue concerning active voluntary euthanasia aware of who are generally understood to be possible candidates for euthanasia.

In particular, the victims of state action to effect "racial hygiene" are not part of the discussion of active voluntary euthanasia. This must be recognized since the Nazi programmes of medical killing prior to and during the Second World War were labelled by their practitioners as

"euthanasia" policies.<sup>19</sup> In contemporary discussions within Great Britain, Australia, the United States, and Canada, the element of personal choice, which was absent for the victims of Nazi atrocities, is integral to discussions of active voluntary euthanasia.

Infants born with grave mental and physical handicaps are likewise excluded from this discussion of active voluntary euthanasia. Some writers have suggested that what they call "euthanasia" be performed upon such infants.<sup>20</sup> Because these individuals lack the capacity to make choices concerning medical treatment, they are obviously not capable of articulating their wishes, thoughts, or requests. Consequently, support for the performance of active euthanasia involving such infants is limited, since the ability to make conscious decisions is usually understood to be the most integral aspects of any request for euthanasia.<sup>21</sup> Although a full discussion of "euthanasia" incorporating nonvoluntary forms would consider the cases of such newly borns, my more limited exploration of the subject of active voluntary euthanasia does not examine the situation of "incompetent" infants. My normative analysis and public policy suggestions addresses active voluntary euthanasia insofar as this would pertain to competent individuals able to make choices for themselves. While many children could fall under the rubric of "competent," decisions concerning the newly born, of necessity, must be made by adults. I therefore do not address the moral issues surrounding moral

decisions that must be made for infants. A different set of issues needs to be explored in regard to active euthanasia as it pertains to infants. Although I eventually plan to explore the ethical issues surrounding this element of the euthanasia debate, I choose a more limited consideration of active voluntary euthanasia as it pertains to adults. Since this is one of the most significant social and moral issues being addressed today by theologians, ethicists, physicians, nurses, journalists, and members of the legal profession, it needs to be treated separately, at least to some degree, from related but distinct moral issues.

In the course of striving to understand the debate surrounding active voluntary euthanasia debate, through the exploration of theological, medical, and legal material, it became obvious to me that issues of interpretation are fundamental to the debate. The history of ethics in medicine, historical events, and even the medical treatment of specific individuals such as Nancy Cruzan and Janet Adkins are used by participants in the contemporary debate in distinct and sometimes contradictory ways to illustrate positions about whether or not euthanasia could ever be appropriate.<sup>22</sup> During the course of my research, I realized that interpretive contexts and processes would need to be explored. The subject of active voluntary euthanasia demands an appreciation of salient narratives, symbols, and cultural norms, as well as social relations, physician-patient interaction and health care delivery systems. These

constitutive elements of culture provide the resources and constraints for moral reflection.<sup>23</sup> How questions about euthanasia are posed, and which arguments and answers are deemed acceptable, depend upon a breadth of understanding which might be called "world-view," "narrative context," or "tradition." What these terms disclose is that genuine consideration of a subject as complex as active voluntary euthanasia requires an appreciation for the interpretive horizons involved in comprehending and constraining the very nature of human existence.

What makes the debate surrounding active voluntary euthanasia so intriguing, dramatic, and difficult to evaluate is that the symbols, images and forms of discourse which seem "natural" and "true" within some interpretive communities are irrelevant or inappropriate within others. Obviously, this creates enormous controversy since the subject of active voluntary euthanasia is not merely a philosophical idea or public policy issue, but, rather, is an issue that is perceived by current participants in the moral debate as reaching to the very roots of what it means to be a reflective and mortal organism. Consideration of the active voluntary euthanasia debate necessitates examining what it means to be human, what communal bonds should be found in caring communities, what it means to grow ill or aged, to suffer, and to die. In addition to confronting these terrifying existential issues, there is a range of more specific, mundane, practical matters such as a knowledge of

hospital care, pain management strategies, and varieties of disease and illness, that is integral to moral analysis.

Having completed over two years of research, I want to use the opportunity of writing a dissertation to clarify my own understanding of the active voluntary euthanasia debate, by critically responding to what I learned and read, and by integrating the various aspects of my research. I decided to call the dissertation "Understanding the Active Voluntary Euthanasia Debate" because although I think normative conclusions and public policy recommendations are important, I think it even more significant to place these moral evaluations and public policy proposals within the context of the formative cultural elements of the debate. Rather than choosing to dwell upon a specific topic within the debate, I attempt to address a variety of subjects through an exploration of the broad contours of the issue.

In chapter Two, following this present introductory chapter, I consider one end of a range of possible positions on the subject of active voluntary euthanasia by examining the normative stance of George and Sheila Grant, who represent a relatively conservative, traditional Christian stance to the issue.

I consider the essay by George and Sheila Grant, "The Language of Euthanasia," partly because of George Grant's status as one of Canada's most prominent moral philosophers, and also because of the sheer rhetorical power of the Grants' paper. As a thinker who considered not only the specific

ethical issues of euthanasia and abortion, but also the much larger horizons of the impact of technology and the liberal tradition on modernity, George Grant provides one significant voice that articulates an important facet of the debate. His writings deserve to be considered in the moral analysis of active voluntary euthanasia.

Consideration of the response of George and Sheila Grant to the subject of euthanasia reveals a body of convictions originating from a Christian theological context.<sup>24</sup> These Christian mores include an appreciation of the sanctity of all human life to God, and the meaningfulness of enduring suffering. Within this moral frame, the performance of active voluntary euthanasia under almost all circumstances is regarded as unacceptable. Humans, since their lives are gifts from God, should not choose suicide or euthanasia even in times of great agony, torment, or devastating illness. Values, such as the sanctity of human life, and the dignity of every individual, are regarded as non-negotiable. Furthermore, the whole ethos of Christian thought is understood by the Grants to be in opposition to the performance or toleration of active voluntary euthanasia. Human life is interpreted as inherently sacred, and not to be willfully ended by human decisions and behavior.

Of course, not all Christians agree with the interpretations of George and Sheila Grant. There is a spectrum of Christian views on euthanasia, and the Grants represent only one segment of that spectrum.<sup>25</sup> However,

without wanting to present an image of a monolithic Christian view on euthanasia, I think it fair to insist that Christian groups have played a major role in defeating legislative attempts at legalizing euthanasia wherever there have been attempts to alter the laws prohibiting active voluntary euthanasia. In Holland, and Washington and California in the United States, Christian groups were instrumental in challenging the attempts at legalization of active voluntary euthanasia. I think it important to understand why many Christians are so opposed to the legalization of euthanasia, and the article by George and Sheila Grant helps to illuminate the subject. Ultimately, even though I share many of the Grants' concerns about euthanasia, I do not accept all of their conclusions.

To gain a better appreciation of where "moral lines" ought to be established, I consider in chapters Three, Four, and Five, three related subjects that are crucial to the contemporary debate surrounding active voluntary euthanasia: the development of modern medicine and the growing mastery of the human body (Ch.3), the breakdown of religious traditions providing an interpretive context for suffering (Ch.4), and the development of individualism and increasing patient autonomy (Ch.5). These chapters will enable us to comprehend more fully the contemporary euthanasia debate in its complexity.

In Chapter Three, "Biomedical Developments and the Mastery of the Human Body," the development of the medical

sciences and their concomitant technologies are explored. This demonstrates the extent to which perception of human life has shifted from the realm of the "natural" and "God-given" to that of "manipulated" biological entities of scientific enquiry. As a result, choices concerning the origin, development, and prolongation of human life must now be made--choices that were inconceivable as long as matters were viewed under the older, much more static theological umbrella. In addition, the medical revolution which began in the latter half of the nineteenth century greatly enhanced the ability to intervene in biological processes. Thus, a paradigm shift involving the expanding powers of the medical profession has occurred in a context in which scientific rather than religious accounts of human nature have become increasingly predominant. Life and death now typically occur in modern technological societies in a hospital context with immense resources for the identification and manipulation of biological processes. Medical progress provides a serious impetus to reflection upon the ethical dimensions of the extent to which human life should be manipulated.

In particular, the technological capacities of contemporary medicine can prolong life while also undermining the quality of life. Hence, there is often a clash between the requests of patients concerned with the qualitative, experiential manner of their dying, and physicians' desires to employ the most effective medical procedures available to extend life. Since medical progress

occurred in a period when increasing power was acquired by patients over medical treatment, conscious, reflective, well-informed decision-making can scarcely be limited to the realm of medical personnel.<sup>26</sup> Furthermore, if we want to respect the interpretations, decisions, and autonomy of most individual patients, we need to foster this development. Therefore, there is a need for citizens to be aware of the medical scenario as it relates to the active voluntary euthanasia debate. Since the demand for euthanasia becomes particularly cogent in the context of the current medical situation, it seems vital that active voluntary euthanasia be discussed within a broader consideration of the development of medical sciences and technologies.

Another central topic of analysis is the subject of the secular interpretation of suffering predominant in contemporary North America and Europe. This issue is developed in Chapter Four, "Changing Attitudes Toward The Meaning of Suffering." Following the implicit and explicit critiques of the religious traditions which previously provided interpretive contexts for suffering, as offered by Freud, Darwin, Nietzsche, and Marx, meaningful social contexts for suffering have been undermined to a significant degree. Attitudinal changes toward suffering are evident not only in medical and philosophical discourse, but are also apparent in changing understandings of the practical administration of anaesthetics. Whereas there was a great debate during the nineteenth century which addressed whether

women experiencing childbirth ought to receive painkillers, contemporary theologians do not deplore the use of painkillers during childbirth.<sup>27</sup> Moral accounts which assume that pain serves a redemptive purpose and makes the sufferer a better person, or is deserved by the sufferer are likely to be ignored in communities which go to enormous lengths to eliminate the experience of suffering. Changing attitudes toward the experience of suffering are examined in order to demonstrate how this relates to the euthanasia debate. It seems plausible to suggest that active voluntary euthanasia has become increasingly imaginable because disease, illness, and suffering have become de-sacralized.

The final topic relevant to the social context of the debate to be explored is discussed in Chapter Five, "The Development of Individualism and The Rise of Patient Autonomy." Here, I examine the unfolding of individualism within the general social order as well as in physician-patient interaction. The rise of an increasing appreciation of personal autonomy is examined as a broad cultural shift with immense ramifications for the current controversies surrounding active voluntary euthanasia. There has been an historical shift in North America and Europe from the "paternalism" of church, state, and medical community which has resulted in the considerable transfer of power to the individual. Within the medical context, for example, competent patients are much more likely than in the past to be actively involved in treatment choices. Patients are no

longer shielded in a paternalistic fashion from threatening diagnoses and poor prognoses.

The development of individualism is often described as a decline in traditional mores in which the individual, rather than institutions and groups, becomes the primary repository of values.<sup>28</sup> While it is apparent that institutions once capable of exercising much greater control over individuals have indeed lost some of their power, it is equally obvious that such a process has its humane, beneficial elements.<sup>29</sup> Nonetheless, whether the development of individualism is understood as catastrophic, wonderful, or embodying the potential for both great benefits and dangers, there can be little doubt that the rise of individualism as the concern for personal autonomy has a direct bearing upon the current debate regarding euthanasia. This is particularly evident in the literature concerning active voluntary euthanasia produced in the United States, where the language of personal rights and freedoms is so prevalent.

In particular, the ascendancy of individualism is apparent in the modern physician-patient encounter. In recent years, physicians have lost some of their prestige and social status, and patients play an increasingly significant role in "medical" decisionmaking. "Informed consent" regulations established through court cases and the development of institutional and professional requirements ensure that patients are aware of their diagnoses, prognoses, and treatment options.

With an appreciation of one Christian position on euthanasia, and an awareness of the social and historical context of the debate, I think we can begin to consider public policy proposals for the legalization of active voluntary euthanasia under carefully controlled circumstances. In Chapter Six, "Proposition 161: The California Initiative," I evaluate a recent Act enabling active voluntary euthanasia that was defeated by a narrow margin in California last fall.<sup>30</sup> I was in California during the campaign, and I had an opportunity to follow the public debate surrounding the "physician aid in dying" initiative.

Even though I now support active voluntary euthanasia under certain circumstances, I do not support the Act, because of its lack of adequate procedural safeguards, its unreasonable requirement that the provision of active voluntary euthanasia be limited to those individuals with six months or less to live, and its failure to acknowledge the systemic shortcomings of the provision of health care in California. I consider these shortcomings in Chapter Six, and try to overcome them in my own examination of how active voluntary euthanasia might be provided without jeopardizing physician-patient relations or the proper care of ill individuals.

Finally, the interpretations and insights of the preceding chapters are gathered in a conclusion offered in Chapter Seven, "Understanding the Euthanasia Debate: Normative Analysis and Public Policy Implications." Insights

derived from the critique of the positions of George and Sheila Grant, as well as the chapters on the social, historical, cultural, and institutional context of the debate, followed by the analysis of the California Initiative, are integrated in order better to understand what might be a critical, reflective response to the current euthanasia debate at the level of public philosophy and public policy. I attempt to proceed beyond the interpretations and description of the preceding chapters toward a normative position cognizant of the social contours of the debate and a public policy proposal that provides guidelines for the tentative introduction of carefully restricted, active voluntary euthanasia.

<sup>1</sup>Renato Rosaldo, Culture and Truth: The Remaking of Social Analysis, (Boston: Beacon Press, 1989): 9.

<sup>2</sup>Ibid., 12-15.

<sup>3</sup>Sean Fine, "Rodriguez decision reserved by court," The Globe and Mail, (Friday, May 21, 1993): A1.

<sup>4</sup>John Paul II, "Euthanasia: Declaration of the Sacred Congregation for the Doctrine of the Faith," The Pope Speaks 25, (Winter 1980): 289-296. In, Stephen E. Lammers, Allen Verhey, (Eds.), On Moral Medicine: Theological Perspectives on Medical Ethics, (Grand Rapids: Michigan: William B. Eerdmans Publishing Company, 1987): 442.

<sup>5</sup>Ludovic Kennedy, Euthanasia: The Good Death (London: Chatto & Windus, 1990): 7.

<sup>6</sup>Barney Sneiderman, John C. Irvine, Philip H. Osborne, Canadian Medical Law (Toronto: Carswell, 1989): 225.

<sup>7</sup>Ibid., 227.

<sup>8</sup>Dr. Bruce Zawacki, Head of the Burn Unit at Los Angeles County Medical Centre and a faculty member of the School of Religion at the University of Southern California first brought the significance of this distinction to my attention.

<sup>9</sup>Dan Brock, "Voluntary Active Euthanasia," Hastings Center Report (March-April 1992): 10.

<sup>10</sup>Barney Sneiderman, John C. Irvine, Philip H. Osborne, Canadian Medical Law (Toronto: Carswell, 1989): 228-229.

<sup>11</sup>Ibid., 228

<sup>12</sup>Working Paper 28: Euthanasia, Aiding Suicide and Cessation of Treatment, (Ottawa: Law Reform Commission of Canada, 1982): 29.

<sup>13</sup>Ibid., 55-57.

<sup>14</sup>Douglas M. Sawyer, John R. Williams, Frederick Lowy, "Canadian Physicians and Euthanasia: Definitions and Distinctions," Canadian Medical Association Journal 148, 9 (1993): 1464.

<sup>15</sup>Dan Brock, "Voluntary Active Euthanasia," Hastings Center Report, (March-April 1992): 10.

<sup>16</sup>Leon R. Kass, "Is There a Right to Die?" Hastings Center Report (January-February 1993): 34.

<sup>17</sup>Franklin G. Miller and John C. Fletcher, "The Case for Legalized Euthanasia," Perspectives in Biology and Medicine 36, 2 (Winter 1993): 169-170.

<sup>18</sup>Ibid., 170.

<sup>19</sup>Robert J. Lifton, The Nazi Doctors: Medical Killing and the Psychology of Genocide (New York: Basic Books, 1986): 45-52.

<sup>20</sup>Helga Kuhse and Peter Singer, Should the Baby Live? (New York: Oxford University Press, 1985): .

<sup>21</sup>Jean Davies, "Raping and making love are different concepts. So are Killing and Voluntary Euthanasia," Journal of Medical Ethics 14, (1988): 148-149.

<sup>22</sup>Robert M. Baird and Stuart E. Rosenbaum, Euthanasia: The Moral Issues. (Buffalo, New York: Prometheus Books, 1989): 23-34.

<sup>23</sup>Renee C. Fox and Judith P. Swazey, "Medical Morality is Not Bioethics--Medical Ethics in China and the United States," Perspectives in Biology and Medicine 27, 3, (Spring 1984): 338.

<sup>24</sup>George and Sheila Grant, "The Language of Euthanasia," in George Grant, Technology and Justice, (Toronto: Anansi, 1986): 103-115.

<sup>25</sup>Courtney S. Campbell, "Religious Ethics and Active Euthanasia in a Pluralistic Society," Kennedy Institute of Ethics Journal 2,3 (1992): 253-277.

<sup>26</sup>David J. Rothman, Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making (New York: Basic Books, Inc., 1991): 1-2.

<sup>27</sup>W. Bruce Fye, "Active Euthanasia: An Historical Survey of its Conceptual Origins and Introduction Into Medical Thought," Bulletin of the History of Medicine 52, 4 (Winter 1978): 497-498.

<sup>28</sup>Robert N. Bellah, Richard Madsen, William M. Sullivan, Ann Swidler, and Steven M. Tipton, Habits of the Heart: Individualism and Commitment in American Life, (New York: Harper & Row, 1985): 142-143.

<sup>29</sup>Ibid., 142.

<sup>30</sup>The California Death With Dignity Act. Californians Against Human Suffering.

## CHAPTER TWO

## EUTHANASIA: A CHRISTIAN PERSPECTIVE

Although it would be misleading to represent all Christians as opposed to euthanasia, it is accurate to claim that many Christian communities and organizations maintain a very active role in opposing current demands for changes in legal and social policy regarding euthanasia.<sup>1</sup> To their credit, numerous Christian theologians and moral philosophers have played a significant part in calling attention to the difficulties associated with legalizing even the most carefully qualified form of active voluntary euthanasia. However, many Christians have failed to grapple with the pluralistic, multicultural, technologically oriented world in which all discussions of active voluntary euthanasia occur. To illustrate some of the characteristics, both beneficial and detrimental, of Christian reflection upon euthanasia, I examine "The Language of Euthanasia" by George and Sheila Grant.

George and Sheila Grant articulate a linguistic and interpretive understanding of euthanasia which informs and is informed by, Christian theology. They incorporate into their discussion of euthanasia broad issues such as the very nature of human embodiment, the limitations which ought to constrain the "right" to self-determination, and the meaning of personal suffering. "The Language of Euthanasia," is a powerful exposition that outlines one Christian response to

the euthanasia debate. The essay by George and Sheila Grant is particularly significant because George Grant, perhaps more than any other Canadian thinker, has attempted to grasp both the rise of liberal thought and the development of technology as the fundamental expressions of modernity.<sup>2</sup> Though his explicit discussion of euthanasia is brief, the subject is one germane to most of his published work. Therefore, given the depth of George Grant's thought and the Grants' general willingness as Christians and critical philosophers to address the most integral aspects of modern secular, technological life, their essay is examined in detail before proceeding in the next chapter to an exploration of the impact of biomedicine upon the active voluntary euthanasia debate.

Despite numerous shortcomings, the Grants' essay "The Language of Euthanasia," in George Grant's, Technology and Justice, is an eloquent, seminal contribution to the growing dialogue which constitutes the Canadian context of the euthanasia debate.<sup>3</sup> Although euthanasia has only recently begun to garner the Canadian popular media's attention in the manner of abortion, the Supreme Court Case of Sue Rodriguez, the publication of a Canadian Law Reform Commission paper on euthanasia, aiding suicide and cessation of treatment in 1983, and the numerous international signs suggesting that euthanasia is a topic of increasing concern, all suggest that this is an issue demanding reflective, responsible analysis.<sup>4</sup> Though the Grants' theological rhetoric and strong emphasis

upon traditional Christian themes is unlikely to garner their essay a large, receptive audience in a society where religious institutions, symbols, and languages have lost much of their previous potency, their critique of the contemporary turn to euthanasia serves as an antidote to more cavalier perspectives upon such an agonizing, significant subject. Without wholly endorsing the Grants' assumptions, arguments, or conclusions, I think it is possible to gain insight into the topic of euthanasia through analysis of their essay.

Euthanasia is a topic where it can seem as though the meaning of virtually every word is contested and manipulated by the various "interests" groups and political activists. The rhetoric of euthanasia, then, cannot be taken for granted. The words required for critical reflection must themselves be scrutinized with attentive care. Because the Grants are preoccupied with the discourse of euthanasia, particularly the changing meanings that alter the significance of words, it is appropriate to begin with their understanding of the term, "euthanasia." When traced to its roots, they observe, euthanasia means "a good death."<sup>5</sup> Currently, however, euthanasia carries a much broader connotation, though its earlier meaning has not entirely disappeared. Grant states:

The current meaning of the word is 'deliberate intervention to bring about the death of another human being, usually because the life of that person is judged valueless.'<sup>6</sup>

Clearly, such an understanding of the term bears little in

common with proponents of active voluntary euthanasia who support their cause not because they regard some lives as without value, but, rather because they feel that individuals ought to be able to decide for themselves when they wish their lives to end.

For George and Sheila Grant, euthanasia does not include

the refusal to initiate or continue life-supporting treatments such as respirators, on those who are already in the process of dying.<sup>7</sup>

Unlike some commentators, the Grants do not label such behavior as "passive euthanasia," a term which can, if used carelessly, create confusion about what is at issue. Likewise, the Grants assert, euthanasia is not being practised when painkillers are administered, since such medication may "have the side effect of somewhat hastening death, but are given to alleviate pain."<sup>8</sup> The removal of life support equipment and the use of pain-killing drugs can both result in a hastened death for the patient. According to the Grants, the morality of such behavior depends upon the broad medical context. If the individual is already dying, and wishes to have life-prolonging technologies removed, such measures are quite appropriate, and constitute just, ethical behavior. The cause of death remains the underlying illness and cannot be attributed to the actions of physicians. Should other motives exist, such as the economic one of "cost-containment" in a context where the individual is not dying of a particular illness that can be claimed to be the

cause of death, then euthanasia is being committed and the act should be recognized, labelled and condemned as such.

While the administration of a lethal injection is distinct from acts such as the cessation of treatment insofar as an injection unequivocally plays a direct role in causing death, the distinction between dis-continuation of treatment and the administration of injections is a source of controversy in the medical ethics literature on active voluntary euthanasia. What the Grants affirm is that euthanasia is not simply an act, such as the removal of life-prolonging equipment, but involves the element of intent.<sup>9</sup> If a patient is dying, and technological implements are removed with the recognition that they can only prolong dying, then euthanasia is not performed.<sup>10</sup> If the patient is not dying, and the removal of equipment is done with some motive other than that of allowing the dying process to occur as "naturally" as possible, then euthanasia is performed. Clearly, however, the Grants state that merely allowing a disease to take its course when a patient is in the process of dying is not euthanasia.<sup>11</sup>

A vocabulary exists to describe distinctions that I regard as germane to the debate, yet the Grants insist that such terms only serve to confuse the subject of euthanasia. They state,

The sacredness of human life becomes overlaid in the muddle as to what euthanasia is and is not. The old distinction about euthanasia, direct and indirect, active and passive, also obscure more than they illuminate.<sup>12</sup>

The argument is made by philosopher James Rachels, that there

is no moral difference between "active," "direct" euthanasia such as the intentional administration of a lethal injection, and "indirect," "passive" euthanasia in which the death of the patient is not directly caused but has been accompanied by measures such as the removal of life-prolonging devices.<sup>13</sup> What the Grants oppose is the labelling of such behavior as "passive" or "indirect" euthanasia. By using these terms to describe forms of "euthanasia," the Grants hold that it becomes possible to ease the introduction of intentionally caused euthanasia, by making it seem as though some form of "euthanasia" already exists.<sup>14</sup> The Grants seem to reject the application of the term "passive euthanasia" to these acts as well as other qualifying phrases, because they are concerned that such phrases ease the slide down a moral slippery slope.

Unlike the Grants, I find the qualificatory words surrounding euthanasia are quite helpful. Terms such as "active" and "passive," "direct" and "indirect" are not simply used as clever forms of rhetoric intended to blind citizens from pressing moral issues. However, I admit that I share Grants concern that if the unqualified term "euthanasia" is used to refer to forms of behavior which do not involve the intended, deliberate attempt to cause death, but is associated with commonly accepted forms of treatment cessation and withdrawal, there is some danger of an uncritical descent down the slippery slope. The Grants' style of discourse challenges my support of Sneiderman's

typology by questioning the use of the term "passive euthanasia" to describe the cessation and withdrawal of treatment. I think "passive euthanasia is a helpful phrase, as long as we recognize that the form of "euthanasia" currently practised is distinguishable from what we mean by "active voluntary euthanasia." According to the Grants,

If the public rightly disapproves of the abuse of technology on the dying, yet wrongly identifies euthanasia with letting the dying die, then our attitude to euthanasia inevitably becomes more positive.<sup>15</sup>

It is this illicit confusion over the meaning of euthanasia that the Grants seek to dispel. The Grants want to restrict the meaning of the term "euthanasia" to include only those actions which directly cause death. For them, the intentional administration of nothing but sedatives, water, and glucose to the newly born are examples of euthanasia because even in the absence of an underlying illness, such behaviour must eventually result in death. Forms of euthanasia may also be administered to those persons "who for reasons of age, incurable disease, coma, or potential brain damage have a life expectation of very low quality."<sup>16</sup> In such cases, the Grants assert, "methods of omission are likely to be used rather than lethal injection."<sup>17</sup> It is not just a deliberate act such as the administration of an injection which causes the behavior to fall under the rubric of euthanasia for the Grants. Rather, the moral intent of the actions or omissions must be considered. Increasingly, the Grants insist, patients are not simply allowed to die in

a manner where life-prolonging technologies are restrained rather than fully implemented, but are killed in deliberate fashion through less obviously intentional, yet nonetheless causal means based upon presumptions concerning determination of the quality of life.

Yet, the Grants fail to think completely enough--fail to reflect upon the actual human and medical situation. Though unethical decisions regarding cessation of medical treatment based upon quality of life decisions likely occurs in some neonatal and geriatric units, the Grants example of Down's Syndrome infants as common recipients of euthanasia fails to reflect the severity of disorders to be found in neonatal intensive care units. Insofar as the Grants grapple with quality of life issues, they fail to address the subject of just, human medical care in the most agonizing cases. Unfortunately, this is a common shortcoming of theologians and ethicists unwilling to entertain any decisions based on "quality of life." I think it fair to raise the issue as to whether many of these individuals are aware of the magnitude of pointless suffering caused by some physical and neurological disorders.

The most important aspect of the contemporary debate over euthanasia that the Grants do not consider in sufficient detail is what I describe as "active voluntary euthanasia." With regard to this topic, the Grants assume, as proponents and opponents of active euthanasia often do, that the presence of pain is a crucial motivating factor

initiating the request for active euthanasia. However, the Grants provide little more than the platitude that such pain ought to be relieved. They state:

Most doctors would presumably try to put a patient out of his misery, not by killing him, but by relieving his pain and fear, which may be all he actually wants. There have been no requests for euthanasia at hospices and palliative care units.<sup>18</sup>

However, certain forms of illness are accompanied by suffering that cannot be altogether controlled through "pain management." As even a cursory study of the material endorsing voluntary euthanasia reveals, the presence of intolerable suffering is a prominent reason for the consideration of active voluntary euthanasia.<sup>19</sup> Even the most competent physicians in hospices and palliative care units cannot entirely relieve all of the suffering of dying even if much of the physical pain cause by the disease or injury can be controlled.<sup>20</sup>

What I find most disturbing about the Grants' remarks is their assumption that requests for active voluntary euthanasia have not come from hospices and palliative care units. Even in these settings, there are occasional requests for active voluntary euthanasia.<sup>21</sup> Not only are there recorded requests, but, given the secrecy with which the medical profession has traditionally cloaked the subject of euthanasia, it is tempting to speculate upon the number of instances in which active voluntary euthanasia has been requested and either ignored, or addressed with medications and instructions about excessive dosages. Furthermore, even

the most advanced palliative care units cannot altogether relieve "suffering." While "pain" may sometimes be controlled through analgesics, and various forms of treatment can help to control diarrhoea, nausea, and other experiences of dying patients, suffering, as a holistic psychological, interpersonal, and existential experience cannot always be controlled or eradicated. While I do not argue that the first response to suffering should be active voluntary euthanasia, I do think the Grants belittle the experience of suffering of many individuals.

Having dealt in a cursory fashion with active voluntary euthanasia, which is the real source of debate today, the Grants' develop the brunt of their essay against involuntary forms of euthanasia that are imposed upon an individual rather than requested as a matter of personal choice. In doing so, the Grants avoid the less easily assailable arguments for the legalization of a qualified, carefully restricted form of active voluntary euthanasia. This is very unfortunate, because the existence of texts such as George Grant's English Speaking Justice, and "Thinking About Technology," demonstrate the resources possessed by the Grants for responding to the complex challenge of the development of the understanding of the autonomous self and the ascent of the technological paradigm in modernity.<sup>22</sup> Although the active voluntary euthanasia debate has continued since the Grants published their paper, the issues have not changed to such a degree that their lack of

exploration of the issue of active voluntary euthanasia can be dismissed.

Crucial to understanding the Grants' position on euthanasia is their conviction that there has been a collapse of traditional religious values which once acted to curtail the performance of euthanasia. The Grants begin their essay by asserting:

During the last decade there has arisen on this continent a new threat to the traditional account of life and death. Some forms of mercy killing have become acceptable to the public conscience, and there is pressure for these to be widely extended.<sup>23</sup>

The Grants emphasize this notion later in their paper stating:

the sacred restraints which once protected the life of the weak and the unwanted have now substantially broken down.<sup>24</sup>

According to the Grants' interpretation of historical processes, there has been a decline in the appreciation for the sanctity of life and a corresponding increase in the practise of, and societal desire for, "mercy killing."

Undoubtedly, the Grants are quite accurate in their analysis that the Christian values which once played a central role in the establishment of public policy in Europe and North America are no longer as pervasive as has historically been the case. Nonetheless, it would be most interesting if current rates of infant mortality could be compared with similar recorded rates from previous eras more respectful of Christian theology. Rather than placing the golden age of "ethical" medical care in some nebulous, albeit

religious, past, it might be more prudent to recognize that agonizing questions about moral medical care have arisen not exclusively due to the decline of Christian patterns of morality, but because of significant developments in medical care. It has only recently become possible to enable individuals with previously deadly infirmities to survive their illnesses due to anti-biotics, for example, and it has thereby become necessary to reflect upon whether all such individuals ought to be the recipients of everything that medical practise and technology can offer. Recognition of the effect the progressive development of biomedicine has had upon the euthanasia debate helps to reveal that it is not simply a case of the disintegration of societal mores through processes of secularization. Rather, it seems plausible that questions of "quality of life" have arisen to a considerable degree due to medical advances which can enable an infant to survive premature birth, but at the price of lifelong suffering.

In what can only be construed as a simplistic rendering of the history of medical practices, the Grants write:

Under the older medical ethics of the Hippocratic oath, gravely defective infants were treated, like other patients, according to a policy of medical indications alone. They were helped if it was possible. If treatment could not help their condition, they were made comfortable and allowed, but not forced, to die.<sup>25</sup>

Now, however, with the vast transformations undergone by medical treatments, settings, and professionals, there is almost always some form of treatment available. In some cases, for example, "fetal surgery," is possible before

birth. Should medical practitioners invariably act to preserve and prolong life, through the performance of invasive procedures even before the infant is born? It is not surprising that "quality of life" decisions, however agonizing, have become a subject of intense ethical reflection. Nor is this development merely due to the "rise of individualism." Indeed, the theologian's choice of that as the principal or only cause reflects her professions and her limitations.

Although the Grants inappropriately ignore the involvement of the extraordinary developments in biomedicine and biotechnology in rendering complexity to ethical issues, their comments concerning the collapse of a once significant theological language of the care of the "soul," rather than the "self" or the "body," illustrate the extent to which religious traditions have lost much of their transformative language and power. Undeniably, the Grants manage to reveal the extent to which this historical development has informed the contemporary euthanasia debate. Too often, the decline in the use of Christian language and symbols is not sufficiently recognized for its transformative impact upon modern society. Secularizing processes involve far more than the eradication of school prayers, and the opening of stores on Sunday. The Grants are right in suggesting that the processes of secularization involve fundamental alterations in the way members of our culture understand human nature. The briefest glance at a modern text about molecular biology,

biochemistry, or genetics will reveal that what constitutes knowledge in the modern university curriculum is very distinct from what used to constitute knowledge in a less secularized, more biblically oriented, society. Hence, while the Grants idealize a past with a much more static, homogenous account of human nature when Christian accounts of suffering and dying received fewer challenges from other moral traditions, and belittle the influence of the development of biomedicine as a causal force in the generation of modern ethical issues, the Grants do recognize a crucial factor in the transformations which have resulted in a society increasingly uncertain of a cohesive moral stance concerning the moral medical care of human life.

While questions of the "quality of life" frequently enter the euthanasia debate, the Grants, as supporters of a Christian theological stance on euthanasia are opposed to such considerations wherever they involve the deliberate termination of human life. A primary target of their criticisms is Joseph Fletcher and his emphasis upon indicators of humanhood.

Fletcher relies upon intellectual ability of a certain minimal level as a crucial criterion for distinguishing between "persons" and "non-persons."<sup>26</sup> The Grants perceive a danger in equating intelligence with personhood and thereby deciding upon issues of care and treatment. As is often the case with those opposed to euthanasia, the Grants invoke the spectre of the Nazi "euthanasia" program. They affirm:

This identification of cleverness with 'personhood' must also have obvious social implications in terms of the era we are living in. It should not be forgotten that the country which had the highest rate of literacy and the most advanced educational system in the world was Germany. Yet Germany produced the Hitlerian regime of total war and genocide. Indeed euthanasia was carried out because of the belief that certain human beings were "non-persons."<sup>27</sup>

The obvious implication is that an emphasis upon intellect as an arbiter of personhood can have the most horrifying impact upon whoever is deemed to lack personhood. While an insistence upon intellect, taken to extremes, could have terrible consequences for social policy, it is difficult to avoid the issue entirely given the current use of brain-death as a criterion for the death of the human. There have to be some qualities which distinguish the living body from the corpse. However, the Grants are not referring to tests of electrical activity in the brain, but to examinations of "sufficient" intelligence. They fear that such tests could be used to kill selectively certain citizens:

If the soul can be measured and its value to God determined by an I.Q. test, does this not give society the right to rid itself not only of the retarded, but also of the useless aged? From there it is a small step to the permanently ill and then beyond that to the non-conformists and beyond that to the politically dissident.<sup>28</sup>

The Grants argue that a slide down the "slippery slope" will occur if intelligence tests are used to determine the value of human life. Those who consider degrees of intellectual capacity as a means of sanctioning the state supported killing of citizens are grouped together with Hitler, Nietzsche, and Hoche and Binding, authors of the infamous

text, The Release of the Destruction of Life Devoid of Value.<sup>29</sup> This outright condemnation of any involvement of the state in the selective eradication of its citizens is not surprising, given the Grants' affirmation of the infinite value of the human soul. Though I think that there are circumstances where physicians should accommodate requests for active voluntary euthanasia, I share an element of their fear of the consequences of the sanctioning of active voluntary euthanasia. However, unlike the Grants, I am not convinced that a carefully restricted policy allowing the performance of active voluntary euthanasia must lead, in an inevitable fashion, down the "slippery slope."

Is it invariably heinous to consider "quality of life" as an issue in determining medical treatment? Cannot such judgements be made with a measure of responsibility? If so, who should serve as decision-maker? The Grants would seem to suggest that no such moral judgements should ever be made:

Decisions for euthanasia based on 'quality of life' assumes that we are in a position to judge when someone else's life is not worth living. There is absolutely no evidence that the handicapped or the retarded would prefer to be dead. How do we compare an imperfect or restricted life with no life at all?<sup>30</sup>

The Grants insist that humans are not in a position ever to assess the ultimate value of another human being's life. Though I affirm the Grants' respect for human life and their concern for the potential dangers that can exist in any considerations of quality of life, I think it important to realize that by trying to present the euthanasia debate as if it involved only decision-making by some regarding the

killing of others, the central aspect of the contemporary dialogue is ignored. The "politically dissident," "non-conformists," and others are not subject to state-sponsored programs of "euthanasia" in North America. Though such individuals were state target of destruction in Nazi Germany, there are few individuals who would equate current systems of medical care, state control, or professional medical ethics with the situation which existed in the totalitarian state of Nazi Germany. Hence, while the Grants manage to address the question of how horrible social programs of euthanasia could be, they do little to address the morality of the subject of active voluntary euthanasia at the top of the slippery slope. By presenting "euthanasia" policies taken to their ultimate extreme, the Grants fail to respond with care to the pressing question as to why individuals who request euthanasia for themselves should be refused, given the careful establishment of procedural safeguards which would exist to limit the possibilities of abuse discussed by the Grants.

Most supporters of euthanasia restrict their current arguments on behalf of social changes in social policy and medical care to active voluntary euthanasia. Although it is conceivable that some of these individuals may possess a covert agenda more expansive than their demands for active voluntary euthanasia would suggest, I think that their stated arguments ought to be addressed without taking recourse solely in the imagined possibilities of abuse.

The subject of patient autonomy, of course, is at the

core of this issue. Though the rationale of a "right to choose" which ends in the cessation of all choices can and should be questioned, there is no doubt that the notion of active voluntary euthanasia has gained much support in Europe and North America for excellent reasons. First, the judgement of the patient results in self-annihilation and not the death of another person. If, as it is so often asserted, it is individualism and its language of individual "rights" which has reached its apotheosis in modernity, then the "right" of a person to cease to live in instances where the quality of life is diminished, is as fundamental as any other right. One humane benefit of this libertarian tradition of personal autonomy is that it is also possible to perceive the increasing involvement of patients in determining their own "medical care" in the demand for the decriminalization of active voluntary euthanasia. Just as patients are now told of their illnesses and may even self-administer certain analgesics, an increased emphasis upon the right of personal autonomy for patients could result in a scenario where patients develop legitimate control over the time of their death. Finally, if, as the Grants emphasize, secularization processes are germane to the current debate surrounding euthanasia, it may be that the presence of suffering provides sufficient reasons for demanding active voluntary euthanasia. In a time when suffering is no longer interpreted by most individuals as the "will of God," or the necessary product of the fallen, sinful nature of humanity, there ceases to be

theological justification for the endurance of suffering, however the Grants might wish that it not be so. Are all the consequences of the secular process to be thought deplorable?

In any case, if, as I suggest, changing interpretations of pain, illness, disease and suffering are integral to understanding the active voluntary euthanasia debate, then there is likely to be dwindling support for the Grants' treatment of the experience of suffering. They describe the former situation:

Most of us have forgotten our true status. We do not have complete control of ourselves, we are not independent of others, at birth and death we are helpless, and never at any time are we autonomous (the maker of our own laws). In much modern theology about death, it seems to have been forgotten that we are creatures, dependent on God's love, and not simply our own masters. Autonomy is far from Gethsemane, and man is never more supremely dignified than when he manages, with whatever agony, to say with Christ: "Not my will but thine be done."<sup>31</sup>

Far from Gethsemane, as we are, inevitably, it is common practise not only to increase control at the boundaries of life, but also to experience suffering shorn of any "sacred" connotations. It is not difficult to discern why those individuals whose beliefs are not informed by Christian theology perceive active voluntary euthanasia as a means of avoiding some of the agony of dying. And the question must be raised, also, whether Christian theology is capable of responding to the new situation as though it were not simply an evil as the Grants present it.<sup>32</sup>

The conflict that exists between the conflicting interpretive frames of some forms of Christian theology and

the liberal, secular perspective advocating personal autonomy become even more evident when other contributions to the dialogue in active voluntary euthanasia from various Christian scholars and communities are explored. Many of the strengths and shortcomings of the Grants' essay are also apparent in other Christian evaluations of euthanasia.<sup>33</sup> While it would be grossly inaccurate to pretend that there is one monolithic "Christian" perspective on active voluntary euthanasia, many Christian groups have condemned the practice of active voluntary euthanasia.<sup>34</sup>

Although Christian doctrine concerning the sanctity of life bears many parallels to both the professional ethical codes of physicians, and the Criminal Codes of many European and North American nations, the Christian framework is distinctive insofar as the argument against euthanasia proceeds upon grounds foreign to non-theological contexts. Outside of a theological framework, it makes little sense to oppose euthanasia through recourse to divine law, "God's plan," or any conception of human nature which claims that human life is a gift from God. In a secularized, pluralistic society, it is very difficult to develop social policy based upon such claims since there is no guarantee that the necessary presuppositions will be commonly shared by community members. Those social policies which do rely upon Christian theological justifications become increasingly open to criticism if not outright dismissal wherever processes of secularization have occurred. In particular, Christian

attitudes toward suffering--which play an important role in the Christian theological rejection of euthanasia--are unlikely to receive a sympathetic ear in the larger community which does not celebrate suffering as a meaningful, deserved experience.

As European and North American societies grow increasingly secularized, Christian communities have difficulty maintaining their hold upon the establishment and preservation of general public policy. As frustrating as this may seem to members of Christian theological communities, individuals working within a non-theological framework are scarcely likely to be supportive of conclusions such as the inappropriate nature of euthanasia when the arguments against active voluntary euthanasia rely upon presuppositions they do not hold to be valid accounts of human nature. Therefore, it seems likely that those Christian communities which continue to support the convictions expressed in "The Language of Euthanasia," are going to be faced with arguments on behalf of the performance of active voluntary euthanasia which will not be willing to recognize some of the basic constraints placed upon moral action and reflection by Christian theology.

Finally, if Christian theologians and moral philosophers want to continue to participate in the debate surrounding active voluntary euthanasia, they are going to have to grapple with the central issues of active voluntary euthanasia, rather than deploring involuntary euthanasia,

which is not a focus of the current debate. Although the Grants, like many Christian participants in the debate appropriately capture the possible dangers related to any involvement of the state in providing for the killing of its citizens, they bypass the main issue of the contemporary dialogue by paying insufficient attention to the subject of active voluntary euthanasia.

<sup>1</sup>Rob Carson, "Washington's I-119," Hastings Center Report 22/2 (March-April, 1992): 7.

<sup>2</sup>George Grant, English-Speaking Justice (Toronto: Anansi, 1974).

<sup>3</sup>George and Sheila Grant, "The Language of Euthanasia," in George Grant, Technology and Justice (Toronto: Anansi, 1986): 103-115.

<sup>4</sup>Report 20: Euthanasia, Aiding Suicide and Cessation of Treatment (Ottawa: Law Reform Commission of Canada, 1983).

<sup>5</sup>George Grant, "The Language of Euthanasia," in George Grant, Technology and Justice (Toronto: Anansi, 1986): 104.

<sup>6</sup>Ibid., 104.

<sup>7</sup>Ibid., 104.

<sup>8</sup>Ibid., 104.

<sup>9</sup>Ibid., 106.

<sup>10</sup>Ibid., 106.

<sup>11</sup>Ibid., 104.

<sup>12</sup>Ibid., 105.

<sup>13</sup>James Rachels, "Active and Passive Euthanasia," The New England Journal of Medicine 292/2 (January 9, 1975): 78-80.

<sup>14</sup>George and Sheila Grant, "The Language of Euthanasia," in George Grant, Technology and Justice (Toronto: Anansi, 1986): 105.

<sup>15</sup>Ibid., 105.

<sup>16</sup>Ibid., 107.

<sup>17</sup>Ibid., 106.

<sup>18</sup>Ibid., 105-106.

<sup>19</sup>For example, see the statement prepared by Gerald A. Larue, "The Case for Active Voluntary Euthanasia" in Euthanasia: The Social Issues, ed. Robert M. Baird and Stuart E. Rosenbaum (New York: Prometheus Books, 1989): 159-161.

<sup>20</sup>Timothy Quill, Christine Cassell, Diane Meier, "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide," The New England Journal of Medicine 5, (1992): 1380.

<sup>21</sup>For one example of a patient in a hospice who did request euthanasia, see Anthony M. Smith, "Recent Ethical Statements on Euthanasia: a Physician's Perspective," in Death Without Dignity: Euthanasia in Perspective, ed. Nigel M. de S. Cameron (Edinburgh: Rutherford House Books, 1990): 149-162. See also, Stephanie Cote, "Death By Choice," American Journal of Nursing 91, 7 (June 1991): 32-34.

<sup>22</sup>George Grant, English Speaking Justice (Toronto: Anansi, 1974). See also, George Grant, "Thinking About Technology," in George Grant, Technology and Justice (Toronto: Anansi, 1986): 11-34.

<sup>23</sup>George and Sheila Grant, "The Language of Euthanasia," in George Grant, Technology and Justice (Toronto: Anansi, 1986): 103.

<sup>24</sup>Ibid., 108.

<sup>25</sup>Ibid., 108.

<sup>26</sup>Ibid., 110.

<sup>27</sup>Ibid., 111.

<sup>28</sup>Ibid., 112.

<sup>29</sup>Ibid., 113.

<sup>30</sup>Ibid., 115.

<sup>31</sup>Ibid., 113.

<sup>32</sup>For example, see the discussion of assisted suicide as an expression of mercy in Mark A. Duntley, Jr., "Covenantal Ethics and Care for The Dying," Christian Century 108, 35, (December 4, 1991): 1135-1137.

<sup>33</sup>For example, See "Always to Care, Never to Kill," The Wall Street Journal, (November 27, 1991): 1.

<sup>34</sup>Courtney S. Campbell, "Religious Ethics and Active Euthanasia in a Pluralistic Society," Kennedy Institute of Ethics Journal 2,3 (1992): 258-263.

## CHAPTER THREE

## BIOMEDICAL DEVELOPMENTS AND THE MASTERY OF THE HUMAN BODY

The complexity of the contemporary debate surrounding active voluntary euthanasia is ignored if the increasing interest in the establishment of a social policy supporting a qualified form of euthanasia surrounded by safeguards is attributed solely to a decline in traditional religious or specifically Christian theological values. Though secularization processes undeniably affect the subject of active voluntary euthanasia, the remarkable technological developments within the medical sciences constitute a significant aspect of the social context in which the debate proceeds. The incredible transformations in the practice of biomedicine, understood as the modern cultural system engaged in the systemic, scientific, empirically oriented pursuit of health, must also be recognized because they, too, help to provide a "frame" for the euthanasia debate.<sup>1</sup> The terrain of "the natural", and "unalterable" is increasingly replaced by the measurable and manipulable as the assorted health sciences combine to achieve a remarkable degree of power over the human body.<sup>2</sup> In a social context where the scientific dimensions of medicine have achieved unprecedented power, moral reflection in the form of conscious decision-making becomes unavoidable because decisions must be made in situations previously outside the realm of significant human intervention.<sup>3</sup> Consequently, it becomes imperative for

patients, physicians, nurses, lawmakers, and other citizens to decide not merely what can be done in the technological preservation of human life, but to what degree medical technology and procedures ought to be utilized. This transformation of medical care clearly distinguishes the current social context of the euthanasia debates from previous cultural milieus in which the absence of significant medical power over the human body created different parameters for ethical reflection.<sup>4</sup> With the ascendancy of medicine as a discipline of control over the body, other extraordinarily difficult questions of restraint and constraint begin to arise. For example, should parents be allowed to select the gender of their children? Should corporations be allowed access to the medical records of prospective employees to screen from consideration for employment those individuals with potential genetic disorders? To what degree should new reproductive technologies be allowed to alter more traditional methods of child-bearing? Should useful tissues and body organs be removed from anencephalic infants or aborted "fetuses" and "installed" in "wanted" children and adults? Ought animals such as baboons and pigs be used for cross-species organ transplants? These, and many other pressing questions are not simply a product of the decline of religious and moral traditions previously placing constraints on human thought, motivation, and action. Instead, they are also products of the increasing power of biomedicine over the human organism.<sup>5</sup>

The significance of this medical transformation may be lost if it is simplistically noted that arguments on behalf of forms of euthanasia existed prior to the development of modern medicine. The remarkable ability of current medical practitioners to provide reasonably accurate diagnoses and prognoses is based upon historical developments in medicine that alter how the case on behalf of active voluntary euthanasia can be presented. Therefore, a serious consideration of the contemporary debate concerning euthanasia must recognize these changes, and explore their impact upon the active voluntary euthanasia issue.

What I found particularly startling to discover in my exploration of the history of medicine, was that almost every strand which winds into the fabric of contemporary medicine is less than two hundred years old.<sup>6</sup> Most of the medical procedures, specialties, and technologies that form the backdrop of contemporary medical practice developed either in this century, or in the latter part of the nineteenth century. For example, the sciences of bacteriology, histology, and pathological anatomy, which form such a seemingly obvious element of medical knowledge, only entered the education of physicians in North America in 1871, at Harvard Medical School.<sup>7</sup>

One psychiatrist and ethicist, Jan Hendrik van den Berg, in Medical Power and Medical Ethics, insists that the history of Western medicine can be divided into three main periods.<sup>8</sup> The first epoch was a lengthy period of medical powerlessness

which extended "from primeval times until 1870."<sup>9</sup> The second medical era was a time of "transition from technical powerlessness to technical power."<sup>10</sup> This period proceeded from 1870, when Pasteur demonstrated that micro-organisms cause infection, Koch shortly thereafter, in 1882, discovered the tuberculosis bacillus, and many other pioneering developments in medicine occurred, until the 1960's, when the fields of genetics, biochemistry, and molecular biology began to provide radically innovative resources for medical scientists. The final historical division, which includes the years following the 1960's, is the most recent period of "medico-technical power."<sup>11</sup> During this stage, medical power increased at an incredible rate, particularly due to discoveries concerning the genetic mechanisms of life. Increased knowledge of the molecular structure of deoxyribonucleic acid, or DNA, and RNA, protein synthesis, cell formation and structure and numerous other subjects enabled the human organism to be understood and manipulated to an unprecedented degree at the levels of organ systems, tissues, cells, and genes. The most recent fruits of this development are becoming discernable in gene therapy and provide incredible resources for the future treatment of human diseases.

Although narratives of progress can be viewed with justifiable suspicion, I find it difficult to avoid discerning a general tale of progressive development with regard to the history of medicine.<sup>12</sup> There is perhaps no

other human endeavor which has so quickly and effectively transformed the "natural" into the "manipulable" and thereby gained considerable powers of control. A few specific examples of this historical process may serve as illustration.

Not until 1865 did the surgeon Joseph Lister recognize that carbolic spray could be used to cleanse equipment, environment, and wounds, of infectious organisms, and thereby reduce the likelihood of postoperative death due to infection of the surgical area.<sup>13</sup> Shortly after, asepsis, in which instruments were sterilized, was developed.<sup>14</sup> Prior to this, surgical procedures always carried immense danger even for what are now regarded as relatively minor injuries. Today, surgery is not only far safer than prior to the development of sterilization techniques, but can sometimes be replaced by far less invasive measures.

Similarly, prior to the nineteenth century, surgical anaesthesia often consisted of nothing more than the poorly regulated stupor provided by alcoholic substances. It was only in 1800 that Humphry Davy recognized the anaesthetic capacities of nitrous oxide and suggested that it might be used in surgical procedures.<sup>15</sup> By 1842, ether narcosis was used as a surgical anaesthesia for a tooth extraction.<sup>16</sup> Acetylsalicylic acid, a product to which all those individuals using aspirin are indebted, was first used in medical practice only in 1899.<sup>17</sup> Finally, it was only in the twentieth century that the fields of anaesthesiology, and

pharmacology, based upon increased awareness of how chemical substances act within and upon the body, truly became scientific medical specialties.

The history of radiology is also very brief. The first roentogram taken for medical purposes was developed in 1896.<sup>19</sup> One hundred years later, the "X-ray machine" is used around the world and serves as but one diagnostic device amongst many that can reveal detailed internal structures of the human body. It is tempting to overlook the recent development of biomedicine and take for granted its enormous effects upon contemporary society. Today, sitting in an emergency room with a fractured arm, for example, it is difficult not to assume that pain will be effectively relieved with "painkillers" administered in appropriate dosages, "X-rays" will reveal the exact location and nature of the fracture, and surgery, should it prove necessary, will be an inconvenience, but not a reasonably likely cause of death due to hemorrhaging or post-operative infection. It is only through travel to regions lacking modern medical care, isolation from the large urban centers that can be found throughout Europe and North America, or study of the history of medicine, that the cloak of security provided for many individuals by advanced medical care can be properly appreciated. Just as the car, airplane, radio, and television set have transformed transportation, communication, and the physical environment, advances in medical sciences have altered conceptions of illness,

disease, and treatment. While it may now seem almost a natural "right" that competent medical care should form a backdrop for all our activities, it should not be forgotten that home births and deaths, physicians travelling on horseback from one small community to another, deaths due to tuberculosis, cholera, and influenza, and medical compassion with only very limited medical capabilities are not historically remote in even the most industrially advanced urban regions. Indeed, nostalgia such as that expressed by Ivan Illich in his classic attack on modern medicine, Medical Nemesis, for a period prior to that of the development of biomedicine, demonstrates little more than intellectual apathy.<sup>19</sup> Such nostalgia fails as well to recognize just how much modern medicine has done to alleviate some of the suffering of life's most traumatic events.

This shift in medical powers has not occurred in an institutional or cultural vacuum. Closely tied to the development of modern biomedicine is the rise of the hospital as a social institution. The medical specialties, support staff, technological equipment, and educational facilities are brought together in the form of the hospital. Notwithstanding all of the criticisms that have recently been directed at modern hospital care, few wish to abolish these massive centres of technological power. The development of healthcare within the structure of the hospital has resulted in extraordinary powers of detection and regulation. Within the contemporary hospital there now

exists a site dedicated to the observation, regulation, and manipulation of the human body. Indeed, developing a concept of Michel Foucault, the modern hospital may be considered as a "panopticon".<sup>20</sup> This means that the hospital is a location for "all-seeing." This capacity for observation, regulation, and manipulation is the driving ethos, the ingrained goal of current institutionalized medical "systems."

Historically, it was the prison which was imagined and designed by social reformer Jeremy Bentham as a panopticon in order to observe the behavior of prison inmates.<sup>21</sup> However, notwithstanding the very limited privacy that is afforded by the modern prison environment, it is the contemporary hospital that undeniably serves as penultimate panoptic site. In the prison, cameras, guards, recording devices and other surveillance systems do still maintain a vigilant watch. However, the quality and quantity of the observing devices in the prison provide no match for the myriad investigative modes of the hospital. It is in the hospital that the human eye can proceed everywhere--into the uterus, down the respiratory system, and around the internal organs. The entire body of the patient becomes subject to the roving "eye" of medicine.<sup>22</sup> In obstetrics, for example, there develops a "panoptics of the womb" which revises conceptions of the human organism.<sup>23</sup> As Michael Harrison states, The fetus could not be taken seriously as long as he remained a medical recluse in an opaque womb; and it was not until the last half of this century that the prying eye of the ultrasonogram...rendered the once opaque womb transparent, stripping the veil of mystery from the dark inner sanctum and letting the light of scientific observation fall on the shy

and secretive fetus...The sonographic voyeur, spying on the unwary fetus, finds him or her a surprisingly active little creature, and not at all the passive parasite we had imagined.<sup>24</sup>

Whether it is the unaided eye, or the eye assisted by "X-rays," the electron microscope, laparoscope, cardiograms, or Magnetic Resonance Imaging devices, the human body is open for inspection. Scarcely hindered by the skin, once a protective, opaque envelope torn only by wounds, surgery, and dissection, and which served to render the body opaque, the interior of the body is now unveiled. The hidden becomes transparent, observed, even while within an embodied being, and mores cannot but be altered by the newly available image of the human organism.

Notwithstanding the ideals behind modern health care, the hospital as panoptic site raises some very problematic issues. The "eye" of modern medicine not only reaches everywhere into the body, sometimes detecting disease before the felt experience of illness, but proliferates, creating eyes watching eyes. Modern medical care with its penchant for observation is itself under incredible scrutiny due to processes of bureaucratization and professionalization. Charts, records, medical histories, test results, and prescriptions for medications all carefully document the course of medical care. Medical decision-making is scrutinized by health-care teams, mortality and morbidity conferences, hospital ethics committees, wary patients and family members, and, sometimes, legal institutions. This

means that the dying patient within a hospital context cannot simply request a medication or medical procedure to hasten dying and assume that such an act will remain a hidden, private matter. The various checks and safeguards currently in place to regulate institutionalized medical care mean that such an act cannot easily occur unnoticed. Indeed, I find it tempting to consider the possibility that one reason why euthanasia has become such an issue today is because whereas physicians in the past could easily hasten death without the knowledge of their peers, and without even knowing with certainty themselves whether their actions had accelerated the process of dying, the regulatory process has become so entrenched that occasional exceptions to general rules can no longer escape scrutiny. The control mechanisms within the medical system significantly constrain the possibility of private compacts between only patient and physician and mean that if active voluntary euthanasia is to exist within highly regulated institutionalized medical care, it too must be regulated and institutionalized.

As the ancient hospice able to provide little more than palliative care, rest, and perhaps sustenance, the forerunners of the hospital provided little source for ethical debate. The modern hospital bears little resemblance to its historical antecedents. In that modern giant conglomerate, in which all medical specialties, technologies, laboratory facilities, are combined to inscribe medical progress onto the flesh of living patients, ethical issues

arise precisely because of the extent of the perception and manipulability of the human body. Furthermore, the religious organizations which previously provided hospice care are not entirely replaced, but have only a limited sphere of provenance, providing further testimony to the development of the hospital from religious sanctuary to secular establishment.

The current enterprise of medical mastery over the human body within the hospital setting, however beneficial it may be, is sustained by the almost unbridled will to master human biological nature. This process is clearly recognized and articulated by George Grant, who was influenced by Martin Heidegger's account of technology in modernity. In his essay, "Thinking About Technology", Grant, observes that

The new adage of rulers and educators is that to the mastery of non-human nature must now be added mastery of ourselves. The desire for 'mastery of ourselves' (which generally means the mastery of other people) results in the proliferation of new arts and sciences directed toward human control so that we can be shaped to live consonantly with the demands of mass society. These can be seen applied through the computerised bureaucracies of the private and public corporations, through mass education, medicine, and the media etc. Many scientists are now, above all, planners and central members of the ruling class. The proliferating power of the medical profession illustrates our drive to new technologies of human nature. This expanding power has generally been developed by people concerned with human betterment.<sup>25</sup>

A number of insights are available in this brief nugget. First, according to Grant, medicine, as with other disciplines, works within an intellectual context that

perceives immense humanistic value in the mastery of nature. This mode of enquiry has come to include human nature. For example, in contrast to the mores of historically antecedent Christian and Jewish communities, autopsies may be performed, surgery may be performed upon the head and heart, fertilization may occur in vitro, and other previously unacceptable manipulations of the human body may be performed. The acceptability of these manipulative actions is widely recognized in contemporary society. In addition, the quest for the mastery of the human genetic code is viewed as a benevolent and humanitarian just mode of inquiry. I think that the Grants' analysis of the impulse toward the "rational" mastery of humans as biological organisms as well as their observation of the concomitant assumption that such a task is accorded tremendous respect and social status in contemporary society is quite accurate.

If this is so, then two conclusions can be reached. First, contemporary moral dilemmas involving medical care are not going to disappear but will have to be critically addressed in all their complexity. Second, we have only begun to face the challenges that are a result of the medical aspects of the drive to master "nature."

The relationship of the development of biomedicine to the subject of active voluntary euthanasia is very significant. It is impossible to grasp the nuances of the subject without realizing the extent to which transformations in biomedicine have played a role in generating the debate

over euthanasia. Probably the greatest impact the development of biomedicine has had upon the euthanasia debate is in the extension of human life. When one thinks of death today, it is the aged, not the newly-born who come to mind. Neonates born with various defects can now have their ailments surgically repaired, when these same disorders would have only recently caused inevitable death. Premature babies can be sustained in neonatal units pushing the period of the "viability" of life further towards conception. Because of all that can be done to preserve the lives of newly-borns with serious complications, it becomes necessary to reflect upon issues of quality of life. Which babies should be surgically treated? What will be their best and worst prospects? Who will be capable of caring for them? While these questions can bespeak an era of moral turpitude, they also reflect a technologically sophisticated medical scenario that, because of its very nature, demands choices concerning the moral application of medical practises. If the medical profession does not extend every available means of support to preserve life, does it, through inaction, perform what some would describe as a variety of "euthanasia?" These questions are a product of a medical science more capable of intervention than ever before. With a powerless medical profession these issues would not arise since neonates would simply die without there being even the possibility of medical intercession.

Such questions continue to arise in other hospital

wards. Medical control over the human organism extends throughout the lifespan. "Brain-dead" patients can have their organ systems biologically sustained to facilitate organ donation. Hospitals are not regarded as guilty of performing euthanasia when such technological devices are then withdrawn after the organs have been removed. However, the issue becomes more complex in cases of activity manifested only in the "lower" parts of the brain. When very accurate electrical recordings can be made to determine the brain's status, it becomes necessary to address the issue of what constitutes "being alive".

Finally, there is the central theme of patient demand for active voluntary euthanasia. Such a demand can be partially comprehended as a response to the current status of the medical sciences as capable of providing significant but only partial control over the human organism. In the space between complete control and utter powerlessness, significant moral questions arise.

Most individuals will know of friends and family members, or be familiar with cases publicized by various media about individuals with degenerative neural illnesses. Such individuals, aware that they will suffer loss of memory, motor skills, even what could be regarded as the loss of their "personality", may request active voluntary euthanasia prior to, or once they begin to suffer the more serious effects of their illness. Conversely, there are those with a healthy mind, "personality" intact, but quadraplegic and

unable even to breath without technological assistance. In either case, whether the brain degenerates before the rest of the body, or the body becomes a prison for the mind, medical technology can often preserve and sustain some form of life. With contemporary medical diagnosis and prognosis, it is sometimes, though not always, possible for such patients to have a well-defined picture of just how their "medical development" will proceed. It is scarcely startling that in such agonizing contexts there is sometimes a demand for active voluntary euthanasia. Some patients may be unwilling to continue living but are physically incapable of ending their own lives. Without all of the medical technology and procedures available to enable such conditions to continue for long periods following accurate diagnosis and prognosis, it would be surprising if there was anything approaching the interest in active voluntary euthanasia which exists today.

Given the current status of medical care, with the medical profession and many sectors of the larger community quite aware of its manipulative abilities, and the consequences of those resources of the medical professions, there is increasing willingness to consider the previously unacceptable practice of some limited form of active voluntary euthanasia as public policy. W. Bruce Fye, in his paper, "Active Euthanasia: An Historical Survey of Its Conceptual Origins and Introduction Into Medical Thought," notes that there is a limited historical period, from approximately the nineteenth century onwards in which the

concept of active euthanasia could even come to seem reasonable. He states,

Only when a patient's condition could be judged incurable with reasonable accuracy would it be feasible to propose a concept as radical as "active" euthanasia.<sup>26</sup>

With the historical development of biomedicine, a stage has been reached in which such judgements can be made with reasonable accuracy in some situations. The ability to diagnose disease and provide prognoses before the actual experience of the most debilitating aspects of illness has created a context where there is deserved consideration of active voluntary euthanasia. The ability of modern medical practitioners to prolong life but not altogether regulate illness, suffering and dying has, for some, heightened the need for the establishment of a social policy which would allow provision for active voluntary euthanasia.<sup>27</sup>

For example, the woman who first used Jack Kevorkian's "suicide machine" was Janet Adkins, who was diagnosed by her neurologist as suffering from Alzheimer's disease.<sup>28</sup> Rather than accepting the loss of memory and disintegration of mental faculties which accompany the disease, Adkins decided to avoid this fate by utilizing Kevorkian's machine. While many patients and their families have no doubt been equally distressed by their medical prognosis, Adkins' case is unusual because Kevorkian was willing to offer a relatively painless means of euthanasia to a woman who was not "his" patient, provide his machine some time before Adkins would begin to suffer the most

devastating consequences of her disease, and reveal his actions. Subsequent public discussion of the issue has revealed that other medical professionals, while more reticent than Kevorkian about such incidents, have performed active voluntary euthanasia.<sup>29</sup>

Given that medical professionals are likely to further refine their capacity for accurate diagnosis and prognosis, the possibility that such scenarios in which the patient seeks to avoid a relatively certain medical prognosis suggesting the likelihood of unrelievable suffering, will become increasingly common. Because restricted drugs available only to physicians can provide for deliberate deaths less painful, prolonged, and sometimes miscalculated than those attempted by non-physicians, it is scarcely startling that there is a growing demand for physicians to utilize their professional powers and medical knowledge of the human body by assisting in the deliberate deaths of some patients.<sup>30</sup>

Most adults know how agonizing the final period of some illnesses can be, and the establishment of a social policy enabling active voluntary euthanasia could provide some control over suffering. In lieu of complete control over the preservation of the health of the human organism, the performance of active voluntary euthanasia by medical practitioners could provide an infrequent but occasionally utilized means of avoiding unrelievable suffering.

The current context in which prognoses and diagnoses can be somewhat reliably established means that there now exists a medical setting for the experience of illness where it is unsurprising that active voluntary euthanasia is a considered option for many individuals. When patients can become aware of the probable course of their illness some time before the most serious consequences of illness and disease take their greatest effect, it is an appropriate time to have a public debate on a social policy and a reformulation of medical care and legal restrictions that could accomodate the provision of active voluntary euthanasia.

<sup>1</sup>For a discussion of the ethos of biomedicine, see Lorna Amaraingham Rhodes, "Studying biomedicine as a Cultural System" in Medical Anthropology: Contemporary Theory and Method ed., Thomas M. Johnson and Carolyn F. Sargent (New York: Praeger, 1990): 159-173.

<sup>2</sup>George Grant, "Thinking about Technology," in Technology and Justice (Toronto: Anansi, 1986): 16.

<sup>3</sup>Norbert Wiener, God and Golem, Inc.: A Comment on Certain Points Where Cybernetics Impinges on Religion (Cambridge, MA: The M.I.T. Press, 1964): 66-69.

<sup>4</sup>W. Bruce Fye, "Active Euthanasia: An Historical Survey of its Conceptual Origins and Introduction into Medical Thought," Bulletin of the History of Medicine 52/4 (Winter 1978): 496.

<sup>5</sup>Bartha Maria Knoppers, Human Dignity and Genetic Heritage, (Ottawa: Law Reform Commission of Canada, 1991): 1.

<sup>6</sup>Michel Foucault, The Birth of The Clinic: An Archaeology of Medical Perception (New York: Pantheon Books, 1973): 146.

<sup>7</sup>Jon Wesley Boyd, "The Place of Science in medical education," The Pharos 154/2 (Spring 1991): 7.

<sup>8</sup>Jan Hendrik van den Berg, Medical Power and Medical Ethics (New York: W. W. Norton and Co., 1978): 24.

<sup>9</sup>Ibid., 24

<sup>10</sup>Ibid., 24.

<sup>11</sup>Ibid., 24.

<sup>12</sup>Lewis Thomas, The Youngest Science: Notes of a Medicine Watcher (New York: Bantam Books, 1983): 33-34.

<sup>13</sup>Cecil Helman, Body Myths (London: Chatto & Windus, 1991): 142.

<sup>14</sup>Ibid., 142.

<sup>15</sup>Norman A. Bergman, "Humphry Davy's Contribution to the Introduction of Anesthesia: A New Perspective," Perspectives in Biology and Medicine 34/4 (Winter 1991): 534.

<sup>16</sup>Daniel De Moulin, "A Historical Phenomenological Study of Bodily Pain in Western Man," Bulletin of the History of Medicine 48/4 (Winter 1974): 544.

<sup>17</sup>Ibid., 541.

<sup>18</sup>Cecil Helman, Body Myths (London: Chatto & Windus, 1991): 140.

<sup>19</sup>Ivan Illich, Medical Nemesis: The Expropriation of Health, (New York: Random House, 1976): 3.

<sup>20</sup>Michel Foucault, Discipline and Punish: The Birth of the Prison (New York: Vintage Books, 1979): 195-228.

<sup>21</sup>Ibid., 200.

<sup>22</sup>Michel Foucault, The Birth of the Clinic: An Archaeology of Medical Perception (New York: Pantheon Books, 1973): 89.

<sup>23</sup>Rosalind Pollack Petchesky, "Fetal Images: The Power of Visual Culture in the Politics of Reproduction," Feminist Studies 13/2 (Summer 1987): 277.

<sup>24</sup>Michael R. Harrison et al., "Management of the Fetus with a Correctable Congenital Defect," Journal of the American Medical Association 246 (1981): 774.

<sup>25</sup>George Grant, "Thinking About Technology," in Technology and Justice (Toronto: Anansi, 1986): 16.

<sup>26</sup>W. Bruce Fye, "Active Euthanasia: An Historical Survey of its Conceptual Origins and Introduction into Medical Thought," Bulletin of the History of Medicine 52/4 (Winter 1978): 496.

<sup>27</sup>Margaret Murphy, "Reflection," Active Euthanasia, Religion, and the Public Debate (Chicago: The Park Ridge Center, 1991): 94-95.

<sup>28</sup>Jack Kevorkian, Prescription Medicide: The Goodness of Planned Death (Buffalo, New York: Prometheus Books, 1991): 221.

<sup>29</sup>B.D. Colen "Death on Request," Hastings Center Report (March-April 1992): 12.

<sup>30</sup>Frederick R. Abrams, "Physician Participation in Assisted Suicide," Journal of the American Medical Association 263, 91, (March 2, 1990): 1197-1198.

## CHAPTER FOUR

## CHANGING ATTITUDES TOWARD THE MEANING OF SUFFERING

While the tremendous impact of the very recent development of biomedicine has transformed the issue of active voluntary euthanasia, it is also important to recognize other social and historical processes which weave into the euthanasia debate. In particular, changing attitudes toward the experience of suffering make the performance of active voluntary euthanasia more comprehensible than it once seemed within a less secularized context.

A primary characteristic of modern biomedicine is the predominating ethos of the mitigation of suffering through therapeutic intervention.<sup>1</sup> This amelioristic attitude toward suffering may be contrasted with cultural attitudes that existed in responses to illness and suffering occurring within religious theodicies.<sup>2</sup> The current refusal to accept the suffering of dying and disease processes may even be comprehended as a revolt against one significant strand of the Christian theological tradition.<sup>3</sup> Processes of secularization in which religious traditions have lost much of their cohesiveness and strength have affected the active voluntary euthanasia debate by making the platitude that individual and collective suffering is always a part of God's order or plan virtually impossible to maintain.<sup>4</sup> Consequently, to better comprehend the current active

voluntary euthanasia debate, the subject of changing attitudes towards suffering needs to be incorporated into our analysis.

While there exist many studies of the historical and social meaning of suffering from anthropological, behavioral sciences, historical, theological, and psychiatric perspectives, there does not seem to have been a consistent, sustained attempt to relate studies concerning suffering to the euthanasia debate. Yet, the social construction of suffering needs to be explored, further to enhance our understanding of modern attitudes toward active voluntary euthanasia. It is unlikely that an informed response to the euthanasia debate can be fashioned without serious consideration of the changing cultural context of this dimension of the debate.

In contemporary North American and European culture, there are few occasions for any "positive" evaluation of the experience of suffering.<sup>5</sup> In particular, medical practitioners commonly assume that suffering is an aspect of human embodiment to be avoided and even conquered through "pain management."<sup>6</sup> This attitude of medical caregivers toward pain and suffering is captured in a segment of a poem read by S. Weir Mitchell, an American neurologist of the nineteenth century. Speaking on the fiftieth anniversary of Ether Day, the date of the first application of ether in pain control at Massachusetts General Hospital, Mitchell recited:

Whatever triumphs still shall hold the mind,  
Whatever gift shall yet enrich mankind,  
Ah! here no hour shall strike through all the years,  
No hour as sweet as when hope, doubt, and fears,  
'Mid deepening stillness, watched one eager brain,  
With Godlike will, decree the Death of Pain.<sup>7</sup>

With no coherent grounds for allowing the experience of suffering, biomedicine, as the most potent means of defence against suffering, is granted the task in modernity of vanquishing suffering.

Furthermore, other disciplines which regulate the body and inform the experience of embodied life, such as contemporary punitive systems in industrialized nations, have eliminated most forms of corporal punishment.<sup>8</sup> Only special circumstances, such as times of state warfare, or occasions of self-defence provide sufficient state-sanctioned justification for the deliberate infliction of pain on another individual. In addition, when one person causes another person to suffer, punishment is supposed to be provided by the state rather than the victim. The modern nation-state assumes responsibility for determining the appropriate nature of punishment or treatment, and fines and incarceration have taken the place of more corporeal forms of punishment in most Western nations. Serious transgressions of cultural mores that require us not to inflict pain upon others are responded to with penalties, incarceration, and even capital punishment in those American states which allow such a punishment. However, state-regulated punishment overtly tries to avoid the deliberate infliction of pain even

in cases of state-sanctioned executions through the provision of what is assumed to be the most painless form of execution available. Hence, murderers convicted of the most gruesome crimes are not likewise disposed of, but are given lethal treatments which are not supposed to prolong the agony of suffering. While prison sentences and death penalties do cause tremendous suffering, contemporary society has displaced the more explicit forms of state retribution from the public square to the confined, concealed prison chamber.<sup>9</sup>

While it may currently seem axiomatic that humans would avoid the experience of suffering, protect society members from suffering, and inflict pain only under exceptional circumstances, this attitude toward suffering is socially and historically constructed.<sup>10</sup> This aspect of modern life developed in such a way as to provide no place for the experience of suffering. The issue can be explored through the consideration of several subjects.

First, the historical pacification of sport provides traces of the development of contemporary attitudes toward violence and suffering. According to sociologists Norbert Elias and Eric Dunning, modern sporting events are relatively free of violence and the infliction of pain compared to their historical antecedents.<sup>11</sup> Even the more violent contemporary sports such as football, rugby, and boxing, where fractures, sprains, and various contusions are common do not match the brutality of their historical precursors.<sup>12</sup> Rules developed and enforced by athletic organizations ensure that certain

forms of conduct likely to cause injury are not permitted. Furthermore, equipment exists in contact sports such as hockey and football to protect the modern athlete from pain and injury. Referees and video replays help to ensure that violence is meticulously regulated and occurs only within delineated rules of conduct. When the modern athlete is injured, a bevy of individuals who have come to be affiliated with athletic organizations can provide some form of therapeutic treatment. Even amateur teams have athletic trainers, physiotherapists, perhaps even a team physician to reduce the likelihood of injuries and alleviate suffering. Although it would seem that the world of contact sports has come to serve as the institutional choice for the modern-day ascetic, the experience of suffering is supposed to be a by-product of the quest for victory, or reaching high plateaus of achievement. While sporting activities provide localized interpretive frameworks for understanding some forms of pain and injury, they do not provide an overarching nomos for the larger society.

Nowadays, contact sports occupy almost the only realm in modern society where violent acts and the infliction of pain retain a degree of social acceptability. In other social spheres, rules of conduct and law exist to protect individuals from assault, injury, and the infliction of pain. These norms apply even to criminals who have broken such social mores. North American and Western European legal institutions do not inflict most forms of corporal punishment

upon prisoners of the state in retribution for criminal behavior.<sup>13</sup> Floggings, which in the region of what is now the nation of Canada could be inflicted by Hudson's Bay Company officers upon insubordinate labourers, are no longer regarded as appropriate forms of punishment in the military, corporate, or penal spheres. The amputation of digits and limbs as a form of punishment, still practised in some penal institutions around the world, is regarded by modern Europeans and North Americans with horror.<sup>14</sup> Where capital punishment, once nearly abolished in North America, is still performed, it is not to the enthusiastic clamor of large enthusiastic crowds gathered in the town square ready for a tableau of state-sponsored agony.<sup>15</sup> The means of death is prepared without an attempt to prolong the experience of agony.

In educational institutions, corporal punishment has lost widespread approval as an appropriate means of regulating the conduct of students.<sup>16</sup> This is a fairly recent shift in the use of power within educational institutions, and I can remember "the Strap" still being used while I was a junior high student. Similarly, despite the lament of specialists in ritual studies for the loss of adolescent rites of initiation, there has been no movement in educational reform for the incorporation of "transformative" rites that mark changes in human development around the world into the modern school system.<sup>17</sup> In many respects, our current prohibition of such rites of transition is stranger

than the rites themselves, since the infliction of suffering played such a significant role in marking transitions in social status. For example, Alan Morinis, a research anthropologist at the University of British Columbia is so enamoured of rites involving the experience of suffering that he glowingly affirms:

Its unique effects recommend pain for the important role it plays in consummating the psychic and social change that the rite of passage is intended to induce.<sup>18</sup>

Nonetheless, notwithstanding the transformative power of painful rites of bodily scarification, clitoridectomy, teeth filing, the subincision of the penis, the removal of finger digits, the binding of feet, and the establishment of permanent burn marks, or flesh wounds to mark changes in individual and social status, these activities are usually viewed with extreme disapproval in modern Europe and North America.<sup>19</sup> Other rituals also associated with rites of passage such as flagellation, extreme asceticism in the form of refusal of nutritive sustenance, the wearing of crowns of thorns, the creation of stigmata through various means of bodily mutilation--all forms of human behaviour recorded by ethnographers and students of anthropology, religion, and ritual--are not a part of modern phenomenon in Europe and North America although they remain elements of religious traditions in some communities.<sup>20</sup> Indeed, such behavior in some social contexts is bound to practices understood by ritual participants to elevate perception to a higher, more genuine understanding of existence. In his analysis of

rituals of pain, Morinis asserts:

All ascetic religious traditions have based their practices of mutilation, flagellation, and self-abuse on the observation that experiences such as these result in spiritual development and wisdom, that is, keener perception of the nature of self and reality. ...Pain serves to initiate the subject into a reality that remains closed to those who remain in innocence.<sup>21</sup>

While these remarks may do justice to the ethnographic record, they do not seem to provide a plausible platform for the regeneration of concepts of status demarcation through the deliberate infliction of pain. Notwithstanding the seeming admiration of the ritual infliction of pain Morinis displays in his idiosyncratic article, it seems implausible that the deliberate infliction of pain is likely to be perceived as an appropriate modern catalyst and symbol of change in the "stages" of life within contemporary societies. These culturally constructed narratives of suffering inhere within larger nomic structures that have not survived the transition to post-modernity with the concomitant collapse of overarching meta-narratives.

While rituals of suffering and manifestations of violent behavior may be admired by those who view other times or cultures with the rosy lenses of romantic nostalgia, or the gaze of those in search of "enlightenment," the sheer banality of their claims when matched against the suffering of those forced to undergo such rituals provide a clear antidote for those who wish for more visible means of marking the changes from child to adolescent, or adolescent to adult. Such markers are very visible, and require the endurance of

extreme suffering.<sup>22</sup> And yet, to do justice to the research of Morinis, it is true that they often form a vital part of the social life of some communities and such rites are viewed as "pathological" only from within our own culturally constructed attitudes toward suffering.<sup>23</sup>

Though the question as to the extent to which secularization processes contributed to the cultural decline of pain-filled ritual experiences is fascinating, it is more important to observe that regardless of how these traditions have failed to inform contemporary life, there can be little doubt that they are largely anthropological exotica removed from the daily life of those citizens from areas of Europe and North America where the experience of suffering is currently under consideration as providing a legitimate justification for the performance of active voluntary euthanasia. Whether or not isolated individuals lament the absence of rituals of pain and desire the restoration of these religious rites, there is no widespread interest in the restoration of the more painful displays of human ritual that were recorded around the globe. Most of the more painful aspects of ritualized social life do not constitute significant elements of European or North American social behavior.

The disappearance of corporal punishment from schools, the eradication of physical punishment as a state-sanctioned response to criminal activities, the regulation of violence and aggressive behavior in even the most brutal of sports,

and the loss of rituals promulgating the experience of pain and suffering, all provide traces of the current cultural construction of suffering because of the collapse of narratives that could justify such experiences, or at least render them more comprehensible. For example, Roman Catholics may be called, as Pope John II declares, to participate through their own suffering in the suffering of "Christ", but Christian churches in North America and Europe do not sponsor the seemingly pain-filled rituals that form a part of religious worship in other parts of the world.<sup>24</sup>

The implications of this socially and historically constructed interpretation of the meaninglessness of suffering permeate every sphere of social life. In particular, this understanding of the nature of suffering significantly informs modern attitudes towards health, disease, and dying.

In modern secularized societies, there is little meaning for most individuals in enduring a process of dying filled with suffering. Non-Christians, perhaps many Christians as well, do not find their suffering to be a means of participating in "God's plan." Fatalistic narratives of justifiable suffering constructed about biblical interpretations of the Adam and Eve stories have lost much of their efficacy. To an increasing degree, the notion that disease, illness, or injury is a just consequence of a righteous God has fallen into disfavour. The theological language of personal and collective sin fails to justify

experiences of suffering. Similarly, with AIDS as a notable exception, most diseases have ceased to be widely regarded as divinely decreed plagues thrust upon the "sinner" by a righteous and just deity.<sup>25</sup>

The language of biomedicine concerning illness and suffering has greatly eclipsed theological accounts of the proper place of suffering.<sup>26</sup> In contrast to the experience in secularized modernity of meaningless suffering, the Christian tradition historically maintained an understanding of the purposefulness of suffering. Courtney Campbell, in "Plague, Piety, and Policy," insists:

Plague and pestilence have repeatedly been understood in Christian tradition as punishments from God for human sinfulness. Such a theological interpretation, which was especially compelling before medical science identified more precisely the natural mechanisms for disease transmission, reflects the tradition's strong affirmation of ultimate divine sovereignty. The words of Camus' priest, Paneloux, to his congregation, are surely representative of many a sermon in time of plague: 'Calamity has come on you my brethren, and my brethren, you deserved it'....A chronicler of Pope Gregory I, who assumed the papacy in 590 during a plague, relates the following account: Gregory 'preached a sermon...declaring the plague to be a punishment from God and calling upon the people to do penance and repent of their sins. He ordered them to pray and sing psalms for three days, and at the end of that time arranged for a massive city-wide litany.'<sup>27</sup>

Likewise, Campbell observes,

In the smallpox epidemics that ravaged England and Europe in the seventeenth and eighteenth centuries, inoculation was criticized and opposed as an impious interference with providential judgment and was believed to assist the further spread of the disease.<sup>28</sup>

This Christian theological understanding of suffering and disease which serves to justify the role of God in administering pestilence, disease, and agony to a wayward,

sinful Christian community was not limited to "religious radicals," but rather had a decisive influence upon public policy. Theodicies of suffering were not marginal voices relegated to the sphere of private morality incapable of affecting the public realm, but actually informed social policies. Campbell notes,

Since sinful conduct had brought down the judgment of God, what was now needed in the view of many was penance and the commitment and devotion to a moral life. At the least, it was held, the moral renewal including abstention from food, might forestall even harsher measures of divine justice. In 1349, the town council of the French city of Tournai put this belief into legal force. Men and women living together without benefit of marriage were ordered either to marry or to end their relationship, and swearing, dice games, and labor on the Sabbath were prohibited.<sup>29</sup>

Herzlich and Pierret, in Illness and Self in Society, also explore the significance of Christian narratives of suffering. They suggest,

Throughout the ages, we can discern the influence of the Christian conception of suffering in diaries, letters, memoirs, and even novels. The sick considered and defined themselves as sinners from the outset; they had no doubt that they were being punished for their sins.<sup>30</sup>

Suffering was understood by Christians to be a product of both personal sin and the general sinfulness of humanity. For example, Pascal, in "Prayer for Making Good Use of Illness," states,

Though gavest me health to serve Thee, and I have used it only for wordly ends. Now thou has sent me illness in order to correct me. Do not permit me to use it to irritate Thee by my impatience. I have made bad use of my health, and Thou hast justly punished me for it; do not let me make bad use of Thy punishment.<sup>31</sup>

Theodicies of suffering provide interpretive schemas which provide convincing explanations of illness and serve as indicators concerning appropriate responses to suffering. However baffling or banal this response may seem within a secularized context, Christian narratives of suffering once provided a meaningful and common tradition which was understood not as an abstract theological doctrine, but as a deeply rooted, convincing understanding of human life. This is evident in the description of the death of Anne d'Autriche recorded by Madame de Montpesier. She writes,

A moment later, she opened her dying eyes and, looking at her confessor, said to him: 'Padre mio, yo me muero' [Father, I am dying]. After had she said these words, her agony became so overwhelming and so painful that, feeling her suffering increase, and her strength diminish, an impulse of nature, which hates suffering, made her say, albeit reluctantly to the Archbishop Auch: 'I am in great pain; will I not die soon?' Whereupon, the Archbishop having told her that one must not be too impatient to die, and that one must suffer as much as God has ordained, she acquiesced at once and repeatedly expressed her submission to God's will.<sup>32</sup>

While this Christian tradition remained dominant, strong normative constraints served to create a compelling vision of the meaningfulness of suffering, dying, and death. However, in a pluralistic, secular culture, illness is not typically interpreted as the deserved manifestation of divine will, but is construed as an undeserved ailment lacking meaning and purpose. Today, in Europe and North America, the various theodicies of suffering no longer possess this power over social policy. Hence, while Christian narratives of suffering may be recognized by inhabitants of secular traditions as of considerable therapeutic value, there would

seem to be no method of meaningfully re-entering this tradition without neglecting the entire biomedical approach to disease and illness. Furthermore, attempts to create personal psychological narratives are not likely to be very convincing if they are constructed within larger social settings that do not relate health and illness to "saintly" and "sinful" behaviour.

The desire to avoid suffering is increasingly predominant. In secularized societies, the demand for active voluntary euthanasia to avoid unnecessary suffering has proven to be immense. Previous interpretations of suffering collapse, and there are no overarching narratives concerning the deservedness of suffering to "explain" illness experiences. Clearly, this paradigmatic shift is related to the current demand for active voluntary euthanasia.

Though "AIDS" may be currently described by televangelists as the just deserts of "sexual deviants," this form of discourse is marginalized by less moralistic accounts informed by biomedicine. Not only are diseases viewed as secular processes that can be biomedically interpreted and understood, but suffering is likewise viewed from a similar interpretive framework.<sup>33</sup> Suffering is understood as the bodily response to breakdown, illness, disease, injury, and it serves no other purpose than to signify this "malfunctioning" of the body. Because of this, there are few intelligible reasons for enduring suffering if there is no benefit such as an eventual return to health, or the desire

to achieve a particular goal. Instead, there is every reason to ameliorate the suffering, since it lacks all purpose once its "cause" has been discerned. Thus, if medication does not control the suffering, or results in an unbearable bodily state, it is scarcely surprising that active voluntary euthanasia is interpreted in certain instances as a final alternative to prolonged suffering.

Evidence of this increased demand for active voluntary euthanasia as a response to purposeless suffering can be found in almost every Hemlock publication, the literary products of a society striving for the legalization of active voluntary euthanasia. In The Right to Die: Understanding Euthanasia, for example, Derek Humphry, the founder of the Hemlock Society, and co-author Ann Wickett describe the suffering endured by numerous individuals.<sup>34</sup> The experience of sufficient severity of suffering is understood to justify the performance of active voluntary euthanasia. This claim, which is surely an effective appeal to common sense, would seem much less convincing in other historical and social contexts. The increased demand for, and interest in active voluntary euthanasia suggests that Christian attitudes toward suffering face a very powerful alternative in interpretive understandings that challenge theological explanations of suffering.

Most contemporary cultural theorists, such as Ivan Illich, Daniel Callaghan, and Stanley Hauerwas, suggest that few modern individuals seriously perceive meaning in

enduring the experience of suffering. For example, Ivan Illich, in a chapter from Medical Nemesis, provocatively titled, "The Killing of Pain," states:

By the end of the last century, pain had become a regulator of body functions, subject to the laws of nature; it needed no more metaphysical explanation. It had ceased to deserve any mystical respect and could be subjected to empirical study in order to do away with it. By 1853, barely a century and a half after pain was recognized as a mere physiological safeguard, a medicine labeled as a "pain-killer" was marketed in La Crosse, Wisconsin. A new sensibility had developed which was dissatisfied with the world, not because it was dreary or sinful or lacking in enlightenment or threatened by the barbarians, but because it was full of suffering and pain. Progress in civilization became synonymous with the reduction of the sum total of suffering.<sup>35</sup>

Illich briefly sketches the cultural history of suffering and contrasts modern society with its medical attempts to eradicate pain with traditional cultures capable of providing mythical, comprehensive frameworks which make the experience of suffering endurable.<sup>36</sup> Likewise, social theorist Daniel Callahan, recognizes the significance of the absence of any understanding of meaningful suffering in his book, Setting Limits: Medical Goals in an Aging Society. There, exploring the difficulties of establishing any social restraints on the application of medicine in order to prolong life, he writes:

Yet the greatest obstacle may be our almost utter inability to find a meaningful place in public discourse for suffering and decline in life. They are recognized only as enemies to be fought: with science, with social programs, and with a supreme optimism that with sufficient energy and imagination they can be overcome. We have created a way of life that can only leave serious questions of limits, finitude, the proper ends of human life, of evil and suffering, in the realm of the private self or of religion; they are thus treated as incorrigibly subjective or merely pietistic.<sup>37</sup>

When the meaning of suffering and illness is perceived as a subjective, personal interpretation, there ceases to be any public understanding of the meaningfulness of suffering. As Warren Thomas Reich insists, "we simply don't know what to think of suffering: we would rather avoid it than face it, let alone explain its meaning."<sup>38</sup> To the contrary, because suffering in a secular context has very little meaning, and cannot be "explained" apart from physiological interpretations, there cease to be widely-held and convincing moral grounds for prolonging the experience of suffering.

Given the decline of the valorization of suffering in contexts bound both to medical care and unrelated to health, disease, and illness, these cultural commentators upon suffering can tell us a great deal about the current demand for active voluntary euthanasia. Unless this socially constructed interpretation of suffering is substantially altered, it seems unlikely that the demand for active voluntary euthanasia based upon the presence of suffering will decline. When suffering comes to lack meaning and purpose, it becomes possible to develop a very persuasive case for active voluntary euthanasia. Suffering provides no possibility of salvation, or redressal of previous "sin," but is construed in a negative fashion that cannot justify the experience of suffering. When suffering does not possess a significant place in the stories told about illness, disease, and dying but is experienced as an unnecessary, purposeless, meaningless product of illness to be one day conquered by

medical progress, it is not surprising that in the perceived interim period there is immense interest in active voluntary euthanasia.

Given that doctors, nurses, and other caregivers can provide a scenario where the experience of suffering can be palliated but not eliminated, and since most individuals in North America die in some degree of contact with medical personnel, it is not surprising that there is a strong demand for moral and legal reform that would allow the performance of active voluntary euthanasia by physicians. To further support changes in policies concerning the prohibition of euthanasia, the case can also be developed that those individuals experiencing considerable suffering but still capable of action will kill themselves in a particularly violent fashion or even cause further suffering for themselves. This argument assumes that medical personnel should perform active voluntary euthanasia because they possess the intellectual and material resources best suited to providing a death with minimal suffering.

No doubt, medical personnel, especially physicians, due to their intimate knowledge of the workings of the human organism, could very capably perform the technical act of active voluntary euthanasia. However, some physicians claim that even legally sanctioned policies and procedures enabling active voluntary euthanasia, should not be implemented by members of the medical profession.<sup>39</sup> To do so, they claim, would betray the trust founded upon the healing and caring

relation between patient and practitioner that is a time-honored aspect of medical practice in that a physician must never utilize her skills to cause through deliberate actions the death of a patient. Behind this argument is the conviction that physicians may alleviate suffering but should never deliberately cause the death of their patients. Even extreme cases should not provide grounds for legalizing active voluntary euthanasia, lest such instances serve as the thin edge of a wedge which would extend to individuals in less dire straits.

Physicians, like other medical personnel, are acutely aware of the frailties of human beings, and the horrifying menagerie of ailments to which they are susceptible. The endurance of suffering may be advocated by some, but those in touch with the everyday actualities of disease, injury, and dying, are unlikely to prohibit active voluntary euthanasia on the grounds that there is an appropriate place for suffering.

Perhaps the experience of suffering in modernity may be summarized by stating that there is no longer a believable narrative capable of framing suffering in any sort of positive cohesive context. This *nomos* is unavailable in modern life. Stanley Hauerwas, one Christian theologian who has addressed the relationship between contemporary theology, medicine, and suffering, suggests,

medicine is probably best thought of as trying to alleviate unnecessary suffering, but it is at least reasonable to suggest that the very character of all suffering is unnecessary. If that is the case, there is no point in enduring suffering except as a way of expressing our irrational desire to go on living.

The idea that suffering has no point is so threatening to us that we are hardly even able to contemplate, much less embody, the implications of such a view. As Paul Claudel suggests, "Happy is he who suffers and who knows why." I suspect that as much as one might intellectually reject the suggestion made by some Christians that our suffering, including our suffering from disease, is the appropriate punishment for our sins, we continue to accept much of our suffering in terms of some crude sense of desert. For it seems infinitely preferable to suffer for a wrong, even if we think the suffering is inappropriate to the wrong, than to suffer for no reason. From this perspective, the Christian notion of sin turns out to be a remarkably comforting notion.<sup>40</sup>

However baffling or banal the Christian account of sin, suffering, and death may seem to contemporary secularized individuals, there can be no doubt that the Christian narrative did at least provide a buffer against the horrifying notion of the pointlessness of human suffering. However, this narrative of suffering also tends to blame sufferers and victims, and its emphasis on the deservedness of suffering reveals its dangers and shortcomings. There is limited opportunity for compassion and solidarity with sufferers when the experience of pain is construed as a product of "just deserts."

There are many justifiable arguments which can be made against the establishment of some form of public policy enabling a carefully qualified form of active voluntary euthanasia. However, the assertion that there exists patients experiencing suffering of a sort that techniques of

"pain management" cannot restore them to an acceptable quality of life lends a great deal of substance to the deservedness of the current debate.<sup>41</sup> The contemporary support for active voluntary euthanasia possesses as an important element in its generative story the common though not universal conviction that little constructive meaning can be detected in the experience of suffering. This cultural narrative not only creates a context where, at worst, it may seem desirable by the healthy to eradicate the most persistent reminders of the fragility of being human, but also likely informs the lives of some of those who seek active voluntary euthanasia for themselves as a means of avoiding what would otherwise be experienced as meaningless, absurd suffering. It seems plausible to suggest that should this account of suffering become even more widespread, the demand for active voluntary euthanasia will continue to increase. Indeed, if active voluntary euthanasia ever becomes acceptable as public policy in North America, it seems likely that certain guidelines will be used to recognize and accommodate the special cases of suffering individuals.

Notwithstanding the remarkable development of pain-management treatments and effective hospice and palliative care, there are some suffering individuals who truly illustrate the difficulty of imposing in every situation a policy prohibiting active voluntary euthanasia. That these policies are intended to benefit the majority of patients is

unlikely to appease the suffering of the most appalling cases of agony and torment. For this reason, patients, physicians, lawyers, and others will continue to grapple with the serious consideration of active voluntary euthanasia where the patient is experiencing unrelievable suffering.

Just how the active voluntary euthanasia debate will proceed is impossible to predict. What is apparent, however, is the significance of changing attitudes toward suffering which alter the contours of the debate and instigate profound moral reflection. By becoming aware of the social and historical contexts of the debate, it is possible to appreciate not only the complexity of the issue, but the tremendous import attached to the debate by lawyers, ethicists, reflective citizens in general, and especially patients and medical practitioners. At stake are not only the lives of specific suffering individuals, but ways of worldmaking, visions of human nature, and deeply-rooted convictions concerning an appropriate moral stance in the face of suffering, illness, and death. There is a very large gulf between the "worldviews" of those citizens guided by narratives suggesting the valuable nature of the experience of suffering, and the moral visions of individuals who perceive little purpose in the suffering of terminal illnesses or incurable diseases. Because of this, it is vital that agonized, reflective deliberation not surrender to facile reporting, manipulative usage of polls and statistics, and the slick slogans of skillfully managed media campaigns.

Catch phrases, sound bites and television advertisements cannot capture the depth of the ways of imagining the world that lie behind opposing perspectives on active voluntary euthanasia.

<sup>1</sup>Ivan Illich, Medical Nemesis: The Expropriation of Health (New York: Pantheon Books, 1976): 137.

<sup>2</sup>Ibid., 135.

<sup>3</sup>Claudine Herzlich and Janine Pierret, Illness and Self in Society (Baltimore: The Johns Hopkins University Press, 1987): 139.

<sup>4</sup>Peter L. Berger, The Sacred Canopy: Elements of a Sociological Theory of Religion (New York: Doubleday, 1967): 79.

<sup>5</sup>Paul Farmer and Arthur Kleinman, "AIDS as Human Suffering," Daedalus, 118, 2 (Spring 1989): 138.

<sup>6</sup>Emmanuel M. Papper, "The Influence of Romantic Literature on the Medical Understanding of Pain and Suffering--The Stimulus to The Discovery of Anesthesia," Perspectives in Biology and Medicine 35, 3 (Spring 1992): 414.

<sup>7</sup>S. Weir Mitchell, "The Life and Death of Pain," in The Wager and Other Poems (New York: The Century Company, 1900): 18, In, David B. Morris, The Culture of Pain (Berkeley: University of California Press, 1991): 65.

<sup>8</sup>Michel Foucault, Discipline and Punish: The Birth of the Prison (New York: Vintage Books, 1979): 25.

<sup>9</sup>Ibid., 8-10.

<sup>10</sup>Alan Morinis, "The Ritual Experience: Pain and the Transformation of Consciousness in Ordeals of Initiation," Ethos 13, 2 (Summer 1985): 151.

<sup>11</sup>Norbert Elias and Eric Dunning, Quest for Excitement: Sport and Leisure in the Civilizing Process (Oxford: Basil Blackwell, 1986): 58.

<sup>12</sup>Ibid., 165.

<sup>13</sup>Michel Foucault, Discipline and Punish: The Birth of the Prison (New York: Vintage Books, 1979): 3-31.

<sup>14</sup>Alan Morinis, "The Ritual Experience: Pain and the Transformation of Consciousness in Ordeals of Initiation," Ethos 13,2 (Summer 1985): 151.

<sup>15</sup>For a discussion of public executions in France, see John McManners, Death and the Enlightenment: Changing Attitudes to Death Among Christians and Unbelievers in Eighteenth-Century France (Oxford: Clarendon Press, 1981): 368-408.

<sup>16</sup>For a fascinating examination of the relationship between the physical abuse of children and the religious justification of punishment, see Philip Greven, Spare The Child: Religious Roots of Punishment and the Psychological Impact of Physical Abuse (New York: Alfred A. Knopf, 1991).

<sup>17</sup>Alan Morinis, "The Ritual Experience: Pain and the Transformation of Consciousness in Ordeals of Initiation," Ethos 13/2 (Summer 1985): 172.

<sup>18</sup>Ibid., 172.

<sup>19</sup>Ibid., 151.

<sup>20</sup>Ibid., 151.

<sup>21</sup>Ibid., 166.

<sup>22</sup>Hanny Lightfoot-Klein, Prisoners of Ritual: An Odyssey into Female Genital Circumcision in Africa (New York: Haworth Press, Inc., 1989): 9.

<sup>23</sup>Ibid., 9.

<sup>24</sup>Declaration of the Sacred Congregation for the Doctrine of the Faith (May 5, 1980) in Gerald A. Larue, Euthanasia and Religion, (Los Angeles: The Hemlock Society, 1985):

<sup>25</sup>Claudine Herzlich and Janine Pierret, Illness and Self in Society (Baltimore: The Johns Hopkins University Press, 1987): 139.

<sup>26</sup>Paul Farmer and Arthur Kleinman, "AIDS as Human Suffering," Daedalus 118, 2 (Spring 1989): 135-139.

<sup>27</sup>Courtney Campbell, "Plague, Piety, and Policy" Second Opinion 9 (November 1988): 76-77.

<sup>28</sup>Ibid., 78-79.

<sup>29</sup>Ibid., 78.

<sup>30</sup>Claudine Herzlich and Janine Pierret, Illness and Self in Society (Baltimore: The Johns Hopkins University Press, 1987): 140.

<sup>31</sup>Ibid., 140.

<sup>32</sup>Ibid., 145.

<sup>33</sup>David B. Morris, The Culture of Pain (Berkeley: University of California Press, 1991): 1-7.

<sup>34</sup>Derek Humphry and Ann Wickett, The Right to Die: Understanding Euthanasia (Eugene, Oregon: The Hemlock Society, 1990): 33-144.

<sup>35</sup>Ivan Illich, Medical Nemesis: The Expropriation of Health (New York: Pantheon Books, 1976): 151.

<sup>36</sup>Ibid., 133-154.

<sup>37</sup>Daniel Callahan, Setting Limits: Medical Goals in an Aging Society (New York: Simon and Schuster, 1987): 220.

<sup>38</sup>Warren Thomas Reich, "Speaking of Suffering: A Moral Account of Compassion," Soundings LXXII/1 (Spring 1989): 84.

<sup>39</sup>Willard Gaylin, Leon R. Kass, Edmund D. Pellegrino, and Mark Siegler, "Doctors Must Not Kill," Journal of the American Medical Association 259/14 (April 8, 1988): 2139-2140.

<sup>40</sup>Stanley Hauerwas, Suffering Presence (Notre Dame, Indiana: University of Notre Dame Press, 1986): 30-31.

<sup>41</sup>Timothy E. Quill, Christine K. Cassel, Diane E. Meier, "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide," The New England Journal of Medicine 327, 19 (November 5, 1992): 1380.

## CHAPTER FIVE

THE DEVELOPMENT OF INDIVIDUALISM AND THE RISE OF  
PATIENT AUTONOMY

While effective palliative care can do much to alleviate suffering, there remains the legitimate question as to why individuals whose suffering cannot be adequately relieved except by rendering them unconscious are prohibited from requesting active, voluntary euthanasia. Those individuals opposed to the establishment of a social policy enabling active voluntary euthanasia for patients experiencing unrelievable suffering need to articulate the defensible grounds for forcing some patients to endure such suffering. Thus far, justifications for the prohibition of active voluntary euthanasia have been asserted on a variety of grounds. For example, some theologians and non-theologians alike insist that the sanctity of human life makes active voluntary euthanasia an unacceptable act.<sup>1</sup> Physicians, and nurses lay claim to traditions of professional ethics which prohibit the deliberate taking of human life.<sup>2</sup> Lawyers refer to existing criminal codes as one justification of the continued unacceptability of active voluntary euthanasia.<sup>3</sup> The Canadian Law Reform Commission claims, accurately or inaccurately, that public opinion does not support the decriminalization of active voluntary euthanasia.<sup>4</sup> What all of these individuals and organizations face, however, in their sometimes abstract discussions of theory and value is actual patients who can be acutely aware of the suffering

which they will have to endure as a result of the absence of a social policy which allows for the performance of active voluntary euthanasia.

Furthermore, some individuals, such as quadraplegics, are physically incapable of performing an act of suicide that could lessen or remove the responsibilities of others in their dying. The issue, then, in a context where patients can some sometimes acquire fairly accurate prognoses of how their illnesses will proceed, is whether patient autonomy coupled with the presence of suffering provides sufficient justification for the performance of active voluntary euthanasia.

Currently, patient autonomy is respected with regard to the removal or cessation of medical devices and treatments, the establishment of advanced directives and living wills, and the increasing recognition that patients need to be incorporated into most treatment decisions. However, one of the most wrenching contemporary moral issues is whether this emphasis upon personal freedom can be exercised in a manner that would involve medical practitioners in the performance of acts of active voluntary euthanasia. When medical professionals possess the capacity to provide reasonably accurate prognoses, there exists a situation where patients may wish to exercise further their personal autonomy by deciding to avoid the worst elements of the illness trajectory.<sup>5</sup> This could be achieved by providing members of the medical community with the legal, moral, and medical

perogative to perform active voluntary euthanasia. The key issue is whether or not personal autonomy does provide sufficient grounds for alterations of current law and public policy which prohibit the performance of active voluntary euthanasia. Since the performance of active voluntary euthanasia is, at least to some extent, a public act, there must be some question as to the appropriateness of a language of individual rights in a situation where the larger community must always be involved. I think the American Civil Liberties Union, for example, has erred in construing the active voluntary euthanasia debate within the confines of the "right to privacy."<sup>6</sup> Whereas suicide can arguably be an isolated, "private" act, assisted suicide and active voluntary euthanasia, by their very nature, involve at least one other member of the community. The larger social order is further involved if it sanctions a policy enabling medical professionals to perform active voluntary euthanasia. Notwithstanding the significance of personal choice in this issue, any public policy endorsing some form of active voluntary euthanasia needs to recognize that medical professionals, family members, and the larger community would all be affected by the provision of active voluntary euthanasia.

Interestingly, the goals of medicine and the language of individual rights share a common element. Their shared ethos incorporates a relentless emphasis upon the significance of control. As Daniel Callahan, puts it in What

Kind of Life: The Limits of Medical Progress, the growing movement for legalizing euthanasia

rests upon precisely the same assumptions about human need, health, and the role of medicine that have created our present crises--the right to, and necessity of, full control over our fate. Legally available active euthanasia would worsen, not help, that crises. By assuming that, in the face of a failure of medicine to cure our illness or stop our dying, we should have the right to be killed the euthanasia movement gives to the value of control over self and nature too high a place at too high a social cost. Euthanasia is...the other side of the coin of unlimited medical progress. The compassion it seeks is not just in response to pain and suffering. It is more deeply a response to our failure to achieve final control over our destiny.<sup>7</sup>

Callahan detects in the argument for active voluntary euthanasia a hubris that steps beyond the acceptable boundaries of personal choice. To a degree, I accept his insistent claim that there must be some limits placed upon the expression of personal choice. For example, I do not think it would be wise to make active voluntary euthanasia available merely upon request for any circumstance. Even though I see no means of "quantifying" suffering in order to develop a scale for the provision of active voluntary euthanasia, I think the experience of some degree of suffering, or the likelihood of future suffering, needs to be coupled with personal autonomy before any provision of active voluntary euthanasia. However, Callahan ignores the positive, constructive dimension of personal autonomy and individual decision-making. The significance of the involvement of the suffering individual in participating in decisions about the cessation of treatment, alternative treatment modalities, and even the performance of active

voluntary euthanasia becomes more apparent when the often deleterious consequences of institutional and medical paternalism are acknowledged.

For these sorts of reasons, conflicting interpretations of the nature of the individual play a major role in generating the contemporary active voluntary euthanasia debate. The traditional Roman Catholic theological stance which insists that personal decision-making occur within a context of constraints, duties, and responsibilities is distinct from the libertarian moral tradition that attempts to limit morality to the sphere of the "private," "autonomous" self. From this perspective, it is the individual who chooses obligations and values. The morality of behavior as understood within the libertarian tradition is determined by autonomous human rationality and is not provided by any "spiritual" source. Between these two extremes, I want to argue for a middle ground that acknowledges the significance of individual decision-making, but also recognizes that "personal decisions" affect the community just as the larger social order in turn influences the context of personal reflection.

There is a large body of scholarship that traces the gradual social construction of the autonomous, isolated, individual self. Over the last 130 years, particularly, the liberal tradition has become predominant. As a result of numerous social processes, individuals now play a significant role in choosing values, personal choices, and

religious orientation from a range of options. Within the liberal state, religious beliefs have been relegated to a private sphere which is not supposed to impinge upon the determination of the public good.<sup>9</sup> Obviously, this poses immense difficulties for the preservation of social policies which restrict certain forms of behaviour through the limitation of personal autonomy. Indeed, conservative scholars such as Hauerwas, Grant, and Alasdair MacIntyre, as well as many socialists and communitarians who challenge the morality of the autonomous self of the liberal tradition, question how there can be any understanding of the public good, when ethical reflection is understood as a purely subjective, private, and personal option.<sup>9</sup> They also lament the manner in which theological discourse, once an integral element of public discussion on morality, has lost much of its influence upon the public realm. It has not altogether disappeared, but faces grave difficulties when it tries to do more than affirm popular consensus. As George Grant states in English Speaking Justice,

The language of traditional religion can sustain itself in the public realm only insofar as it responds to issues on the same side as the dominating liberalism. If it does, it is allowed to express itself about social issues. But if there is a conflict between the religious voices and the liberalism, then the religious voices are condemned as reactionary and told to confine themselves to the proper place of religion, which is the private realm.<sup>10</sup>

Within the liberal state, virtually all theological discourse is excluded from the establishment of shared conceptions about the public good. Everyone is free to possess

theological "values," but these are not to be dragged into the public sphere of social policy. As Grant insists, a central aspect of liberalism is that,

the state should not interfere with the actions of its citizens, except when those actions infringe the external freedom of other citizens. The state is concerned with the preservation of the external freedom of all, and must leave moral freedom to the individual.<sup>11</sup>

Whereas Grant sees in this process the eclipse of genuine moral reflection, I view the development of the liberal tradition in a more positive fashion. However, regardless of the morality of this process, at this stage of analysis it is important merely to observe that this cultural shift has occurred. Liberal values of the significance of personal autonomy significantly reduce the sphere of moral reflection, by removing it from the public realm, and relegating morality to the private concerns of uncoerced individuals.

The ascent of the liberal tradition makes it difficult to sustain or even comprehend public policies which circumscribe the moral and behavioural freedom of individuals. The "right" of personal autonomy would dictate that any behaviour not clearly harming other individuals and so violating the "social contract" is permissible and should not be constrained. This view was eloquently articulated by John Stuart Mill in his nineteenth century classic, "On Liberty." There, Mill insists,

The object of this essay is to assert one very simple principle, as entitled to govern absolutely the dealings of society with the individual in the way of compulsion

and control whether the means used be physical force in the form of legal penalties, or the moral coercion of public opinion. That principle is that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.<sup>12</sup>

According to the most basic principle of the liberal tradition, the actions of an individual can only be prevented if they harm, or threaten to harm, other individuals. If it is only the isolated, autonomous person, and not society at large, who will be harmed, then no other individual or community has the right to interfere. This means that the lone person is--almost--the lone repository of values. The sole injunction which would ever prevent the fulfillment of personal choices, is the prohibition which demands that others not be harmed. If the personal behaviour of an individual is self-destructive, but not dangerous toward others, then there can be no opposition from within the liberal tradition. Admittedly, Mill's thought, like that of most subsequent liberal philosophers, is far more complex than this interpretation would suggest. However, there is a widespread, popular rendition of libertarian thought that proceeds along these lines. Thus, it is easy to comprehend why libertarian thought is described by Daniel Callahan as possessing a "minimalist" theory of social justice.<sup>13</sup>

One consequence of such an interpretation of the nature of the individual, and community relations, is that physicians should provide all medical services requested by patients, so long as the general community is not harmed. Hence, the liberal argument proceeds, while abortions and active voluntary euthanasia might be inappropriate within Roman Catholic hospitals, secular institutions should not be constrained from catering to the moral values of citizens of the liberal state. From the libertarian perspective, active voluntary euthanasia should not be restricted since this involves the imposition of private morality upon the public sphere, and results in a corresponding limitation of personal autonomy inappropriate to liberal society.

However, although active voluntary euthanasia might seem to be unambiguously supported by the libertarian position, this is not quite the case. Because the act of active voluntary euthanasia involves the cessation, through deliberately chosen death, of the personal autonomy of the individual, the libertarian tradition does not speak in a single affirmative voice for policies affirming active voluntary euthanasia. While Mill does not speak for all libertarians, his essay does restrict the degree of personal autonomy. There, he insists,

By selling himself for a slave, [a person] abdicates his liberty; he forgoes any future use of it beyond that single act....The principle of freedom cannot require that he should be free not to be free. It is not freedom to alienate his freedom.<sup>14</sup>

Thus, even though it is possible to draw upon libertarian

thought to develop the case for a normative stance supporting active voluntary euthanasia, it is not evident that even this moral tradition that places such a strong emphasis upon the personal liberty of the individual would necessarily support active voluntary euthanasia based exclusively on the significance of individual autonomy.

Admittedly, libertarians often do support active voluntary euthanasia. However, whether they should logically do so is another matter. Since personal autonomy and the "individual genius" of Mill is so important to this tradition, there is an inconsistency to advocating decisions that would result in the inability to continue to exercise personal autonomy. If the liberty of the self is the pre-eminent moral value of the libertarian moral theorist, then it does not necessarily follow that a policy of active voluntary euthanasia should be supported. Conversely, the libertarian can argue for the morality of active voluntary euthanasia by noting that the course of illness has already served to undermine personal autonomy. In practice, libertarians often support other principles, as did Mill, such as the mitigation of suffering, and do not raise the autonomy of the self to the position of lone, absolute moral value.

Just as the ascendancy of the liberal tradition has challenged institutional paternalism, feudal forms of government, theological values, and replaced communal norms with individual choices, transformations in communal

structures and social kinship relations have also altered the experience of dying and suffering.

Perhaps the most disturbing aspect of the current active voluntary euthanasia debate is that it is occurring in a context where physicians are frequently encountered as strangers or mere acquaintances, medical care is provided by professionalized bureaucratic institutions, and the extended family has largely disappeared. Today, a large social network will not necessarily be available to provide supportive care to suffering individuals. There are no longer many tribes, clans, or other communities of closely-bonded kin within Europe and North America able to partake either in rituals of healing or lament, or in solidarity in suffering. Professionals whose considerable technical responsibilities can make personal identification with those in their care difficult, often fulfill the role of body technician rather than care-giver, and the "nuclear family," where it remains, is left to fill the social vacuum with solace, companionship, and comfort. Telephone calls, video messages, and corporate fruit baskets may provide some indication that there is a larger community not altogether indifferent to the suffering of the particular individual, but remain distinct from genuine embodied care which has to deal with the very tangible unpleasanties and horrors for comforters and sufferers alike that can accompany processes of illness and dying.

The implications of the waning of kinship ties for modern social life is discussed by British sociologist Anthony Giddens in The Consequences of Modernity. Giddens states,

Kinship relations, for the majority of the population, remain important, especially within the nuclear family, but they are no longer the carriers of intensively organized social ties across time-space.<sup>15</sup>

Giddens further writes,

Kinship connections are often a focus of tension and conflict. But however many conflicts they involve and anxieties they provoke, they are very generally bonds which can be relied upon in the structuring of actions in fields of time-space. This is true on the level of both fairly impersonal and more personal connections. In other words, kinspeople can usually be relied upon to meet a range of obligations more or less regardless of whether they feel personally sympathetic towards the specific individuals involved. Moreover, kinship often does provide a stabilising network of amicable or intimate relations which endure across time-space. Kinship, in sum, provides a nexus of reliable social connections which, in principle and very commonly in practice, form an organizing medium of trust relations.<sup>16</sup>

In terms of the active voluntary euthanasia debate, this means that kin can provide a social web of very significant, trust-filled relationships that provide an extensive social support network. Such ties between kin can weave through processes of birth, the construction of homes, marriage, illness, dying, and death. However, Giddens relates such kinship ties to "pre-modernity," and not to contemporary social relations. Such communal ties are far less common in modernity. Instead, other obligations such as occupational demands require that the individual or nuclear family move frequently and never stay closely bound to one particular

region, job, school, neighborhood, or group of friends. Possibilities of global travel and the experience of living within many different regions over the span of a lifetime increase, but only with the loss of a sense of place, time, and community. It becomes possible to live anywhere, but at the cost of the loss of rootedness to a particular region and human community.

This alienating, isolating process can easily be exaggerated, and it would be misleading to suggest that the familial bonds involved in pre-modern kinship networks were always desired or beneficial. However, it is not difficult to realize that a modern context of limited, highly abbreviated social relations that may lack the bonds of trust found between kin create a climate where active voluntary euthanasia may be given serious consideration as a solution to social ailments when it is merely but one further symptom of a much larger social crises.<sup>17</sup> Contemporary fears including lack of trust of physicians, horror at the prospects of dying while being cared for only by paid professionals, and disgust that the larger community is seemingly unaffected by the death of one of its own members are scarcely solved by the establishment of active voluntary euthanasia as social policy. It may be that other significant forms of social transformation are required, and I support hospice programs, palliative care, and home care programs that strive to integrate the dying patient within a larger community. Whatever policies of active voluntary

euthanasia may be, they should not be the first responses to suffering individuals.

The absence of powerful ties between kin and the lack of genuine social embeddedness beyond the "nuclear" family probably plays some role in heightening fears of suffering, illness, and dying, and making these processes even more unbearable than might otherwise be the case. While the lack of a sense of community, the care of the ill by paid strangers, the breakdown of binding social ties, and the disappearance of communal rituals of healing do not mean that active voluntary euthanasia should be altogether unimaginable in the current social context, they surely illustrate that the demand for active voluntary euthanasia exists in a period when there is a considerable need for significant social changes. In particular, hospice and palliative care desperately needs to be developed around the world.

However, even though the "pre-modern" version of kinship arrangements is compelling, I do not think a return to this form of social arrangement, even if it could somehow be achieved, would eradicate the dilemmas that we currently face. Rather, such an interpretation tends to equate suffering with isolation, or social alienation, and does not adequately attend to the experiences of suffering which can occur even within contexts of social solidarity and extended family relations, and the presence of caring medical caregivers.

In addition to acknowledging the development of the significance of personal freedom in the liberal philosophical tradition as well as in the transition from "pre-modern" to "modern" social arrangements and kinship networks, I think we also need to attend to the changing nature of the physician-patient relationship.

Historically, the patient has existed in a subordinate status to that of the physician. The physician-patient relationship was often viewed as analogous to the interaction between parent and child by previous generations of physicians and their patients. For example, within the Hippocratic corpus of texts, there is an emphasis on paternalism and physician beneficence rather than patient autonomy. Only recently was this hierarchical model of the powerful physician and the passive, pliant patient challenged.

Since at least the 1970's, patients have come to play a more active role in their own treatment, at least within such countries as Canada, Australia, and the United States. For example, until the late 1960's and early 1970's, cancer patients were rarely informed of their diagnoses and prognoses.<sup>18</sup> Often, the physician would deceive the patient, or remain silent about the serious nature of the illness, in order to maintain hope. Since it was presumed that patients lacked the technical knowledge to comprehend the nature of their illnesses, there was no point in expecting them to play an active role in making complex medical decisions.

Furthermore, since there was often little that the physician could do to alter the course of cancer, as well as many other diseases, the silence of the physician was understood to be therapeutic because it allowed the patient some "hope." However, in 1977, a study of physicians' attitudes in North America towards truth telling revealed that almost all physicians would now inform their patients of their illnesses through the provision of accurate diagnoses.<sup>19</sup> Medical care had undergone a social transformation. Patients gradually expected to play a greater role in deciding the course of their treatment, and physicians became much more open to disclosing the truth about illness, diagnosis, and prognosis. In addition, the elevated social status of physicians as authority figures was challenged during the civil rights, womens' rights, and consumer rights movements. Various grassroots organizations affirming non-professionalized knowledge attempted to de-mystify illness and question the professional autonomy of physicians.

This dynamic process, which continues to evolve and alter medical care as midwives, for example, gain increasing recognition, and the legal community challenges the autonomy of physicians through informed consent laws and other restrictions, has transformed the physician-patient encounter.

Presently, North American patients tend to expect to be told their diagnoses and prognoses, and to play some role in reaching treatment decisions. Furthermore, they usually also

assume that they should play an important role in their medical care, by selecting between alternative treatment modalities, declining treatment, or ordering the cessation of treatment. Thus, there currently exists a situation in which the choices of patients play a major role in the provision of medical care. Of course, the implications of this development can be exaggerated. Many patients will unquestioningly follow the advice of physicians and numerous studies by medical sociologists demonstrate the manner in which physicians continue to maintain authority and power within the clinical encounter.<sup>20</sup> Nonetheless, the paternalistic tradition within medicine has been undermined over the last several decades in North America and other regions.

While these transitions influence all forms of medical care, they have especially altered decision-making at the end of life. For example, quadraplegics can choose to have themselves removed from respirators even though the consequence of this action leads to death.<sup>21</sup> Likewise, the right of the patient to decline treatment is well-established in Canada and the United States.<sup>22</sup>

However, although patients have acquired considerable autonomy within physician-patient interaction as well as the larger medical setting, over the last quarter century the legal and medical communities, as well as many theologians and medical ethicists, have drawn a "bright line" between the decline, cessation, or withdrawal of treatment,

which is referred to by some as "passive voluntary euthanasia," and the provision of active voluntary euthanasia.<sup>23</sup>

Some prominent physicians have even argued that the moral centre of medical ethics resides within this distinction between ceasing or withdrawing treatment and active voluntary euthanasia. Four of the most prominent medical ethicists in the United States, physicians Gaylin, Kass, Pellegrino, and Siegler, assert in their article, "Doctors Must Not Kill"

The very soul of medicine is on trial. For this is not one of those peripheral issues about which pluralism and relativism can be tolerated, about which a value-free stand on the substance can be hedged around with procedural safeguards to ensure informed consent or "sound decision making." Nor is this an issue, like advertising, fee-splitting, or cooperation with chiropractors, that touches medicine only as a trade. This issue touches medicine at its very moral centre; if this moral centre collapses, if physicians become killers or are even merely licensed to kill, the profession--and therewith, each physician--will never again be worthy of trust and respect as healer and comforter and protector of life in all its frailty. For if medicine's power over life may be used equally to heal or to kill, the doctor is no more a moral professional but rather a morally neutered technician.<sup>24</sup>

Whereas these physicians support the right of the patient to withdraw from treatment, they affirm the "bright line" that demarcates "passive euthanasia" from "active voluntary euthanasia." However, even though I do not affirm an unqualified form of personal autonomy, I think this interpretation of active voluntary euthanasia diminishes the meaning of patient autonomy. In contrast to the authors of "Doctors Must Not Kill," I think physicians would not be

"morally neutered technicians" if active voluntary euthanasia were performed, as long as active voluntary euthanasia were limited to suffering patients competent at the time of their request for active voluntary euthanasia. Though I agree that the moral centre of medicine would be shattered if physicians deliberately killed unwilling patients, as occurred in the "euthanasia" programs of Nazi Germany, I think that the circumstances of competent and suffering patients are inadequately addressed by this moral dogmatism.

As previously observed, "passive euthanasia," in which patients exercise their autonomy by requesting the cessation of treatment is widely accepted by ethicists, lawyers, and physicians. However, I think there are also circumstances when physicians should be allowed to honour the requests of patients for active voluntary euthanasia. What would seem to distinguish the morality of these actions, or absence of actions, "passive," or "active" behaviour, is the underlying motives guiding the request of the patient and the actions of the physician rather than whether or not death occurs as a result of removal from a ventilator or the provision of a lethal injection. The morality of an action is determined not by whether a respirator is stopped or an injection provided, but by the autonomy of the patient, the beneficence and mercy of caregivers, and a host of other factors such as the implication of such actions for other members of society. The rise of the significance of personal freedom within

Western thought and institutions, and the development of patient autonomy lends considerable support to a carefully circumscribed policy supporting active voluntary euthanasia.

The current situation concerning patient autonomy leads to a strange scenario. Patients can expect to receive information concerning truthful diagnosis and prognosis. They can also assume that they will play a key role in medical decision-making while they are competent. Through living wills and advanced directives, their personal choices can even be acknowledged when they are incompetent. They can elect to participate in experimental therapies, pursue aggressive treatments, choose to cease such therapies, or request the removal of technological life-sustaining devices. Patients can even request, and physicians can provide, medications that help to control suffering but also hasten death. This degree of personal autonomy exists in contrast to the cultural responses to illness in other regions of the world. For example, in Japan, Italy, Ethiopia, and many other nations, family members of patients as well as physicians, not patients, make these decisions.<sup>25</sup> Patients in Northern Europe, Australia, and North America probably exhibit greater expressions of personal autonomy within physician-patient relations than in any other region of the world. And yet almost all nations continue to prohibit the provision of active voluntary euthanasia. However, if we are to respect patient autonomy and the ability of competent individuals to make their own choices, I think there needs to

be a re-consideration of where our "moral lines" ought to be drawn. Rather than placing undue emphasis upon whether euthanasia is "active" or "passive," there should be much more attention concerning whether it is "voluntary" or "involuntary." The guiding motives behind such decisions need to be better incorporated into moral analysis.<sup>26</sup>

Admittedly, there can be some distinction between "passive euthanasia" and "active euthanasia." In active euthanasia, there is a direct link between the provision of an injection by a physician, for example, and the death of a patient. With "passive euthanasia," the causal chain of actions and consequences is blurred. For example, when a nasogastric tube is removed, the patient slowly dies of dehydration. When a ventilator is removed, the death of the patient can be blamed on a failure of the respiratory system, rather than on the actions of the physician. While in such cases death is "caused" by the removal of a technological device or the cessation of a particular type of treatment, death is also "caused" by the moral decisions guiding the continued use, or discontinuation, of these therapies. "Passive euthanasia" disguises the moral agency of the medical caregivers by divorcing decisions from the consequences of those decisions, and making it appear as though a machine or organ system is exclusively responsible for the death of the patient. While it might be comforting for some medical caregivers to remove human moral choice from the decision-making process, this cannot be achieved. Even

when physicians label treatment "medically futile," they are making a judgement that is both moral and technical.

I think much greater attention needs to be given to the normative justification for the withdrawal of treatment or the provision of a lethal injection, rather than the "passive" or "active" nature of the cause of death. The bright line drawn between "passive" and "active" euthanasia is misleading because it obfuscates the human moral agency that exists on both sides of the line. Instead, our moral boundaries should not be based upon technical causes of death, but upon the morality of the choices, decisions, and actions of physicians and other caregivers, as well as patients. Key components of this moral dimension should include respect for the autonomy of the patient, as well as the desire for the mitigation of human suffering. It is to be hoped that in most cases, palliative and hospice care can hopefully meet the needs of patients and medical caregivers. However, in occasional cases of unrelievable suffering, active voluntary euthanasia may be the responsible, moral choice.

<sup>1</sup>Pope John Paul II, "Euthanasia: Declaration of the Sacred Congregation for the Doctrine of the Faith," The Pope Speaks 25, (Winter 1980): 289-296. In, Stephen E. Lammers, Allen Verhey, (Eds.), On Moral Medicine: Theological Perspectives in Medical Ethics (Grand Rapids, Michigan: William B. Eerdmans Publishing Company, 1987): 442.

<sup>2</sup>Franklin G. Miller and John C. Fletcher, "The Case for Legalized Euthanasia," Perspectives in Biology and Medicine 36, 2 (Winter 1993): 162.

<sup>3</sup>Barney Sneiderman, John C. Irvine, Philip H. Osborne, Canadian Medical Law (Toronto: Carswell, 1989): 227.

<sup>4</sup>Euthanasia, Aiding Suicide and Cessation of Treatment, (Ottawa: Law Reform Commission of Canada, 1983): 18.

<sup>5</sup>Timothy E. Quill, Christine K. Cassell, Diane E. Meier, "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide," The New England Journal of Medicine 327, 19, (November 5, 1992): 1380.

<sup>6</sup>Nancy Gibbs, "Death Giving," Time (May 31, 1993): 45.

<sup>7</sup>Daniel Callahan, What Kind of Life: The Limits of Medical Progress (New York: Simon & Schuster, 1990).

<sup>8</sup>Eike-Henner W. Kluge, Biomedical Ethics in a Canadian Context (Scarborough, Ontario: Prentice-Hall Canada, Inc., 1992): 29.

<sup>9</sup>Alasdair MacIntyre, After Virtue: A Study in Moral Theory (Notre Dame, Indiana: University of Notre Dame Press, 1989): 22.

<sup>10</sup>George Grant, English-Speaking Justice (Toronto: Anansi, 1974): 6.

<sup>11</sup>Ibid., 28.

<sup>12</sup>John Stuart Mill, On Liberty, Ed. Gertrude Himmelfarb, (London: Penguin Books, [1859] 1985): 68.

<sup>13</sup>Daniel Callahan, "Minimalist Ethics," Hastings Center Report 11, 5 (October 1981): 20.

<sup>14</sup>John Stuart Mill, "On Liberty," in Utilitarianism, ed., Mary Warnock (New York: Meridan, 1962): 236.

<sup>15</sup>Anthony Giddens, The Consequences of Modernity (Stanford, California: Stanford University Press, 1990): 108.

<sup>16</sup>Ibid., 101.

<sup>17</sup>Norbert Elias, The Loneliness of the Dying (Oxford: Basil Blackwell, 1985): 28-29.

<sup>18</sup>D. Oken, "What to tell cancer patients: A study of medical attitudes," Journal of the American Medical Association 175, (1961): 1120-1128.

<sup>19</sup>D.H. Novack, R. Plumer, R.L. Smith, H. Ochitill, G.R. Morrow, J.M. Bennett, "Changes in physicians' attitudes toward telling the cancer patient," Journal of the American Medical Association 241 (1978): 897-900.

<sup>20</sup> Howard Waitzkin, "Doctor-Patient Communication: Clinical Implications of Social Science Research," Journal of the American Medical Association 252, 17 (November 2, 1984): 2441-2446.

<sup>21</sup>Barney Sneiderman, "Remembering Nancy B.," Manitoba Medicine 63, 1 (1993): 22.

<sup>22</sup>Ibid., 22.

<sup>23</sup>Christine K. Cassell, "Physician-Assisted Suicide: Are We Asking the Right Questions?" Second Opinion (October 1992): 95.

<sup>24</sup>Willard Gaylin, Leon R. Kass, Edmund D. Pellegrino, and Mark Siegler, "Doctors Must Not Kill," Journal of the American Medical Association 259, 14 (April 8, 1988): 2139-2140.

<sup>25</sup>Yewoubdar Beyene, "Medical Disclosure and Refugees: Telling Bad News to Ethiopian Patients," Western Journal of Medicine 157, (September 1992): 328.

<sup>26</sup>Dan Brock, "Voluntary Active Euthanasia," Hastings Center Report, (March-April 1992): 2-13.

## CHAPTER SIX

## PROPOSITION 161: THE CALIFORNIA DEATH WITH DIGNITY ACT

On November 3, 1992, citizens of the state of California voted upon Proposition 161, "The California Death With Dignity Act." Despite early predictions and polls taken prior to voting day that suggested the proposal for the legalization of active voluntary euthanasia would succeed, the initiative was narrowly defeated by a 54-46 majority vote.<sup>1</sup> Had this initiative received majority support, physicians in California would have received the legal mandate to provide "physician-aid-in-dying" through the provision of both assisted suicide and active voluntary euthanasia.

Because there is a debate surrounding the proposed legalization of active voluntary euthanasia in many nations such as Canada, the United States, the United Kingdom, Germany, and Australia, proponents and opponents of active voluntary euthanasia ought to have an interest in, and understanding of, the California initiative. Unquestionably, the Act, had it passed, would have set a legal precedent in the United States. Even though the Act did not receive a majority vote, it deserves to be examined in order to understand its strengths, weaknesses, and implications for future medical and social policy and practice. I was in California during the voting process, and I noticed that after the initiative failed, both its proponents and

opponents alike recognized that further legislative efforts to legalize active voluntary euthanasia would be influenced by the California initiative.

Even though I support a qualified, carefully circumscribed form of active voluntary euthanasia by physicians, I would not have voted for the California initiative, had I been a citizen of California . Because I think that the document contains flaws that must be addressed by similar pieces of legislation in other nations, I think it important to examine the document with care and develop a reasonable descriptive and normative analysis of the text.

Because the Act is very brief and can be easily read and obtained by anyone with an interest in the subject, there is no need to summarize every point and statement in the document. Instead, after placing in context the subject of "physician aid in dying," the phrase used in the Act to refer to behaviour that I call active voluntary euthanasia, I will present and probe its key passages. I have tried not to willfully distort the text for the sake of my own position. One of my goals is to demonstrate that this act did not deserve the support of the citizens of California, and should not serve as an ideal model for similar documents in other regions. However, my objective is not to deliver a mere critique of the Act and ignore the need for constructive alternatives. Though my primary focus is on the specific flaws of the Act, I develop this critical commentary to suggest future directions for any attempt to legalize active

voluntary euthanasia.

As we have seen, although the subject of active voluntary euthanasia is extremely complex and requires and appreciation of many subjects such as the history of the liberal philosophical tradition, changes in medical care and technology, and shifting cultural attitudes toward illness, disease, and suffering, the basic ethical conflict is fairly straightforward. In essence, conflicts arise over the extent to which significance is placed on the right of individuals to self-determination. Proponents of active voluntary euthanasia argue that competent patients should have the right to request "physician aid in dying."<sup>2</sup> For example, Derek Humphry, founder of Hemlock Society, states, "The option of self-deliverance for the terminally ill person is the ultimate civil liberty."<sup>3</sup> Conversely, opponents of active voluntary euthanasia argue that personal autonomy should not be extended to the right to "physician aid in dying," the phrase used in the Act to represent assisted suicide and active voluntary euthanasia. A second significant source of debate relates to the subject of suffering. Proponents of The California Death with Dignity Act were convinced that the legalization of "physician aid in dying" would help to reduce human suffering.<sup>4</sup> Opponents of the initiative argued that there were other methods of controlling human pain and mitigating human suffering that had less dangerous social and moral implications.<sup>5</sup> The ethical "quandary" can be further explicated by examining the

major principles, rules, values, and axioms guiding ethical reflection that inform the Act.

Several key principles establish the normative presuppositions of the California Death With Dignity Act. One basic principle maintained by proponents of The California Death With Dignity Act was that humans should not have to suffer. The document was distributed by a group known as "Californians Against Human Suffering," and this provides a sense of the benevolent aims of the supporters of the initiative. Proponents of the Act perceived themselves doing battle to reduce the suffering of extremely ill, dying Californians. According to the Act,

The right to choose to eliminate pain and suffering, and to die with dignity at the time and place of our own choosing when we are terminally ill is an integral part of our right to control our own destinies.<sup>6</sup>

The language of rights was used to claim that "physician aid in dying" should be legalized to reduce human suffering. Related to this discourse of rights was the primacy given by the promulgators of the document to personal autonomy. According to the text of the Act, "Self-determination is the most basic of freedoms."<sup>7</sup> This expresses the conviction that humans ought to be able to control their own lives and deaths. The process of dying should be directed by self-determining dying individuals. A third value that bolsters the argument to legalize "physician aid in dying" relates to the principle that the process of dying should not be controlled by medical technology. According to the document,

Modern medical technology has made possible the artificial prolongation of human life beyond natural limits. This prolongation of life for persons with terminal conditions may cause loss of patient dignity and unnecessary pain and suffering for both the patient and the family while providing nothing medically necessary or beneficial to the patient.<sup>8</sup>

The formulators of The California Death With Dignity Act, like many supporters of active voluntary euthanasia, maintained that legalizing "physician aid in dying" would reduce the likelihood of patients suffering from an oppressive, unconsidered use of medical technology.

Serving as the cornerstone of all the guiding principles of the Act was the central conviction that humans ought to be able to achieve a "death with dignity." Supporters of the Act were guided by the conviction that death should be a dignified process largely controlled by the dying individual.

To summarize, the guiding principles of The California Death With Dignity Act were the primacy of self determination, the right to be free from unnecessary suffering, and the right to a controlled death with dignity unencumbered by technological devices. Thus, I think we can see the Act as a response to all three of the transformations in the social order that I previously explored.

In opposition to the principles espoused by supporters of the Act is another group of powerful and convincing values. For example, opponents of the Act can agree with its supporters that personal autonomy is significant, yet differ as to the degree to which personal autonomy should be

justifiably expressed. Leon Kass, an American bioethicist who is a staunch opponent of attempts at the legalization of active voluntary euthanasia in the United States, notes that the very founders of the liberal tradition, such as John Locke and Immanuel Kant, did not emphasize personal autonomy and individual rights to the extent that they supported assisted suicide or active voluntary euthanasia.<sup>9</sup> The modern notion that there is a "right" to die that could extend to physician aid in dying is not a traditional element of the liberal discourse to which the formulators of the act appeal.<sup>10</sup> Supporters of a more qualified principle of personal autonomy are rather skeptical that humans possess an unqualified "right" to control their own deaths through the receipt of active voluntary euthanasia.<sup>11</sup> Instead, opponents of active voluntary euthanasia frequently argue that the traditional duty of physicians to do no harm and to desist from deliberately causing death even in instances involving suffering patients serves as a limit upon the extent to which physicians, at least, ought to support patients claims to personal autonomy.<sup>12</sup>

Some groups, particularly Roman Catholic organizations, invoke the "sanctity of life" principle to assert that it is always impermissible to willfully hasten the death of another human being.<sup>13</sup> Although the principle of the sanctity of life need not necessarily preclude active voluntary euthanasia, many opponents of the legalization of active voluntary euthanasia in California proceeded from this

deontological position that precludes any serious consideration of active voluntary euthanasia. Since this position obviates the need for any critical discussion of the "Death With Dignity Act," my discussion of it is for those individuals willing to consider seriously the consequences of the implementation of such an Act.

With regards to the subject of human suffering, some religious communities perceive considerable redemptive value in suffering and therefore place themselves in opposition to arguments that humans should not suffer.<sup>14</sup> Although I find this response to the subject of active voluntary euthanasia abhorrent, I think it obvious that theodicies of suffering that seek to explain suffering by placing experiences within theological contexts have played a significant role in debates surrounding active voluntary euthanasia. In particular, the Roman Catholic Church supports an interpretation of suffering as redemptive, and it played a prominent role in opposing the California initiative.<sup>15</sup> Many other religious traditions also provide a place for suffering that is lacking in secular, liberal discourse.<sup>16</sup> However, although I do not think the Act deserved the support of Californians, I do not criticize the Act on the basis of some principle that active voluntary euthanasia should be prohibited because suffering is redemptive. If that were the only ground for challenging the Act, I think that its formulators would have been justified in merely providing the opportunity for dissenting individuals and private

institutions to avoid participation in active voluntary euthanasia.

There are two common methods predominant in secular discourse utilized to oppose the position that physicians ought to be able to perform active voluntary euthanasia. The first approach is to assert that the very calling of physician precludes participating in such an act.<sup>17</sup> Professional codes of ethics are often used to bolster this form of professional regulation of the conduct of physicians. This position is supported by individuals making statements like, "doctors are healers, not killers." I do not support this sort of response to the subject of "physician aid in dying" because, without adequate elaboration, it begs the question as to what ought to be labelled as "healing," and what should be categorized as "killing." A key point of supporters of the legalization of active voluntary euthanasia is that such an act is morally distinguishable from other acts of killing. The second shortcoming of this position is that many physicians are clearly willing to consider the provision of active voluntary euthanasia as one part of their professional responsibilities.<sup>18</sup> Finally, the most significant charge that can be directed at this approach is that it is a form of moral fundamentalism which assumes that Hippocratic principles must be uncritically accepted without reflection or possibilities of transformation.

The second approach used during the California initiative to condemn active voluntary euthanasia was to

argue that the moral and social consequences of allowing physicians to perform active voluntary euthanasia through legal reform were far too grave to justify supporting the Act.<sup>19</sup> This position admitted the legitimate concerns of supporters of The Death With Dignity Act, but was hesitant to endorse a social policy enabling active voluntary euthanasia because of concerns about the practical consequences of the legalization of active voluntary euthanasia.

Having noted some of the significant principles and arguments for and against The California Death With Dignity Act, I think we also need to evaluate the issue of pain management and palliative care.

Probably the most significant contemporary response to patient dissatisfaction with medical care, unnecessary suffering, and lack of control over the process of dying has been the development of improved hospice and palliative care. This approach affirms that humans should not suffer needlessly during the process of dying, and that proper pain-management by skilled medical teams can often eliminate the most painful elements of the dying process. Palliative and hospice care often involves grassroots organizations, community support groups, and sometimes religious organizations, and they attempt to avoid the imposition of unrestrained technology on the dying process. Home care with adequate nursing and visits by physicians and nurses is a related response that also serves to mitigate human suffering. In many respects, supporters of hospice and

palliative care share common concerns with advocates of physician aid in dying. Both groups are driven by the convictions that humans should not suffer needlessly, and that medical technology should not be applied in an unconstrained fashion to prolong the dying process. What separates proponents of active voluntary euthanasia from those who support palliative and hospice care only is disagreement upon the role of the physician and the extent of the autonomy of the patient. Proponents of palliative care such as Dr. David Cundiff, a pain specialist at the University of Southern California, argued on behalf of a "natural" death that utilizes improvements in medical knowledge and pain management therapies without deliberately causing death.<sup>21</sup> In contrast, proponents of active voluntary euthanasia asserted that physicians ought to be allowed to actively cause death at the explicit, considered request of the patient.

Californian proponents of active voluntary euthanasia thought that adequate procedural restraints could be established that would enable the provision of active voluntary euthanasia in a manner that would have beneficial social consequences. The California Death With Dignity Act contains a number of regulations intended to control active voluntary euthanasia. These procedural stipulations need to be carefully described and questioned because they reveal the most significant shortcomings of the Act.

The most prominent feature of The Death With Dignity Act was that it applied only to terminally ill, mentally competent adults who voluntarily request physician aid in dying and have six months or less to live.<sup>22</sup> Hence, children were excluded from receiving physician aid in dying as were incompetent adults and individuals who were not terminally ill, or who had a prognosis extending beyond the six month mark. The patient was to make an enduring request for physician aid in dying. This meant that the request must be made on "more than one occasion." Two physicians were to examine the patient and they were to both diagnose and certify in writing that the patient had a terminal condition. This meant that in the opinion of two certifying physicians exercising reasonable medical judgment, the patient would die in six months or less due to the terminal condition. One of the physicians making the diagnosis was to be the attending physician. This was the physician selected by, or assigned to, the patient, who had primary responsibility for the treatment and care of the patient. The method of providing aid in dying was to be a medical procedure that was humane and dignified. Either the physician could perform the procedure at the patient's choice or provide the means to the patient so that he or she could deliberately control the time and place of dying. The patient was to request aid in dying by signing a valid revocable directive. The directive was to be signed by the declarant and was also to be witnessed by two adults who had to meet several requirements. These

stipulations were to ensure that none of the witnesses would benefit from the death of the patient. For example, the witness could not be related to the patient through blood, marriage, or adoption and could not be entitled in any fashion to the estate of the patient. If the patient was in a skilled nursing facility, a Patient Advocate or Ombudsman was to serve as a witness to the directive. This was to ensure that the patient was indeed "capable of willingly and voluntarily executing a Directive."<sup>23</sup>

Should the patient decide that the directive did not represent her current decision, the directive could always be revoked. Of course, if this occurred, a directive could also be re-executed.

With regards to the rights of health care providers, no physician or private health care facility was obliged to provide physician aid in dying. However, the patient was to be transferred upon the request of the patient to a physician or facility that would provide physician aid in dying. To help ensure that there was adequate medical judgment, the two certifying physicians could not be "partners or shareholders in the same medical practice." Clearly, one of the most significant points of all the regulations was that the patient's decision in favour of physician aid in dying must be voluntary. Individuals, families, insurance companies and others were prohibited from pressuring or encouraging patients to sign the directive. According to the Act,

No patient may be pressured to make a decision to seek aid in dying because that patient is a financial, emotional or other burden to his or her family, other persons, or the state.<sup>24</sup>

If coercion lead to the execution of a directive, the guilty party was described as having committed a misdemeanor. If death occurred as a result of this pressure, the guilty party had committed a felony. If physician aid in dying was administered to a patient as a result of falsification or forgery of a directive, the person was to be prosecuted for unlawful homicide.

With regards to the reporting of physician aid in dying, hospitals and health care providers were to annually report to the state department of Health Services details concerning the patient's "age, type of illness, and the date the Directive was carried out." Clearly, adequate statistics were supposed to be maintained regarding such patients.

Finally, no doubt in response to supporters of slippery slope or wedge arguments, the text stated, "Nothing in this Act shall be construed to condone, authorize, or approve mercy killing."<sup>25</sup> This qualifying remark represented an attempt to ensure that physician aid in dying was limited solely to mentally competent, adult, terminally ill patients.

All of the regulations and procedural requirements were intended to constrain physician aid in dying by excluding numerous possible categories of individuals. Whatever the fears of opponents of physician aid in dying, the proponents of the act attempted to mitigate concerns about the

consequences of the Act through the provision of numerous procedural safeguards. The procedural limitations were intended to limit "physician aid in dying" to a select group. Ideally, these stipulations would have served to mitigate concerns about a descent down the proverbial slippery slope.

Having briefly described the palliative and hospice care response to dying earlier in the dissertation, and having noted the major principles, guidelines, and regulations of the proposed California Death With Dignity Act, it is important to develop a more extended normative response. Should the two approaches to the care of dying patients be allowed to co-exist? Is one response superior to the other? My response is that although The California Death With Dignity Act was a reasoned attempt to enable active voluntary euthanasia, it was not an adequate piece of legislation. While I do not think that palliative and hospice care can effectively control the pain and suffering of all patients in every circumstance, I think the shortcomings of the Act, coupled with the social context of health care in California, made improvements in palliative care a superior option to the legalization of active voluntary euthanasia. What was more appealing about the hospice and palliative response to illness was that whatever their shortcomings, these forms of care were not faced with the serious pitfalls of The Death With Dignity Act.

My greatest concern about The California Death With

Dignity Act was that it embodied principles that could not be adequately maintained in practice. Not only do I think that a slide down the slippery slope might have easily occurred had the Act come into effect, I think that several of the safeguards contradicted the logic of the document itself. For example, as previously noted, "The California Death With Dignity Act" was prepared and distributed by a group known as "Californians Against Human Suffering." Clearly, the authors of the text did not think that patients should have to experience pain and suffering. It follows from this principle that physician aid in dying should be extended to mentally competent patients who are not terminally ill. Why should individuals facing six months or less of suffering be allowed to request active voluntary euthanasia while other patients face a lifetime of prolonged suffering? For example, mentally competent quadriplegic adults might be included in this category. If they are mentally competent adults who wish to die, why should they not be allowed to exercise their "right" to self-determination given the ultimate significance of this principle in the document? Clearly, this restriction was discriminatory insofar as it impinged upon the right to autonomy of severely physically disable patients.<sup>26</sup> Were the physically disabled overlooked by the implicit assumption that their suffering is less legitimate than that of "terminally ill" patients? In addition, was it fair to exclude all children and adolescents from receiving "physician aid in dying" when they can suffer

from illnesses as painful as those suffered by adults? In particular, if a child and his or her parents provided consent for active voluntary euthanasia, was there any legitimate ground for failing to provide "physician aid in dying" based upon "adult" status? Within the ethos of the Act, what justification was there for asserting that children be excluded from receiving active voluntary euthanasia?

Several questions can also be raised regarding the time perimeters for the provision of active voluntary euthanasia. Why should six months serve as the "magic line" for limiting the availability of active voluntary euthanasia? What grounds exist for excluding individuals with chronic degenerative illnesses in cases where the general course of the illness is well-known? For example, it is possible to live many years with advanced Alzheimer's disease. Might it not be reasonable to expect that some individuals diagnosed with Alzheimer's might want to request active voluntary euthanasia while they remain competent yet have it performed once they became incompetent? Furthermore, if self-determination is the most basic of freedoms, it is unclear why patients must have a terminal illness with only six months to live in order to qualify for active voluntary euthanasia. Given the internal logic of the Act, this would seem to involve an infringement of the rights of patients to self-determination.

I think we can also challenge the credibility of the claim that physicians can accurately predict that death due

to a terminal illness will occur in six months or less. I think there is dissonance between the medical reality of diagnosis and prognosis, and the assumption within the Act that such refined prognoses can be provided.<sup>27</sup> Certainly, there are occasions when such a prognosis may prove accurate. However, I think the available evidence suggests that the use of a six month timeline as a legitimate "medical criterion" is unrealistic.

There is a second category of individuals to consider whose concerns were not adequately addressed by the Act. Is it appropriate to exclude from consideration for active voluntary euthanasia those individuals who suffer from a serious illness, are terminally ill with six months or less to live, have previously expressed their unwillingness to persist in such an "undignified" state, yet are no longer mentally competent? If friends and family, or a surrogate decision-maker can attest to the previous remarks of the individual, or if the patient at some prior time signed a document stating she wished to receive active voluntary euthanasia at a certain stage of their illness even if she was no longer mentally competent, why should active voluntary euthanasia not be allowed in these circumstances? Given the priority of the right to self determination, why would competent patients not be justified in preparing "advanced directives" for active voluntary euthanasia to occur at some later stage of their illness when they were no longer competent? What compelling grounds existed for excluding no

longer mentally competent individuals from receiving active voluntary euthanasia if they had prepared previously an advanced directive and appointed a surrogate decision-maker who could represent the interests of the patient?

The decision-making process supposed to surround the decision to perform active voluntary euthanasia was also appropriately criticized during the campaign. Should merely two physicians be allowed to determine that the individual suffers from a terminal condition? Should these physicians be specialists or could any two physicians be utilized? The Act provided no guidelines concerning the qualifications of the physicians participating in the medical procedure. What sort of reasonable medical judgment was being guaranteed by the document? What sort of qualifications should be expected of medical practitioners participating in active voluntary euthanasia? Although the utilization of two physicians to review the case was intended as a procedural safeguard, I do not think that this stipulation could have served as a meaningful check on the provision of active voluntary euthanasia. A physician willing to perform active voluntary euthanasia was unlikely to consult a physician with an opposing viewpoint. Thus, while the provision of a second physician could help to ensure that the diagnosis and prognosis was reliable, it did not serve as a very effective safeguard.

Psychiatrists should have been disturbed by their minor role in ensuring that active voluntary euthanasia was

provided in only carefully circumscribed occasions.

According to the Act,

An attending physician who is requested to give aid-in-dying may request a psychiatric or psychological consultation if that physician has any concerns about the patient's competence, with the consent of a qualified patient.<sup>28</sup>

This circumscribed the involvement of psychiatrists in the medical decision-making process, since the patient could decide to exclude the psychiatrist. Conceivably, the very patients most in need of psychiatric consultation and assistance might have elected to prohibit the involvement of a psychiatrist in their medical care.

Another source of concern was that neither the physician nor the patient were obliged to inform family members and friends of the decision to proceed with active voluntary euthanasia. Since there was no time limit between the first and second request for physician aid in dying, a family could leave the hospital one evening and return to find that active voluntary euthanasia had been performed on their relative. The emphasis on personal autonomy was so extreme that there was no legal duty established to include the family and broader community in the decision to proceed with active voluntary euthanasia. While such a requirement would exist in opposition to current standards of respecting patient autonomy, opponents of the Act feared the possibility that some patients might make rash decisions without consulting their family.

A final question worth addressing is whether or not

physicians were the only individuals supposed to provide active voluntary euthanasia. The document is vague on this subject. First, if aid in dying was limited to physicians, should other health care providers be precluded from performing active voluntary euthanasia? Second, if aid in dying is not limited to physicians, just who was to be eligible to perform active voluntary euthanasia? Finally, should physicians or nurses have been the ones supposed to perform active voluntary euthanasia? Might it not have been better to have active voluntary euthanasia performed by individuals other than physicians and nurses given the danger that the provision of active voluntary euthanasia by medical personnel could jeopardize relations between patients and medical caregivers? Proponents of the Act failed to address these subjects before the initiative was placed on the California ballot.

Finally, critics of the initiative appropriately questioned the rhetorical strategies of the formulators of the act. Staunch opponents of active voluntary euthanasia shuddered at having it described as a "medical procedure" leading to "death with dignity."<sup>29</sup> In particular, the phrase "physician aid in dying" was a meaningless phrase. "Physician aid in dying" could range from hand holding to providing medication to providing a lethal injection at the request of the patient. By using vague phrases such as "physician aid in dying," and then attempting to distance this phrase from concepts such as "mercy killing," the

proponents of the Act seemed to resort to strategic, but misleading euphemisms.

I raise these questions and issues because I think the Act had several shortcomings that were appropriately attacked by its opponents. Even though I support the provision of active voluntary euthanasia in carefully circumscribed situations with realistic provisions, I think it very difficult to regulate active voluntary euthanasia and implement it into medical practice. The internal logic of The California Death With Dignity Act simply did not support all of the limitations that it attempted to justify. As a result, I think the initiative deserved to fail because I do not think that its procedural limitations were realistic or could have curtailed other forms of euthanasia. Furthermore, I think that its formulators were naive if they actually believe that it is justifiable to limit active voluntary euthanasia to only mentally competent patients with six months or less to live, and who have signed a legal document with two witnesses. Although I am suspicious of criticisms that rely upon "slippery slope" arguments, I think there were enough unanswered questions and unrealistic presumptions to generate the strong suspicion that the act, had it come into effect, would not have served as an effective deterrent to forms of euthanasia that it seeks to circumscribe. I do not think this document deserved to be supported because it makes claims for a particular kind of "aid in dying," yet cannot justify the limits provided to control this practice. There

are clear grounds for questioning whether support for this document would have lead only to the behavior endorsed in the document. Although I think there are legitimate grounds for allowing active voluntary euthanasia, the California Death with Dignity Act was not an adequate blueprint for the legalization of active voluntary euthanasia.

The most significant shortcoming of the Act was its selection of safeguards to regulate active voluntary euthanasia. First, children were not given the right to request "physician aid in dying," yet children and adolescents can suffer just as adults do. Furthermore, some, though not all children, are capable of articulating their own interests. Rather than using age as a criterion, "competency" could have been used as a means of determining whether or not an individual could comprehend the consequences of her choices. Children could be protected, while also having their autonomy constrained, by including their parents within such a process.

Second, the Act was supposed to serve as a vehicle for reducing the suffering of individuals, yet the only category of patients legitimized by the document were those with six months or less to live. This criterion failed to acknowledge the suffering of those with degenerative disorders or various forms of debilitating illness that can leave an individual mentally competent for a lengthy period of time, as in the case of patients with Alzheimer's disease, or leave a competent, alert, reflective individual without an ability to

move, as in the case of patients with ALS. The former category of patients suggests that perhaps individuals ought to be accorded the right to request active voluntary euthanasia while competent, yet receive active voluntary euthanasia at some later stage when they have become incompetent. The second category of individuals reveals that the provision of a six month timeline does not acknowledge the suffering of patients not designated as terminally ill.

Third, the Act tries to establish a timeline based on the designation of patients as having six months or less to live. And yet, the available medical studies of such prognoses undermines claims that such long-term prognoses can be provided with such accuracy. Obviously, some diseases are fatal and follow well-defined patterns. However, current evidence does not support a vision of physicians as able to provide reliable prognoses of the sort presumed in the Act. Consequently, rather than reify medical interpretations into legal categories, I think we might want to dispense with this means of regulating active voluntary euthanasia.

Fourth, the Act asserts that patients are not to be allowed to request active voluntary euthanasia based upon their financial circumstances. And yet, Californians live in a country where medical costs for illnesses often destroy the savings of individuals and families. In a social context where medical care can cost an individual hundreds of thousands of dollars, it seems unrealistic to assume that patients will not request active voluntary euthanasia

based upon the recognition that they cannot afford effective medical care. I think it evident that one of the most significant ways of eliminating unjustifiable psychological and social pressures upon individuals to request active voluntary euthanasia is to establish a more "socialized" system of medical care that is better able to distribute the financial burdens of medical care across society than the "market" model of medical care in California. Without such a system of medical care, it is difficult to avoid the charge that many suffering individuals will be faced with assuming catastrophic financial burdens or "requesting" the provision of active voluntary euthanasia. Given the existing form of health care in California, as in the rest of the United States, critics of the Act legitimately charged its proponents with ignoring the vulnerable status of many ill individuals.

Thus, my criticisms of the Act range from the technical nature of the provision of reliable prognoses to the systemic issue of the inadequacies of health care in the society into which the Act was to be introduced.

The Act fails to meet these many challenges. Proponents of the Act tried to "soften" its implications by limiting active voluntary euthanasia to a select group of individuals. In this respect, it provided a too narrow view of who ought to be accorded the right to request active voluntary euthanasia. And yet, the Act also suffered because of its uncritical assumptions about the social context of health

care in California. With several unrealistic regulations that inappropriately limited the provision of active voluntary euthanasia, the Act also failed to address the broader, more important challenge of the morality of providing active voluntary euthanasia as a medical service to patients in a social setting with gross inequities in access to health care, and in the affordability of health care. A thoughtful proposal for the legalization of active voluntary euthanasia has to respond to all of these challenges.

<sup>1</sup>Alexander Morgan Capron, "Even in Defeat, Proposition 161 Sounds a Warning," Hastings Center Report (January-February 1993): 32.

<sup>2</sup>Leon R. Kass, "Is There a Right to Die?" Hastings Center Report (January-February 1993): 34.

<sup>3</sup>Derek Humphry, Dying With Dignity: Understanding Euthanasia (New York: A Birch Lane Press Book, 1992): 11.

<sup>4</sup>Californians Against Human Suffering, "The California Death With Dignity Act." 1.

<sup>5</sup>David Cundiff, Euthanasia is Not The Answer: A Hospice Physician's View (Totowa, New Jersey: Humana Press, 1992): 162.

<sup>6</sup>Californians Against Human Suffering, "The California Death With Dignity Act." 1.

<sup>7</sup>Ibid., 1.

<sup>8</sup>Ibid., 1

<sup>9</sup>Leon R. Kass, "Is There A Right to Die?" Hastings Center Report (January-February 1993): 38-39.

<sup>10</sup>Ibid., 43.

<sup>11</sup>Ibid., 43.

<sup>12</sup>Willard Gaylin, Leon R. Kass, Edmund D. Pellegrino, and Mark Siegler, "Doctors Must Not Kill," Journal of the American Medical Association 259, 14 (April 8, 1988): 2139-2140.

<sup>13</sup>Roman Catholic organizations played significant roles in defeating campaigns for the legalization of active voluntary euthanasia in both California and Washington.

<sup>14</sup>Courtney S. Campbell, "Religious Ethics and Active Euthanasia in a Pluralistic Society," Kennedy Institute of Ethics Journal 2, 3 (1992): 258-263.

<sup>15</sup>Pope John Paul II, "Euthanasia: Declaration of the Sacred Congregation for the Doctrine of the Faith (May 5, 1980)," The Pope Speaks 25 (Winter 1980): 289-296, In, Stephen E. Lammers, Allen Verhey, On Moral Medicine: Theological Perspectives in Medical Ethics (Grand Rapids, Michigan: William B. Eerdmans Publishing Company, 1987): 443.

<sup>16</sup>David Little, "Human Suffering in Comparative Perspective," In, They Shall Not Hurt: Human Suffering and Human Caring, (Eds.), Rodney L. Taylor and Jean Watson (Colorado: Colorado Associated University Press, 1989): 53-72.

<sup>17</sup>Willard Gaylin, Leon R. Kass, Edmund D. Pellegrino, and Mark Siegler, "Doctors Must Not Kill," Journal of the American Medical Association 259, 14 (April 8, 1988): 2139-2140.

<sup>18</sup>T. Douglas Kinsella, Marja Verhoef, "Alberta Euthanasia Survey: Physicians opinions about the morality and legalization of active euthanasia," Canadian Medical Association Journal 148, 11, (June 1, 1993): 1921.

<sup>19</sup>Alexander Morgan Capron, Vicki Michel, "Proposition 161: What is At Stake?" Commonweal (September 1992): 2-5.

<sup>20</sup>Ibid., 2-5.

<sup>21</sup>David R. Cundiff, Euthanasia Is Not the Answer: A Hospice Physician's View (Totowa, New Jersey, Humana Press, 1992): 162.

<sup>22</sup>Californians Against Human Suffering, "The California Death With Dignity Act," 2-3.

<sup>23</sup>Ibid., 4.

<sup>24</sup>Ibid., 7.

<sup>25</sup>Ibid., 8.

<sup>26</sup>Andrew I. Batavia, "A Disability Rights-Independent Living Perspective on Euthanasia," Western Journal of Medicine (May 1991): 616-618.

<sup>27</sup>Timothy E. Quill, Christine K. Cassel, Diane E. Meier, "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician Assisted Suicide," The New England Journal of Medicine (November 5, 1992): 1381.

<sup>28</sup>Californians Against Human Suffering, "The California Death With Dignity Act," 6.

<sup>29</sup>Alexander Morgan Capron, Vicki Michel, "Proposition 161: What Is at Stake?" Commonweal (September 1992): 5.

## CHAPTER SEVEN

ACTIVE VOLUNTARY EUTHANASIA: NORMATIVE ANALYSIS AND POLICY  
RECOMMENDATIONS

Once the general features of the contemporary active voluntary euthanasia debate are grasped and placed in their social and historical context, a response that integrates normative analysis with public policy recommendations needs to be developed. The scholarly study of the morality of active voluntary euthanasia should not halt at mere description. Instead, it ought to strive to inform and guide the debate.

First, the normative stance of George and Sheila Grant does not adequately address the intricacies of the current debate. George and Sheila Grant recognize the dangers of policies supporting any form of euthanasia, but they do not distinguish in an adequate fashion between the differences separating "active voluntary euthanasia" from "passive euthanasia." In addition, the Grants neglect the positive dimension of the the rise of individualism and the development of biomedicine.

Thus, while the Grants succeed in articulating a Christian view of euthanasia that shares common features with many other Christian opponents of euthanasia, they do not present a middle ground that recognizes the importance of individual choice as well as the presence of unrelievable suffering, but also acknowledges the difficulties of

establishing a policy of active voluntary euthanasia. They fail to attend to many of the legitimate claims of their opponents, and take as given principles and values that need to be critically examined.

With regard to the historical and social context of the active voluntary euthanasia debate, biomedical progress has generated a scenario where the demand for active voluntary euthanasia becomes more intelligible than in previous historical periods. The body is now less opaque, and far more open to manipulation and control than during even the recent past. Many patients can now be given diagnoses and prognoses before the most serious, debilitating aspects of their illnesses become apparent. Aware of their probable illness trajectory, and of the consequences of the therapeutic regime designed to alter the course of illness, patients have the opportunity for better informed, conscious decision-making. For example, patients can elect to follow a prescribed path of intensive medical intervention, or they can choose palliative care, with less aggressive medical intervention provided primarily to ease suffering and discomfort. This increased involvement of patients in all forms of decision-making is particularly apparent in the increased demand to extend the right to decide upon forms of medical treatments to the "right" to request active voluntary euthanasia from physicians or other caregivers. Many individuals, aware of the suffering they could endure during the process of dying, despite significant advances in pain-

management, insist that active voluntary euthanasia be made available in order to have better control over the process of dying, and the experience of suffering. The effects of improved medical diagnosis and prognosis upon decision-making are evident. For example, Janet Adkins, who used Jack Kevorkian's "suicide machine," did not want to suffer the breakdown of "personality" and progressive degeneration of mental capabilities that accompanies Alzheimer's disease.<sup>1</sup> At the time of her decision to contact Jack Kevorkian she was aware that she would remain "mentally competent" for at least one year. Yet, because Kevorkian assisted competent patients only, she chose to utilize Kevorkian's suicide machine within that time period rather than endure the full effects of her disease. Similarly, "Diane," a patient of Dr. Timothy Quill's, diagnosed with acute leukemia and with poor prospects for long-term survival, chose palliative treatment followed by physician-assisted suicide rather than enduring the extremely difficult course of treatment.<sup>2</sup> Dr. Quill provided her with the barbiturates she used to end her life. Furthermore, in his article, "Death and Dignity: A Case of Individualized Decision Making," published in the New England Journal of Medicine, he not only commended her own ability to make informed decisions on behalf of herself, but suggested that as a medical professional he should have been able to do more than merely offer the drugs facilitating suicide.<sup>3</sup> Quill suggested that the mere provision of a deadly medication was questionable medical practice because it involved abandoning

Diane at a time when she should have been surrounded by caregivers.

The ability to provide refined diagnosis and prognosis coupled with the medical capacity to intervene in the course of illness is not going to disappear. It is a factor of increasing importance to the active voluntary euthanasia debate. However, notwithstanding the radical transformation of biomedicine, contemporary medicine has not banished uncertainty from evaluation and treatment. This provides legitimate grounds for caution, and should serve as a constraint upon any policy endorsing active voluntary euthanasia.

According to Dutch physician Richard Fenigsen, voluntary euthanasia should be regarded as unacceptable

because of the fundamental discrepancy between the uncertainty of human (and medical) judgments, which are fallible, and the deadly certainty of the act.

Clinicians have traditionally rejected euthanasia because they realized that we all make mistakes, that diagnoses are uncertain and prognoses notoriously unreliable. Erroneous diagnosis of fatal disease remains a very real possibility.

In their efforts to improve a patient's condition or save his life, doctors often have to rely on a diagnosis that is only probable. This course of action is unavoidable and justifiable intellectually. Yet, to perform euthanasia on the grounds of a diagnosis that might prove incorrect is as evil as it is mindless.<sup>4</sup>

Despite the partially successful regulation of the human organism by biomedicine, there remain elements of uncertainty in diagnosis and prognosis. Because the act of euthanasia is irreversible, there is the danger that the unalterable act of active voluntary euthanasia could be based upon inaccurate medical evaluations. The development of biomedicine has

not created a context of ultimate, absolute control where the human organism can be entirely managed or the precise course of illness accurately predicted. There remains a significant element of indeterminacy in most forms of medical care.

One method of addressing this issue is to limit the provision of active voluntary euthanasia to only the final stages of the illness trajectory. For example, some supporters of active voluntary euthanasia argue that it should be limited to the period of six months before death is estimated.<sup>5</sup> However, even if euthanasia were to be restricted to the "terminally ill," given six months or less to live, difficulties would not be resolved, because the diagnosis of "terminal illness" is rarely accompanied by a calibrated medical schedule which can place the dying process onto a precise time-line. The prognosis following diagnosis of terminal illness is an interpretation, and the course of a patient's illness can sometimes prove such medical evaluations to be incorrect.<sup>6</sup> Therefore, I view with misgivings procedural guidelines for active voluntary euthanasia which rely upon a specific, delineated prognosis. Furthermore, even if a timeline was established to regulate active voluntary active euthanasia, it would be misleading to think that a tidy resolution of the issue had been achieved. Perhaps the best means of responding to the uncertainty of medical knowledge is to let patients incorporate this awareness of uncertainty into their own decision-making. In this fashion, patients could better assess their options, by

having a sense of the uncertainty of their prognosis and the possible trajectory of their illness.

Furthermore, by the time some patients reach the stage where they are determined to have six months or less to live, many of them are not the "rational," "autonomous," competent figures typically regarded as the sort of person able to make the decision for active voluntary euthanasia. In addition, such a criterion would not address the plight of those individuals with chronic, degenerative, and painful illnesses who might suffer for years before dying.<sup>7</sup> Thus, I do not think that it is possible to argue for a "medically indicated" timeline that could be used as a procedural safeguard to help regulate the medical provision of active voluntary euthanasia.

Even given the absence of the medical capacity to provide a precise timeline for predicting the illness course, it is not sufficient to merely oppose active voluntary euthanasia, since patients can make decisions based upon uncertain medical interpretations of illness, as they currently do with regards to the cessation of treatment. To condemn proposals for active voluntary euthanasia simply because there can be no adequate procedural guidelines for regulating such a policy based upon a six month period, or a similar criteria, is, I believe, to overlook the magnitude of suffering faced by many ill individuals.

However, like those who condemn proposals for active voluntary euthanasia, I, too, think we need to

be very careful about the way in which we try to address suffering.

In particular, patients need to be aware of, and have ready access to, other alternatives that can help to control suffering. No individual should ever be faced with a choice between either aggressive medical treatment or active voluntary euthanasia. Instead, because there are widespread fears of a technological, needlessly prolonged process of suffering, medical caregivers need to inform citizens of the important possibilities of care offered by hospices, and palliative care units. Furthermore, funds need to be provided to improve these facilities and to ensure their availability to those most in need of their services. Home care with visiting nurses and aides also represents a significant possibility for improving the care of seriously ill and dying patients. To support or oppose active voluntary euthanasia without promoting these significant alternatives would be irresponsible. Important alternatives to active voluntary euthanasia exist, and they need to be better examined in the popular media in order to avoid any tendency to polarize the issues by making it appear as though options are limited to active voluntary euthanasia or a technologized, painful death. In particular, pain-management strategies and hospice and palliative care need to be promoted without creating the false illusion of the possibility of dying without suffering, which can only deepen the anger and frustration directed towards physicians.

As the professionals most likely to be affected by the legalization of some restricted form of active voluntary euthanasia, physicians and nurses have a special responsibility to serve as concerned participants in the active voluntary euthanasia debate, and to promote alternatives to both unwanted aggressive therapies and active voluntary euthanasia.

Changing attitudes towards the nature and meaning of suffering play a major role in the current euthanasia debate. Suffering has lost much of its religious justification, with the collapse of traditional theodicies, and this has created a context where much suffering is, for many people, purposeless, and to be avoided rather than endured or celebrated. Formerly, theodicies of suffering provided interpretive schematas, or narratives which served as cultural explanations of illness and helped to mold individual responses to suffering. While this Christian tradition remained dominant, strong religious convictions served to create a meaningful context for suffering, dying, and death. However, in a pluralistic, secular culture such as our own, the desire to avoid suffering, rather than experience suffering as redemptive, is increasingly predominant. In the secularized societies to be found in Canada, the United States, Australia, and Great Britain, the demand for active voluntary euthanasia, to avoid unnecessary suffering has proven to be intense.

Even though I support hospice and palliative care, and

think that the forms of care they provide can address the needs of most suffering individuals, I do not think that they can respond in an adequate fashion to the suffering of all patients.<sup>a</sup> For some individuals, suffering can only be controlled by rendering them unconscious. This does not provide an acceptable quality of life for every ill person. I think we need to recognize, then, that the provision of hospice and palliative care does not entirely resolve the active voluntary euthanasia issue.

And yet, although the presence of unrelievable suffering lends moral authority to the case for active voluntary euthanasia, there are legitimate reasons for proceeding with great caution toward a policy advocating active voluntary euthanasia.

In the contemporary discussion surrounding the possibility of the establishment of a policy of active voluntary euthanasia in Canada, I think it advisable to consider particular social and historical contexts in which euthanasia has been performed. By considering particular settings in which euthanasia has been performed on a widespread basis, I think it plausible that some insight might be generated with regards to the current controversy.

Probably the most well-known instances of euthanasia as public policy are the current situation in the Netherlands in which euthanasia, though officially illegal, is accepted by the courts, the medical profession, and the public, and the medicalized killings which occurred in

Germany while the Nazi party was in power. These two cases are quite dissimilar, and only the Netherlands situation remotely resembles the current demand in North America for the involvement of physicians in active euthanasia. While the involvement of physicians in the killing of patients in Nazi Germany continues to influence the contemporary euthanasia debate, and should not be ignored, I think we need to recognize that the Nazi programmes of "euthanasia" have very little to do with the current concept of active voluntary euthanasia for competent, suffering patients able to demonstrate that they understand the implications of their choices.

Unfortunately, although the situation in the Netherlands possesses some potential for generating insight into how Canadians and Americans might want to regulate the provision of active voluntary euthanasia, it is far too ambiguous at present for the development of cogent policy transformations. Officially, euthanasia is still illegal in the Netherlands although physicians are not punished provided they follow certain guidelines.<sup>9</sup> Several court decisions in combination with ethical policies developed by the medical profession, and actual medical practice have created a situation in which euthanasia can be performed by physicians without the laying of criminal charges. Beyond these general remarks, it is difficult to reach any definitive conclusions concerning euthanasia in the Netherlands due to the paucity of comprehensive, reliable

material evaluating the performance of active voluntary euthanasia in the Netherlands.<sup>10</sup>

What we do know about medical care in the Netherlands is that active voluntary euthanasia is performed. Actual numbers of cases are very difficult to ascertain, since there is no certainty that all cases of active voluntary euthanasia are reported. Likewise, the range of occasions in which active voluntary euthanasia occurs is difficult to establish. According to Pieter Admiraal,

Justifiable active euthanasia is practiced in Holland only with patients who are in the terminal phase of an incurable, usually malignant, disease.<sup>11</sup>

However, Richard Fenigsen, who is also a Dutch physician, provides a much different interpretation of the performance of euthanasia in the Netherlands:

There is now ample evidence that 'voluntary' euthanasia is accompanied by the practice of crypthanasia (active euthanasia on sick people without their knowledge.)<sup>12</sup>

Fenigsen insists that there are many cases in which euthanasia is performed upon patients ignorant of the physician's decision to perform euthanasia. He also states that there have been documented cases in which patients have been coerced by physicians, other medical personnel, and family members to "choose" euthanasia.<sup>13</sup>

Given the conflicting accounts of the available material concerning active voluntary euthanasia in the Netherlands, it currently seems impossible to utilize the practice of active voluntary euthanasia in the Netherlands as a model for changes in social policy concerning active voluntary

euthanasia in Canada. Furthermore, since there is at least some evidence that euthanasia is not always voluntary in the Netherlands, I think the main lesson that can currently be drawn from the developing situation in the Netherlands is that any policy that we wish to establish had better ensure that patients are voluntarily requesting euthanasia without being coerced by physicians and family members. Thus, although the performance of euthanasia in the Netherlands is often touted as a model of use to North Americans, there is still limited research available to enable us to transfer their practices to North America. Any attempt to transfer the Netherland model to Canada is also challenged by the close ties that tend to exist between most family physicians and their patients in Holland. Thus, I think we need to develop our own policies that incorporate what little we do know about euthanasia in the Netherlands. In particular, I think we want to be careful to develop a policy that helps to ensure that individuals do not experience needless suffering while also developing criteria to ensure that euthanasia is provided only when the voluntariness of the act is well established.

The crucial factor distinguishing current attitudes toward active voluntary euthanasia from the "euthanasia program" which took place in Nazi Germany, is the significance of personal autonomy in the modern debate. The "euthanasia" program in Nazi Germany was not a response to the personal choices of suffering individuals.<sup>14</sup> While the

program was in operation, patients did not voluntarily request euthanasia. Rather, groups of physicians established criteria which separated those who would live from those who would be killed. Responsibility for the euthanasia program initiated with Hitler, his personal physician, and a select group of physicians who supported the Nazi party.

Candidates for "euthanasia" officially included the "retarded," the "deformed," schizophrenics, the "criminally insane," asylum inmates, the blind, the "senile," and the "feebleminded." The program, which was initially applied to patients with varying illnesses, would eventually be applied to those with "racial impurities." Thus, euthanasia was not guided by benevolence or respect for the autonomy of individuals, but by genocidal and racist policies that also targetted the weak, aged, and vulnerable members of society.

According to Hugh Gregory Gallagher, in By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich, concern for the rights and autonomy of patients was irrelevant to every element of the euthanasia program. Instead, choices were made by physicians that determined life and death. Direct responsibility for the performance of euthanasia was diffused amongst several individuals.<sup>15</sup> Because the "euthanasia" program in Nazi Germany was not a response to the autonomous choices of suffering patients, there is no direct correlation with the contemporary euthanasia debate. I do not think current

proposals for the legalization of active voluntary euthanasia should be condemned in response to the medicalized killing of Nazi Germany. The differences between the Nazi program and current proposals are too distinct, insofar as current considerations of euthanasia involve the patient as primary decision-maker, and provide many procedural safeguards.

Nonetheless, I think we can note some possible parallels between euthanasia as it occurred in the Third Reich, and any policies of active voluntary euthanasia established in a contemporary medical setting. The bureaucratic nature of the Nazi program serves as a warning to anyone tempted to institutionalize euthanasia. As Gallagher states,

The psychological reasons why physicians were willing to participate in these killings are no doubt complex. There is, however, an aspect of the program's structure which made it easier: there was no single point of responsibility-no place in the procedure at which it was possible to say Here is where the patient receives his death warrant; no point where it could be said, This physician is responsible for this patient's death.

The local practicing physician simply filled out the questionnaires as he was required to do. The members of the assessing committee simply gave their individual opinion on each case. Nothing more would happen unless the members were in substantial agreement. The senior review physician simply went along with the committee or else expressed an objection. He was expressing a medical opinion, nothing more. Neither the assessors nor the review physicians ever saw the patient. The transportation staff was involved in transporting patients-but it was no business of theirs where or why the patients were being moved. The staff which ran the centres were simply doing their jobs. Even the physician whose job it was to operate the gas chamber was not responsible for the death of the patients-after all, he played no part in their selection; he knew nothing of their cases. He was only following the procedures laid down by his superiors, carrying out the policy of his government as advised by the most eminent members of the medical profession.

Responsibility was diluted. Any one of the participants could say, 'I am not responsible for the killing. The others are responsible.'<sup>16</sup>

I think we need to face the danger that with multiple physicians such as psychiatrists, anesthesiologists, geriatricians, and general practitioners involved in the process, hospital ethics committees, advisory boards, legal consultants, and bioethical specialists, there could be a dispersal of responsibility even as we try to establish a regulatory process with checks and balances. Indeed, the very existence of committees to ensure that euthanasia is, indeed, voluntary, could lead to such a dispersal of responsibility. With the legalization of active voluntary euthanasia, I think we would need to be careful to insist that it be scrutinized with care by review boards, yet also take steps to ensure that it not be transformed into just one more medicalized, bureaucratized action. Thus, the Nazi program of euthanasia calls into question current attitudes toward the bureaucratization and institutionalization of euthanasia by revealing the dangers to be potentially found in the dispersal of responsibility this is likely to involve.

Unless patient autonomy is carelessly given complete freedom so that any request for active voluntary euthanasia is immediately complied with, there has to be some sort of process which can distinguish the reflective, competent individual from the clinically depressed person, the terminally ill from the temporarily ill, the sufferer who cannot be further aided from one who is not receiving adequate medical care. Such a process, admittedly, will

probably require some dispersal of responsibility in which psychiatrists, psychologists, palliative care specialists, other physicians, social workers, nurses, and patients are all involved in regulating the provision of active voluntary euthanasia. Admittedly, the very process of creating institutional safeguards could result in a situation where no specific individual has to assume complete responsibility for participating in the act of active voluntary euthanasia. Even so, I think the best way of ensuring the voluntariness of patient requests for active euthanasia, as well as ascertaining the experience of the patient's suffering, is to form committees that would resemble, yet be distinct from, the ethics committees established in most hospitals to review particularly difficult, controversial, "cases." Their main purpose would be to ensure that the request for active voluntary euthanasia was genuinely voluntary, and that the patient is experiencing suffering, or is likely to face a future of suffering, that cannot be adequately addressed through improved physical, spiritual, or psychological care.<sup>17</sup> Though I do not think that a precise "timeline" could be established, I think the provision of active voluntary euthanasia should be explored only when other alternatives have been exhaustively considered.

There are several advantages to providing active voluntary euthanasia within a hospital context. First, physicians can prescribe the medications needed for active voluntary euthanasia. Second, some of the patients demanding

active voluntary euthanasia would likely already reside in a hospital environment. Third, hospitals contain the personnel who could form the committees to address requests for active voluntary euthanasia. Fourth, physicians in hospital settings will already be familiar with the diagnoses and prognoses of patients demanding active voluntary euthanasia. Finally, and I think most significantly, the provision of active voluntary euthanasia within the hospital setting provides a continuum of care in which patients are not transferred to another place during their period of greatest suffering. Thus, I think there are several reasons for providing active voluntary euthanasia within a hospital context. However, other options are also worth considering.

Instead of allowing active voluntary euthanasia to become a part of the traditional hospital system, separate "euthanasia centres," much like free-standing abortion clinics or hospices could be established. Michel Foucault recently suggested this option, which was first explored by a French physician in 1919.<sup>18</sup> However, I fear the possible shortcomings of such institutions. Specifically, I am concerned that the enormity of the act of active voluntary euthanasia would not be recognized in a center established for the provision of active voluntary euthanasia. However, the development of centres created for the purpose of active voluntary euthanasia is worth considering given some of the difficulties in involving hospital personnel in active voluntary euthanasia.

Another possibility is to allow active voluntary euthanasia to occur in the home of patients. Since many patients prefer to receive terminal care at home, physicians and nurses could be allowed to provide active voluntary euthanasia in the homes of patients. Before this could occur, however, safeguards would have to be established to ensure that the requests of patients are genuine.

Why are physicians or other medical personnel necessary for the actual performance of active voluntary euthanasia?

While it requires many years of arduous training to become a competent healer, the act of deliberately ending a human life demands does not require extensive medical skills. There are no medical procedures associated with the provision of active voluntary euthanasia that actually require a medical practitioner to perform the act of voluntary euthanasia. Therefore, we do not have to assume that physicians must be the only individuals capable of performing active voluntary euthanasia. True, physicians are capable of establishing the diagnoses and prognoses of patients. However, the act of active voluntary euthanasia does not require four years of undergraduate preparation in the sciences, followed by four years attending a medical school, supplemented by the even further training that goes into the making of a physician. Active voluntary euthanasia, whether performed by the administration of a pill, poisonous gas, or injection, simply does not require the extensive skills and knowledge of a physician. Likewise, there is no device associated with the

provision of active voluntary euthanasia sufficiently sophisticated or complicated that it could only be situated in hospitals, clinics, or other medical centres. If physicians refuse to provide active voluntary euthanasia, it might be possible to train other individuals to perform active voluntary euthanasia inside the hospital environment, within a centre for active voluntary euthanasia, or at the homes of patients.

Although I think that physicians and nurses are best suited to provide active voluntary euthanasia, I admit that there are difficulties in allowing such medical personnel to perform active voluntary euthanasia. There are some obvious advantages to separating physicians, nurses, and other medical personnel as well as the sites in which they work from any setting where active voluntary euthanasia is performed. Physicians and nurses must have the trust of patients. Without this basic bond of trust, all of the clinical expertise, scientific research, and sophisticated technology found in hospitals are insignificant. Thus, by banning physicians and nurses from actually performing active voluntary euthanasia in hospitals, they might maintain the trust that they are healers who cure and care, but do not actively serve as the cause of death. Conversely, special centers for active voluntary euthanasia could be established outside of the hospital setting, to reduce the possibility of damaging the relations between physicians and patients.

Thus, physicians and nurses could staff special clinics

that would provide the only sanctioned setting for active voluntary euthanasia. Or, non-physicians could perform active voluntary euthanasia in such facilities if the involvement of physicians in the provision of active euthanasia is perceived as too much of a challenge to the professional mandate of the medical profession. Selection from this range of options would have to depend on the willingness of some physicians and nurses to perform active voluntary euthanasia, the preferences of communities, and the capacity to establish safeguards for whatever method or set of methods selected.

Physicians and nurses, it must be remembered, must be concerned with the element of trust linking them to all patients. They cannot respect the unfettered personal autonomy of patients without also considering the social consequences of their actions. Whereas suicide is an individual, private act, however significant a role the community may play in the act of suicide, the legalization of active voluntary euthanasia would place it in the public realm. Allowing physicians and nurses to perform active voluntary euthanasia would represent a change in the role of medical caregivers and alter society by publicly sanctioning controlled death. Although I do not think that the involvement of physicians in the provision of active voluntary euthanasia would necessarily undermine the integrity of the medical profession, I think Canadians should recognize that there are alternatives to involving physicians

in the direct provision of active voluntary euthanasia. Furthermore, I would also agree with opponents of active voluntary euthanasia that there are grave dangers in publicly acquiescing too early to any individual's decision that it would be better to die than continue living. It takes little imaginative capacity to recognize the dangers of such a position in contexts such as now exist in North America where there is minimal support of disabled rights groups, concerns over the escalating costs of medical care accompanied by suggestions that age be used as a criterion in the rationing of health care, considerable social movement which hampers extended family and communal relations and a health-care system where the physician is often a stranger rather than a friend of many years whose life is intertwined with the life of her patient. This social and economic context--so different from that in Holland--provides a setting where we must be very cautious in deciding whether or not the community should lend its support to sanctioning the establishment of active voluntary euthanasia as public policy.

Although the image of the autonomous, rational thinker able to analyze her personal options may be applicable to a few patients, it is surely misleading to imagine that most patients exist as rational calculators able to assess available alternatives. Depression, fear, nausea, diarrhea, uncertainty concerning the future due to the ambiguousness of the effects of treatment, economic concerns, family

responsibilities are not factors which the suffering thinker can objectively, rationally assess. Rather, they belong to the very nature of the reflective process. By subscribing to the image of the enlightened patient who should possess primary responsibility for the medical decision-making process, many other patients who must rely upon the judgment of physicians are ignored. It may be that to maintain the essential trust of these patients, the prohibition of the performance of active voluntary euthanasia by physicians and nurses must be maintained. Conceivably, that trust could be destroyed by legalizing active voluntary euthanasia.

Despite these many legitimate concerns, I think physicians should be allowed to perform active voluntary euthanasia either in the traditional hospital setting, in specially established centres for active voluntary euthanasia, or in the homes of patients. I favour the first and third options. First, some patients cannot be transferred from hospitals to "euthanasia centres" because of the nature of their illness. Second, I think the difficulties involved in allowing physicians to perform active voluntary euthanasia are outweighed by the dangers of making the provision of active voluntary euthanasia the routinized occupation of a small group of individuals who are not medical professionals. Third, and most importantly, I think the provision of active voluntary euthanasia by physicians in carefully circumscribed instances can be viewed as an element of moral medical care. Medical caregivers have

always been guided by the duty to relieve suffering. More recently, ethical medical care has come to respect the voices of patients in making decisions about the withdrawal and cessation of treatment. Physicians should not abandon their patients by idealistically refusing to perform active voluntary euthanasia and placing this responsibility on individuals who would most likely have had little prior contact with the patient. Rather than continuing to view active voluntary euthanasia in cases of considerable suffering where the patient requests active voluntary euthanasia, as an act to be prohibited or furtively performed, it should sometimes be viewed as an ethical component of medical care.

To proceed from this normative position to particular policy recommendations, we need to consider the specific details of what safeguards would exist, and who should be allowed to receive active voluntary euthanasia.

First, special committees could be established to evaluate requests for active voluntary euthanasia. These committees could consist of members of the community able to consider medical information relevant to the "case" of the particular individual, as well as the social, psychological, and interpersonal contexts of the request for active voluntary euthanasia. Since, as we have seen, it is unrealistic to presume that a medical timeline can be established to replace moral reflection, members of the committee should take steps to enquire about certain details.

First, the committee should become aware of the general medical consensus about the individual's diagnosis and prognosis. Second, the committee should come to an understanding about why the individual is requesting active voluntary euthanasia, and how the individual reached this decision. In this process, the committee should ensure that patients are aware of, and have full access to, alternatives such as palliative care, home care, and hospice care. The committee should also ascertain that the individual understands the implications of the provision of active voluntary euthanasia. The emphasis should be on the awareness and comprehension of the patient, rather than on any particular age limit. Consequently, some children may request active voluntary euthanasia. In such circumstances, wherever possible, it would seem advised to let the child and her guardian, or guardians reach a joint decision. This requirement emphasizes the importance of respect for the autonomy of minors, but also respects an appreciation of the familial, communal, and social context in which such decision-making can occur.

With regards to the subject of suffering, committees should rely to a considerable extent on a "patient-centred" evaluation of suffering. Since the experience of suffering cannot be quantified, the committee should strive to become aware of the existential, experiential circumstances of the individual. However, certain broad community standards would likely need to exist if the committees were ever challenged

by cases where individuals made a request for active voluntary euthanasia with no appreciable justification for their actions.

Under most circumstances, individuals ought to have a period of reflection in which to re-consider their request for active voluntary euthanasia. The length of this period could emerge from the practical experience of the committee. Individuals wishing to make an exception to this requirement could, under extenuating circumstances, petition that the committee waive this requirement.

Finally, such committees would have to address the plight of individuals competent when making the request for active voluntary euthanasia, yet incompetent after the establishment of this request. In such circumstances, the establishment of advanced directives coupled with the appointment of a surrogate decision-maker by the individual to represent her interests could help to ensure that active voluntary euthanasia was performed based upon the decision of the individual.

With regard to the social context of the provision of active voluntary euthanasia, I suspect that the best safeguards that can be established against abuses is to develop effective programs of palliative, home, and hospice care, improve the education of physicians and nurses in "pain-management," and interaction with patients, and develop social structures that support the seriously ill, the disabled, and the terminally ill. For example, I suspect

that no amount of regulations and supervision could ever make active voluntary euthanasia justifiable and legitimate in a society that does not provide medical care for the poorest, most vulnerable members of society. Thus, I do not think that the implementation of a policy enabling active voluntary euthanasia is dependent upon the mere ability to establish the autonomy of patients and the capacity to create responsible committees able to assess the circumstances of particular individuals. Rather, I think it apparent that such a shift in social and professional mores must be accompanied by broader communal efforts at the provision of care and comfort to the most vulnerable members of society. Consequently, my support of a policy that would allow active voluntary euthanasia under certain conditions depends very much on the moral, social, and economic context within which active voluntary euthanasia would be performed.

<sup>1</sup>Jack Kevorkian, Prescription Medicide: The Goodness of Planned Death (Buffalo, New York: Prometheus Books, 1991): 221.

<sup>2</sup>Timothy E. Quill, "Death and Dignity: A Case of Individualized Decision Making," The New England Journal of Medicine 324, 10 (March 7, 1991): 692.

<sup>3</sup>Ibid., 694.

<sup>4</sup>Richard Fenigsen, "A Case Against Dutch Euthanasia," Hastings Center Report 19, 1 (January/February 1989): 26-27.

<sup>5</sup>Californians Against Human Suffering, "The California Death With Dignity Act," Los Angeles, California.

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<sup>8</sup>Timothy E. Quill, "Death and Dignity: A Case of Individualized Decision Making," The New England Journal of Medicine 324, 10, (March 7, 1991): 694.

<sup>9</sup>Margaret P. Battin, "Seven Caveats Concerning the Discussion of Euthanasia in Holland," Perspectives in Biology and Medicine 34, 1 (Autumn 1990): 75.

<sup>10</sup>Ibid., 73.

<sup>11</sup>Pieter Admiraal, "Justifiable Active Euthanasia in the Netherlands," in Robert M. Baird and Stuart E. Rosenbaum, (Eds.), Euthanasia: The Moral Issues (Buffalo, New York: Prometheus Books, 1989): 125.

<sup>12</sup>Richard Fenigsen, "A Case Against Dutch Euthanasia," Hastings Center Report 19, 1 (January/February 1989): 25.

<sup>13</sup>Ibid., 24.

<sup>14</sup>Hugh Gregory Gallagher, By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich (New York: Henry Holt and Company, 1990): 59.

<sup>15</sup>Ibid., 58.

<sup>16</sup>Ibid., 103-104.

<sup>17</sup>Franklin G. Miller and John C. Fletcher, "The Case for Legalized Euthanasia," Perspectives in Biology and Medicine 36, 2 (Winter 1993): 172.

<sup>18</sup>Derek Humphry and Ann Wickett, The Right to Die (New York: Harper & Row, 1986).

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